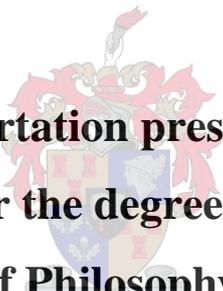


PATIENT AUTONOMY AND EVIDENCE-BASED PATIENT CHOICE - PHILOSOPHICAL AND ETHICAL PERSPECTIVES

Willem Moore



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Promoter: Prof. A.A. van Niekerk

Co-Promoter: Prof. J.A. Louw

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DECLARATION

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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SUMMARY

This study involves a critically evaluation of evidence-based patient choice as partnership model in clinical decision making. It pays attention to the emergence of the concept of autonomy in modern moral philosophy and in particular to the pivotal contributions of Immanuel Kant and John Stuart Mill in this regard. Against this background, it elaborates on the ethical principle of respect for autonomy, informed consent as paradigm for patient autonomy in clinical decision making, the conflicts that arise between the ethical concepts of autonomy and beneficence, the dominance of paternalism in clinical decision making, the challenges posed to the dominance of paternalism, the resulting emergence of the concept of partnership in clinical decision making and evidence-based patient choice as partnership model in clinical decision making. Moreover, it provides an exposition of the context, nature and practice of evidence-based patient choice and of the four key decision making skills required from health care professionals to involve patients in clinical decision making, namely shared decision making, risk communication, decision analysis, and the use of decision aids. Against this background, it critically evaluates the effectiveness of evidence-based patient choice as partnership model in clinical decision making by judging it in terms of the ethical concept of patient autonomy as reflected in the informed consent elements of competence, disclosure, understanding and voluntariness and indicates that none of the key skills of evidence-based patient choice can be regarded as completely adequate in honouring the principle of respect for autonomy in clinical decision making and that consequently each of these four key skills leave evidence-based patient choice with a challenge that needs to be addressed from another angle in order to establish and maintain the ethical principle of respect for autonomy. In response to these challenges, the study makes three recommendations for the transformation of evidence-based patient choice to a therapeutic alliance health care, namely to review and further develop the philosophical foundations of evidence-based patient choice, to consider the continental philosophical perspectives of Edmund Husserl, Jean-Paul Sartre, Maurice Merleau-Ponty and Jürgen Habermas on the evidence-based patient choice challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and the dangers of abstractions and informational manipulation in health care and to transform the practice of evidence-based patient choice to a therapeutic alliance in health care by individualising the provision of information by embedding it in the human processes of sense making, knowledge creation and decision making through which information is transformed into insight, knowledge and action.

OPSOMMING

Die studie behels 'n kritiese evaluering van *evidence-based patient choice* as vennootskapsmodel in kliniese besluitneming. Dit verwys na die opkoms van moderne morele filosofie en in die besonder na die deurslaggewende bydraes van Immanuel Kant en John Stuart Mill in hierdie verband. Teen hierdie agtergrond bespreek dit die etiese beginsel van respek vir outonomie, ingeligte toestemming as paradigma vir pasiënt outonomie in kliniese besluitneming, die moontlike konflikte tussen die etiese konsepte van outonomie en weldadigheid, die dominansie van paternalisme in kliniese besluitneming en die uitdagings wat dit ontlok het, die gevolglike ontstaan van die konsep van vennootskappe in kliniese besluitneming, asook *evidence-based patient choice* as vennootskapsmodel in kliniese besluitneming. Voorts verskaf die studie 'n uiteensetting van die konteks, wese en praktyk van *evidence-based patient choice*, asook van die vier sleutelvaardighede wat van medici vereis word ten einde pasiënte in kliniese besluitneming te betrek, naamlik gedeelde besluitneming, die kommunikasie van risikos, die analise van besluitneming en die gebruik van besluitnemingshulpmiddels. Teen hierdie agtergrond onderneem die studie 'n kritiese evaluering van die effektiwiteit van *evidence-based patient choice* deur dit te meet aan die ingeligte toestemming elemente van kompetensie, blootlegging, verstaan en vrywilligheid en toon aan dat geeneen van hierdie sleutelvaardighede as volledig toereikend in die nastreef van die beginsel van respek vir outonomie in kliniese besluitneming beskou kan word nie en *evidence-based patient choice* daarom met uitdagings laat wat vanuit 'n ander hoek bearbei moet word ten einde die beginsel in die praktyk te vestig en te onderhou. In reaksie hierop maak die studie drie aanbevelings met die oog op die transformering van *evidence-based patient choice* na 'n terapeutiese alliansie in gesondheidsorg, naamlik om die filosofiese grondslae van *evidence-based patient choice* in oënskou te neem en verder te ontwikkel, om oorweging te skenk aan die kontinentaal filosofiese perspektiewe van Edmund Husserl, Jean-Paul Sartre, Maurice Merleau-Ponty en Jürgen Habermas met betrekking tot die *evidence-based patient choice* uitdagings van die verskillende wêreldes van dokter en pasiënt, die konstituering van betekenis in siekte en die gevare verbonde aan die abstrahering en manipulering van inligting in gesondheidsorg en om op grond hiervan die praktyk van *evidence-based patient choice* te transformeer. Dit sal gedoen word deur die verskaffing van inligting aan pasiënte te individualiseer deur dit in te bed in die menslike prosesse van sinmaking, kennis generering en besluitneming waardeur inligting getransformeer word tot insig, kennis en aksie.

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Soli Deo Gloria

Where there is sorrow there is holy ground. Someday people will realize what that means. They will know nothing of life till they do ... When I was brought down from my prison to the Court of Bankruptcy, between two policemen, (Robert Ross) waited in the long dreary corridor that, before the whole crowd, whom an action so sweet and simple hushed into silence, he might gravely raise his hat to me, as, handcuffed and with bowed head, I passed him by ... When wisdom has been profitless to me, philosophy barren, and the proverbs and phrases of those who have sought to give me consolation as dust and ashes in my mouth, the memory of that little, lovely, silent act of love has unsealed for me the wells of pity: made the desert blossom like a rose, and brought me out of the bitterness of lonely exile into harmony with the wounded, broken, and great heart of the world.

Oscar Wilde - *De Profundis*

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CHAPTER 1

ORIENTATION

1.1 INTRODUCTION

This study is aimed at determining an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making. It can be argued that one of the most remarkable developments in medical ethics, as this field of study (now named "bioethics") was "reborn" in the course of the 20th century, has been the ever-increasing insistence on (some would even say clamour for) the involvement of a patient in his/her own medical treatment. The requirement of "informed consent" from the patient for any intervention in/on his/her body has, some will argue, become the holy grail of bioethics. Informed consent, as has persuasively been argued by a host of ethicists, none the least of which are Tom Beauchamp and James Childress in their seminal *Principles of Biomedical Ethics*, is a non-negotiable ethical desideratum that is grounded in the now equally famous "Principle of Respect for the Autonomy of Persons". Much attention will, in the course of this study, be paid to the intricacies of what this principle entails.

This dissertation fundamentally asks the question: What is the role of reliable information in a patient's ability to give informed consent and to thus become a meaningful player in the chain of actions that will, hopefully, result in efficacious medical treatment for him or her? More particularly, how can the idea of "evidence-based patient choice" - a central aspect of informed consent and not to be confused with evidence-based patient choice as partnership model in clinical decision making - be so understood that, in eventually arriving at an informed treatment choice, a patient will do so in a manner that is a sincere and credible expression of his/her personal autonomy? The notion of "evidence-based patient choice" simply refers to the (as will be argued, *moral*) requirement that patients' treatment choices be based on adequate evidence that a certain line of treatment will be the most efficacious in the particular situation of the relevant patient. The issue therefore also is not simply that of a desirable choice in general, but a choice that is *individualised* for this particular patient in his/her particular circumstances. What is pivotal for this problematic, is the phenomenon of *information*: what it is, how it functions, what role it can (and does) play in medical therapy, what its relationship is to ethics (i.e. whether the communication of information has ethical dimensions, and, if so, what they are), how is it best to be attained, and, central for the eventual argument in this piece, what roles specific

professionals might play in mediating relevant and accessible information to patients - in such a way that their autonomy is optimally respected and provided the leeway to function.

The specific objective of this study is therefore to analyse the current situation with regard to the involvement of patients in clinical decision making through a critical evaluation of evidence-based patient choice as partnership model in clinical decision making and to in view of this evaluation, make a contribution to the debate regarding this increasingly urgent matter.

With regard to this objective, this chapter provides an exposition of the general context and resulting rationale of the study, the theoretical context in which the study will be conducted, as well as the research approach, methodology, structure and desired outcome of the study.

1.2 GENERAL CONTEXT AND RATIONALE OF THE STUDY

There is an international increase in awareness that patients are not only able, but should also be allowed to play an important role in deciding on their care, in defining ideal care and in generally improving health care delivery. This trend is reflected in a host of new concepts like patient-centred care, patient empowerment, patients as partners, shared decision making and informed choice and is also evident in a variety of current theoretical perspectives. While from an ethical perspective, patient autonomy is increasingly being regarded as a basic value and an important goal in health care, the involvement of patients in health care is from a psychological perspective recognised as the key to better adherence to advice and treatment and, therefore, to better health outcomes. Also from an epidemiological perspective, patients are increasingly seen as rational beings that are able to, after being properly informed about the advantages and disadvantages of treatment options, decide on relevant alternatives. It is however argued that whatever approach is adopted, the involvement of patients in decisions about health care remains important for a number of reasons. To these belong that patients are nowadays much better informed than previously, are in possession of information that is of importance, but often unknown to health care professionals, that their needs differ considerably from those of professionals and that often the effectiveness of treatment depends on the cooperation of the patient (Grol 2002:xvi). Most importantly, as was suggested above, is the argument from personal autonomy: patient choice is a moral desideratum because it gives expression to informed consent as based in the moral requirement that patients' personal autonomy, and thus their right to act on their own behalf, be respected.

Furthermore, the emancipation of the patient in health care is expected to cause considerable changes in the relationship between patients or consumers and their health care providers. While

there has for quite some time been concern about the paternalistic attitudes of health care professionals, there currently is a further and growing concern that unrealistic expectations of patient autonomy and consumerism might foster *laissez-faire* attitudes and a loss of morale among health care professionals. It is also increasingly recognised that health care professionals in future will have to strike a balance between losing their clients and failing to cope with consumerist expectations and that patients need to achieve a balance between their own expectations and the means of their health care systems (Grol 2002:xvii).

In view of the above mentioned scenarios, many different approaches have already been employed to empower and involve patients in clinical decision making. To these not only belong the two important movements of evidence-based and patient-centred medicine, but also communication training of health care professionals and the development of amongst others needs assessment tools, interactive educational material, informational websites and various types of decision aids.

However, enormous challenges remain. Traditional theories and anecdotal experiences still dominate the debate and continuing developments, while research evidence on the value and effectiveness of these new approaches continues to be inconsistent. Moreover, the individualisation of the provision of information is still regarded as the great challenge of evidence-based medicine,¹ since the latter seemingly remains unable to resolve competing claims of different interest groups and there are also indications that increased patient choice does not necessarily support patient autonomy or health care reforms (Grol 2002:xvi).

What is meant by individualisation as the great challenge of evidence-based medicine? It is commonly recognised that knowledge, whether expressed as facts or guidelines, is usually based

¹ Refer for instance to the following quotation from Elwyn and Edwards: "Although this book concentrates on individual choices within clinical consultations we nevertheless recognise that this process cannot, and should not, be considered in a vacuum but should be placed in the wider discourse of health care delivery to populations. Most of the examples in this book are from medical settings in the developed world, where professionals and patients are engaged in the process of redefining roles. Although the detail of these examples will seem hypothetical to four of the six billion people on the globe who live in grinding poverty, the basic principles at the heart of the relationship between the professional and the patient are just as relevant, even if the choices available are more restricted. In many ways, this is the dilemma that faces any discussion about choice ... Nevertheless, even in developed consumer economies, the issue of providing individual choice is bound to cause tension between individuals and society. The arguments in political science and economics about public choice and the extent to which the 'free riding' occurs on collectively organized benefits are issues that deserve much more attention than we have been able to give them in this volume. It is instructive how public choice scholars think about this area. Choice, they state, is the act of selecting from alternatives. 'Public' refers to people. But people do not choose. Choices are made by individuals, and these may be private or public. Private choices are made in the course of daily living, and are usually narrowly circumscribed. Public choices are made when an individual selects among alternatives for others as well as for himself. Traditional economic theory has been narrowly interpreted to include only the private choices of individuals in the market process and traditional political science has rarely analysed individual choice behaviour and how it is to be regulated to ensure a wider good. As Hardin notes, 'the narrow rationality of self interest that can benefit us all in the market exchange can also prevent us from succeeding in collective endeavours [sic]'" (Elwyn & Edwards 2002:3-4).

on information that has been obtained through the study of groups of patients or of populations (Muir Gray 2002:30). The statement "screening for high blood pressure is an effective means of preventing strokes" might for instance certainly be true when applied to populations. However, the question of interest to the individual health care professional or patient is what the effect, good or bad, will be on a particular individual? Individualisation has been identified as a central trend in modern society which developed due to the dissolution of the welfare consensus that dominated the industrial countries up to the late 1970s, as well as to the final discrediting of Marxism and was coupled to all the profound social, economic and technological changes that brought these about. The emphasis on the individual therefore complemented and perhaps even resulted from the apparently opposite trend of globalisation and from the recognition that although people are all members of a global society, this does not diminish their individuality (Giddens 1998). The individual in the twenty-first century therefore not only expects, but has also acquired a right to be offered information about the probabilities of risk and benefit as it affects them as individuals. It can therefore be summarised that "individualisation" refers to the need to make patients choices relevant for individual patients in their individual situations.

In this regard, Kerridge et al. note that although evidence-based medicine is based on strong ethical and clinical ideals, it remains unable to resolve competing claims of different interest groups. Moreover, the collecting of satisfactory evidence continues to pose a challenge and it is feared that a crude application of results of clinical trials to individual care may disadvantage some patients (Kerridge et al. 1998:1151-1153).²

With reference to its strong ethical and clinical ideal, it is argued that evidence-based medicine identifies the best evaluated methods of health care in order to facilitate better informed decisions and leads to improvements in clinician's knowledge, reading habits and computer literacy. Furthermore, it is claimed to allow junior members of the team to contribute to decisions and facilitates better communication with patients and a more effective use of resources (Bastian 1994). However, indications are that even the availability of reliable information does not ensure better decisions. This, it is argued, is due to the fact that medical decision making is dependent on a broad spectrum of knowledge, including scientific evidence, personal experiences and values, philosophical principles and even economical and political considerations.

The fact that evidence-based medicine remains unable to resolve competing claims of different interest groups is therefore attributed to the fact that many important outcomes cannot be

² See also Dowie 1996:104-113.

adequately measured or defined; that it is often not clear whose interests should be considered in the determining of outcomes and those decisions may be regarded as unethical from other points of view. Whereas evidence-based medicine can be regarded as a practical example of consequentialism and claims to provide a simple and logical process for reasoning and decision making, some outcomes of medical treatment remain immeasurable and even indefinable and may therefore make it impossible to decide between competing claims of different stakeholders. Moreover, due to the fact that evidence-based medicine assesses interventions solely in terms of evidence of efficacy, it may lead to decisions in for instance meta-analysis that are at odds with common morality (Smith 1997:1059-1060). Also with regard to the challenge of the collecting of satisfactory evidence, it is recognised that randomised controlled trials are only possible where there is genuine therapeutic equipoise. While equipoise³ is not normally regarded as a problem in large clinical trials designed to explore treatment options aimed at moderate effect sizes, it may not be achievable in cases where proposed interventions may have very big benefits, or major risks (Yusof et al. 1984:409-420).

In addition and with specific reference to the use of decision aids⁴ in empowering patients, the question is also raised whether the informing of patients of existing choice options indeed support patient choice?⁵ It is noted that while patient choice is gaining popularity amongst policy makers as a way of transforming health care, there are also indications that increased patient choice does not necessarily support patient autonomy or health care reforms and that the latter may instead be enhanced by less choice.

As a case in point, Holmes-Rovner refers to a recently formulated set of standards for the presentation of data concerning different choices presented in a decision aid. According to these standards, a patient decision aid:

- Describes the health condition related to the decision.
- Lists the health care options.

³ "The ethics of clinical research requires equipoise - a state of genuine uncertainty on the part of the clinical investigator regarding the comparative therapeutic merits of each arm in a trial. Should the investigator discover that one treatment is of superior therapeutic merit, he or she is ethically obliged to offer that treatment. The current understanding of this requirement, which entails that the investigator have no "treatment preference" throughout the course of the trial, presents nearly insuperable obstacles to the ethical commencement or completion of a controlled trial and may also contribute to the termination of trials because of the failure to enroll enough patients. I suggest an alternative concept of equipoise, which would be based on present or imminent controversy in the clinical community over the preferred treatment. According to this concept of "clinical equipoise," the requirement is satisfied if there is genuine uncertainty within the expert medical community - not necessarily on the part of the individual investigator - about the preferred treatment." (Freedman, <http://www.ncbi.nlm.nih.gov/pubmed/3600702>)

⁴ The use of decision aids in clinical practice is recognised as one of the key skills of evidence-based patient choice and there are many publications attesting to their usefulness. See for instance Guin and Donaldson 1991:123-128; Agre et al. 1994:271-276; De Roubaix 2005:125-129; De Roubaix 2006:199-205.

⁵ Holmes-Rovner: <http://www.bioethics.msu.edu/mhr/07W/Holmes-Rovner.htm>

- Provides the option of choosing none of the health care options (e.g. doing nothing).
- Describes what happens in the natural course of a health condition if none of the health care options are chosen.
- Provides information about the procedures involved (e.g. what is done before, during, and after the health care option).
- Provides information about the positive features of the options (e.g. benefits, advantages).
- Provides information about the negative features of the options (e.g. harms, side effects, disadvantages).
- Provides information about outcomes of options (positive and negative) and includes the chances they may happen.
- Provides information about diagnostic tests and what the test is supposed to measure.
- Provides information about the chances of receiving a true positive, true negative, false positive and false negative test result.
- Describes possible next steps based on the test results.
- Provides information about the chances of disease being found with and without screening.
- Provides information in screening about detection and treatment of disease that would never have caused problems if screening had not been done.

However, conspicuously absent from this list, she says, is an indication of what could be regarded as the *best* answer for a particular individual with specific risks. She writes: "In the shared decision making and decision support movement, we have shied away from presenting a rational 'best' choice. Population-relevant answers probably are not offered because decision supports are largely designed to help individuals. At the individual level, there are two reasons for not revealing a 'best' answer. One is the belief that patients should always have the right to be 'irrational' if they are fully informed. The other is that measurement error in model construction and in patient value elicitation is simply too large to support recommending specific choices as being the best for a particular patient. Health care professionals for well-intentioned reasons often do not present recommendations resulting from a technology assessment of information designed to directly aid patients in making decisions about their own health choices. However, I argue that in doing so they may ultimately defeat the very objectives

they mean to endorse, both in terms of supporting healthcare reform and supporting shared decision making and patient autonomy".⁶

Whereas increased patient choice in healthcare reform is motivated by a decrease of costs in the use of health care services and by efforts to please the public by offering more control over health care, the theory underlying these motivations suggests that patients' self-interest is different from that of health care providers and that deliberation will therefore not only put patients' interests first, but also decrease costs. However, evidence to date indicates that the involvement of patients in clinical decision making has only decreased demand in a number of conditions, such as the use of hysterectomies, screening and treatment for prostate cancer and the choice between mastectomies and breast conserving treatments (Whelan et al. 2004:435-441). In having to deal with the majority of clinical problems, patients tend to follow their doctors in decisions on treatment. Whereas this tendency could be interpreted as trust in doctors' opinions, increases in demand for treatment options can however also be attributed to social and commercial forces such as consumerism.

With regard to the support of patient autonomy by the use of decision aids, it thus remains an open question exactly how much and what type of choice would enhance patient autonomy? It is furthermore argued that a reluctance to provide a weighted evaluation of options reflects a misunderstanding of the moral requirements related to respect for patient autonomy and equally fails to take account of contemporary research in the field of the psychology of choice. In response, Quill and Brody therefore for instance reject the independent choice model in favour of the enhanced autonomy model and instead propose a dialogue in which patients and health care professionals aim to influence each other and which allows the patient a full appreciation of the medical options (Quill & Brody 1996:763-769). Regarding her support for this approach, Holmes-Rovner writes: "When a decision-maker (patient) has limited competence or information and the physician does not offer guidance, the patient cannot then benefit from the available expertise and support. Systematically laying out pros and cons of each choice, as is done in good decision aids, is an important start. However, people have limited capacity to process information; recent research has amply demonstrated that the more choices we are asked to process, the less well we are able to do so. Furthermore, people become overwhelmed and are unable to choose at all when choices proliferate. Providing patients with the analytically 'best' choice and the reasons for it makes the decision making process simpler for patients while still

⁶ Holmes-Rovner: <http://www.bioethics.msu.edu/mhr/07W/Holmes-Rovner.htm>

allowing them to critically reflect on their values, goals, and preferences - that is, allowing them to make an autonomous decision".⁷

With regard to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making it is therefore argued that a bridge between evidence-based medicine and guidelines on the one hand and the empowering and involving of patients on the other is urgently needed. It is also recognised that new approaches to interaction between health care professionals and patients or consumers need to be developed, along with a new conceptualisation of patient-centred care, perhaps as dialogue-centred care in which there will be shared responsibilities and mutual rights and obligations in health care (Grol 2002:xvii).

In view of these challenging circumstances, evidence-based patient choice is regarded as an important contribution to the development of partnership models aimed at establishing and maintaining patient autonomy in the involvement of patients in clinical decision making. However, despite the fact that evidence-based patient choice emphasises the importance of the provision of information in the involving of patients in clinical decision making and is inspired by the ethical principles of autonomy and beneficence, it is recognised that it has as yet not seen widespread acceptance and implementation in clinical settings (Holmes-Rovner et al. 2002:270). While evidence-based medicine eventually exerted an unparalleled influence on medicine, the representatives of its recent extension into the realm of patient choice are apparently facing an even more arduous journey than the pioneers of evidence-based medicine. Reasons for this state of affairs are diverse. Whereas many fear that introducing unfettered choice may result in the slippery slope of unbridled and inappropriate consumer demand for health care and that the treatments that are demanded may overstretch agreed upon resources (Holmes-Rovner et al. 2002:271), others acknowledge that clinical practice has proved to be very resistant to change and that the concept of patient choice might not have sufficient inherent force to overcome this resistance (O'Connor et al. 1999).

However, despite these less than ideal realities and projected outcomes, evidence-based patient choice is still regarded as pointing the way to a potential future scenario of health care in which patients and professionals will operate as real partners, have shared goals and will make shared decisions on the best management of health care problems (Grol 2002:xvii) and is furthermore

⁷ Holmes-Rovner: <http://www.bioethics.msu.edu/mhr/07W/Holmes-Rovner.htm>

considered to be of considerable significance to health care professionals in addressing the ever present threat of litigation.⁸

It is however also argued that effective evidence-based patient-centred health care would only be possible within a deliberative context, since any ethical approach to clinical decision making should be able to accommodate both the moral status of the individual and the moral significance of the social dimensions of such choices (Parker 2001:87). This implies that an ethical approach to decision making in health-care should be capable of taking seriously both the moral status of the individual (and of his or her choices) and the social dimensions of such choices. It is argued that the best way to satisfy these demands is through the encouragement of processes of deliberation and public reasoning and that the justification for this emphasis on deliberation is to be found in its central role in the development and enhancement of personal autonomy. The apparent opposition between the individual and the social could therefore be spurious, for it is considered that the best way to ensure respect for the principle of autonomy is to facilitate and encourage social processes of a particular and deliberative kind. Such processes can be expected to take a wide range of forms: from patient-practitioner consultations, to the involvement of family members in decision making and perhaps even consensus conferences or deliberative opinion polls to decide matters of wider concern. In all cases however, such processes would have to be guided by ethical principles fundamental to the creation and sustenance of practices and communities which are conducive to the development and expression of personal autonomy (Parker 2001:90).⁹

⁸ Refer for instance to the following comments by Muir Gray regarding the proposed value of evidence-based patient choice in combating litigation: "So much for the evidence. What about its implications for patient choice and litigation outside the United States? The review group wisely avoided the temptation to classify implants as 'safe' but did state that silicone gel breast implants 'are not associated with any greater health risk than other surgical implants'. It did, however, emphasise that there is 'no evidence of an association with an abnormal immune response or typical or atypical connective tissue diseases or syndromes'. The report focuses on the need for evidence based patient choice, and perhaps the most interesting section, certainly for United Kingdom readers, is the chapter on 'Consent to medical treatment' - which emphasises the need for full, clear, and written information. The reaction of those women who make the choice - the term 'patient' seems inappropriate - was expressed and polarized in an exchange of letters in the 'Guardian' in the summer between Maxine Heasman, founder of the Breast Implantation Information Society and author of 'The Ultimate Cleavage', and Yvonne Roberts. Ms Heasman saw the report as giving comfort to 'thousands of women who have been worrying unnecessarily as a result of public scaremongering ... Now that women have been given the all clear, women can make an informed choice. 'How many times have we been given authoritative medical opinion only to discover that these men are fallible human beings?' Her main argument is, however, not against the experts but based on the values of women who choose to have silicon gel breast implants. There, hopefully, the debate will rest, in the United Kingdom at least. By clarifying the evidence the review group should keep the issue out of the courts, except where it can be shown that the women has not been given sound written information - and this is perhaps the main consequence of this saga. For the first time the need for patients to have 'full knowledge' has been explicitly described in a document of this type. As we move into an era in which knowledge will be the dominant commodity, the provision of best current knowledge to patients and carers will have to become standard practice" (Muir Gray 1999:414).

⁹ See also Parker 1995.

In its exploration of an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, the study therefore takes its point of departure in a critical evaluation of evidence-based patient choice in order to not only determine the grounds on which this partnership model, despite all its limitations, is still regarded as pointing the way to a potential future scenario of health care in which patients and professionals will operate as real partners, have shared goals and will make shared decisions on the best management of health care problems, but to also illuminate the challenges it encounters in the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

On the basis of this evaluation and drawing on the conclusion that the challenges of evidence-based patient choice all amount to the challenge of the individualisation of the provision of information in health care, the study will, with regard to the evidence-based patient choice insistence on unprecedented access to information, argue that from an information science perspective, it is considered as impossible to tap into the real value of information resources and technologies without a clear understanding of the human processes involved in the transformation of information (Chun Wei Choo 1998:1). It will therefore moreover be argued that the mere recognition of the importance of the provision of information and the provision thereof through predominantly technical means in evidence-based patient choice is inadequate. Instead, it will be argued that the provision of information in health care needs to be individualised by embedding it in a clear understanding of the human processes through which information is transformed into insight, knowledge and action.

Furthermore, it will be argued that the employment of the therapeutic value of information in a broadened understanding of the generic concept of information therapy will not only thoroughly individualise the provision of information in health care and consequently provide an adequate approach to establishing and maintaining patient autonomy in the involvement of patients in clinical decision making, but also reveal why information science considers it impossible to tap into the real value of information resources and technologies without a clear understanding of the human processes involved in the transformation of information into insight, knowledge and action.

In conclusion, the study will argue that a broadened understanding of the generic concept of information therapy will not only provide an adequate approach to the individualisation of the provision of information in health care and establishing and maintaining patient autonomy in the involvement of patients in clinical decision making, but will also pave the way for a

reconciliation of the opposing perspectives of patients and doctors in a therapeutic alliance and for the establishment of an ethics of responsibility in health care. In this regard, it will be argued that the human processes through which information is transformed into insight, understanding and action are closely related to other human activities such as intentionality and therefore also extends and renders explicit the mysterious human processes through which the lifeworld is constituted. It will be argued that it is this extension and explication of acts of consciousness that enables shared meanings in health care and a scenario in which patients and health care professionals can operate as real partners, have shared goals and will make shared decisions on the best management of health care problems.

1.3 THEORETICAL CONTEXT OF THE STUDY

The study provides philosophical and ethical perspectives on the matter of the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making and is therefore conducted within the following theoretical contexts.

In Part I, the critical evaluation of evidence-based patient choice as partnership model in clinical decision making is conducted in the context of and exploration of the ethical principle of respect for autonomy as represented in the consent elements of competence, disclosure, understanding and voluntariness. In this regard, the following questions will be directive:

Acknowledging that specifically in medical contexts, a person would be regarded as competent if able to understand a therapeutic or research procedure, to deliberate regarding its major risks and benefits and to make a decision in the light of this deliberation, the study would like to determine to what extent shared decision making as key skill of the evidence-based patient choice model succeeds in establishing and maintaining patients' competence in clinical decision making.

In recognition of the subjective standard of disclosure which judges the adequacy of information disclosure by reference to the informational needs of the individual person, rather than to that of the hypothetical reasonable person, the study would like to establish whether risk management as a second key skill of the evidence-based patient choice model adequately provides for the disclosure of information to patients.

Employing the principle that persons understand if they have acquired pertinent information and have justified and relevant beliefs about the nature and consequences of their actions, the study would like to inquire to what extent individual patients' understanding is facilitated by decision analysis as a third key skill of the evidence-based patient choice model.

Interpreting the norm of voluntariness in the sense that a person acts voluntarily to the degree that he or she wills an action without being under the control of another individual or some form of debilitating influence, the study would like to determine to what extent the use of decision aids as a fourth key skill of evidence-based patient choice model succeeds in protecting patients against the influence of approaches such as paternalism.

In Part II, and drawing on the conclusions of the critical analysis of evidence-based patient choice conducted in the first part, recommendations for the transformation of evidence-based patient choice to a therapeutic alliance in health care will be offered and argued for in a philosophical context and will be directed by the following themes:

Acknowledging that evidence-based patient choice brings together the two important movements of evidence-based and patient-centred medicine and derives its inspiration from two great philosophical ideas, namely the empirical tradition initiated by John Locke and the thought of Søren Kierkegaard who argued for decision making as the most important human activity, the study will further explore and develop the philosophical foundations of evidence-based patient choice in order to illuminate the complexity of the challenges posed by the individualisation of the provision of information in the context of personal identity.

Furthermore and cognisant of the complexities attached to a contemporary understanding of the concept of personal identity, the study will consider the continental philosophical perspectives of Edmund Husserl, Jean-Paul Sartre, Maurice Merleau-Ponty and Jürgen Habermas on the evidence-based patient choice challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and abstractions and informational manipulation in health care in order to illuminate the complexities attached to the application of the ethical principle of respect for autonomy in medical practice.

Finally and drawing on the conclusions derived from the discussion, the study will make philosophical recommendations regarding the transformation of the practice of evidence-based patient choice to a therapeutic alliance in health care.

1.4 RESEARCH APPROACH, METHODOLOGY AND STRUCTURE OF THE STUDY

The study will follow the research approach of conceptual analysis and will conduct this analysis according to the following methodology.

In Part I, a critical evaluation of evidence-based patient choice as partnership model in clinical decision making will be conducted through an evaluation of its four key skills in terms of the

ethical principle of respect for autonomy as represented in the informed consent elements of competence, disclosure, understanding and voluntariness. This analysis will be used to identify the core elements, as well as the challenges in transforming evidence-based patient choice to a therapeutic alliance in health care.

In Part II, the analysis of the options for the transformation of evidence-based patient choice to a therapeutic alliance in health care, will be conducted by a combination of a conceptual analysis of the philosophical foundations of evidence-based patient choice and the relevance of continental philosophical perspectives on the challenges of evidence-based patient choice and by a philosophical argument for the transformation thereof.

This approach to and methodology in conducting the study will be displayed in the following structure.

In Part I, Chapter 2 will trace the emergence and development of the concept of patient autonomy in ethical thinking since its inception in the sixteenth century to its applications in the twenty first century. It will pay attention to the emergence of the concept in modern moral philosophy and in particular to the pivotal contributions of Immanuel Kant and John Stuart Mill in this regard. Against this background, the chapter will elaborate on the ethical principle of respect for autonomy and informed consent as paradigm for patient autonomy in clinical decision making, but also on the conflicts that arise between the ethical principles of autonomy and beneficence and on the dominance that paternalism used to enjoy in clinical decision making. The chapter will close with an exposition of the challenges posed to the dominance of paternalism, the resulting emergence of the concept of partnership in clinical decision making and evidence-based patient choice as partnership model in clinical decision making.

Against this background and in continuation of Part I, Chapter 3 will provide an exposition of the context, nature and practice of evidence-based patient choice. Reference will be made to important political, economic and ethical developments such as a change in rhetoric depicting patients as consumers, the narrowing of the gap between expert and lay knowledge, an increasing emphasis on patient rights and autonomy, as well as on the accountability of the public services that since the mid 1990s constituted the context in which medicine was to move forward under the banner of evidence-based patient choice. In addition it will be noted that evidence-based patient choice advocates the sharing of good quality evidence-based information and respect for patient preferences and involvement in health care, is aimed at providing patients with evidence-based information in a way that facilitates their ability to make choices and decisions about their health care and as such, brings together two important movements in

modern medicine. In the last paragraph of the chapter it will be argued that the practice of evidence-based patient choice is directly related to its nature and can be conceptualised in terms of four key decision making skills required from health care professionals to involve patients in clinical decision making, namely shared decision making, risk communication, decision analysis, and the use of decision aids.

Against the background of the discussion in Chapters 2 and 3, Chapter 4 will critically evaluate evidence-based patient choice as partnership model in clinical decision making by evaluating it in the light of the ethical principle of patient autonomy as reflected in the informed consent elements of competence, disclosure, understanding and voluntariness. It will be indicated that, judged against these elements and due to a wide variety of reasons, none of the key skills of evidence-based patient choice can be regarded as completely adequate in honouring the principle of respect for autonomy in clinical decision making and that huge gaps still exist between the ideal and current practices of evidence-based patient choice. It will also be shown that consequently each of these four key skills leave evidence-based patient choice with a challenge that needs to be addressed from another angle in order to establish and maintain the ethical principle of respect for autonomy.

Against the background of the discussion in Part II and as a first recommendation for the transformation of evidence-based patient choice to a therapeutic alliance in health care, Chapter 5 will review and further explore the philosophical foundations of evidence-based patient choice. It will trace the ideas of John Locke who initiated the empirical tradition and indicate that the legacy of his distinction between the primary and secondary qualities of knowledge is still perceptible in not only the ontological and methodological assumptions of the natural science paradigm, but also in the constitution of the clinical method. Similarly, it will outline the thought of Søren Kierkegaard who argued for decision making as the most important human activity and also indicate that the traces of his thought are still to be found in the four key skills of evidence-based patient choice. In addition, the chapter will indicate that although the philosophical thought of John Locke and Søren Kierkegaard seem widely divergent, the concept of personal identity seems to have interested both and will continue to analyse this shared interest in terms of an investigation of a significant feature of many contemporary Neo-Lockean discussions of the concept of personal identity. With reference to this feature, namely the perceived dichotomy between the self understood as a human being with its various forms of physical, psychological and social continuity and history and the self understood as the present locus of psychological experience, the chapter will however also argue that the threat of the bifurcation of self and person encountered in the thought of John Locke and Søren Kierkegaard

is not only a matter of academic interest, but is also perceptible in medicine in general and in the practice of clinical decision making in particular and is to be understood within the larger context of a universal interest in the concept of the self. The chapter will close with a discussion of the complexities attached to the contemporary understanding of personal identity.

As a second recommendation for the transformation of evidence-based patient choice to a therapeutic alliance health care, Chapter 6, will in view of the central position of the self in continental philosophy and in the phenomenological method, consider continental philosophical perspectives on the evidence-based patient choice challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and the danger of abstractions and informational manipulation in health care. The chapter will in succession discuss the perspectives of Edmund Husserl on the separate worlds we live in, of Jean-Paul Sartre on the distinct levels of the constitution of meaning in illness, of Maurice Merleau-Ponty on the transcendental role of the body in human existence and of Jürgen Habermas on the elimination of paternalism/authoritarianism in society and will close with a discussion of the complexities attached to the application of the principle of respect for autonomy in medical practice.

Against the background of the discussions in Chapters 5 and 6 and as a third and final recommendation for the transformation of the current practice of evidence-based patient choice to a therapeutic alliance in health care, Chapter 7 will discuss a broadened understanding of the generic concept of information therapy as an adequate approach to the individualisation of the provision of information in health care and consequently also to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, the information therapist as a postmodern ethics consultant and information therapy as an approach to the establishing of a therapeutic alliance in health care.

1.5 DESIRED OUTCOME OF THE STUDY

The desired outcome of the study is to determine an adequate approach to the individualisation of the provision of information in health care and consequently also to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making to serve as a foundation for a therapeutic alliance in health care and for the eventual training and integration into the health care system of people practising in this capacity.

PART I

A Critical Evaluation of Evidence-Based Patient Choice as Partnership Model in Clinical Decision Making

INTRODUCTION

As stated in Chapter 1, the specific objective of this study is to analyse the current situation with regard to the involvement of patients in clinical decision making through a critical evaluation of evidence-based patient choice as partnership model in clinical decision making and to in view of this evaluation, make a contribution to the debate regarding this increasingly urgent matter.

In order to perform a critical evaluation of evidence-based patient choice, Part I of the study is devoted to a threefold task.

Employing the ethical principle of patient autonomy as a measure for the critical evaluation of evidence-based patient choice, Chapter 2 traces the emergence and development of this concept since its inception in the sixteenth century to its applications in the twenty first century.

In turn, Chapter 3 provides an exposition of the context, nature and practice of evidence-based patient choice as partnership model for the involvement of patients in clinical decision making.

Against this background, Chapter 4 critically evaluates evidence-based patient choice by analysing it in terms of the ethical principle of respect for patient autonomy as reflected in the informed consent elements of competence, disclosure, understanding and voluntariness.

CHAPTER 2

PATIENT AUTONOMY: ORIGINS, CONTENT AND CHALLENGES

INTRODUCTION

In view of the aim of Part I, namely to critically evaluate evidence-based patient choice as partnership model in clinical decision making by judging it in terms of the ethical concept of respect for patient autonomy as reflected in the elements of informed consent, this chapter traces the emergence and development of the concept of autonomy in ethical thinking since its inception in the sixteenth century to its applications in the twenty first century. It therefore firstly pays attention to the emergence of the concept in modern moral philosophy and in particular to the central contributions of Immanuel Kant and John Stuart Mill in this regard. Against this background, the chapter elaborates on the ethical principle of respect for autonomy and informed consent as paradigm for patient autonomy in clinical decision making, but also on the conflicts that arise between the ethical concepts of autonomy and beneficence and on the dominance that paternalism used to enjoy in clinical decision making. The chapter closes with an exposition of the challenges posed to the dominance of paternalism, the resulting emergence of the concept of partnership in clinical decision making and of evidence-based patient choice as partnership model in clinical decision making.

2.1 THE EMERGENCE OF MODERN MORAL PHILOSOPHY

The tradition of Western moral philosophy originated in ancient Greece when Socrates, Plato and Aristotle started deliberating on the question "how a man should live in order to achieve happiness?" (Rowe 1999:123). While already in these early days it was intended that virtue should govern one's relations with others, it was foremost an attaining of the good for oneself. Christianity brought about a change by teaching that the ultimate good could only be achieved through salvation and furthermore hampered the pursuit thereof by the insistence on obedience to the commands of God. The gradual demise of the traditional view that morality had to come from an authoritative source outside of human nature and of the ideas of the ultimate good and of the will of the Christian deity, however coincided with the emergence of modern moral philosophy and the view that morality might also occur from within human nature itself. As such, modern moral philosophy represented a shift from the view that morality had to be

imposed on human beings, towards the belief that morality could be understood as human self-governance or autonomy. The first stage of this new approach to moral deliberation took effect with the essays of Montaigne and culminated in the work of Kant, Reid and Bentham (Schneewind 1999:147-152).

Michel de Montaigne's (1533-1592) times were characterised by a European society that increasingly became diversified, self-reliant and literate, but also by seemingly endless and ferocious wars that necessitated the peaceful settlement of political disputes. Although everybody still took religion to be somehow essential to morality, Christianity could no longer be regarded as a guideline, since was split so deeply by Protestantism that agreements could not be reached on religious grounds anymore (Schneewind 1999:147). Moreover, universities persisted in lecturing substandard versions of the ethics of Aristotle that could hardly address the pressing needs of the time. While not yet able to supply an alternative, Montaigne radically challenged both the ideas of the good life as suggested from ancient times and of Catholicism as too far removed from reality and from his view of authoritative morality which held that apart from the laws of the country there are no clear norms that govern social and political life and that individuals therefore should personally find a way of life that suits their nature (Montaigne 1965).

This trend was continued in the seventeenth century when Thomism was still considered to be the dominant moral tradition. This tradition claimed that there are principles concerning public life that are available to human reason independent of revelation and free from Christian bias and had the advantage that it was accepted by both Catholics and Protestants. Its major teachings were that man is required by the laws of God to act in ways that, whether recognised or not, are for the benefit of all people and that these principles could be known by at least those who could instruct the rest. Moral thought in the seventeenth century thus took its departure in the theories of classical natural law, viewing humans as beings that were created to express God's glory and to play a part in a divinely ordained community. However, it also witnessed the emergence of the modern natural law assertion that individuals are entitled to determine their own purposes and that morality comprises the conditions under which these can best be pursued (Schneewind 1999:148).

Hailed as the originator of this outlook, Hugo Grotius (1583-1645) was the first to claim that rights can be regarded as natural attributes of the individual and are independent of any contributions that can be made by an individual to society. He maintained that man is by nature a sociable creature, but that when engaged in political societies, it should be on condition that

individual rights are respected, since man is naturally entitled to make decisions concerning his own life within the realm created by his rights (Grotius 1925).

In turn, Thomas Hobbes (1588-1679) denied the concepts of the natural sociability of man and of an ultimate good, but stressed man's self-interested aims and the fact that he is continuously looking for ways of protecting himself from death. Since all men are engaged in these endeavours, strife and even war is almost inevitable, unless men can come to the agreement to be ruled by a sovereign that will be able to enforce peace while all are pursuing their private goals. The laws of nature and morality are therefore ultimately no more than indicators of the most important actions to be taken to ensure an orderly society in which man's limitless desires can be managed. However, the idea that a political society has its roots in a social contract also made man and not God the creator of the secular powers that govern him. This view was accepted by seventeenth century proponents of natural law who also argued that humans are disorderly beings in need of strong control by governments - a view that would be further developed by Locke (Hobbes 1946).

John Locke (1632-1704) strongly supported the inalienability of basic human rights and therefore opposed Grotius and Hobbes in stating that there should be moral limits even to what a government may do. However, he agreed with his contemporaries that although the laws of nature can be regarded as guidance to the individual as well as common well-being of man and man might be competent in setting up a decent political order, most people remain in need of guidance by means of the threat of punishment to ensure that the majority behave decently (Locke 1988).

The late seventeenth and eighteenth centuries saw a change from viewing morality as imposed on human nature to that of morality as an expression of human nature. While Pierre Bayle in 1681 caused a major uproar by claiming that a group of atheists could form a perfectly decent society (Schneewind 1999:149), Lord Shaftesbury argued that man has a moral faculty at his disposal that enables him to judge his own motives and that acts can therefore be judged as virtuous when approved as of a benevolent and sociable nature. He even extended the abilities of this human moral sense to determining whether divine commands had their origins in God or in some demon and thereby established morality as an outgrowth of human feelings (Shaftesbury 1968).

Inspired by the distinctions of Lord Shaftesbury, the eighteenth century witnessed an increasing interest in the respective roles of the concepts of benevolence and self-interest in human psychology and whether either of them could be regarded as the a single explanation of the ways

in which humans behave morally. Similarly, there were discussions on whether man's moral convictions resulted from his feelings, as indicated by Shaftesbury or from his reason, as argued by the proponents of natural law and whether and to what extent man could be regarded as autonomous? While it was accepted by all that virtue demanded of man to work for the good of others, some maintained that this was to be achieved by moral judgements of agreement and disagreement, while others insisted that it was to be acquired through intuition or direct moral insight. However, in either case it could be argued that all could be aware of the demands of morality, as education could not be regarded as a prerequisite for either feelings or intuition.

Also Hobbes's assertion that morality serves human selfishness engendered a vigorous debate with some criticising his psychology and arguing that man naturally desires the good for others and does not need to be motivated or guided in bringing the good to his fellow man. Others, agreeing with Hobbes, held that the very constitution of nature will ensure that man, when acting for his own best interests, will indeed be serving others. The idea that morality might serve human interest, furthermore inspired some to claim that nothing can be more virtuous than virtue and others that it pays to live a virtuous life, since it assisted the pursuit of own objectives. However, these motivations were despite their diverging nature, unified by a single objective, namely to show that self-interest that has always been ridiculed as the source of all evil, could through its nature lead to virtuous behaviour and that even human nature, considered as selfish, could be regarded as expressing itself through morality. Though no-one participating in these debates seemed able or even willing to identify the good with more than what provided happiness or pleasure, the underlying assumption was that what man ought to do, always represent a function of what it would be good to bring about and that an action could therefore only be regarded as right in view of the good it produces. This deeply rooted concept was to be indirectly and directly challenged by Hume and Kant (Schneewind 1999:150).

David Hume (1711-1776) firmly rejected natural law models of morality and instead insisted that moral convictions should be based on a virtue-centred moral theory. He furthermore argued that morality should be rooted in man's feelings, as reason alone would never be able to motivate moral action. He therefore typified agreement and disagreement as moral feelings, directed at the basic likes and dislikes that motivate man to action and argued that man approves of that which motivates general beneficial action and disapproves of that which might cause harm or injury. Furthermore, while acknowledging that man often acts with self-interest, Hume insisted that man also displays desires for the benefit of others and that regular action arising from these desires would indeed constitute virtue (Hume 1978).

Contrary to Hume, Immanuel Kant (1724-1804) maintained a much more radical version of the view that morality arises from human nature by arguing that morality imposes absolute duties on man that have to be performed under all circumstances and that these duties could only arise from a law imposed by man on himself. As will be argued in greater detail in 2.2, the key to this view is the concept of freedom, since freedom in action excludes any form of determination from outside and solely relies on determination by something from within human nature. Moral obligations can therefore not be derived from natural laws or even from laws imposed by God, but arise from a law that man himself legislates with no requirements to do good to others, but to rather only act in ways that could be rationally agreed to be applicable to all. In thus determining what is right before knowing what is good, Kant offered a far more thorough alternative to the idea that what can be considered as right is always determined by good consequences (Schneewind 1999:151).

While Kant thus held an extreme form of the conception that morality is to be regarded as an expression of human nature, the view that ordinary people can be adequately guided in action by consciously applying abstract moral principles was independently advocated by Reid and Bentham. Thomas Reid (1710-1796) was the founder of the important nineteenth century Scottish school of Common Sense and held that morality embodies common-sense principles of which the truth can be grasped intuitively by all and which can be readily applied (Reid 1969).

On the contrary, Jeremy Bentham (1748-1832) argued that appeals to intuition simply hide the dangerous self-interest of those posing them and instead maintained that his utilitarian principle, namely that we are to act so as to bring about the greatest happiness of the greatest number of people, was rational on the face of it and provided a rational method of making moral decisions (Bentham 1948). With these views, Reid and Bentham concluded the first stage of the emergence of modern moral philosophy from the traditional assumption that morality had to be imposed from some authoritative source outside of human nature to the view that it could be understood as human self-governance or autonomy (Schneewind 1999:152).

This shift towards liberalism in moral deliberations has since inextricably been linked to the names of Immanuel Kant and John Stuart Mill. What makes them jointly liberal in their approach, is their commitment to what Kant called autonomy and what Mill defended as individuality. Kant argued that respect for autonomy flows from the recognition that all persons have unconditional worth, as well as the capacity to determine his or her own moral destiny. To thus violate a person's autonomy would be to treat that person merely as a means and in accordance with others goals without regard to that person's own goals. While Mill was

primarily concerned about the individuality of autonomous agents, he argued that society should permit individuals to develop according to their convictions, provided that they do not interfere with similar expressions of freedom by others, but also insisted that it might sometimes be necessary to dissuade others when they have false or ill considered views (Mill 1991:chs. 1, 3). Kant's position thus entails a moral imperative of respectful treatment of persons as ends in themselves, while Mill's requires both not interfering with, as well as actively strengthening autonomous expression (Beauchamp & Childress 2001:63-64).

2.2 IMMANUEL KANT AND AUTONOMY

Kant argued that morality is based on a standard of rationality which he called the Categorical Imperative and that immorality thus involves a violation of this standard and is therefore irrational.¹⁰ While philosophers such as Locke and Hobbes also argued that moral requirements are based on standards of rationality, these standards were either desire-based instrumental principles of rationality or based on *sui generis* rational intuitions. In this regard, Johnson notes: "Kant agreed with many of his predecessors that an analysis of practical reason will reveal only the requirement that rational agents must conform to instrumental principles. Yet he argued that conformity to the Categorical Imperative (a non-instrumental principle) and hence to moral requirements themselves, can nevertheless be shown to be essential to rational agency. This argument was based on his striking doctrine that a rational will must be regarded as autonomous, or free in the sense of being the author of the law that binds it. The fundamental principle of morality - the Categorical Imperative - is none other than the law of an autonomous will. Thus, at the heart of Kant's moral philosophy is a conception of reason of which the application in practical affairs goes well beyond that of a Humean 'slave' to the passions. Moreover, it is the presence of this self-governing reason in each person that Kant considered as an adequate ground for viewing each person as possessing equal worth and deserving equal respect. Kant's most influential positions are found in *Groundwork of the Metaphysic of Morals* but he developed, enriched, and in some cases modified those views in later works such as *The Critique of Practical Reason*, *Metaphysic of Morals*, *Anthropology from a Pragmatic Point of View* and *Religion within the Boundaries of Mere Reason*".¹¹

Kant's *Groundwork of the Metaphysic of Morals* had the limited and yet all important aim of establishing the supreme principle of morality and therefore excluded a complete exposition of

¹⁰ Schneewind argues that Kant invented the concept of *morality as autonomy* in part in support of conceptions of *morality as self-governance* that had developed in competition with conceptions of *morality as obedience*. Schneewind 1998:3.

¹¹ Johnson 2008: <http://plato.stanford.edu/archives/fall2008/entries/kant-moral/> See also Kant 1964:127.

the *a priori* part of ethics, as well as any applications of this principle, to which he only attended to in his much neglected *Metaphysic of Morals* (Kant 1989:xi-xiii).

In this endeavour, Kant takes his departure in the concept of the good will which he describes as the only thing that can be regarded as good without qualification or restriction. For Kant, a good will alone is good in itself and under all circumstances and in that sense represents an absolute or unconditioned good. While there may be plenty of other things that are good in many respects, none of them are good in all circumstances and may even all be thoroughly bad when used in bad will. On the contrary, a good will retains its own unique goodness even when by some misfortune, it might be unable to produce the results it is aiming at and therefore does not derive its goodness from any of the results which it produces (Kant 1989:1-4).

From this foundation, Kant proceeds by stating that under normal human conditions, which are characterised by a struggle against unruly impulses and desires, good will is manifested in acting for the sake of duty. However, since human goodness is most conspicuous in its struggle against the obstacles created by unruly impulses, goodness should according to Kant not be regarded as consisting in the overcoming of obstacles, as a perfectly good will would have no obstacles to overcome. The concept of duty, which involves the overcoming of obstacles, would not apply to such a perfect will and an examination of the concept of duty is therefore required in order to understand human goodness. Kant thus develops his first proposition about duty by stating that *a* human action is morally good, not because it is done from immediate inclination or from self-interest, but because it is done for the sake of duty. While actions solely done out of self-interest is not commonly regarded as morally good, those done out of some immediate inclination, might be regarded as such. However, when properly analysed, it becomes clear that an action solely done out of sympathy might be right and praiseworthy, but would lack distinctive moral worth. The goodness shown in helping others is all the more conspicuous when done for the sake of duty at times when somebody is fully occupied with his or her own difficulties and when not impelled to do so by natural inclinations. Kant's assumption in this regard is thus that if an action is to be morally good, the motive of duty, while it may be flanked by other motives, must by itself be sufficient to determine the action. He herewith however does not disregard the value of generous inclinations in the performing good actions, but rather stresses the duty to cultivate them and in addition holds that man at least has an indirect duty to seek his own happiness (Kant 1989:8-13).

Following from the first proposition, Kant's second proposition about duty states that an action done from moral duty has its moral worth, not from the results it attains, but from a formal

principle or maxim - the principle of doing one's duty whatever that may be. While the first proposition stated that the unconditioned goodness of goodwill cannot be derived from the conditioned goodness of the results at which it is aimed, this proposition restates the first proposition in a more technical way by demanding its statement in terms of maxims. Maxims are purely subjective principles upon which people act and may be good or bad. Furthermore, Kant regards maxims as subjective principles due to the fact that they, other than objective principles, are manifested in actions that are in fact performed by rational agents. Maxims of action therefore need not be formulated in words, but always represent some sort of general principle under which a particular action is willed and can therefore be regarded as material maxims, as they generalise a particular action with its particular motive and its intended result. The maxim thus providing moral worth to actions is that of doing your duty whatever that may be and is empty of any particular matter, as it is not aimed at satisfying any particular desires or attaining any particular results. Kant therefore also denotes it as a formal maxim, for to act for the sake of duty, is to act on a formal maxim irrespective of all objects of the faculty of desire (Kant 1989:13-14).

To these two propositions about duty, Kant adds a third stating that duty is the necessity to act out of reverence for the law. He herein argues that since the maxim of a morally good action is to be regarded as a formal maxim, it furthermore has to be a maxim of acting reasonably - that is, of acting on a law valid for all rational beings as such independently of their particular desires. Due to human frailty, such a law on the one hand has to appear to man as a law of duty and as one which commands or compels obedience and excites a feeling analogous to fear, but on the other and due to being self-imposed, it has to excite a feeling analogous to inclination or attraction. This complex combination of feelings, Kant circumscribes as reverence that is not due to any stimulus of the senses, but to the thought that an individual's will is subordinate to a universal law independent of any influence of sense. Since the motive of a morally good action is to be found in feeling, it is thus due to it being done out of reverence for the law that provides it with its unique and unconditioned value (Kant 1989:14-17).

With these propositions about duty, Kant typifies the morally good man as not seeking to satisfy his own desires or to attain his own happiness, though he may do both of these, but as seeking to obey a law valid for all men and to follow an objective standard not determined by his own desires. Due to the obstacles of human impulses and desires, this law appears as a law that ought to be obeyed for its own sake and is therefore denoted by Kant as a categorical imperative, stating that I ought never to act except in such a way that I can also will that my maxim should become a universal law (Kant 1989:17-20).

As such, this standard of rationality not only represents Kant's first formulation of autonomy as the supreme principle of morality and as the ultimate condition of all particular moral laws and of all moral judgements, but also lays the foundation for the connection of morality and freedom that is enabled by autonomy. Arguing from the fact that a categorical imperative merely bids man to act in accordance with universal law, Kant in the second chapter of his *Groundwork of the Metaphysic of Morals*, changed the somewhat negative formulation of the categorical imperative in the first chapter to The Formula of Universal Law. Now stated as "Act only on that maxim through which you can at the same time will that it should become a universal law", he joined this formula with The Formula of the Law of Nature stated as "Act as if the maxim of your action were to become through your will a universal law of nature". Though subordinate to the Formula of Universal Law, this formula is entirely distinct from it and refers to a law of nature and not of freedom. However, while a law of nature is primarily regarded as a law of cause and effect, Kant treats laws of nature as purposive or teleological laws and thereby suggests that human nature is teleological or what he later on calls *a* kingdom of nature and not a mere mechanism. In this formula Kant thus adheres to his declared essence of morality, namely that a man is morally good, not so far as he acts from passion or self-interest, but so far as he acts on an impersonal principle valid for others as well as for himself. He however adds that should one wish to test the maxim of a proposed action, it should furthermore be asked whether, if universally adopted, this maxim would further a systematic harmony of purposes in the individual as well as in the human race at large, as it could only on this condition be willed as a universal moral law (Kant 1989:51-52).

On strength of these two formulas, Kant proceeds with his analytical argument towards the establishment of autonomy as the supreme principle of morality by positing The Formula of the End in Itself, which implies to "Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end". This formula follows the very essence of the Categorical Imperative and accentuates the fact that all rational actions, besides having a principle, also have ends and that ends, like principles, may be merely subjective and arbitrarily adopted by an individual. Subjective or relative ends can however only provide the ground for hypothetical imperatives and also only have a very relative and conditioned value and Kant thus only regards rational agents or persons as ends in themselves, as rational agents or persons alone can have an unconditioned and absolute value. It would therefore be wrong to simply use them as means to an end whose value is only relative. To this Kant adds that every rational agent necessarily

conceives his own existence in this way and on grounds that are valid for every rational agent as such (Kant 1989:63-67).

These arguments eventually brings Kant to The Formula of Autonomy which stipulates "so act that your will can regard itself at the same time as making universal law through its maxim". This formula is derived from a combination of The Formulas of the Universal Law and of the End in Itself and at first sight seems a mere repetition of The Formula of Universal Law. However, it is aimed at accentuating the doctrine that the Categorical Imperative bids man to not merely follow universal law, but to follow a universal law which has been made by man as a rational agent and has been particularised through his maxims. Man, according to Kant, is not only bound to obey the Categorical Imperative due to its universality and objective validity for all rational agents, but also because rational agents as subjects form the ground of the Categorical Imperative. The law to be obeyed is the product of man's own will and therefore rests on the Idea of the will of every rational being as a will which makes universal law possible. Thus, if a rational agent is truly regarded as an end in himself, he has to be the author of the laws he is bound to obey and is subject to the moral law only because it is the necessary expression of his nature as rational agent. A categorical imperative therefore also excludes all interest, for it is only if the will is conceived of as making its own laws, that it can be understood how an imperative can exclude interest and so be fully categorical. Hence, The Formula of Autonomy follows directly from the character of the Categorical Imperative itself by the express statement that a rational will makes the laws which it is bound to obey (Kant 1989:69-74).

For Kant, this formula represents the most important formulation of the supreme principle of morality, since it leads directly to the Idea of freedom. Will or practical reason may be defined as a power of causal action belonging to living rational beings. To describe such a will as free would mean that it is able to act causally without being caused to do so by something other than itself. On the contrary, non-rational beings can only act causally when caused to do so by something other than themselves. Thus, if the laws of freedom cannot be other-imposed, it has to be self-imposed. That implies that freedom is identical with autonomy and since autonomy is the principle of morality, a free will has to be a will under moral laws. The principle of autonomy, being a synthetic a priori principle, can only be justified by introducing a third term to connect the subject and predicate of the proposition. The positive concept of freedom furnishes this third term, but demands further specification in order to be deduced from the concept of pure practical reason.

In this regard Kant argues that if morality is to be derived from freedom and has to be valid for all rational beings, it has to be proved that the will of rational beings is as such necessarily free. While this can neither be proved by any experience of merely human action, nor from the point of view of philosophical theory, it would suffice if it could be shown that a rational being can act only under the presupposition of freedom. If this could be achieved, Kant believes, the moral laws attached to freedom would be valid for him just as much as if he would be known to be free. Since reason as such necessarily functions under the presupposition that it is both positively and negatively free and is both not determined by outside influences and remains the source of its own principles, a rational agent can regard himself as capable of acting freely on his own rational principles and of acting according to a will of his own. For Kant, freedom is thus a necessary presupposition of all action, as well as of all thinking (Kant 1989:97-100).

2.3 JOHN STUART MILL AND INDIVIDUALITY

John Stuart Mill's views on individuality are to be understood within the context of his famous essay, *On Liberty* which was published in London in 1859. His declared object in writing this essay was to assert the principles "that the sole end for which mankind is warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection and that the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others" (Mill 1991:14).

For Mill, the struggle between Liberty and Authority represents the most conspicuous feature of history. In ancient times, this struggle manifested itself between subjects or some classes of subjects and the Government and by liberty was meant protection from the tyranny of political rulers. However, these rulers were conceived as a necessarily antagonistic position to the people whom they ruled and derived their authority from inheritance or conquest. Their power was regarded as necessary, but also as highly dangerous and as a weapon that could be used against their subjects, no less than against external enemies. Protection of the weaker members of the community was therefore required and this was attained through liberty or the setting of limits to the powers of the rulers by firstly obtaining recognition of certain immunities or political rights which were to be regarded as a breaches of duty in the ruler to infringe and by secondly establishing constitutional checks through which the consent of the community was made a necessary condition of some of the more important acts of the governing power (Mill 1991:6).

Men, says Mill, however, over time ceased to regard it a necessity of nature for their governors to be an independent power, opposed in interest to themselves. What was now required, was that rulers should be identified with the people and that their interest and will should be the interest

and will of the people. The nation did not need to be protected against its own will. The ruler's power was to be regarded as the power of the nation, concentrated and in a form convenient for exercise. However, while this mode of thought was common among the last generation of European liberalism, it also gradually became clear that phrases such as the power of the people over themselves did not express the true state of the case. The people who exercise the power are not always the same as those over whom it is exercised and the self-government is not the government of each by himself, but of each by all the rest. Furthermore, the will of the people practically means the will of the most numerous or the most active part of the people or the majority or those that succeed in making themselves accepted as the majority. It was thus recognised that the limitation of the power of the government lost none of its importance when the holders of power remain accountable to the strongest party in the community (Mill 1991:8).

The tyranny of the majority was at first held in dread, chiefly as operating through the acts of the public authorities. It was however perceived that when society itself becomes the tyrant, its means of tyranny are not restricted to the acts of political functionaries. Society can and does execute its own mandates and should it issue wrong mandates, it practices a social tyranny more formidable than many kinds of political oppression, since it leaves fewer means of escape, penetrates much more deeply into the detail of life and enslaves the soul itself. For Mill, protection against the tyranny of the magistrate is therefore not sufficient. There also needs to be protection against the tyranny of the prevailing opinion and feeling, against the tendency of society to impose, by other means than civil penalties, its own ideas and practices as rules of conduct on those who differ from it, against the tendency to restrict and if possible to also prevent the formation of any form of individuality not in accordance with the ways of society and against the possibility of compelling all people to fashion themselves upon the model of society. There thus should also be a limit to the legitimate interference of public opinion on individual independence and to find that limit and to maintain it against encroachment, should be regarded as indispensable to a good condition of human affairs as protection against political despotism (Mill 1991:9).

It is the challenge of finding this limit that motivates Mill towards his objective of asserting the principles that the sole end for which mankind is warranted in interfering with the liberty of others, is self-protection and that the only purpose for which power can be rightfully exercised over any member of a civilised community, is to prevent harm to others. For Mill, man's own good, either physical or moral, could therefore not be a sufficient warrant for the exercising power or the rightful compelling of actions. However, in order to justify any such action, the conduct from which it is desired to deter man, must be calculated to produce evil to someone

else. The only part of conduct of anyone, for which he or she might be amenable to society, is that which concerns others, while the individual remains sovereign in deliberations over his own body and mind (Mill 1991:14).

Mill therefore argues that no society, whatever its form of government, in which these liberties are not on the whole respected, can be regarded as free and that none in which these do not absolutely and unqualifiedly occur can be conceived of as completely free. Each individual is therefore to be regarded as the proper guardian of his or her own health, whether bodily or mentally or spiritual and the only freedom deserving the name, could be that of pursuing your own good in your own way, as long as you do not attempt to deprive others of theirs, or impede their efforts to obtain it (Mill 1991:17).

However, to Mill the dilemma is that although this doctrine is anything but new, there is none that stands more directly opposed to the general tendency of existing opinion and practice. Not only has society, both by the force of opinion and even by that of legislation, gradually expanded its efforts in compelling people to its notions of personal and social excellence, but the modern world also witnessed the separation between spiritual and temporal authorities which placed the direction of men's consciences in other hands than those which controlled their worldly affairs. While this separation did prevent interference by law in the detail of private life, religion became a powerful force in seeking control over every aspect of human conduct. To Mill, the disposition of mankind, whether as rulers or as fellow citizens, to impose their own opinions and inclinations as a rule of conduct on others, is so deeply rooted in human nature that it is hardly ever restrained by anything but want of power and as the power is not declining, but increasing, it is to be expected that also the interference in the lives of individuals will increase. In addressing this dilemma, Mill therefore opts to take his departure in the concept of the Liberty of Thought from which it is impossible to separate the cognate liberty of speaking and of writing (Mill 1991:19).

In arguing the Liberty of Thought and Discussion in Chapter 2 of his *On Liberty*, Mill concludes that the necessity of the mental wellbeing of mankind, on which all other wellbeing depends, as well as the freedom of opinion and the expression of opinion, needs to be recognised on four distinct grounds. The first ground is that, should any opinion be compelled to silence, that opinion may be true and to deny this, may assume an attitude of infallibility. The second ground is that, though a silenced opinion may be wrong, it however may and very commonly does contain a portion of truth and that since the general or prevailing opinion on any subject can rarely or never be regarded as the whole truth, it is only by the collision of opposing opinions

that the remaining truth has any change of being heard. Following from this, the third ground stipulates that unless a received opinion, that may not only be true, but also the whole truth, is vigorously and earnestly contested, it will by most of those who receive it, be held in the manner of a prejudice with little comprehension or feeling of its rational grounds. Furthermore, the meaning of a doctrine might itself fourthly be in danger of being lost or enfeebled and deprived of its vital effect on the character and conduct of people, as the dogma becomes a mere formal profession, inefficacious for good, but cumbering the ground and preventing the growth of any real and heartfelt conviction deriving from reason or personal experience (Mill 1991:59).

On strength of these reasons which make it imperative that human beings should be free to form opinions and to express their opinions without reserve, Mill in Chapter 3 of *On Liberty* proceeds to inquire whether the same reasons do not require that men should be free to act upon their opinions and apply these in their own lives without hindrance from their fellow men, but on condition that it be at their own risk and peril? For Mill, this last proviso is indispensable, as no one would pretend that actions could be as free as opinions. Acts of whatever kind which without justifiable cause may harm others should be controlled by the negative sentiments and if necessary, by the active interference of mankind, as the individual should not make himself a nuisance to other people (Mill 1991:62).

However, should man refrain from molesting others in what concerns them and merely acts in accordance with his own inclination and judgement in issues that concern himself, Mill believes that the same reasons indicating that opinion should be free, prove that man should be allowed to without molestation, carry his opinions into practice at his own cost. Also in this realm it holds that man is not infallible, that their truths are for the most part half truths that unity of opinion, unless resulting from the fullest and freest comparison of opposite opinions, is not desirable and that diversity is not to be regarded as an evil, but as a good. It should therefore be regarded as imperative that while mankind's imperfection demands different opinions, there should also be different experiments of living, free scope to varieties of character and opportunities to in practice prove the worth of different modes of life. For Mill, it is in short desirable that in issues which do not primarily concern others, individuality should assert itself. However, where not an individual's character, but the traditions or customs of other people are the rule of conduct, there exists a need for one of the principal ingredients of human happiness and of perhaps the chief ingredient of individual and social progress (Mill 1991:63).

For Mill, the greatest difficulty in maintaining this principle is not to be found in the appreciation of means towards an acknowledged end, but in the indifference of people in general

to the end itself. If only there could be agreement that the free development of individuality is one of the leading essentials of wellbeing and that it is to be regarded as not only a co-ordinate element of terms such as civilisation, instruction, education and culture, but itself a necessary condition thereof, there would be no danger of liberty being undervalued. However, while the majority of people are apparently satisfied with the ways of mankind as they are, individual spontaneity is hardly recognised by common modes of thinking as of any intrinsic worth and few even comprehend William von Humboldt's doctrine "that the end of man or that which is prescribed by the eternal or immutable dictates of reason and not suggested by vague and transient desires, is the highest and most harmonious development of his powers to a complete and consistent whole; that therefore the object towards which every human being must ceaselessly direct his efforts and on which especially those who design to influence their fellow men must ever keep their eyes, is the individuality of power and development; that for this there are two requisites, freedom and a variety of situations; that from the unity of these arise individual vigour and manifold diversity which combine themselves in originality" (Mill 1991:64).

While Mill does not deny that people should be taught and trained in youth in order to benefit from the ascertained results of human experience, he insists that it remains the privilege and proper condition of a human being to upon maturity, use and interpret this experience in his or her own way. For him, the traditions and customs of other people represent what they learned from experience, but their experience might be too narrow for the next person or represent an incorrect interpretation. Even in cases where experience was interpreted correctly, it might be unsuitable to other and will in any case not be conducive to the development of these qualities which are to be regarded as the distinctive endowments of human beings. For Mill, the human faculties of perception, judgement, discriminative feeling, mental activity and even moral preference are only exercised in making a choice, as he who does anything because it is the custom, makes no choice and gains no experience either in discerning or in desiring what is best. The human faculties are called into no exercise by just conforming to what others are doing and are even likely to be weakened by simply adopting these opinions. Moreover, he who lets the world choose his plan of life has according to Mill no need of any other faculty than the ape-like one of imitation. He now has to utilise observation to see, reasoning and judgement to foresee, activity to gather materials for decision, discrimination to decide and when he has decided, firmness and self-control to adhere to his decision. While it is possible that man might along this path be kept out of harm's way, his comparative worth as a human being will be low, as it is really of importance not only what man does, but also in what manner he does it. For

Mill, human nature is thus not to be compared with a machine that is built after a model and set to exactly do the work prescribed for it, but rather to a tree which requires to grow and develop itself on all sides according to the inward forces which make it a living thing (Mill 1991:66).

Although there were times when the elements of spontaneity and individuality were in excess and the difficulty was to induce men of strong bodies and minds to pay obedience to rules which required of them to control their impulses, things have vastly changed. Nowadays, according to Mill, people from the top classes of society down to the lowest live under the eye of an often hostile and dreaded censorship, causing them to not even contemplate something outside the customary. A case in point is found in the Calvinistic theory teaching that, in view of the radically corruptness of human nature, the one great offence of mankind is to be found in self-will, that all the good of which mankind is capable is comprised in obedience and that man thus have no choice but to obey. To one holding this conviction, the elimination of any of the human faculties and capacities is of no evil, as man is in need of no capacity but to surrender himself to the will of God. While this conviction is mainly held by the religiously orientated, it is also held in a mitigated form by many who do not consider themselves Calvinists, but asserts it to be God's will that mankind should gratify some of their inclinations, but in a way prescribed to them by authority (Mill 1991:69).

According to Mill, there is at present a strong tendency to this narrow theory of life and to the pinched and hidebound type of human character which it patronises. It is however only by cultivating individuality within the limits imposed by others that human beings become more valuable to themselves and therefore also become capable of being valuable to the undeveloped others. These well developed human beings, cultivated through the promotion of individuality, are to be regarded as the salt of the earth, as they not only introduce good things in life which did not exist before, but also maintain those which already existed. Mill thus emphatically insists on the importance of genius and the necessity of allowing it to unfold itself freely in both thought and practice. An openness in this regard is necessitated by the fact that at present individuals are lost in the crowd and the only power deserving the name is that of the masses and of governments employing themselves as the organ of the tendencies and instincts of the masses (Mill 1991:73).

However, to Mill there is no reason that all humans should be forced into a single or a small number of patterns. To him, human beings are not like sheep, but require different conditions for their development and can no more exist healthily in the same moral environment than all the varieties of plants can in the same physical atmosphere and climate. The despotism of custom

therefore demands urgent action, as a delay in resistance will result in deviations from the uniform type regarded as impious, immoral and contrary to nature (Mill 1991:82).

2.4 THE ETHICAL PRINCIPLE OF RESPECT FOR AUTONOMY

Historically, the word autonomy is a legacy from ancient Greece where the concepts of *autos* (self) and *nomos* (rule or law) were joined to refer to political self-governance in the Greek city states. The concept has however since also been extended to individuals and has in the process acquired meanings as diverse as self-governance, liberty rights, privacy, individual choice, freedom of will, causing one's own behaviour and being one's own person. Autonomy can therefore not be conceived as a univocal concept and needs to be refined with regard to particular objectives (Beauchamp & Childress 2001:58-64).

Within these diverse meanings, the concept of personal autonomy is considered to at a minimum signify self-rule that is free from limitations, such as inadequate understanding that could prevent meaningful choice, as well as from controlling interference by others (Berlin 1969).¹² Henceforth, almost all theories of autonomy agree that two conditions are required for the establishment of personal autonomy, namely agency or the ability for intentional action and liberty or the freedom from controlling influences (Beauchamp & Childress 2001:58). The ethical concept of personal autonomy therefore became connected to the liberal moral and political tradition of the importance of individual freedom and choice and in this tradition refers to personal self-governance or the personal rule of the self by adequate understanding while remaining free from controlling influences by others and from personal limitations that might prevent individual choice.

Firmly linked to the concept of the autonomous person, is that of autonomous choice. A distinction between these concepts of autonomy is required by the fact that even autonomous persons with self-governing capacities sometimes fail to govern themselves in particular choices because of temporary constraints such as ignorance and coercion. Consequently, some writers maintain that autonomy could be regarded as a matter of having the capacity to reflectively control and identify with one's basic desires or preferences through higher level desires or preferences (Dworkin 1988:chs. 1-4).¹³

However, serious difficulties confront this view, as the acceptance or repudiation of a desire can be motivated by an overriding desire that is simply stronger and not necessarily more rational or autonomous. Moreover, few choosers and also few choices could be regarded as autonomous if

¹² See also Feinberg 1986; Hill 1991.

¹³ See also Frankfurt 1971:5-20.

held to the standards of higher order reflection, as it in effect would present an aspirational ideal of autonomy that would be beyond the reach of normal choosers.

On the contrary, it is argued that an adequate theory of autonomy needs to be closely tied to non-ideal moral requirements of respect for autonomy and should provide ordinary persons with a means of qualifying for respect of autonomy without having to reflect on their preferences on a higher level (Beauchamp & Childress 2001:59).

It is therefore maintained that the moral requirements of respect for autonomy should be determined in terms of normal choosers who act (1) intentionally, (2) with understanding and (3) without controlling influences that might determine their actions and that while the condition of acting intentionally is normally not subject to degrees of action, acts can satisfy both the conditions of understanding and the absence of controlling influences to a greater and lesser extent. Actions can therefore be autonomous by degrees, as a function of satisfying these two conditions to different degrees. This might have the implication that for an action to be autonomous, only a substantial and not a full degree of understanding and freedom from constraints might be possible (Beauchamp & Childress 2001:59).

To thus respect an autonomous agent, is to recognise with due appreciation that person's capacities and perspective, including his or her right to hold certain views, to make certain choices and to take certain actions based on personal values and beliefs (Beauchamp & Walters 1989:28). Respect for autonomy can however never remain a mere ideal in health care, but is a professional obligation and should involve autonomous choice as a right and not as a duty of patients. Furthermore, this obligation does not only involve a respectful attitude of acknowledging a person's right to hold views, make choices and take actions based on personal values and beliefs, but also respectful action directed at building up or maintaining others' capacities for autonomous choice and at allaying fears and other conditions that could disrupt or destroy their autonomous actions. Respect, on this account, thus involves acknowledging decision making rights and enabling people to act autonomously, while disrespect for autonomy involves attitudes and actions that ignore, insult or demean others' rights of autonomy (Beauchamp & Childress 2001:63).

The motivation for the principle of respect for autonomy is firmly linked to the views of Immanuel Kant and John Stuart Mill discussed in 2.2 and 2.3. In summary, Kant argued that respect for autonomy flows from the recognition that all persons have unconditional worth and that each has the capacity to determine his or her own moral destiny. To therefore violate a person's autonomy is to treat that person merely as a means and in accordance with others goals

with an accompanying disregard of that person's own goals. Mill primarily focused on the individuality of autonomous agents and argued that society should permit individuals to develop according to their convictions on condition that they do not interfere with a similar expression of freedom by others. Kant's position therefore entailed a moral imperative of respectful treatment of persons as ends in themselves and Mill's the perspective of both not interfering with and actively strengthening autonomous expression and taken together they both thus support the principle of respect for autonomy, although from different angles.

According to Beauchamp and Childress, the principle of respect for autonomy can therefore be either stated as a negative or a positive obligation. As a negative obligation, it entails that autonomous actions should not be subject to controlling constraints by others and thus asserts a broad and abstract obligation that is free from any exclusion criteria. However, this statement of the principle of respect for autonomy requires specification in particular contexts in the form of elements like the rights and obligations of liberty, privacy, confidentiality, truthfulness and informed consent in order to become a practical guide to conduct. As a positive obligation, this principle requires respectful treatment in disclosing information and fostering autonomous decision making. It is acknowledged that many autonomous actions are impossible without others' material cooperation in making options available and people are therefore in some cases obliged to increase the options available to others. In the health care context, the principle of respect for autonomy therefore obligates health care professionals to disclose information, to probe for and ensure understanding and voluntariness and to foster adequate decision making.

Against this background, contemporary Kantians like Barbara Herman and Onora O'Neill argue that that the demand to treat others as ends implies that people have to be assisted in achieving their ends and fostering their capacities as agents and that it is not sufficient to avoid treating them simply as means to others' ends (Herman 1984:600-602).¹⁴ Thus, while temptations sometimes arise in health care to foster or even perpetuate patients' dependency rather than promoting their autonomy, the moral obligation to respect patients' autonomy demands equipping them to overcome this sense of dependency and to achieve the desired control (Beauchamp & Childress 2001:64).

¹⁴ See also O'Neill 1989:341-361.

2.5 INFORMED CONSENT AS PARADIGM FOR PATIENT AUTONOMY IN CLINICAL DECISION MAKING

With regard to these considerations, the elements of the concept of informed consent provide a valuable paradigm for meeting the professional obligations of respect for patient autonomy in clinical decision making.

The term informed consent first appeared about a decade after the Nuremberg Trials during the late 1940s, but did not receive much attention until the 1970s when, amongst others, the focus in thought on the concept shifted from the obligations of physicians to disclose information to the quality of a patient's understanding and consent. This shift in emphasis was autonomy driven and were brought about by forces such as the regulation of research, case law governing medical practice, changes in the physician-patient relationship and ethical analysis.¹⁵

While informed consent is not to be reduced to shared decision making,¹⁶ it is considered that one gives informed consent to an intervention if (and perhaps only if) one is competent to act, receives a thorough disclosure, comprehends the disclosed material, acts voluntarily and finally consents to the intervention (Beauchamp & Childress 2001:69-95). Following this broad definition, legal, regulatory, philosophical, medical and psychological sources distinguish between the information and consent components of informed consent and tend to favour the following five elements as the main components thereof: (1) competence, (2) disclosure, (3) understanding, (4) voluntariness and (5) consent (Meisel & Roth 1981:2473-2477).

2.5.1 Competence

In view of the fact that many patients and potential subjects are not competent to give a valid consent, inquiries about competence focus on whether patients or potential subjects are psychologically and legally capable of adequate decision making and are therefore closely connected to the concept of autonomous decision making. While the concept of competence could broadly be defined as the ability to perform a task (Culver & Gert 1982:123-126), the criteria of particular competencies may vary from context to context, due to the fact that criteria are relative to specific tasks. Competence may furthermore vary over time and even be intermittent and judgements about whether a person is competent to authorise or refuse an

¹⁵ For an excellent exposition of the concept of *informed consent* in the legal context, see Van Oosten 2002. Refer also the HPCSA Guidelines in this regard. HPCSA Guidelines 2002: Parts thirteen and fourteen.

¹⁶ Some commentators attempt to reduce the concept of informed consent to shared decision making between doctor and patient. Refer in this regard to Katz 1984. See also President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research 1982.

intervention should thus be based on whether that person can choose autonomously in particular circumstances (Beauchamp & Childress 2001:70).

However, law, medicine and philosophy presume a context in which the characteristics of the competent person are similar to the properties possessed by the autonomous person and therefore consider patients or subjects competent to make a decision if they have the capacity to understand the material information, to make a judgement about the information in light of their values, to intend a certain outcome and to communicate their wishes freely to care givers or investigators. Specifically in medical contexts, a person would be regarded as competent if able to understand a therapeutic or research procedure, to deliberate regarding its major risks and benefits and to make a decision in the light of this deliberation (Beauchamp & Childress 2001:72).

2.5.2 Disclosure

The ethical obligation to disclose information to patients has often been presented as a necessary and sometimes as the sole condition of informed consent (Beauchamp & Childress 2001:80). As a case in point, the legal doctrine of informed consent in the United States has primarily been a requirement of disclosure based on a physician's general obligation to exercise reasonable care by providing information. Similarly, civil litigation emanating from issues regarding informed consent emerged because of injury to an individual's person or property that was intentionally or negligently caused by a physician's failure to disclose. While from a moral point of view, informed consent has less to do with the liability of professionals as agents of disclosure and more with the autonomous choices of patients and subjects, disclosure remains of pivotal importance. Although some recent studies suggest that a high percentage of physician-patient encounters in especially outpatient practices fail to include discussions of elements that are of importance in informed consent (Braddock et al. 1999:2313-2320), professionals are generally obligated to disclose a core set of information including (1) those facts or descriptions that patients or subjects usually consider material in deciding whether to refuse or consent to the proposed intervention or research, (2) information that the professional believes to be material, (3) the professional's recommendation, (4) the purpose of seeking consent and (5) the nature and limits of consent as an act of authorisation (Beauchamp & Childress 2001:81).

Although these requirements can be expanded almost indefinitely, the disclosure of information is normally governed by one of the following standards of disclosure. The professional practice or reasonable doctor standard holds that a professional community's customary practices determine the amounts and kinds of information to be disclosed. Within this standard and due to

their expertise, physicians remain responsible for the disclosure of information and as a result, only expert testimony from members of the profession is regarded as evidence that a physician has violated a patient's right to the disclosure of information.

However, several difficulties affect this standard of disclosure. It firstly remains uncertain in many instances whether a customary standard for the disclosure of information exists at all and secondly has the implication that should custom alone be conclusive, pervasive negligence could be perpetuated with impunity. It is thirdly also questionable whether all physicians have developed the skills required to determine the information that might be in their patients' best interests (Braddock et al. 1997:339-345) and whether this standard does not seriously subvert patient's right to autonomous choice (Beauchamp & Childress 2001:82)?

While the professional practice standard is retained by many legal jurisdictions, the reasonable person standard has recently gradually been gaining acceptance. This standard determines the information to be disclosed to patients by reference to a hypothetical reasonable person and thus measures the significance a reasonable person would attach to it in deciding whether to undergo a procedure or not. Within this standard, the authoritative determination of informational needs therefore shifts from the physician to the patient with the implication that even physicians conforming to recognised professional practice, may be found guilty of negligent disclosures.

However, also this standard of disclosure is affected by various difficulties. The concepts of material information and the reasonable person that are pivotal in the application of this standard have firstly never been carefully defined. Secondly, the abstract and hypothetical nature thereof makes it difficult for physicians to determine what a reasonable person would need to know and this difficulty is thirdly increased by the studies suggesting that patients generally make their decisions prior to and independent of the process of receiving information (Simmons et al. 1987:ch. 8) and often deferentially accept physicians recommendations without carefully weighing the risks and benefits (Blanchard et al. 1988:1139-1145).

In contrast to the reasonable person standard, the subjective standard of disclosure judges the adequacy of information disclosure by reference to the informational needs of the individual person, rather than to that of the hypothetical reasonable person. This standard is motivated by the fact that individual needs differ due to people having unconventional beliefs, unusual health problems or unique family histories and therefore require a different informational base than the reasonable person. While the subjective standard is thus to be preferred as the moral standard of disclosure, it is claimed that it remains insufficient for both law and ethics, as patients simply do not know what information would be relevant for their deliberations and doctors cannot

reasonably be expected to do an exhaustive background analysis of each patient in order to determine what information would be relevant (Beauchamp & Childress 2001:83). However, these objections to the validity of the subjective standard of disclosure in clinical decision making will again be addressed in the final chapter of the study where the *need for the facilitation and mediation of information* in the physician-patient relationship will be discussed.

2.5.3 Understanding

Regarding the element of understanding, clinical experience and empirical data indicate that patients and subjects exhibit a wide variation in their understanding of information about diagnoses, procedures, risks and prognosis (Beauchamp & Childress 2001:88-90). This variation is strongly related to the fact that some patients and subjects are calm, attentive and eager for dialogue, whereas others may be nervous or distracted in ways that impair their understanding (Bernhardt et al. 1996:336-340).

While little consensus exists about the nature of understanding, a sufficient definition of this element of informed consent could be that persons understand if they have acquired pertinent information and have justified and relevant beliefs about the nature and consequences of their actions. It is however argued that such understanding need in principle not be complete, but should include an adequate comprehension of elements such as the diagnosis and prognosis of the condition and the nature, purpose, alternatives, risks, benefits and recommendations of the proposed intervention. Furthermore, patients and subjects need to share an understanding of the terms of authorisation with professionals, as no assurance can exist that a patient or a subject has made an autonomous decision without an agreement on the essential features of a procedure.

To thus enable a patient to not only comprehend, but also to appreciate the risks and benefits of a proposed procedure, can be a formidable task. As a case in point, it is argued that while some patients have such a limited knowledge basis that any communication about alien situations incorporating new concepts and cognitive constructs can be exceedingly difficult, these patients' understanding of scientific goals and procedures are furthermore likely to be both distorted and impoverished (Dougherty et al. 1995:1062-1072). Too much information can therefore be as much of a problem as too little and may even prevent adequate understanding, especially if unfamiliar terms are used or information cannot be meaningfully integrated. It is furthermore argued that patients and potential subjects may in the process of trying to gain understanding, rely on modes of selective perception which in turn could make it difficult to determine whether words might have special meanings for them, preconceptions might distort their processing of information or other biases might intrude in the process. These difficulties are aggravated by

framing effects that can be misleading to both professionals and patients and can reduce understanding with direct implications for autonomous.

2.5.4 Voluntariness

The element of voluntariness has been analysed by some as the presence of adequate knowledge and the absence of psychological compulsion and external constraints (Feinberg 1973:48). While this analysis seems too broad, it is instead argued that a person acts voluntarily to the degree that he or she wills an action without being under the control of another individual's or some form of debilitating influence (Beauchamp & Childress 2001:93). With regard to influences that might have a negative effect on autonomous choice, the following three categories are distinguished: coercion, persuasion and manipulation.

Coercion occurs if and only if one person intentionally uses a credible and severe threat of harm or force to control another (Nozick 1969:440-472), while in persuasion a person must come to believe in something through the merit of reasons another person advances (Beauchamp & Childress 2001:94). However, of special importance for this study is the category of manipulation which in health care often manifests itself in informational manipulation as a deliberate act of managing information that non-persuasively alters a person's understanding of a situation and thereby motivates him or her to do what the agent of influence intends (Beauchamp & Childress 2001:95). As such, informational manipulation is to be found in cases ranging from a clinician's abuse of his or her therapeutic privilege to withhold information in order to manipulate patients into consenting to a medically desirable procedure to the manner - by tone of voice, forceful gesture or the framing of information - in which information is presented to patients.¹⁷

2.6 CONFLICTS BETWEEN AUTONOMY AND BENEFICENCE AND THE DOMINANCE OF PATERNALISM

As reflected in the Hippocratic Oath,¹⁸ the health care professional's obligations and virtues have throughout history been interpreted as commitments to beneficence. Physicians have therefore

¹⁷ With regard to the ever present danger of coercion and informational manipulation in health care, refer to the following statements: "If options are limited, the question of whether people should be told about all available options or all possible options is a difficult one. If people are told about options that they cannot access within their current health care system, they may be dissatisfied because they are being denied these options. Having been made aware of their existence, however, they might try to seek them elsewhere"; "Even for topics on which research evidence exists, it is not always available in forms that are accessible to patients. Many of the information materials that are given to patients are not designed to support them in decision making, do not reflect the best available research evidence and do not meet patients' information needs" (Entwistle & O'Donnell 2002:45,47).

¹⁸ "I swear by Apollo Physician and Asclepius and Hygieia and Panacea and all the gods and goddesses, making them my witnesses, that I will fulfill according to my ability and judgement this and this covenant: To hold him

traditionally relied almost exclusively on their own judgements concerning patients' needs for information, consultation and treatment.

This reliance on own judgements concerning patients' needs for information, consultation and treatment can be described as the residue of an ancient ethos¹⁹ of medicine that has its origins in the times of Hippocrates. While Hippocratic medicine was regarded as a skill, its practitioners as craftsmen and its objective the attaining of good living, studies of Greek medical literature produce precious little indications of altruism in the ethics of the Hippocratic physician. Ethics was rather related to self-interest and the aim of building a reputation and a clientele, providing that no harm would be done in the process. The Christian Church adopted the care of the sick as a duty of charity and married it to the parable of the Good Samaritan who bound the wounds of a stranger beaten by robbers and had him cared for at his own expense. Even during the Middle Ages, the *Knights Hospitallers* founded to care for those on pilgrimage and crusades, were commanded to treat the sick *as their lords*. Medicine thus became Judeo-Christian and altruism and medical care was bound in a moral covenant (Jonsen 1990:8-9).

However, both traditions still exist as the deep moral foundation of medicine. On the one hand, medicine remains a skill so rare that it can be sold at great price and once acquired with effort, it promises great rewards, not only of income, but also of prestige, reputation and gratitude. On the other, medicine offers help to people in desperate need thereof and often hard pressed to purchase it and thus also makes modern physicians the heirs of a tradition of monastic medicine.

In order to safeguard this dual tradition, Western society has invented the medical license which in the most peculiar way reinforces the moral paradox of self-interest and altruism. While licensure has since the Middle Ages represented a state's permission to practice medicine, it has

who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine, and to regard his offspring as equal to my brothers in male lineage and to teach them this art - if they desire to learn it - without fee and covenant; to give a share of precepts and oral instruction and all the other learning to my sons and to the sons of him who has instructed me and to pupils who have signed the covenant and have taken an oath according to medical law, but to no one else. I will apply dietetic measures for the benefit of the sick according to my ability and judgement; I will keep them from harm and injustice. I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. Similarly I will not give a woman an abortive remedy. In purity and holiness I will guard my life and my art. I will not use the knife, not even on sufferers from stone, but will withdraw in favour of such men as are engaged in this work. Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves. What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about. If I fulfil this oath and do not violate it, may it be granted to me to enjoy life and art, being honoured with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot" (Beauchamp & Walters 1989:310).

¹⁹ The concept of *ethos* refers to a framework of beliefs in terms of which the health care worker makes sense and attributes meaning to that with which he or she is engaged on a daily basis. It therefore comprises both of the directive principles and ideals that are appropriated by the physician and the disposition and approach that are constituted in this appropriation (Van Niekerk 2002:151-155).

for the past four centuries also been surrounded by a philosophical and political inspired doctrine of rights. Though the general notion of rights had antecedents in Roman law and medieval political theology, the modern meaning was formulated in the late Renaissance and reached maturity in the seventeenth century in the work of John Locke (Jonsen 1990:10-11).

Locke, primarily known as a philosopher, was also a physician and practiced medicine together with colleagues such as Robert Boyle and Thomas Sydenham at a time when the ancient art was on the verge of significant changes. Locke's way of thinking about rights was compatible with a way of thinking about medicine that he and his friends were generating and consisted in being able to think about rights as the exclusive possession of a property and about one's medical competence as a property over which you might have dominance (Jonsen 1990:84).

Sydenham's contribution to medical science was the initiation of an empirically based nosology by which individual diseases were identified by their discrete signs and symptoms and for which specific remedies could be indicated. Although honoured with the title of the English Hippocrates, his approach was completely different. While Hippocrates recognised only disease and not diseases, knew only cases of illness and regarded a patient and his illness as inseparably connected and unique, Sydenham saw in a patient the typical and pathological process which he had observed in others before and expected to observe in others again. While Hippocrates thus wrote the histories of sick persons, Sydenham wrote the history of diseases (Sigerest 1933:181).

Sydenham's approach radically undermined the speculative medical systems that have dominated the previous centuries and created the medical science and art that have persisted to the present day. According to this science, diseases were now to be regarded as discrete sets of signs and symptoms with discrete pathophysiological causes that can be explained in general scientific terms. One significant implication hereof was the fact that diseases could now be dominated and even conquered by those who have the skill and the science to recognise and explain them. Physicians thus became the ones who, in principle, had power over disease (Jonsen 1990:85).

John Locke's philosophy mirrored his politics. He regarded civil liberty higher than royal authority and taught that there is a natural law rooted and grounded in the reasonable nature of man and manifesting itself in natural rights to life, liberty, health and in particular to property in which men have mixed their labour (Barker 1962:xvi). In addition, Locke argued that man has by nature a power to preserve his property in the form of his life, liberty and estate and furthermore has a property in his own person, since the labour of his body and the work of his hands are properly his (Locke 1966:secs. 27, 87,149). To Locke, men enter into contracts not

only to distribute property among themselves, but to also distribute their liberty in certain ways. While the state comes into existence due to men's agreement in a social contract to transfer some of their natural liberties to government, this social contract is also fiduciary, since those who transfer liberties to the government also entrust the government to act in their best interests.

In this regard, Jonsen argues that in two areas, the Lockean doctrine has had a definitive effect on medical practice in general and on the way in which physicians perceive their role. He writes: "Both the conferral of special privileges on scientific orthodoxy and the establishment of licensure contributed to the formation of a profession in the modern sense. Its members share an identity, a language, lifetime membership, self-regulation, values, explicit social boundaries, and implicit socialization of new members. Professionals enjoy autonomy based on knowing what is best for the client, subjecting their decisions only to peer review, and establishing standards of behavior through their organization. The autonomy of the medical profession has been ratified in most countries by licensure; the state delegates to the profession, in law and in fact, the authority to educate, admit, and discipline its own members. In turn, the institution of licensure reinforces and defines the profession" (Jonsen 1990: 85-87).

Although society started acknowledging these rights of physicians already in the Middle Ages, the philosophical grounds and practical conditions thereof only manifested itself in and after Locke's time. In this development, two conditions have in particular over the past three centuries promoted the notion that physicians enjoy special privileges. The first was that only those who ascribe to certain systems of medical science should be recognised as physicians and allowed to practice. The second revolves around the conception that the activities of physicians create a special relationship between patient and physician over which the physician exercises authority. Both claims thus assert that the physician should exercise jurisdiction in a number of activities, while others are obliged to acknowledge it and are not to interfere. While the first claim is thus justified by an appeal to the value of true knowledge, the second is justified by the benefits that may be bestowed only in the privacy of a special relationship. Taken together, these claims have the structure of a right and express an assertion of jurisdiction over a sphere of activities, while also engendering an obligation on certain others to act or refrain from acting in specific ways (Jonsen 1990:88).

While medicine suffered widespread public skepticism in the eighteenth century, it however also slowly became more scientific which resulted in some impressive demonstrations of efficacy to appear in the second half of the twentieth century. Factors like the widespread success of inoculation, the results of aseptic surgery and the therapeutic promises of bacteriology and

cellular pathology not only restored public faith in scientific medicine, but also persuaded legislatures to reenact licensure laws that previously were repealed or fell into disuse. Of particular importance for this study, is to note that the arguments for licensure were now no longer merely based on the possession of a true science, but also on the evidence of benefit resulting from the application of that science (Jonsen 1990:89).

Whereas many of these benefits were readily demonstrable, it was maintained that they could be bestowed only in the context of an interaction in which the physician ordered a regimen and the patient complied. In this regard, the authority of the physician to dictate a regimen and control the application thereof by patients and care takers alike, was considered to be an essential condition for the realisation of the benefits of medicine. Similarly, there was a growing belief that a proper relationship between physician and patient could only be promoted within the context of certain social and economic arrangements which involved rules about elements such as consultations, advertising and the determining of fees. These arrangements were deemed most suitable for the fostering of a physician-patient relationship that would centralise authority, create a bond of trust, but also encourage patient compliance. In this relationship, physicians were acknowledged to have the primary right of structuring their relationship with a patient in order to best yield his or her scientific skills and derived the title to that right from their expertise, benevolence and intention to structure the relationship for the benefit of the patient (Starr 1982).

Moreover, this right of physicians to autonomously structure their relationships with patients was also acknowledged by medical practice acts devised by professional bodies and passed by legislatures during the second half of the nineteenth century. Whereas on the one hand all subsequent legislation even until quite recently made no provision for the abrogation of this right, the assumption on the other was that physicians were not only skilled in medical science, but also benevolent and had the intention and motivation to turn their medical expertise to the benefit of the patient. Skill and benevolence thus came to be regarded as the titles to the right to control the doctor-patient relationship and was as such also acknowledged in licensure as a property right (Jonsen 1990:90).

These benevolent skills gave Lockean title to health care professionals' claim over their practices, disease and even over their patients.²⁰

In the constitution of medical practice, the legal view of the medical license as a property right became the paradigm of an entire philosophy of physicians' rights during the past century. It

²⁰ Refer in this regard to the principles of medical ethics of the American Medical Association in Leake 1976:241.

entitled physicians to conceive their practice as if it were a property which they brought into existence by their training and labour, through which they offered benefits to those who wish to be helped, in which they could set the conditions for services and compliance and that could be priced and purchased. Solo practice on a fee-for-service basis was considered as the optimum social and economic arrangement for such a contract in which the failure of the patient to comply or the failure of nature to respond would however absolve the physician of responsibility, but not the patient of payment (Jonsen 1990:91).

Regarding health care professionals' claim over disease, it is important to note that in Sydenham's thought, disease became an entity or a natural thing of a discrete sort in the world and in the body of the patient (Jonsen 1990:92). In this regard, also Locke stated: "whatsoever a man removes out of the state that nature hath provided and left it in, he hath mixed his labour with it and joined to it something that is his own, and thereby makes it his property" (Locke 1966:sec. 27). Whereas the medical skills constitute the labour that the physician mixes with the natural entity of disease and thereby dominates it and makes it his property, the disease may be in the patient, but belongs to the physician.

Also with regard to physicians' claim over patients, Locke viewed the most important human transactions as consensual transactions and therefore also conceived of a medical transaction in consensual terms in which one of the parties surrenders a certain amount of freedom in order to obtain the benefits that the other offers. In this regard, Jonsen notes: "The Lockean-Sydenham physician acquires a right over the disease and the patient by double title: he mingles his labor with the disease and masters it; he contracts with the patient to do his work. Even though the physician must get access to the disease through the patient - he cannot trespass - he almost has an independent right over the disease itself" (Jonsen 1990:93).

However, medicine has recently increasingly been confronted by patients' demands to participate in judgements on health care and with these demands also the difficulties related to conflicts between the principles of autonomy and beneficence as well as to the concept of paternalism increased.

It is a central problem in biomedical ethics whether respect for the autonomy of patients should have priority over professional beneficence directed at these very patients (Beauchamp & Childress 2001:176). This dilemma is most evident in the fact that while some might link the obligations of a health care professional to ensure consent, confidentiality and privacy to the principle of respect for autonomy, others may ground these duties in the professional's primary

obligation to act for the patient's medical benefit and not necessarily in his/her duty to encourage autonomous decision making.

Confusion has therefore often marked the debate between proponents of the autonomy and beneficence models and is largely attributed to a common failure to distinguish between the view of the principle of beneficence as incorporating a patient's autonomous choices and that of viewing the principle of beneficence as competing with the principle of respect for autonomy. When it is thus argued that the best interest of patients is intimately linked with their preferences and that these should form the basis of duties towards them (Pellegrino & Thomasma 1988:29), this formulation appears to be little more than a restatement of the principle of respect for autonomy. However, when it is argued that there are no absolute moral principles in the real world of clinical medicine, except the obligation to act in the patient's best interest and that autonomy is superseded by the obligation to act beneficently (Pellegrino & Thomasma 1987:23-46), the principle of beneficence is clearly in competition with that of autonomy and may even be used to override a patient's autonomy in order to ensure his/her best interests. While it has to be adhered to that neither the patient, nor the health care professional has a premier or overriding authority and that no preminent principle exists in bioethics, the conflict between these two ethical principles almost inevitably brings the concept of paternalism to the fore (Beauchamp & Childress 2001:177).

The term paternalism dates from the 1880s and is rooted in the following concepts: "the principle and practice of paternal administration; government as by a father; the claim or attempt to supply the needs or to regulate the life of a nation or community in the same way a father does those of his children".²¹ The analogy to a father accentuates two prominent features of the concept of a paternal role, namely that a father acts beneficently and in the best interests of his children and that he makes all or at least some of the decisions related to his children's welfare, rather than letting them make those decisions themselves. Within a health care context, it is evident that the analogy to a father in the concept of paternalism extends even further, as a health care professional in possession of superior training, knowledge and insight thus finds him or herself in an authoritative position to determine a patient's best interests. Paternalism therefore not only involves some or other form of interference in another's preferences, but typically also acts like coercion, deception, lying, manipulation and non-disclosure. In view then of these constituting elements, paternalism can be defined as the "intentional overriding of a person's known preferences or actions by another person, where the person who overrides

²¹ Oxford English Dictionary

justifies the action by the goal of benefiting or avoiding harm to the person whose preferences or actions are overridden" (Beauchamp & Childress 2001:178).

With the concept of paternalism thus firmly linked to conflicts between the ethical principles of autonomy and beneficence, it has to be noted though that both the principles of beneficence and nonmaleficence have in the history of medical ethics provided a basis for paternalistic actions towards patients and that health care professionals have therefore traditionally held the view that as the disclosing of certain forms of information may cause harm to patients under their care, they are obligated to not cause such harm (Henderson 1935:819-823). It has also long been recognised that while patients suffering from depression or those addicted to potentially harmful drugs are expected to reach inadequately reasoned decisions, even patients who are competent and deliberative may be prone to making poor choices against the courses of action recommended by their health care professionals. It is thus when patients of either type choose potentially harmful courses of action that some health care professionals might respect patient autonomy by not interfering beyond attempts at persuasion, while others would tend to act beneficently by attempting to protect patients against the potentially harmful consequences of their own choices.

This distinction between incompetent and competent patients in need of protection against potentially harmful courses of action has in medical practice led to a further distinction between weak and strong forms of paternalism (Feinberg 1971:105-124). In this distinction weak paternalism refers to interventions by an agent on grounds of both beneficence and nonmaleficence to protect people against their own substantially non-autonomous actions arising from conditions such as depression and addictions. On the contrary, strong paternalism refers to interventions by an agent that are intended to benefit a person, despite the fact that the person's potentially harmful courses of action may be properly informed, voluntary and therefore autonomous.

While supporters of paternalistic intervention hold that any paternalistic action can only be justified if (1) the harms prevented from occurring or the benefits provided to the person outweigh the loss of independence and the sense of invasion the intervention causes, (2) the person's condition seriously limits his or her ability to make an autonomous choice, (3) the intervention is universally justified under relevantly similar circumstances and (4) the beneficiary of the paternalistic actions has consented, will consent or would, if rational, consent to those actions on his or her behalf, both of these forms of paternalism are generally considered to be justified on certain conditions (Beauchamp & Childress 2001:183). Weak paternalism is

therefore normally considered as justified in cases such as preventing patients under the influence of drugs from killing themselves. On the contrary and considering the fact that strong paternalism is a dangerous position and might be subject to abuse, it is normally only regarded as appropriate and justified in health care when (1) a patient is at risk of a significant and preventable harm, (2) the paternalistic action will probably prevent the harm, (3) the projected benefits to the patient involved in the paternalistic action outweighs its risks to the patient and (4) the least autonomy-restrictive alternative that will secure the benefits and reduce the risks is adopted (Beauchamp & Childress 2001:186).²²

With regard to the views of Immanuel Kant and John Stuart Mill on paternalism, it is clear that Kant never considered the possibility that a parental model of benevolence might be considered a form of paternalism (Kant 1974:290-291) and that Mill did not even contemplate the possibility that paternalism might encompass interventions in the lives of those that have little or no autonomy (Mill 1991:ch. 3).²³ However, what they never anticipated, happened in interventions in the lives of substantially non-autonomous dependents and to this day not only remains the most widely accepted model of justified paternalism, but has also become the paradigmatic form of justified paternalism in cases ranging from incompetent children in need of supervision to other incompetents needing care analogous to beneficent parental guidance (Beauchamp & Childress 2001:177).

Despite all the above mentioned criteria for justification, paternalism over the past decades became the dominant approach in clinical decision making (Charles et al. 1999a:780). The extent to which this happened is reflected in a 1999 Editorial of the *British Medical Journal* stating that paternalism has become endemic in health care in Great Britain and has established itself as one of the standard forms of clinical decision making in the world of medicine (Coulter

²² Refer to the following case as an example of justified strong paternalism: "After receiving his preoperative medicine, C, a 23-yearold male athlete scheduled for hernia repair, states that he does not want the side rails up. C is of clear mind and understands why the rule is required: however, C does not feel the rule should apply to him because he is not the least bit drowsy from the preoperative medication and he has no intention of falling out of bed. After considerable discussion between the nurse and the patient, the nurse responsible for C's care puts the rails up. Her justification is as follows: C is not drowsy because he has just received the preoperative medication and its effects have not occurred. Furthermore, if he follows the typical pattern of patients receiving this medication in this dosage, he will become drowsy very quickly. A drowsy patient is at risk for a fall. Since there is no family at the hospital to remain with the patient and since the nurses on the unit are exceptionally busy, no one can constantly stay with C to monitor his level of alertness. Under these circumstances, the patient must be protected from the potential harm of a fall, despite the fact that he does not want this protection ... The nurse restricted this autonomous patient's liberty based on ... protection of the patient from potential harm ... and not as a hedge against liability or for protection from criticism" (Silva 1989:64).

²³ It has to be noted though that Mill, despite his fierce opposition to paternalism, considered temporary beneficent interventions in people's actions to be justified on some occasions. He argued that when somebody is ignorant of a significant risk, he or she may justifiably be restrained to ensure intentional acting, backed by adequate knowledge of the action. However, once warned, the person should have the freedom to choose whatever course he or she might desire.

1999:719).²⁴ In yet another British Medical Journal article from the same year it is stated that the characteristics of the paternalistic model of clinical decision making are well known and in its purest form requires of a patient to passively acquiesce to professional authority by agreeing to the doctor's choice of treatment (Charles et al. 1999a:781). This article furthermore states that it is an underlying assumption of this model that the doctor will make the best treatment decision for the patient and is able to do so without eliciting personal information from the patient or involving him or her in the decision making process. The effect of this approach is that while there is no sharing of any of the normal decision making steps, there also cannot be room for any doctor-patient partnership within this model.²⁵

This effect is further exemplified by the implications of the paternalistic model of clinical decision making on the different phases of the treatment decision making process, namely the exchange of information, deliberation on the treatment preferences and decision on the treatment to be implemented. It has to be noted that while these phases are analytically separate, in practice, they are often woven together in an iterative process and that a comparison of the roles of the health care professional and the patient in each of them help to clarify similarities and differences between them (Charles et al. 1999b:651-661).

The phase of information exchange refers to the type and amount of information exchange between professional and patient and whether the flow of information is in one or two directions. In the paternalistic model the exchange of information is largely one way with the flow mainly from the health care professional to the patient. Of the health care professional is expected to at a minimum communicate legally required information about treatment to the patient and to obtain informed consent for the recommended treatment. Beyond this it is the health care professional's prerogative to determine what other, if any, information needs to be communicated to the patient.

The deliberation phase refers to the process of revealing treatment preferences and expressing and assessing the benefits and dangers of a proposed treatment in a specific clinical context. In a pure version of the paternalistic model, the health care professional will typically deliberate alone or at most with colleagues about the proposed treatment while either not soliciting or even overriding the patient's preferences in this regard. This approach is normally supported by the

²⁴ The others being the *informed* and *shared* models of clinical decision making.

²⁵ It has to be noted though that in cases where the patient and the doctor prefer this approach, it can be argued that they have entered a form of partnership based on agreement about how the process should be undertaken. However, this would require an explicit discussion of alternative decision making models and explicit agreement by the doctor to adopt the patient's preferred model, that would be highly unlikely should the doctor adopts a paternalistic approach at the outset of the decision making process.

underlying assumption that the health care professional knows which treatment would be in the best interest of the patient and that patient input is therefore not required in the decisions being made.

The decision making phase refers to the making of a decision about the treatment to be implemented and in a pure form of the paternalistic model would once more encompass decisions by the health care professional alone.

While paternalism has thus over the past decades established itself as the dominant model of clinical decision making and may be regarded as benign and well intentioned by some, the effect of creating and maintaining an unhealthy dependency and of assumptions such as that the doctor knows best and might feel threatened when patients have access to alternative sources of medical information, caused this model to be challenged by doctors, patients, medical ethicists and researchers who advocate more of a partnership relation between health care professionals and patients (Levine et al. 1992:53-58).²⁶

2.7 THE DOMINANCE OF PATERNALISM CHALLENGED

The benevolent skills that gave Lockean title to health care professionals' claims over their practices, disease and even their patients have however in the twentieth century also been the object of scepticism.

Reference was made in 2.6 to the fact that paternalism can be defined as the intentional overriding of a person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose preferences or actions are overridden. It was noted that the analogy to a father accentuates two prominent features of the concept of a paternal role, namely that a father acts beneficently and in the best interests of his children and that he makes all or at least some of the decisions related to his children's welfare, rather than letting them make those decisions themselves. It was also noted that within a health care context, it is evident that the analogy to a father in the concept of paternalism extends even further, as a health care professional in possession of superior training, knowledge and insight thus finds him or herself in an authoritative position to determine a patient's best interests. However, while granting that patients do not know as much about medicine as their doctors, it has to be acknowledged that they know as much and more about their own interests and values. This fact has since the 1970s not only spurred off a great deal of

²⁶ Also refer to Eddy 1990; Hughes & Larson 1991; Whelan et al. 1995; Cahill 1996; Quill & Brody 1996; Coulter 1997.

criticism against the concept of medical paternalism, but has also established patient autonomy as a central concept in bioethics.

The concept of benevolent skills referred to in 2.6, rested on the Lockean notion that the physician combined his skills and benevolence into a human transaction producing a peculiar property called the patient-physician relationship. This human transaction has however since the days of Locke become more and more complex, as many hands today mix their labour in order to make the medical transaction possible. While for instance a patient's active participation in this transaction has made the so-called contract appear somewhat less fiduciary than in the past, also determinants of disease and health that fall outside the range of medical interventions now called for other than medical skills. Moreover, economists revealed that the volume of care given is not determined by patients seeking care from doctors, but rather by doctors who select those in need of treatment, prescribe medication, recommend surgery and order admittance to hospitals (Jonsen 1990:97).

Against this background it became easy to see that all these powers may serve self-interest instead of benevolence. Whereas in Medicaid scandals it was revealed that medically questionable procedures were prescribed by health care professionals for their own benefit, so-called managed care made it possible to skimp on medically indicated procedures in order to improve a plan's bottom lines. Though such practices could hardly be regarded as prevalent, it cast a shadow over physicians' benevolent intent, dimmed the trust that should exist between physician and patient and made it implausible to any longer consider medical skills as a kind of property which the physician is free to exchange with other men who are free to trade with him or not (Sade 1971:1289).

Moreover, the ever changing technological and scientific capacities of medicine increasingly challenged the benevolent authority of physicians. New diagnostic procedures, resuscitative techniques and supportive measures aroused public concern about the appropriateness of entrusting crucial decisions to health care professionals alone and raised the perception that their judgements had to be supplemented and even replaced by others, such as the government and the citizenry. While recognised as a proponent of individual rights, Locke also campaigned for a civil society in which individuals could live cooperatively and peacefully and more than any other philosopher laid the intellectual groundwork for the institutions of democratic groundwork. Whereas in his social contract, he proposed that autonomous individuals grant powers to government to ensure freedom in the development of their property and in the pursuit of their beliefs, Lockean philosophy in medicine provided a model according to which

autonomous physicians could enter into agreements with autonomous patients in order to create a democracy of medicine (Jonsen 1990:98-99).

However, in modern medicine the legal and ethical concept of informed consent has replaced the old agreements and encapsulates a new and expanded contract. In this new contract, the old and noble justification of paternalism has been banished and the basis for the therapeutic privilege of withholding information from patients has been replaced by the proclamation of the rights of patients. This commendable ideal brought the Lockean view of human relations to its logical conclusion, namely from the possessive individualism of physicians as proprietors of their skills to a cooperative and contractual relationship between autonomous physicians and autonomous patients (Jonsen 1990:100).

The dominance of paternalism as approach in clinical decision making has therefore in recent years been challenged by forces such as the rise of consumerism and the notion of consumer sovereignty in health care decision making, the women's health movement with its emphasis on challenging medical authority and the passing of legislation focusing on patient's rights in health care (Charles et al. 1999a:780).

Consumerism is a system of ideas and values that appeared in a variety of forms during the 1970s and 1980s, but has only more recently emerged in health care. In economics, a consumer is a person who buys goods and services for his or her own personal use and consumerism relates to the protection of a consumer's interests. The relevance of these definitions to health care is evident in an interview conducted by the associate editor of the *British Medical Journal* in 1999 on the topic of how doctors need to work more equitably and effectively with patients (BMJ; 319 1999:730).

This interview was conducted with Hilda Bastian, chairperson of the Australian Consumer's Health Forum and often referred to as Australia's consumer champion. While recognising the fact that public debate on health issues is prominent and increasing and that a political awareness of the need to take consumer's concerns into account is evident in the British Government's NHS partnership strategy and also within the restructuring of the European Commission, Bastian believes that true consumer participation in developing health policy and health service planning and provision is still in its infancy in most countries. To her, lay input into healthcare decision making still largely amounts to tokenism, while the lay voice in expert committees is normally represented by a single person who is easily intimidated by a team of health care professionals. Invited individuals are furthermore often not aligned with other

consumers and may also lack advocacy skills, which may result in their views easily being discounted.

To Bastian, the entrenched medical culture presents another barrier to effective lay participation. According to her, doctors have failed to grasp the implications of societal change and this is reflected in medical language still being jargonistic and littered with derogatory and hurtful terms about patients. More importantly, many doctors have retained a paternalistic approach to health care, leaving little room for an equal partnership with patients and consumer advocates in clinical decision making. This, she says, is due to doctors' failure to acknowledge patients' own expertise in their condition and needs and to adjust to those who are well informed, as they may feel threatened. Doctors, furthermore, do not have a sophisticated understanding of the consultation process and tend to restrict their patients' room for participation, often arguing that patients' desire for communication is to be written off as a desire for information that can be met by the handing out of leaflets.

In addition to this, Bastian concedes that healthcare institutions are often large, impersonal and intimidating and that the increased complexity of medical interventions and diagnostic tests are not only baffling, but also depersonalising. Creeping medicalisation is to be regarded as another threat, from the rampant pressure to comply with screening programmes to constant strictures about adopting healthy lifestyles, as well as the expansion of conditions seen as requiring medical treatment.

To Bastian, all of these amount to the undeniably huge challenge of completely renegotiating the doctor-patient relationship as a healing relationship. Although amongst others, lack of time, patchy access to good information and patient preferences are often cited by health care professionals as barriers on the road to shared decision making, Bastian believes poor communication to be a root cause of the dilemma. Moreover, as a recognised expert in the field of evidence-based medicine, she points out that one of the key effects of this movement was to expose just how marginal the benefits from a wide range of treatments are and how little is known about which approaches really work. This underlines doctors' obligation to let their patients have a transparent account of the risks and benefits of interventions in order to facilitate an awareness of trade offs and eventual informed choices. It also reaffirms the need for continued research in this field, as well as more support to consumer organisations and patient support groups to work closely with the government and health care professionals in a more equitable way.

Consumerist ideals can thus be utilised by a variety of interest groups to further their ends. Not only can people buying a product or using a service appeal to the ideals of consumerism in order to secure better deals, but also those providing goods or services can let these appear more attractive by claiming to meet the demands of consumers. Even politicians can persuade consumers of publicly-provided services that users' interests are of importance in policy considerations and it is well known that professional associations often justify their monopolies over the provision of services by claiming that the exclusion of non-qualified practitioners, best serves the interests of consumers.

However, long before the concept of consumerism entered the thinking about public services it was well established in private business. Modern business has indeed become extremely sophisticated in developing an awareness of consumer preferences and in manipulating these through advertising and other means. Furthermore, market research has since World War II become indispensable in successful business, as has public relations departments in private enterprises. While these developments had their origins and firstly flourished in the United States of America, it soon emigrated to other parts of the world where for instance already in 1957, the Consumer's Association was founded in the United Kingdom. The *Which?* magazine published by this association used to be and still is largely devoted to providing readers with information on the quality of high-street products, especially in these cases where specialist knowledge beyond the resources of individual lay people is required in evaluations. This magazine has more recently spawned various offshoots focussing on particular areas of interest, such as *Which? Way to Health* that was launched in 1989 and publishes, amongst others, surveys relating to public perceptions of the quality of medical care (Seale 1993a:66).

Two such surveys from the Consumer's Association were respectively published on 7 and 14 February 1991 in the *Guardian* and addressed issues which to this day enjoy great prominence in consumer circles. The first was on the issue of Patients being left in ignorance and indicated that one in five people leaving a hospital consultation with a specialist still do not understand what is wrong with them. According to the survey, 35% of the people interviewed indicated that there seemed to be no time for asking questions during the consultation, while 22% felt that they were keeping other patients waiting. In response, the Association recommended that patients make a list of questions and do some homework before entering a consultation and if possible, to take a friend or relative with. The second survey was on the issue of GP's who refuse second opinions and indicated that one in ten people who ask to be referred for a second opinion by their family doctor, is refused. In this case, the Association commented that such conduct is illogical and that doctors should stop thinking that they know best.

These efforts at reflecting consumer expectations were in the United Kingdom also strengthened by the appearance of a host of pressure groups representing the interests of particular health service users. To these belonged groups such as Age Concern, MIND, the National Childbirth Trust, the National Association for the Welfare of Children in Hospital and the Patient's Association. In addition to these, numerous support groups campaigning for better services for people with specific diseases like epilepsy, AIDS and autism also came into being and contributed to the debate on medical interests by either being extremely critical of the current system or devoting a large part of their fundraising efforts to the support of medical research.

A distinctive feature of consumerism in the United Kingdom in the 1980s was the increased application thereof in the public sector services. This development was closely associated with the political ideology of a free market propagated by the so-called New Right of the Conservative Government under Mrs. Thatcher. The New Right had an interest in the countering of a dependency culture encouraged by the Welfare State and placed an emphasis on individual choice exercised through the market in order to improve the efficiency and quality of services. Closely associated with this emphasis was a desire to curb public expenditure and to assert authority over the activities of health care professionals who in the NHS would otherwise determine expenditure by the cumulative effect of their clinical decisions (Seale 1993a:67).

A large amount of forces thus came to bear on the public services as the broad public became more consumer conscious, pressure groups campaigned for change and a government was elected that was committed to assisting individuals in overcoming their dependency on the services of the state. According to Christopher Pollitt, a health policy analyst, consumerism thus became an officially approved fashion that now exhorted public administration managers in hospitals, schools, housing schemes and information services to pay more attention to consumer wishes, offer consumers a wider choice and develop techniques for marketing their particular services (Pollitt 1987:43).

It has to be noted though that, unlike in the private sector, people in the public sector who pay for the services are not necessarily those who make use of it. This is due to the fact that although the demand may be big in a service such as the United Kingdom's NHS, rationing decisions have to be made since those who pay for the service may not wish to meet such a high level of demand. Service users in the public sector therefore do not have the privilege of unlimited access to services, as policy makers and service providers would typically make the rationing decisions on their behalf (Seale 1993a:68).

This fact has serious implications for the principle of consumer choice as the key mechanism for the exercising of consumer sovereignty in the private sector. It implies that in a system where there is a rationing of scarce resources, quasi-political decisions are made about priorities and that a consumer in one part of the service might receive a service to the disadvantage of others in the same service. The creation of public sector services thus represents a rejection of the key mechanism of customer sovereignty in favour of a collectivist solution assuming that there is a collective interest in the provision of health care over and above the interests of individual members of society (Klein 1989:153).

The essence of a public sector service thus involves some degree of redistributive justice and implies that consumerism also concerns the responsiveness of providers to complaints, as well as the humanity in which the service is delivered. The recognition that a service can in theory be responsive and humane without offering choice, therefore also introduced a new phase in the development of consumerism when in the 1980s a number of government and management-led initiatives were launched to improve these aspects of health care (Seale 1993a:69).

Management-led consumerism was promoted vigorously in the 1980s and received a significant impetus in 1983 when the British Government received the Griffiths report on health service management.²⁷ It also had a number of practical manifestations, such as special training for health-authority staff in customer relations and the issue of mission statements in order to focus staff members on the common goal of public service. In addition to these and inspired by the market research initiatives of the private sector, patient satisfaction surveys also flourished in this period. While patient satisfaction surveys were already being done in the 1970s,²⁸ they now became widespread and linked to an overall management philosophy focused on responsiveness to consumers. Of particular importance was the challenge to construct ways of routinely monitoring patients' views and to ensure that these results were fed back into planning decisions.

²⁷ Compare in this regard the Griffiths definition of consumerism in the management-led model: 1. The NHS Management Board and Health Authority Chairman should ensure that it is central to the approach of management, in planning and delivering services for the population as a whole, to: (a) ascertain how well the service is being delivered at local level by obtaining the experience and perceptions of patients and the community: these can be derived from the Community Health Councils and by other methods, including market research and from the experience of general practice and the community health services; (b) respond directly to this information; (c) act on it in formulating policy; (d) monitor performance against it; (e) promote realistic public and professional perceptions of what the NHS can and should provide as the best possible service within the resources available. 2. [The NHS cannot] display a ready assessment of the effectiveness with which it is meeting the needs and expectations of the people it serves. Businessmen have a keen sense of how well they are looking after their customers. Whether the NHS is meeting the needs of the patient and the community and can prove that I am doing so, is open to question. 3. Sufficient management impression must be created at all levels that the centre is passionately concerned with the quality of care and delivery of services at local level (Griffiths 1988:196).

²⁸ A survey of public perceptions of the NHS was already commissioned by The Royal Commission on the NHS in 1979 and indicated widespread overall support for the service, as well as criticism of certain aspects such as the lack of appointment systems in hospital outpatient departments and excessively early waking times for inpatients (Seale 1993:69).

These were not only covering the so-called hotel aspects of care such as cleanliness and food, but also medical effectiveness as arguably the most important aspect of health care for consumers of health services (Seale 1993a:71). In addition, management-led consumerism in Great Britain in 1992 also initiated a publication called *Listening to local voices in the NHS* which argued that purchasing authorities should attend to local people's views on priorities for health care with regard to the rationing decisions they have to make (Sykes et al. 1992).²⁹

These initiatives in management-led consumerism were however also supplemented by an increased awareness of the right of complaint and redress (Mulcahy & Lloyd-Bostock 1996:213-223). Moulded on the private sector practice of the returning of faulty products, it was expected to in a consumer conscious health service, find easy access to high quality services, as well as mechanisms whereby complaints could be heard and acted upon quickly and individual consumers could be compensated for poor quality of service, accidents or negligence (Muir Gray 1998:6). These expectations were however frustrated by numerous reports in newspapers and elsewhere on severe difficulties in having complaints heard and gaining redress.³⁰ These varied from evidence of bureaucratic delay that had the potential of favouring the doctors on charge to even longer delays caused by the legal system and the defensive actions of the health authorities (Seale 1993a:72).³¹

²⁹ Management-led consumerism has however also been subjected to strong criticism by those campaigning a more radical view of consumerism. Not only have the motives thereof been questioned by those regarding it as an attempt in curbing the powers of doctors in making rationing decisions (Winkler 1994).

³⁰ Refer to the following two cases that were reported in the *Guardian* on 13 November 1991 and 4 March 1992 respectively:

"Ten years ago Elsa Bentley, then 66, went into hospital to have her left hip replaced. Immediately after coming round from the operation she knew something had gone terribly wrong: she was in pain and her foot was numb with no sensation. Six weeks later she had an exploratory operation to find out what had happened. The verdict was permanent and severe damage to the sciatic nerve. Mrs. Bentley has never walked more than a few yards since. Little did she realise that the failed operation was just the beginning of a ten year ordeal, still not over, to obtain redress. Injured by a medical accident, she was to be victimised all over again by the legal system. Two solicitors and two barristers advised her she had little chance of proving the surgeon negligent ... but she found a third solicitor and fought a two year High Court battle to allow her writ to proceed. Finally, last August a High Court judge ruled that her injury was caused by the surgeon's negligence. But with each side's costs estimated at £100 000, the fight is still not over. Bristol and Weston health authority has appealed and she has yet to see a penny of the £85 000 damages. Russell Levy, her current solicitor, says: Mrs. Bentley's case should have been concluded in 1986 or '87 at the latest. I've never understood why it has been so strenuously contested. They've made her fight every inch of the way. She stoutly declares: I'm not going to die before this is finished".

"Shortly before Christmas 1990, Jane Hanna's partner Alan died from an epileptic fit in his sleep. He was just 27 years old and a promising young barrister. He had been diagnosed by his GP only seven months before. Not surprisingly, Ms Hanna was distraught. She was also very unhappy with how Alan's GP had treated him, so she made a formal complaint. FHSA regulations laid down by the government state that complaints have to be made within 13 weeks. Despite her grief Hanna met this deadline, only then to be told that the 13 weeks counted not from Alan's death, but from when the treatment from the GP began, seven months before. Ms Hanna protested and eventually the FHSA waived the time limit, although it needed the GP's permission. A year after she complained she is still waiting for a hearing".

³¹ Refer in this regard to the following statement of the Head of GP Services of the Medical Protection Society reported in the *Guardian* on 4 March 1992:

However, in spite of these difficulties in obtaining legal redress in the United Kingdom, the 1970s and 1980s saw an increase in the frequency and severity of medical malpractice claims. A study published by the Centre for Socio-legal Studies at Oxford estimated that the cost of medical litigation in 1988 in England amounted to £75 million (Dingwall et al. 1991). Parallel with these developments, the costs of health care practitioners to insure themselves against such claims rose exponentially which also placed a heavy financial burden on health authorities, since the financial responsibilities simply became intolerable for individual doctors. These tendencies were in this period also prevalent in the United States of America where medical practice became increasingly defensive due to a steady rise in complaints. According to Seale, the dilemma created by complaint and redress can therefore be summarised as both an obligation to compensate consumers for bad and damaging services and as a danger that defensive medicine may be to the disadvantage of other consumers (Seale 1993a:73-74).

While the 1970s thus saw experiments in representation and participation and the 1980s various initiatives in management-led consumerism, the 1990s were characterised by more substantial attempts in enhancing consumer choice in health care. Politically led initiatives in enhancing consumer choice got momentum from the late 1980s with amongst others the proclamation in 1987 of the White Paper on Primary Care³² and of the Patient's Charter³³ in 1991. These documents encouraged consumers to indicate the better services by voting with their feet and provided them with clear guidelines with regard to their basic rights in health care. In addition to these initiatives, the 1990s were characterised by an emphasis on the need to let consumers make informed choices. It was generally acknowledged that while patients might have the ability of judging the quality of the hotel aspects of care and even of the communication between themselves and health care professionals, specialist knowledge was required in order to judge the quality of clinical decisions (Seale 1993a:78). Following trends in the United States of America, the provision of this type of information to consumers became of great importance

"You can't imagine the anxiety a formal FHSA complaint causes a GP. It's often hanging over their heads for months, which can make their clinical judgement erratic. Often the onus is on the GP to prove that he didn't breach his contract, rather than on the patient to prove that he did, especially if there is death involved".

³² The White Paper on Primary Care issued in 1987 under the title of *Promoting Better Health* by the Department of Health and Social Security, amongst others contained the proposal that GP's should indulge in a limited form of advertising of their services in a leaflet indicating what services they have to offer. This resulted in a large proportion of GP's remuneration being determined by the amount of patients on his or her list (Seale 1993:78).

³³ The Patient's Charter included the so-called *Seven existing rights* stating: Every citizen already has the following National Health Service rights: 1. to receive health care on the basis of clinical need, regardless of the ability to pay; 2. to be registered with a GP; 3. to receive emergency medical care at any time; 4. to be referred to a consultant, acceptable to you, when your GP thinks it is necessary and to be referred for a second opinion if you and your GP agree this is desirable; 5. to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before you decide whether you will agree to the treatment; 6. to have access to your health records and to know that those working for the NHS will, by law, keep their contents confidential; 7. to choose whether or not you wish to take part in medical research or medical student training (The Patient's Charter 1991:8).

also in Great Britain and elsewhere and furthermore stimulated the setting up of information gathering services such as databases and clinical audits. However, ownership of this information is in future likely to be vehemently contested with both doctors and healthcare authorities defending their interests against each other, as well as against the demands of consumers (Muir Gray 1998:159-161).

Moreover, while it remains to be seen what the impact of consumerism might be on the balance of power between lay and professional people in healthcare (Winkler 1994), the dominance of paternalism as approach in clinical decision making has in recent years also been challenged by the United States women's health movement with its emphasis on the questioning of medical authority. With a history already spanning two centuries, the United States women's health movement grew rapidly through the 1970s, broadened its base with women of colour in the early 1980s and became institutionalised during the late 1980s and 1990s (Ruzek & Becker 1999:4). Today, this movement is driven by the conviction that trust in mainstream medical institutions and managed care organisations has been eroded to such an extent that both grass-roots and professionalised health advocacy groups are likely to play key roles in defining the quality and trustworthiness of health information.³⁴

This conviction has its origins more than three decades ago when access to medical information was almost exclusively restricted to health care professionals and lay people's insistence on access to medical research was frowned upon. With the exception of books on childbirth, few books on women's health could be found in bookstores, since it was simply assumed that physicians were the experts and that lay people had to be guided in issues on healthcare. However, this system was challenged by laywomen asserting that personal subjective knowledge of one's own body was a valid source of information and that it deserved to be recognised as such (Federation of Feminist Women's Health Centers 1981).

Under this banner, the United States women's health movement grew rapidly under the impetus of several grass-roots groups with strong ties to other social change initiatives, such as anti-abortion, prepared childbirth and consumer health movements. With the general feminist movements of the 1960s and 70s aspiring for equal rights and full participation of women in all spheres of society, many believed that without control over reproduction, all other rights could be in jeopardy. Reproductive issues therefore not only defined many branches of the movement in the early years, but also shaped group consciousness and social action and remained central to feminist health agendas worldwide (Cottingham et al. 1997:9-28).

³⁴ Refer in particular to Ruzek 1997:81-85.

Inspired by feminist health writers such as Barbara Seaman (Seaman 1969), Barbara Ehrenreich and Deidre English (Ehrenreich & English 1972), Ellen Frankfurt (Frankfurt 1972), Gena Correa (Corea 1985) and Claudia Dreifus (Dreifus 1978), the Boston Women's Health Book Collective produced the enormously popular publication *Our Bodies, Ourselves* which saw numerous editions worldwide. Furthermore, the Federation of Feminist Women's Health Centers developed women centred gynaecological self-help health services, while the National Women's Health Network succeeded in joining a wide range of local groups to provide women with a voice in Washington. In addition, health activists travelled, spoke and published widely and thus became spokespersons for a rapidly growing movement (Ruzek & Becker 1999:5).

A further important achievement of the United States women's health movement was the transferal of women's health from a largely male to a female dominated environment. This transferal happened in tandem with a variety of self-help medical care movements aimed at defining women's own health and creating alternative services. Local movement groups in all fifty states were now amongst others providing gynaecological self-help services, women controlled reproductive health clinics and educational health materials together with advocacy activities ranging from accompanying individual women looking for medical care to advising and influencing state and local health departments. By the mid-1970s, these groups not only escalated to more than 250 formally organised and nearly 2000 informally organized units in the United States, but also established itself in more than 70 feminist health groups in Canada, Europe and Australia (Ruzek 1978:241-245).

Although the leadership of the United States women's health movement remained largely white and middle class in the early years, the distinct health needs of diverse women gradually emerged and resulted in women of colour forming their own movement related organisations such as the National Black Women's Health Project. These organizations received national recognition and developed agendas to support women of colour in dealing with medical conditions such as lupus, foetal alcohol syndrome and obesity and protect them against transgressions such as racist sterilisation and contraceptive practices. Furthermore, these agendas were supplemented by initiatives from groups as diverse as lesbians, rural women and women with disabilities who all directed attention to their particular health care needs.

However, like other social movements, the United States women's health movement went through periods of emergence and rapid growth, but also of decline and eventually of institutionalisation. The grass-roots organisations at first providing the impetus to the movement, declined in the 1980s, apparently due to changes in movement adherents, as well as

the social context in which the movement now operated. Furthermore, much of organised feminism now seemed disconnected from ordinary women's dilemmas, while also the rise and success of groups dedicated to single issues such as AIDS tended to dampen the enthusiasm for the women's health movement. As a result, most alternative feminist health clinics and the practice of gynaecological self-help ceased to exist by the end of the 1980s and were gradually replaced by Professional Institutional Agendas (Ruzek & Becker 1999:6).

However, the earlier successes of the United States women's health movement proved to be the main reason why its core ideas were gradually incorporated into mainstream organizations and institutions, thus creating new opportunities for women's health advocates. Feminism has by the 1990s made significant claims for gender equity in most social institutions and with a growing number of women in Congress, the biomedical professions and health advocacy communities, a formidable force in the campaigning for women's rights was re-established. Major achievements in this period was the pressuring of both Congress and the National Institutes of Health in passing the Women's Health Equity Act by the end of 1990 and the establishing of the Office of Research on Women's Health and the Women's Health Initiative, focusing on the prevention and treatment of cancer, cardiovascular diseases and osteoporosis in 1991. The original women's health movement's critique of biomedicine and the call for the demedicalising of women's health care were thus reframed into a bipartisan agenda for equity (Weisman 1998:77-89).

Growing federal investment in women's health and the fringe benefit of Cold War funding of women related research through the Department of Defense, furthermore created opportunities for activists to collaborate with scientists and professionals who were more than eager to take advantage of these new research options. In order to maximise the likelihood of securing federal funding for research on women's health, scientists and their consumer allies narrowed their focus down to specific diseases and thus created a disease orientated approach reflecting the expectations of women for a high level of professionalism. This approach was strongly supported by women's health advocacy groups taking their cues from the successes of AIDS advocacy groups and campaigning for the benefit and support of especially breast and ovarian cancer sufferers in both Congress and the National Institutes of Health.

Finally, a recurring and most important theme in the United States women's health movement's challenge of paternalism has been the demand for evidence-based medicine. Long before this term came in vogue within the context of patient partnership in healthcare, major feminist advocacy groups aligned themselves with scientists and physicians who, at a time when the concept was still being resisted by many health care professionals, were dedicated to securing a

more scientific basis for medical practice. Grass-roots health activists were critical of the side-effects of inadequately tested drugs and devices and in particular early high-dose oral contraceptives, diethylstilbestrol and the intrauterine device. Furthermore, they sought to protect women from unsafe or unnecessary biomedical interventions and especially focussed on the number of unnecessary hysterectomies and mastectomies performed. In addition, the growing number of female physicians, scientists and professionalised advocacy groups were dedicated to ensuring women an equitable share of biopsychosocial science and treatment and to facilitate alliances with women consumers in order to secure mutually beneficial relationships (Ruzek 1995:1-6).

Paternalism as approach in clinical decision making has in recent years however also been challenged by the passing of legislation focusing on patient's rights in health care. Admitted to an unfamiliar institution, separated from friends and family, forced to wear a degrading costume, confined to bed and attended to by a variety of strangers who may or may not keep the patient informed, the average patient is often left intimidated and disorientated and finds him or herself in an environment which encourages dependence and discourages the assertion of individual rights (Annas 1989).³⁵ The movement for the enhancement of patients' rights is therefore based on two premises, namely (1) that citizens possess certain rights that are not automatically forfeited by entering into a relationship with a physician or a health care facility and (2) that most physicians and health care facilities fail to recognise these rights, fail to provide for their protection or assertion and limit their exercise without recourse (Annas 1975).

The concept of rights is all about power and therefore decisions on the establishing of rights often amount to the determination of who should hold the power. Professions and in particular the medical profession have traditionally exercised considerable power over their work and have maintained this partly because of the vulnerable position of patients (Johnson 1972:36). It was therefore to be expected that this degree of occupational control would become increasingly difficult to maintain in the face of movements like consumerism and the women's health movement with their aim of enhancing patient autonomy. It furthermore gradually became clear that a commitment to patient's rights would entail an abandoning of some of the traditional elements of the profession, that debates about rights would increasingly and inevitably involve power struggles between professions and that eventually health care rights would be little more

³⁵ Also refer to the following warning from Dr. M. Rabkin, Physician-Director of the Boston's Beth Israel Hospital: "... today's hospital stands increasingly to become a jungle, whose pathways to the uninitiated are poorly marked and fraught with danger". Quoted in Annas 1974.

than a mechanism for transferring power from health professionals to lawyers in court (Hope 1991:247-253).

The concept of a right in modern political philosophy arose in response to the difficulties experienced by the widespread acceptance of utilitarianism as a foundation for concepts of justice (Montgomery 1996:142-143). Utilitarianism teaches that actions are morally justified if their net consequences are to increase happiness and decrease pain for the largest amount of people, but aggregates total benefits and harms and thus disregards the fact that individuals do not experience those harms and benefits equally (Hart 1983). Rights can however be utilised to balance the excesses of utilitarian theories in two important ways. It can firstly be used to ensure that all individuals are treated with equal concern and respect (Dworkin 1985) and that the distribution as well as the aggregate of benefits is taken into account (Scanlon 1977). Secondly, rights can be employed to identify these elements of an individual's being that are so fundamental that they are not to be traded for collective benefits (Dworkin 1977).

An important contribution to the issue of the nature of rights was also made by Jeremy Bentham who defined the key to an understanding of the concept of rights according to the effect on other people. He argued that since obligations could only be enforced within a legal system, no rights made sense outside a legal context and that any appeal to so-called natural rights therefore had to be regarded as empty rhetoric (Hart 1982). These ideas are still evident in modern jurisprudence which contends that rights can be regarded as a particular way of describing the relationships between people and that people can only have rights when obligations are imposed on others in order to secure the rights of the right-holder. This rights-constituting nature of obligations also throws light on the status of the right-holder, since rights based on interests and not on obligations would open the door to paternalism due to the possibility of formalising it into duties to care for individual patients without enhancing those patients' control over their care. For this reason, some thinkers have gone further to adopt choice or will theories of rights which would not only require obligations serving the interests of the right-holder, but also allow him or her to decide on how and when to exercise these rights. Choice theories of rights have therefore also been more attractive to those who wish to increase the power of patients, as it emphasises the ability of right-holders to also control the position of others (Hart 1983).

The fact that patients have or should have rights, thus offers an important framework for promoting patient-centred care.³⁶ This framework should firstly place the patient at the centre of the relationship with those caring for them and define professional responsibilities in terms of

³⁶ Compare also Annas's suggestion of an Agenda for Patients' Rights for the 80s in Annas 1989.

the interests of the patient and not in terms of the normative values created by the professions. It should secondly aim to empower patients by allowing them control over the exercising of their rights, since only rights maximising choice could contribute to that aim. Conferring rights onto patients would thirdly imply that choices and needs would prevail over general policy considerations, as the rights of patients should not be sacrificed to the common good. The framework should fourthly also emphasise that rights need to be enforceable in order to have any real existence and to enable patients to vindicate their rights in some way (Montgomery 1996:144).

However, when the existing state of for instance British law is examined, it is clear that it does not provide a strong framework for the promotion of patients' rights and that in the key area of the control of information, patients' position can even be regarded as weak. This is reflected by the fact that while there is a clear requirement that consent to treatment should be obtained, the standards of informed consent are set by the professions and not for them. Moreover, in access to health records, the degree of patient control is strongly undermined by the fact that the right of access may be limited by health care professionals believing that a patient's health could be affected. Even in requesting a particular kind of treatment or any treatment at all, the rights of patients are regarded to be weak. This reluctance to build British health law on the concept of rights is contemplated as deliberate and not accidental, since the British judiciary and until recently also the British legislature has been particularly reluctant to compromise the clinical freedom of the medical profession (Montgomery 1989:319-339). Even recent initiatives towards greater constraint of medical freedom with regard to the statutory licensing of embryo research and infertility treatment and the more specific and rigid definitions of the terms of service of general practitioners by the British government, should therefore not be viewed as increases in patients' rights, since patient power is not necessarily increased by a reduction in medical power (Montgomery 1996:146).

However, this situation is currently being contested in Great Britain by lawyers arguing that medical law is essentially an area of human rights and that British law should therefore adopt a rights-based approach (Kennedy 1991). Such an approach would involve a number of fundamental changes of attitude in the professions, some of which may be less acceptable than others. A case in point is the information rights guaranteed by the Optician's act of 1989 which oblige British Opticians to provide a patient with a written prescription of actions to be taken to correct his or her eyesight. While this provision might on the face of it appear to be an honouring of the right to information and a confirmation that consent to treatment is truly informed, the objective thereof, as judged in context, is rather to ensure that patients' power as

economic agents is preserved. While it is normally quite difficult for patients to assess the value of professional services, the provisions of the Act aim to reduce this lack of knowledge, to provide the necessary information in order to empower patients and to ensure that this purchasing power will be real by prohibiting opticians from obliging patients to buy glasses or contact lenses from them as a condition of testing (Montgomery 1996:147).

The main aim of these provisions is thus to enhance patient choice by dividing the process of diagnoses from that of treatment and to allow a patient the opportunity of shopping around for the best deal. However, this approach to rights is also directly linked to an understanding of patients as nothing more than economic actors and as such subject's opticians to the discipline of the economic market. It is even regarded as possible that the patient's rights movement might be so closely linked to consumerism that the attractiveness of rights might match that of consumerism itself. Since the essence of consumerism is to be found in consumers deciding on what they want and not what suppliers choose to offer, it follows that in health care, an increase in the control of patients could result in more restrictions imposed on clinical expertise.

Traditionally, the inability of patients to oblige health care professionals to provide any particular pattern of care, left clinical judgement largely unrestricted. Doctors were in extreme cases and under the guise of clinical freedom, even permitted to deny patients access to health services regarded as inappropriate by society and thus enjoyed superior power at the expense of patients. However, it is contended that the introduction of extensive patients' rights might challenge some fundamental characteristics of the health care professional's image. The assumption that patients can exercise choices might imply that health care issues can be understood by non-experts as well and will straightforwardly deny the notion of an exclusive scientific knowledge base. Furthermore, it might devalue the need for skills of interpretation acquired only in practice and over time even alter the nature of professional practice by undermining the professional and personal values of health care practitioners. A further concern arises from the fact that the language of rights tends to reduce the complex social reality of patient-centred care to an extremely narrow range of entitlements and leaves no room for virtues such as compassion, altruism and sacrifice. It could finally indeed be argued that a rights-based approach in health care could destroy the very virtues on which it has traditionally been based, as such an approach is regarded by many as unnecessarily antagonistic and prone to promoting confrontation rather than partnership (Montgomery 1996:148).

2.8 THE EMERGENCE OF THE CONCEPT OF PARTNERSHIP IN CLINICAL DECISION MAKING

The challenges which the rise of consumerism and the notion of consumer sovereignty in health care decision making, the women's health movement with its emphasis on challenging medical authority and the passing of legislation focusing on patient's rights in health care posed to paternalism as approach in clinical decision making, have in recent years given rise to the concept of partnership in clinical decision making (Coulter 1999:719-720).³⁷

The concern to equalise relationships between health care professionals and lay people has been gaining momentum over the past decade. While consumerism was strongly promoted in the 1980s as part of a market ideology and also infused health policies in many countries, it however also involved the deficiency of encouraging people to make demands, but at the same time failing to emphasise reciprocal responsibilities. A growing awareness of unexplained variations in patterns of medical practice and of the gap between public expectations and the supply of services has also led governments to consider new ways in which this demand for services could be managed (Pencheon 1998:1665-1667).

The concept of partnership has therefore gradually replaced that of consumerism as a key plank of public policy and has become commonplace in official statements where it represents a new emphasis on shared information, shared evaluation, shared decision making and shared responsibilities. Also in health care contexts it is maintained that partners should work together to achieve common goals and that their relationship should be based on mutual respect for each other's skills and competences and the recognition of the advantages of the combining of these resources to achieve beneficial outcomes. It is today therefore increasingly recognised by many in the health care industry that the key to a successful doctor-patient relationship is to be found in also regarding patients as experts (Wennberg 1984:6-32).³⁸ The doctor is or should be well informed about diagnostic techniques, the causes of diseases, the prognosis and treatment options and preventative strategies, but only the patient knows about his or her personal experience of illness, social circumstances, habits and behaviour, attitudes to risk, values and preferences. There should therefore be awareness that both types of knowledge are needed to manage illness successfully and that both parties should be prepared to share information and take decisions jointly (Coulter 1999:719-720).

³⁷ See also Elwyn et al. 1999a:753-756

³⁸ This point has already in 1957 been made by Balint. See Balint 1957. Also refer to Tudor 1988.

As such, the concept of patient partnership has already established itself firmly on the agenda of an institution like the British National Health Service. Elements like a revised Patient's Charter, a relaunch of the patient partnership strategy, the establishment of NHS Direct Online (an online version of the telephone information and triage system), results from the national patient and user survey and a new strategy for healthy citizens are now regarded as priorities in this institution.³⁹ The declared motivation of the government behind initiatives like these is the urgent need to have all better informed about risk, treatment options, outcomes and the limitations of medical care and to achieve this telephone help lines, website links, health skills training programmes, as well as a new handbook for common ailments. Self help and informed choice, it is argued, is to be encouraged in the hope that it will contain costs and ensure that demands for health care are appropriately channelled (Coulter 1999:719-720).

However, several questions with regard to the implementation of the concept of patient partnership in health care remain unanswered. With reference to the role of patients, little is still known about their readiness to assume decision making responsibilities. While some evidence suggests that many patients have strong treatment preferences (Guadagnoli 1998:329-339), others may not want an active role thrust upon them. Furthermore, while younger people tend to be more critical of professional paternalism and are more likely to expect an active role in health care decisions, some older patients still prefer to leave decision making to the doctor for fear of making the wrong decision (Schneider 1998:47).

For health care professionals, it remains a question which patients would opt to participate in their health care and which would prefer a more passive role. While informed consent requires some level of patient participation in clinical decision making and it can no longer be regarded as little more than getting a signature on a form, the question remains how feasible it is to determine patients' preferences and sensitivities and provide full and unbiased information within the time limits set by a normal consultation? (Elwyn et al. 1999a:753-756).

Moreover, several specific challenges attached to the concept of patient partnership have also recently been raised in editorials of the *British Medical Journal*. One aspect of the concept that lately received a lot of attention is the challenge posed by lay partnership. While lay people have long been involved in the health service as part of governance bodies and other committees, it was only recently that they have entered the heart of professional practice and performance and started working with doctors in doctor-patient groups discussing topics like standards, guidelines, clinical audits and revalidations. As could be expected, this involvement seriously

³⁹ Secretary of State for Health 1999.

challenged doctors' belief that they could decide by themselves what patients' interests are and how these should be met (Williamson 1999:721-722).

From the start, the very concept of lay partnership proved to pose its own challenges. Although doctors share core values, norms and skills, but specialise in various ways and to different levels, parallels among lay people are less well understood. It gradually became clear that while some lay people, usually after being a patient, develop expertise in the way patients perceive health care experiences, perceptions and the interests of patients, there also occur variations in knowledge, as patients' expertise are normally related to the immediacy and detail of their own experiences. This challenge could be addressed by the formation of patient groups whose expertise lie in their detail knowledge of issues that are of concern to particular groups of patients (such as cancer patients) and who may disagree about solutions proposed by health care practitioners, but are united by their identification of relevant issues.

It thus became clear that in order to function properly, patient representative groups need a variety of lay members with different perspectives and skills depending on the purpose and level of the group. In such a group, differences of opinion among and between lay members and health care professionals can be attended to in depth by listening, reconsidering and negotiating different points of view with the ultimate aim of reaching a consensus (Wilkie 1998:1623). While consensus can sometimes be reached on the most radical issues and at other times proves not to be possible for the moment, discussions always have the potential of altering the way in which health care professionals look at issues and of strengthening a position that protects patients' interests and weakening another that might threaten them (Williamson 1999:721-722).

Yet another aspect of the concept of patient partnership that created a lot of discussion is the challenge posed by the participation of health care professionals. In a letter to the *British Medical Journal* in 1999, the question was raised whether the concept of patient participation in health care can at all be regarded as viable or whether it simply amounts to utopianism? Since partnership implies the sharing of power in the making of decisions, the question arises how many health care professionals might be willing or even able to share their knowledge and skills, let alone empower a person to decide on the next course of action? Furthermore and regardless of a genuine intention to help and empower people, it is a fact that the realities of participatory processes are often contradictory to the empowering principle and that while participation may be openly encouraged, patients often remain confined to the bottom of the ladder of participation. This may result in partners being heard, but not being taken notice of and could indeed raise the concern that the credibility and legitimacy afforded to health care

professionals may encourage people to acquiesce and so in effect perpetuate the imbalance of power. It is argued, that it therefore remains an unfortunate fact that the bureaucracy of the health services forms a strong barrier to effective participation and that the personal needs and aspirations of many professionals tend to prevent the shift in power needed should patients are to take some control over their health care and become true partners (Lamont 1999:783).

Another letter in this regard echoes many of these sentiments and reiterates the fact that partnerships with patients in sharing medical decisions has become an idea of paramount civil importance for modern health care systems. Partnerships, it is argued, stem on the one hand from the reasons underlying the right to informed consent to medical practices and the humanisation of the approach to patients and on the other from the development of advocacy in health promotion and self determination of civil rights.

However, such a profound innovation inevitably increases the complexity of and turbulence in organisations and might have serious implications. The medical profession, for instance, needs to be trained in this regard and requires education that is not restricted to the questioning of current medical practices, but extends to embrace specific epidemiological knowledge on risks and outcomes, as well as on evidence-based medicine. All such services will furthermore also inevitably become more costly, since doctors will require more time for each patient. These arguments, amongst others, are forwarded to bring home the message that although the equalising of interactions between health care professionals and patients might be a noble and even pressing idea, partnership is no magic formula and that massive financial and cultural investments will be required to fully realise this opportunity (Mariotto 1999:783).

2.9 EVIDENCE-BASED PATIENT CHOICE AS PARTNERSHIP MODEL IN CLINICAL DECISION MAKING

Evidence-based patient choice is of the emerging partnership models for medical encounters that advocate evidence-informed choice and shared decision making. With the term coined by Muir Gray, this model advocates

- the sharing of good quality evidence-based information and
- respect for patient preferences and involvement in health care (Muir Gray 1996).

It is thus aimed at providing patients with evidence-based information in a way that facilitates their ability to make choices and decisions about their health care (Ford et al. 2003:589-602). Within the evidence-based patient choice context, this emphasis on patient choice is justified by three ethically inspired reasons. Firstly, it is regarded as a rights issue according to which patient

autonomy ought to be respected for its own sake. Secondly, patient choice is considered to be instrumental in producing good consequences (Steward 1984:167-175).⁴⁰ Thirdly, it is emphasised that what can be considered as a good outcome, is in part determined by patient's individual values as exercised through choice and that genuine respect for patient choice is therefore to be regarded as good in itself, even though it might lead to poorer health (Hope 2002:100).

While the model of evidence-based patient choice could thus be justified on grounds such as veracity (Edwards & Elwyn 2007:63-65), it is claimed to ultimately rest on two principles in medical ethics, namely patient autonomy and patient benefit (Ashcroft et al. 2002:53). However, being defined as "the use of evidence based information as a way of enhancing people's choices when those people are patients" (Elwyn & Edwards 2002:7), evidence-based patient choice not only rests on the principles of patient autonomy and patient benefit, but is also aimed at enhancing and establishing these principles.

This is to be accomplished by what is referred to as the evidence-based patient choice chain, stipulating that the practising of evidence-based patient choice should

- start with issues that are of importance to patients and that patients need to be involved in identifying these issues,
- provide the best possible quality of information as reflected in systematic reviews and randomised controlled trials,
- ensure that such information is accessible to most patients and is presented in a way that does not manipulate patient choices, as it often concerns the probabilities of risks and benefits and
- actively involve patients in the process of making health care decisions, as patients need to have the power to choose (Hope 2002:100).

From this it follows that the six main components of an evidence-based patient choice consultation can therefore be defined as:

- research evidence/medical information,
- the doctor-patient relationship,
- patient perspectives,

⁴⁰ See also Greenfield et al. 1988:448-457.

- decision making processes,
- time issues and
- establishing the patient's problem.

Research on evidence-based patient choice also stresses the importance of both doctors and patients being well informed and appraised of the latest available medical evidence and of evidence-based information regarding diagnosis and treatment to be shared with patients during a consultation. However, no suggestions of how this might be achieved have yet been published (Ford et al. 2003:589-602).

It is therefore argued that the unprecedented access to information is to be regarded as one of, if not the most important influence in the attainment of these goals (Holmes-Rovner et al. 2002:276) and that a lack of information will result in a diminution of patient autonomy (Schneider 1998:110). It is furthermore argued that in order to attain the goals of evidence-based patient choice, two sorts of evidence is required:

- evidence that patients might need in making their choices of treatment and care and
- evidence that health care professionals might need about the most effective ways of facilitating the participation of patients in such choices (Ashcroft et al. 2002:54).

It is today widely agreed in the world of clinical medicine, that the randomised controlled trial (RCT) is arguably the most reliable kind of evidence for the effectiveness of an intervention (Chalmers et al. 1989:10). In daily practise, this doctrine is flanked by the concept of a hierarchy of evidence (Guyatt et al. 1995:1800-1804) that gives an ordinal ranking of different kinds of evidence in terms of its reliability and generalisability. However, as pointed out by Ashcroft et al, the dilemma with RCT's is that while it can be utilised in some domains to evaluate interventions, it may due to ethical or procedural reasons be of less value in others.⁴¹ Insistence on using RCT evidence as the only standard in evidence-based patient choice would therefore be unrealistic, while other types of evidence might prove to be more accessible and on occasion more reliable or informative.

The rise of qualitative research in medicine has for instance generated a better understanding of the reasons why patients may not choose the apparently 'best' option than was possible by means

⁴¹ RCT evaluations of treatments using patient preference endpoints may for instance be considered meaningless if the view is taken that patient preferences are not static, or objective 'outcomes for comparison'. A RCT of two different ways of breaking bad news to patients may lack external validity over time, as cultural changes affect attitudes to truth-telling in diagnosis; this is unlikely to be a problem in a RCT of two pharmaceutical agents using 'hard' endpoints, such as survival (Ashcroft et al. 2002:54).

of RCT evidence or quantitative surveys (Featherstone & Donovan 1998:1177-1180).⁴² Moreover, both patients and doctors may from the point of meaning or of utility in decision making, find the employment of narrative evidence more valuable than statistics (Charon 2006:17). In order to be successful, evidence-based patient choice thus has to adopt a broad conception of good evidence, while at the same time requiring high standards of methodological rigour in generating this diversity of evidence (Ashcroft et al. 2002:54).

SUMMARY AND CONCLUSIONS

This chapter attended to the shift towards liberalism in moral deliberations on the ethical concept of patient autonomy that became inextricably linked to the names of Immanuel Kant and John Stuart Mill and characterised by what Kant called autonomy and Mill defended as individuality. It noted that to respect an autonomous agent, is to recognise with due appreciation that person's capacities and perspective, including his or her right to hold certain views, to make certain choices and to take certain actions based on personal values and beliefs and that the elements of the concept of informed consent, namely competence, disclosure, understanding and voluntariness provide a valuable paradigm for meeting the professional obligations of respect for patient autonomy in clinical decision making. It however also referred to the conflicts that arise between the ethical concepts of autonomy and beneficence and to the dominance that paternalism used to enjoy in clinical decision making. The chapter proceeded with an exposition of the challenges posed to the dominance of paternalism by elements such as the challenging to the concept of the benevolent skills of the doctor, consumerism, the women's health movement and the passing of legislation focusing on patient's rights in health care. It also noted the resulting emergence of the concept of partnership in clinical decision making, as well as the main characteristics of evidence-based patient choice as partnership model in clinical decision making.

With regard to the aim of the study, namely to determine an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, it can in addition to the discussion in this chapter be concluded that whereas the concept of partnership in clinical decision making arose within the context of the development of the concept of respect for patient autonomy, any endeavour at determining and developing an adequate approach to partnership in clinical decision making should therefore be undertaken within this context. A thorough and adequate understanding and application of the ethical principle of respect for patient autonomy as represented in the informed consent elements of competence, disclosure, understanding and voluntariness is therefore essential in the development of any new concept of patient-centred care. Moreover, it became clear that

⁴² See also Fineman 1991:355-374; Nettleton 1995.

although evidence-based patient choice is claimed to not only ultimately rest on the two ethical principles of patient autonomy and patient benefit, but to also establish and enhance these principles, the practice of this partnership model however remains deprived of a proper embeddedness in the context of the ethical principle of respect for patient autonomy. In thus undertaking the transformation of evidence-based patient choice to a therapeutic alliance in this study, close attention will have to be paid to this cornerstone of partnerships in clinical decision making.

CHAPTER 3

EVIDENCE-BASED PATIENT CHOICE: CONTEXT, NATURE AND PRACTICE

INTRODUCTION

Against the background of the discussions in Chapter 2, this chapter provides an exposition of the context, nature and practice of evidence-based patient choice. Reference is made to important political, economic and ethical developments such as a change in rhetoric depicting patients as consumers, the narrowing of the gap between expert and lay knowledge, an increasing emphasis on patient rights and autonomy, as well as on the accountability of the public services that since the mid 1990s fundamentally determined the environment in which evidence-based patient choice would develop as partnership model in clinical decision making. Furthermore, it is explained that evidence-based patient choice propagates the sharing of good quality evidence-based information and respect for patient preferences and involvement in health care, is aimed at providing patients with evidence-based information in a way that facilitates their ability to make choices and decisions about their health care and as such joins two important movements in modern medicine that have both developed as a critical response to what was perceived to be the excessive authority given to physicians and other health care professionals in medicine. In the last paragraph it is argued that the practice of evidence-based patient choice is directly related to its nature and can therefore be conceptualised in terms of four key decision making skills required from health care professionals to involve patients in clinical decision making, namely shared decision making, risk communication, decision analysis and the use of decision aids.

3.1 THE CONTEXT OF EVIDENCE-BASED PATIENT CHOICE

The origin of the phrase evidence-based patient choice can be traced to the heyday of evidence-based medicine in the mid 1990s which saw medicine moving forward as a sound and applied biological and sociological science, drawing together the themes of evidence and patient centeredness (Elwyn & Edwards 2002:5-7).⁴³

While this development will be dealt with in 3.2, the mid 1990s also saw important political, economical and ethical developments that constituted the context in which medicine was to

⁴³ See also Ellwood 1988:1549-1556.

move forward under the banner of evidence-based patient choice. These included a change in rhetoric now depicting patients as consumers, the narrowing of the gap between expert and lay knowledge and an increasing emphasis on patient rights and autonomy, as well as on the accountability of the public services.

The change in rhetoric depicting patients as consumers was brought about by a complex, and often combative interaction of forces in the recent political framework of the world. The 1990s saw the established certainties of conservative and socialist politics giving way to a so called *third way* or middle ground in which the state would encourage a culture of private enterprise while still intervening judiciously to protect the vulnerable and dependent from social exclusion. As a result, the state withdrew its influence in spheres such as the heavy industry and the provision of utilities such as telecommunication, broadcasting, water and electricity and instead handed the initiative over to market forces as a means of creating wealth (Elwyn & Edwards 2002:8).

The term *third way* seems to have originated in the early 1900s and was already popular among right-wing groups by the 1920s. However, it has mostly been used by social democrats and socialists who in the early post-war period tried to find a way that would be distinct from the American market capitalism and from Soviet communism. By the time of its rediscovery in 1951, the Socialist International explicitly referred to third way politics in this context and twenty years later it became customary to use the term to refer to market socialism. The more recent appropriation of the term by political leaders such as Bill Clinton and Tony Blair has however been met by a lukewarm reception from most Continental social democrats and old left wing critics who simply regarded it as revived version of neo-liberalism (Giddens 1998:25).

To the fundamentals of third way politics firstly belong an acceptance of the fact that while the old left and right views may still be relevant in contemporary politics, there are many issues and problems that this opposition can no longer illuminate and that demand a shift to the centre of the political scene with room for the involvement of more radical policies. Third way politics secondly argues that the three key areas of power namely the government, the economy and the civil society all need to be constrained in the interests of social solidarity and social justice and that a democratic order, as well as an effective market economy depends on a flourishing civil society. Thirdly, third way politics proposes a new type of social contract based on the theorem of no rights without responsibilities and propagating that those who profit from social goods should both use them responsibly and give something back to the wider social community in return. In the economic sphere, third way politics is fourthly aimed at developing a wide ranging

and supple policy, intended to reconcile economic growth mechanisms and a structural reform of the welfare state in a new information economy in which human and social capital will become central to economic success. In third way politics, such an economy would fifthly have to be based upon the employment of egalitarian principles and the maximizing of opportunities, since inequality can no longer be countered by income transfers from the more to the less affluent. All of these sixthly implies that third way politics takes globalization seriously in order to respond to global change on a local, national and international level (Giddens 2000:54).

However, no integrated agenda for social democratic policies can be developed unless at least provisional answers can be given to a number of serious challenges that emerged in politics in recent years. Giddens singles out five such challenges of which the dilemmas of globalisation and individualism have become of paramount importance.⁴⁴

While some aspects of the concept of globalisation are still heavily disputed, it is ordinarily agreed that it should be understood within the context of the expanding role of world financial markets which are increasingly operating on a real time basis. However, the concept of globalisation is misunderstood if it is only applied to connections that are so-called worldwide or are of an economic nature. According to Giddens, globalisation is not only or even primarily about economic interdependence, but about the transformation of time and space in everyday life. It is all about the direct and immediate effect of distant events, whether of economic nature or not, as well as the global effect of locally taken decisions. Globalisation is thus a complex range of processes driven by a mixture of political and economic influences. It has become more than just the backdrop to contemporary policies, but is changing everyday life in particularly developed countries and is undoubtedly directly relevant to the rise of the so-called new individualism (Giddens 1998:33).

With regard to the concept of individualism, Giddens notes that solidarity has long been a theme of social democracy, but that the original legacy of Marxism was ambivalent on the theme of individualism versus collectivism. Marx advocated the disappearance of the state with the arrival of a fully mature socialist society in which the free development of each person would be the condition of the free development of all. Furthermore, socialism and communism placed a firm emphasis on the role of the state in generating solidarity and equality and thus established collectivism as one of the most prominent traits of social democracy in contrast to conservatism which ideologically always placed a much stronger emphasis on the individual. However, much

⁴⁴ The other three being the fact that the traditional distinction between left and right in politics has no meaning any more, the question whether politics is mitigating away from orthodox mechanisms of democracy and the question how ecological problems should be integrated into social democratic politics.

of this has changed since the late 1970s. Social democrats had to respond to both the challenges of neo-liberalism and western countries becoming culturally more pluralistic and correspondingly found it difficult to accommodate to the rising importance of individualism and lifestyle diversity, as the concept of the autonomous individual was the very notion that socialism grew up to contest (Giddens 1998:35).

While social democrats traced the origins of this new individualism to market forces, as well as to the ideological impact of Thatcherism with its emphasis on individuals fending for themselves rather than depending on the state, neo-liberals and other conservatives related it to the permissiveness of the 1960s. However, as noted by Beck, the new individualism is not to be related to Thatcherism or market individualism or even atomisation, but on the contrary to institutionalised individualism. This is evident from the fact that most of the rights and the entitlements of the welfare state are designed for individuals rather for families and in many cases presuppose employment which in turn implies education and mobility. It is by all these requirements that people are motivated to establish themselves as individuals and to plan, understand and design themselves as individuals (Beck 1998).

According to Giddens, the new individualism should thus be associated with the retreat of tradition and custom in modern life and attributed to the impact of globalisation in its widest sense. Under the aegis of collectivism, also welfare institutions helped to liberate individuals from some of the fixtures of the past and to start regarding the present as an age of moral transition. It is becoming increasingly clear that people have to accept responsibility for their actions and for the lifestyle habits they adopt and that a new balance between individual and collective responsibilities need to be found. The new individualism therefore goes hand in hand with pressures towards greater democratisation and the need to live in a more open and reflective manner than previous generations (Giddens 1998:37).

Against this background, the overall aim of third way politics is thus to help citizens pilot their way through the major revolutions of today, namely globalisation, transformations in personal life and man's relationship to nature. It views globalization as a phenomenon ranging much wider than the global marketplace and is therefore aimed at contesting economic and cultural protectionism which is to be regarded as neither sensible nor desirable in the current circumstances. Furthermore, with regard to the modern transformations in personal life, third way politics is inspired by a concern with social justice. To social democrats, freedom means autonomy of action which in turn demands the involvement of the wider social community and a new relationship between the individual and the community and a redefinition of rights and

obligations. Under the banner of no rights without responsibilities, government has a whole cluster of responsibilities towards its citizens, including the protection of the vulnerable. While old style social democracy was inclined to treat rights as unconditional claims, as an ethical principle it now has to apply to everyone and not just to welfare recipients. Closely related to this conception of rights in third way politics, is the concept of no authority without democracy. While right wing orientated politicians have referred to traditional symbols as a norm for justifying authority, the new individualism does not only corrode authority, but also demands it to be recast on an active or participatory basis (Giddens 1998:66).

In its reform of government and economic policy, third way politics thus responded to the great social transformations at the end of the twentieth century, such as globalization, the rise of a new knowledge based economy and the emergence of an "active and reflexive citizenry". While advocates of third way politics remained committed to the view of state provision for social welfare, education, and health care services, individual determination and financial independence was encouraged, especially in terms of the obtaining of higher education and the provision of pensions (Giddens 2000:65).

Also health care had to respond to the demands of this 'reflexive citizenry' exemplified in the complexity of the balancing of individual rights and self determined choices against pooled resources that are in principle, equally available to all. In for instance the United Kingdom, these developments completely redefined the relationship between the state and the individual as the country in this period went through a transition from a conservative to a neo-liberal government in which state industries were privatized and individuals were encouraged to become as self reliant as possible in becoming house and stock holders and taking responsibility for their own wellbeing. While remaining fairly intact, even the National Health Service in this period was subject to market forces with clear distinctions being made between providers and purchasers, hospitals coming under the control of free standing trusts with boards modelled on commercial structures and purchasers regarded as downsized health authorities provided with budgets. This introduction of the market ethos into the health care system just emphasized the transition between the old and modern social democracies being felt in many countries, as well as the extent to which the middle ground in politics and policy was being contested internationally (Elwyn & Edwards 2002:8).

These political and economical developments were at the same time flanked by a narrowing of the gap between expert and lay knowledge, especially in countries where educational opportunities created an increase in general and especially computer literacy. This leveling

process inevitably accelerated the deprofessionalisation of medicine and also in this profession, ushered in the phase of mediation and accountability as described in the work of Johnson.

Johnson described three broad resolutions to the existing tension in the producer-consumer relationship which are historically identifiable, namely collegiate, patronage and mediation.

Collegiate refers to the resolution in which the producer defines the needs of the consumer, as well as the manner in which these needs will be catered for. According to Johnson, this resolution is exemplified by the emergence of autonomous occupational associations and identifiable in the concept of professionalism which originated in nineteenth century Britain as a product of social conditions and guild control and attained its most extreme expression in the organisation of the law practice in England (Johnson 1972:45).

Patronage refers to the resolution in which the consumer defines his or her own needs, as well as the manner in which they are to be met. This resolution includes both oligarchic and corporate forms of patronage, as well as various forms of communal control. Oligarchic patronage had its origins in traditional societies where aristocratic patrons were the major consumers of services and goods and where artists, craftsmen and physicians were commissioned by the rich and famous. Corporate patronage refers to occupations such as accountancy whose services are mainly demanded by large corporate organisations and Communal patronage to situations in which a community as a whole or as a community organisation imposes communal definitions of needs and practice upon producers.

For Johnson, mediation refers to the resolution in which a third party mediates in the relationship between the producer and the consumer and defines both the needs and the manner in which the needs are to be met. Among the various forms of this type of resolution is capitalism in which the capitalist entrepreneur directly intervenes in the relationship between the producer and consumer in order to rationalise production and regulate markets. Further examples of this type of resolution are state mediation and the role of the medieval church in Europe in regulating the practice of a large range of occupations (Johnson 1972:46).

Applied to the world of medicine, Elwyn and Edwards note that while physicians during the seventeenth century were largely supported by patronage due to their advice being sought by the wealthy, the eighteenth century saw a move to a more collegiate profession with the emergence of institutions such as hospitals, colleges and medical schools. The end of the twentieth century, however, also brought with it a third phase in the development of the medical profession with the introduction of the concepts of third party mediation and accountability. Doctors now became managed, appraised, investigated and directed by guidelines with their personal basis of

expertise undermined by the World Wide Web as a ubiquitous source of information. It is therefore no surprise that the decline in professionals' power and authority in this period coincided with an increasing awareness that patients should be involved in health care (Elwyn & Edwards 2002:10).

While the corporate world has long recognized the added value of co-opted customer competences (Prahalad & Ramaswamy 2000:79-87), deliberations on the concept of increased patient involvement only got on the way since the late 1980s. These included discussions on topics such as possible variations in medical practice (Wennberg et al. 1988:3027-3030) and the potential for conflict between individuals and society in collectively funded health care systems (Eddy 1991:1446-1450), as well as the publication of the British National Health Service's *The Patient's Charter* (1991), *Local Voices* (1992) and *Patient Partnership: building a collaborative strategy* (1996), all emphasizing the intention of the government to encourage patients to participate in their health care as active partners with professionals.

The introduction of patient choice in health care settings however also raised a lot of ethical issues, some of which remain unanswered to this day. The exercising of choice at policy level now entailed a debate about the way health services are organized and resources are allocated and also required a willingness to adjust the traditional paternalistic approach to health care. Genuine patient choice furthermore implied a menu of treatment options, the encouragement of informed decisions, and the eventual freedom to move between clinicians and health care organizations. However, while choice on the surface appeared to be a desirable pathway to fairness, equity, and personal freedom, it also proved to have the potential of suddenly becoming perversely impossible to manage (Elwyn & Edwards 2002:9).

3.2 THE NATURE OF EVIDENCE-BASED PATIENT CHOICE

Evidence-based patient choice advocates the sharing of good quality evidence-based information and respect for patient preferences and involvement in health care and is therefore aimed at providing patients with evidence-based information in a way that facilitates their ability to make choices and decisions about their health care. As such, evidence-based patient choice brings together two important movements in modern medicine that have both developed as a critical response to what was perceived to be the excessive authority given to physicians and other health care professionals in traditional medicine (Hope 2002:100).

The first of these movements, evidence-based medicine, has been described as a paradigm shift in medical practice and represents an approach to medicine based on the claim that clinical

interventions are to be justified on the existence of evidence for the effectiveness of the intervention rather than on grounds such as the authority of the clinician (Parker 2001:87).⁴⁵ The second movement, patient-centred medicine, has equally been described as a Copernican Revolution in medical practice and advocates a central role for patients in decisions about their health care as the best protection against excessive paternalism (Battista 1993:301-304).

It is argued that these two movements are to be regarded as natural bedfellows and that taken together, they not only mark a significant shift in thinking about the relationship between health care professionals and their patients, but also has the potential to empower patients and aid the development of an increasingly effective patient-centred health care system (Hope 2002:100).

The term Evidence based medicine (without a hyphen) was coined at the McMaster Medical School in Canada in the 1980s to label a clinical learning strategy which had been developed at the school for over a decade. This strategy can be defined as the process of systematically finding, appraising and using contemporaneous research findings as the basis for clinical decisions. Evidence-based medicine thus asks questions, finds and appraises the relevant data and harnesses that information for everyday clinical practice along four basic steps, namely to formulate a clear clinical question from a patient's problem, search the literature for relevant clinical articles, evaluate and critically appraise the evidence for its validity and usefulness and implement the useful findings in clinical practice (Rosenberg & Donald 1995:1122-1126).

The emergence of evidence-based medicine is to be understood against the background of the successes of medicine in the understanding and control of biological processes over the past three centuries. While the reduced morbidity and mortality rates in Western populations can to a large extent be attributed to socio-economic and lifestyle factors such as improved diets, housing, hygiene, and safety, modern medicine has acquired an undeniable reputation to cure and to prevent illness.

This reputation largely derives its impetus from the so called biomedical model that dominated medicine since the mid-nineteenth century due to the work of the founders of pathophysiology, Magendie and Bichat. While it may be argued that the role of this model in the conquering of ill health may be overestimated (Yardley 1997:4), it remains firmly linked to what is generally known as the realist view of the world which holds that it is only by accurate observation and rational deduction that human beings can attain an objective knowledge of the nature of reality that will enable them to predict and control nature. A realist perspective thus tends to view the objective facts of biological phenomena as more reliable, and also more controllable than the

⁴⁵ Refer also to Hope 1996.

data of the psychosocial context, and thus resulted in the biomedical model wherein physical processes are best explained through biological reductionism (Laura & Heaney 1990:17).⁴⁶

Against this background, the term evidence-based medicine was carefully chosen in order to address complacency about medical decision making and at the same time present biostatistics in a way that would be fundamental to all aspects of patient care and also relevant to health care professionals. As developed in the United Kingdom, the concept of evidence-based medicine was to denote the use of best current knowledge as a basis for decisions about groups of patients or populations (Muir Gray 2002:20). As such, at least as reflected in the original texts, evidence-based medicine represented an emphasis on medical evidence, but did not yet acknowledge the literature that position patients at the centre of the clinical process and was thus still based on medical paternalism (Laine & Davidoff 1996:152-156). This approach is clearly reflected in Sackett's often quoted definition of evidence-based medicine: "Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgement that individual clinicians acquire through clinical experience and clinical practice" (Sackett et al. 1996:71-72).

To Sackett, increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights and preferences in making clinical decisions about their health care. The meaning that Sackett et al. attach to the concept of the best available external clinical evidence is that of clinically relevant research from sources such as the basic sciences of medicine, but especially from patient centred clinical research into the accuracy and precision of diagnostic tests, the power of prognostic markers and the efficacy and safety of therapeutic, rehabilitative and preventative regimens. This implies that external clinical evidence both invalidates previously accepted diagnostic tests and treatments and replaces them with new ones that are more powerful accurate, efficacious and safe.⁴⁷

⁴⁶ See also Yardley: "... whereas physicians and healers in previous non-Western cultures might see the social, subjective or spiritual significance of illness as an intrinsic and significant part of the phenomenon (a view often shared by the afflicted person and his or her associates), modern Western diagnostic practices are designed to exclude, or at least isolate, these aspects of illness in order to focus more clearly on the biological processes, which are regarded as of primary importance" (Yardley 1997:4).

⁴⁷ Refer to the following quotation from Sackett et al.: "Good doctors use both individual clinical expertise and the best available external evidence, and neither alone is enough. Without clinical expertise, practice risks becoming tyrannised by evidence, for even excellent external evidence may be inapplicable to or inappropriate for an individual patient. Without current best evidence, practice risks becoming rapidly out of date to the detriment of patients" (Sackett et al. 1996:71-72).

Portrayed by some as cookbook medicine, medicine by the rules, and as a style of clinical practice devaluating the individual clinician,⁴⁸ others simply regarded evidence-based as the way they have always been practicing medicine.⁴⁹ These views were however challenged by a number of factors that eventually led to a reappraisal of the role of evidence in decision making.

A first of these factors was revealed in studies of clinical practice and service delivery which indicated that the variation in the rate at which a service is provided or an intervention is used, is frequently far greater than can be explained by a variation in the incidence or prevalence of disease. To these belonged variations between countries, between services in the same country, between services in one geographical locality and between clinicians in the same team of which clinicians were largely unaware and which questioned their claims and beliefs that they were all practicing rational and empirical medicine (Muir Gray 2002:20).

A second factor is linked to the development of health care audits in the late 1980s which led to studies of service delivery that compared clinical practices and service delivery with best current practices. Audits revealed that there were frequent gaps between what was known and what eventually happened and attributed it to failures to start interventions that did more good than harm at reasonable costs and failures to stop interventions that were shown to be of low value (Seale 1993b:58).

According to Eddy, economic pressures proved to be a third important factor in the reappraisal of the role of evidence in decision making. These pressures were created by three important trends that influence need and demand in all societies and that normally result in these two entities to increase at a rate faster than the resources that are available (Eddy 1993:520-525). As a consequence, these trends, namely the aging of the population, new technology, and rising expectations, exert pressure on decision makers such as administrators and clinicians to employ more evidence in order to be as transparent as possible in justifying decisions (Eddy 1994:1792-1798).

⁴⁸ Refer for instance to Grahame-Smith 1996:1126-1127; Polychronis et al. 1996:9-11; Stradling & Davies 1997:99-103. Also compare the following quotation from Sackett et al.: "Evidence-based medicine is not "cookbook" medicine. Because it requires a bottom-up approach that integrates the best external evidence with individual clinical expertise and patient-choice, it cannot result in slavish, cook-book approaches to individual patient care. External clinical evidence can inform, but can never replace individual clinical expertise, and it is this expertise that decides whether the external evidence applies to the individual patient at all, and, if so, how it should be integrated into a clinical decision" (Sackett et al. 1996:71-72).

⁴⁹ "This description of what evidence-based medicine is helps clarify what evidence-based medicine is not. Evidence-based medicine is neither old-hat nor impossible to practice. The argument that everyone already is doing it falls before evidence of striking variations in both the integration of patients' values into our clinical behaviour and in the rates with which clinicians provide interventions to their patients" (Sackett et al. 1996:71-72).

However, these factors that brought about a reappraisal of the role of evidence in decision making were flanked by other trends creating a context in which evidence-based medicine could flourish. These trends all belonged to a revolution taking place in the world of knowledge at the time and were to fundamentally challenge the confidence that was formerly placed in the data used by clinicians (Dombal 1996:1-6).

A first of these trends was a growing concern about the adverse side effects of science as for instance epitomised in the Rachel Carson's book *The Silent Spring* (1962). This book severely criticized the widespread ecological degradation that resulted from the use of amongst others insecticides, weed killers, and sprays in agriculture and focussed the attention of the public on the dangers of the modern world. Also in medicine, the confidence of the scientific community was shaken by increasing examples of completely unintended harmful side effects of medicine and health care (Muir Gray 2002:22).

While clinicians up to that stage had to rely on textbooks for the latest expert knowledge, the crisis was deepened by a landmark study indicating the extremely slow response of textbooks to new knowledge, as well as the tendency of textbooks to continue recommending information on ineffective treatments long after their use had been discredited scientifically (Antman et al. 1992:240-248). Moreover, two important papers from the late 1980s also indicated that even review articles and editorials were unscientific, biased and unreliable due to authors amongst others not indicating the methods used in sourcing the information and being selective in the citation of evidence (Mulrow 1987:485-488).⁵⁰ The net effect of this situation was that it made treatments appear more effective or harmful than it actually is, with often negative implications for both clinicians and patients (Muir Gray 2002:23).

The limitations of review articles and editorials eventually gave rise to a new method of synthesising evidence, namely the systematic review. Together with a sub-type, the Cochrane review, it had the characteristics of clearly stating the research objectives, ascertaining as much of the available evidence as possible, using explicit quality criteria for inclusion or exclusion of the studies found, using explicitly stated methods of combining data and producing reports that clearly describe the processes of ascertainment, inclusion and exclusion, and combining data.⁵¹ While these reviews made a valuable contribution to medical literature, it remained subject to the limitations of paper copies, and only came into its own when the information revolution coincided with the Web revolution. The Internet stimulated the development of software tools

⁵⁰ See also Oxman & Guyatt 1988:697-703.

⁵¹ See for instance Drassman, D.A., Talley, N.J., Alden, K.W. & Barriero, M.A. (1995). Sexual and physical abuse and gastrointestinal disease. *Ann. Intern. Med.*, 123:782-794.

like browsers which empowered organisations such as the Cochrane Foundation to function efficiently and forever changed the way in which knowledge is produced, distributed, found, stored, and used (Muir Gray 2002:25).

Once established on the Internet, the concept of evidence-based medicine quickly spread to all corners of the world, but at first appealed differently to different individuals. While the working environment of the ordinary clinician before the advent of evidence-based medicine was sharply divided into research and practice, proponents of evidence-based medicine now emphasised the need for both research and practice to be based on a careful appraisal of best current knowledge, as well as for a scientific interpretation of this knowledge for individualisation in care (Muir Gray 2002:26).

The response of patients to the concept of evidence-based patient choice was usually one of surprise, as they apparently always were under the impression that health care professionals have always based their decisions on the best current knowledge. Moreover, it came as a shock to patients that the available clinical knowledge commonly were not even employed by clinicians, or often was deficient. Evidence-based medicine was thus enthusiastically welcomed by the public who through the new access to information, remarkably quickly turned the tables on professional expertise and power (Muir Gray 2002:27).

In an effort to consolidate the movement of evidence-based medicine and to stimulate the clinical professions to recognise the need and importance of this new approach to medicine, the Centre for Evidence-Based Medicine formulated five steps through which evidence-based decision making could be introduced in clinical settings. To these belong (1) the asking of the right questions, (2) the finding of the relevant evidence, (3) the appraising of the evidence to select the best options, (4) decision making based on the evidence and (5) the storing of the evidence for future use.⁵² Reactions to these guidelines were mixed, with older physicians generally less enthusiastic than younger ones. Also medical journals were mixed in their reactions, with the *New England Journal of Medicine* and *Lancet* being less enthusiastic than the *British Medical Journal*, the *Journal of the American Medical Association*, and *The Annals of Internal Medicine* (Muir Gray 2002:30). However, *Lancet* eventually changed its opinion and stated in an editorial that "the concept of evidence-based medicine has emerged as one of the fundamental elements in Western-style clinical medicine" (*Lancet* (Editorial) 1998:751-752).

⁵² Also note the key stages of evidence-based medicine as identified by Rosenberg and Donald and Sackett et al. These include (1) the identifying of the clinical questions, (2) searching for the evidence, (3) a critical appraisal thereof and (4) applying the evidence in patient care (Rosenberg & Donald 1995; Sackett et al. 1997).

The dominance of this approach in medicine has however never been complete (Elwyn & Edwards 2002:6). While Freud and others in the 1920s brought an awareness of the importance of the psyche, the costs of health care, coupled to an increasing awareness of the limitations of scientific medicine, brought about a growing appreciation of the psychosocial influences on health. This appreciation paved the way for Engel to propose the bio-psychosocial model (Engel 1970:129-136)⁵³ for the practicing of medicine that derived its inspiration from an approach in the Systems Theory of Ludwig von Bertalanffy (Von Bertalanffy 1968:30-53). In turn, this development in the 1970s led to the application of behavioural principles to health care problems and the emergence of new disciplines such as health psychology. Engel's model was widely welcomed by social scientists and those working in generalist clinical work, as it confirmed the importance of psychosocial factors and facilitated an expansion in bio psychosocial research.

It was within this context that the concept of patient-centred medicine emerged through the work of McWhinney and others. McWhinney in 1972 described a paradigm shift for clinicians working in primary care that acknowledged an understanding of the patient perspective on illness as the heart of the biopsychosocial model (McWhinney 1972:384-387). Analytic descriptions of the professional-patient relationship (Balint 1957) and the consultation process (Stott & Davies 1979:201-205) were published, and gradually a patient-centred consulting style was described and promoted (Brown et al. 1986:75-79).⁵⁴ Patient-centred medicine thus emphasises the need of the professional to enter the world of the patient and to recognise that in clinical work, there needs to be an assessment of the disease (the biological dimension), as well as the illness (its effect on the patient). This implies a shift in the mind set of the clinician, as the historical hierarchical notion of a professional being in charge, and the patient being passive, is no longer valid. Moreover, it requires a renouncing of the control which has traditionally been in the hands of the professional and an enabling of the patient to share in the power in the relationship (Stewart et al. 1995:xvi).

Within this broad framework, the patient-centred clinical method evolved over the past decades. This method has much in common with other therapeutic models that were developed in

⁵³ Refer to the following quotation from Engel: "In sum, psychiatry struggles to clarify its status within the mainstream of medicine, if indeed it belongs in medicine at all. The criterion by which this question is supposed to be resolved rests on the degree to which the field of activity of psychiatry is deemed congruent with the existing medical model of disease. But crucial to this problem is another, that of whether the contemporary model is, in fact, any longer adequate for medicine, much less for psychiatry. For if it is not, then perhaps the crisis of psychiatry is part and parcel of a larger crisis that has its roots in the model itself. Should that be the case, then it would be imprudent for psychiatry prematurely to abandon its models in favor of one that may also be flawed". Engel, G.L. (1977). *The need for a New Medical Model: A Challenge for Biomedicine*. Science, 196 (4286):130.

⁵⁴ Refer also to Levenstein et al. 1986: 24-30; Stewart et al. 1995; Tuckett et al. 1985.

disciplines such as psychology, nursing and occupational therapy. Rogers's psychotherapeutic concept of client centred therapy (Rogers 1951), Newman and Young's total person approach to patient's problems in nursing (Newman & Young 1972:264-269), and Mattingly and Fleming's two-body practice (Mattingly & Fleming 1994) are all cases in point (Stewart et al. 1995:xx).

Although issues surrounding this focus on the individual were already being debated in the 1930s, the dominant model in medical practice until about the 1960s was known as the conventional medical model. This model had its roots in the thought of René Descartes whose dualism of mind and body became the paradigm for modern science and in the medical field brought about an analytic and impersonal method focussed on diagnosis and physical pathology. This dichotomy between the physical and the mental was also reflected in the terminology of the conventional medical model and as a result separated patients from their illness experience (Steward & Brown 2002:98).

The conventional medical model enjoyed a widespread influence, but came under increasing criticism during the last decades of the twentieth century for leaving no room for the social, psychological, and behavioural dimensions of illness (Engel 1977:129-136) and for oversimplifying the problems attached to sickness (Odegaard 1986).⁵⁵ In turn, this criticism stimulated several alternative clinical models (Kleinman et al. 1978:251-258),⁵⁶ in particular Engel's biopsychosocial model employing the systems theory as a basis for understanding human illness (Engel 1980:535-544). This model conceptualised the patient as composed of systems and as part of several larger systems and thus emphasised the biological, psychological and social dimensions of illness, though without an understanding of the dynamic interaction of these multiple aspects of a person.

All of these conceptual models thus contributed to the evolution of the patient-centred clinical method by pointing at the importance of acknowledging a distinction between the clinician's theoretical understanding of the patient's disease and his or her personal experiences of the illness and patients' accompanying need for more than a scientific formulation and treatment of their medical problems and concerns (Steward & Brown 2002:99).⁵⁷ It became clear that

⁵⁵ Refer also to White 1988.

⁵⁶ See also Carmichael & Carmichael 1981:123-133; Pendleton et al. 1984; Foss & Rothenberg 1987; Cohen-Cole 1991.

⁵⁷ Compare this description of an illness experience by a patient, being a physician himself: "Through all of these years and despite many encounters with skilled and experienced professionals, no ophthalmologist has at any time suggested any devices that might be of assistance to me. No ophthalmologist has mentioned any of the many ways in which I could stem the deterioration in the quality of my life. Fortunately, I have discovered a number of means whereby I have helped myself, and the purpose of this essay is to call the attention of the ophthalmologic world to some of these devices and, courteously but firmly, to complain of what appears to be the ophthalmologist's attitude: We are interested in vision, but have little interest in blindness". Stetten 1981:458. See also: Fabrega 1974; Reiser

patients generally want to feel understood and valued, become involved in addressing their health problems and also participate in the resolving thereof. Moreover, several key studies emphasised the many benefits of a more compassionate approach to patients, integrating the person in his or her social context and physical environment (Kaplan et al. 1989:5110-5127).

Clinical training in medical schools have traditionally emphasised a doctor-centred or disease-centred approach. This implied that a physician would ascertain a patient's complaints and then set off looking for information that would enable him or her to interpret the patient's illness from a physician's frame of reference, before diagnosing the disease and prescribing a treatment. Following from this, it is obvious that the success of an intervention in a doctor-centred or disease-centred approach would be determined by a precise diagnosis.

In contrast, the patient-centred clinical method is aimed at both a diagnosis of the disease and an understanding of the illness experience, as it recognises the fact that disease and illness are intertwined and can therefore not be artificially separated. While the term patient-centred medicine was first introduced in 1970 by Balint et al. to contrast it with disease-centred medicine and to describe an understanding of the patient's complaints based on patient-centred thinking (Balint et al. 1970), the patient-centred model and method was developed by Levenstein who based it on observations of 1 000 clinical encounters in his practice in Cape Town and further developed it through the University of Western Ontario (McCracken et al. 1983:2313-2316).⁵⁸ The model was further refined and elaborated through feedback from participants (Stevens 1974:5-22)⁵⁹ to clarify the conceptual distinctions between disease as a pathological process and illness as a unique experience of feeling unwell, elucidate interviewing methods, describe an approach of finding common ground with patients, independently define a model for family practice and expand the model to include approaches to prevention, the doctor-patient relationship, and efficiency (Stewart et al. 1995:xx).

These efforts resulted in a clinical method that despite its origins in family medical practice is highly relevant to all health professions and consists of six interconnected components:

- Exploring both the disease and the illness experience
- Understanding the whole person
- Finding common ground

& Schroder 1980; Stephens 1982; Levenstein 1984:276-282; Mishler 1984; Cassell 1985; Levenstein et al. 1986:24-30; Levenstein et al. 1989; McWhinney 1989.

⁵⁸ See also Levenstein et al. 1986:24-30.

⁵⁹ Refer also to Tait 1979; Wright & MacAdam 1979.

- Incorporating prevention and health promotion
- Enhancing the doctor-patient relationship
- Being realistic (Stewart et al. 1995:25).

The first of these components involves an understanding of ill health as manifested in disease and illness, with disease being a theoretical construct, or an abstraction, by which physicians attempt to explain patients' problems in terms of abnormalities of structure and/or function of body organs and illness referring to patients' personal experiences of ill health. According to Stewart, effective patient care therefore requires as much attention to patients' experiences of illness as to their diseases (Stewart et al. 1995:27). Moreover, while a disease is established by using the conventional medical model, an understanding of illness requires a focus on four principle dimensions of patients' illness experiences, namely their ideas about what might be wrong, their feelings about being ill, the impact of the illness on their functioning and their expectations about what should be done. Reaching a therapeutic understanding of patients' illness experiences, thus requires the doctor 'to enter the world of the patient' in order to explore both the disease and the illness experience.

The second component of the patient-centred clinical method is an integrated understanding of the whole person accumulated over time and going beyond diagnosing diseases or attending to illness experiences. Over time, doctors come to understand patients' diseases and experiences of illness in the context of their life settings and stages of personal development. As the serious illness of a family member may have an effect on the whole family system, an understanding of the whole person can indeed enhance a physician's interaction with a patient in a crisis and deepen a doctor's knowledge of the human condition and especially the nature of suffering.

The third component is a mutual undertaking to find common ground, and to develop an effective management plan through which doctor and patient would be able to reach agreement in three key areas, namely (1) the nature of the problem and the priorities thereof, (2) the goals of treatment or management and (3) the respective roles of the doctor and the patient. While clinical situations are often characterised by divergent views, the process of finding a satisfactory solution is therefore not so much one of bargaining or negotiating, but rather of moving towards a meeting of minds or finding common ground (Stewart et al. 1995:28).

The fourth component of the patient-centred clinical method involves prevention and health promotion in the context of an ordinary practice visit. Disease prevention requires an ongoing collaborative effort by both patient and doctor and can hugely benefit by the process of finding

common ground in addressing a wide variety of prevention and health promotion issues. It is only within such a supportive process that physicians and patients can together monitor areas that might need attention in the interest of long term physical and emotional health, and implement a program of health promotion and screening in practice.

The fifth component involves conscious attention to enhancing the doctor-patient relationship. An integrated understanding of the whole person accumulated over time generates a considerable amount of personal knowledge about a patient that may be helpful to the doctor in managing subsequent problems. The employing of this knowledge, together with the basic tools of an effective relationship, such as an unconditional positive regard, empathy and genuineness, enable a physician to fully attend to patients' needs without always having to interpret or intervene. Physicians at the very least thus walk with patients and at most, use themselves and their relationship to mobilise the strengths of patients for a healing purpose (Stewart et al. 1995:30).

The last component of the patient-centred method relates to the need of health care professionals to be realistic with regard to the managing of their time and energy. Physicians should thus develop skills of priority setting, resource allocation and teamwork for the maximum benefit of their patients, and respect their own limits of emotional energy.

While these components of the patient-centred clinical method are often presented as separate entities, they in reality are intimately intertwined and therefore continuously interact with one another. However, the third component to a large extent draws together all six, and furthermore is the one most closely aligned to the principles and issues of evidence-based patient choice. It therefore deserves a little more attention.

The clinical encounter is described by many as a process in which the physician and patient negotiate in order to determine what is wrong, and what should be done (Anstett 1981:503-506).⁶⁰ Reaching mutual understanding or finding common ground therefore often requires the bringing together of potentially divergent viewpoints in a reasonable management plan. It is only once agreement is reached on the nature of the problem, that the goals and priorities of treatment can be determined and the roles to be assumed by the patient and the clinician can be identified.⁶¹

⁶⁰ See also Heaton 1981:845-848; Quill 1983:228-234.

⁶¹ These elements bear passing resemblance to the competences of Shared Decision Making proposed by Elwyn and Charles in Elwyn & Charles 2002.

In this regard, the work of Fisher and Ury is relevant with regard to issues such as the finding of common ground and the overcoming of differences (Fisher & Ury 1983). They describe two common and erroneous approaches to negotiating differences in general. The first approach they call hard bargaining in which participants are regarded as adversaries and the goal of the negotiations is plain victory. Not surprisingly, this approach generates tension and mistrust. Their second approach they call soft bargaining which emphasises the building and maintaining of a relationship and which has agreement as its goal, but is still only able to produce an unclear and vague consensus. In response, Fisher and Ury, recommend what they call a principled negotiation that is constituted by four basic tactics namely a separation of the people from the problem, a focus on interests and not on positions, a generation of a variety of possibilities before deciding what to do and the use of objective criteria to judge the solution (Steward & Brown 2002:105).

Applying these tactics to the three key areas of finding common ground produces interesting results. With reference to the first of these areas, namely defining the problem, it can be regarded as a universal human characteristic to want an explanation for being unwell, as it gives a sense of control over an often terrifying experience (Kleinman 1988).⁶² While it might not be essential for the doctor to hold the same view of the problem as the patient, some sort of agreement on the nature thereof will be necessary for a decision on treatment congruent with the patient's perception of the problem. In this process, separating the person from the problem might be essential, as people often develop magical or irrational notions of what is happening to them and may even blame themselves for the problem, rather than seeing the illness as simply random or impersonal (Steward & Brown 2002:105).

Regarding the defining of goals, a focus on interests and not on positions is of prime importance. Defining the goals of treatment should take the expectations and feelings of both the professional and the patient into account. If both agendas are not acknowledged, it might be difficult to reach an agreement and result in a patient's non-compliance that in fact could be an expression of disagreement about treatment goals. Should health care professionals therefore ignore patients' interests, they risk not understanding them and may result in some patients becoming more demanding in an attempt to be heard or resentful and potentially hostile towards the system. While the distress articulated by patients might challenge especially inexperienced doctors and be both threatening and emotionally draining, there still is no replacement for a

⁶² Refer also to McWhinney 1989; Cassell 1991; Louw 1994.

doctor entering patients' inner lives in order to empathetically experience their pain, confusion, hope and fears (Stewart & Brown 2002:106-107).

In defining the roles of doctors and patients, the generation of a variety of possibilities before deciding what to do and the use of objective criteria to judge a decision, can be of great assistance. Profound disagreement about the nature of the problem or the goals and priorities of treatment, can be an indication of a deficiency in the way doctors and patients perceive their respective roles. Doctors may want to reach a particular treatment goal implying a passive recipient, while patients might be expecting non-invasive treatment reflecting them as autonomous individuals with a right to decide among various forms of treatment. This especially poses a dilemma to the health care professional when the patient's treatment of choice can be considered less effective or even harmful. While a situation like this may lead to either doctors blaming patients for being demanding or doctors blaming themselves for not being successful, a more effective and satisfying reaction would be to realise that the problem is not one-sided and that professionals can therefore give up their need to be perfect and instead be prepared to do their best to be real persons to their patients (Stewart & Brown 2002:108-109).

The nature of evidence-based patient choice is thus to be found in the joining of these two important movements in modern medicine that have both developed as a critical response to what is perceived to be the excessive authority given to physicians and other health care professionals in traditional medicine. The definition of evidence-based patient choice as "... the use of evidence-based information as a way of enhancing people's choices when those people are patients" (Hope 1996), might therefore not be the most elegant of titles, but reveals the rather awkward engagement of the concepts of evidence-based and patient-centred medicine and at the same time anchors the term in a time when patient choice came to be recognised as *a good thing*. It has however since become clear that *choice* is not nearly as benign a concept as it first appears and that it raises a whole range of challenges to the paradigm of evidence-based patient choice (Elwyn & Edwards 2002:7).

3.3 THE KEY SKILLS OF EVIDENCE-BASED PATIENT CHOICE

Evidence-based patient choice may well be regarded by many as the future framework for health care, but has as yet not seen widespread acceptance and implementation in clinical settings (Holmes-Rovner et al. 2002:270). While evidence-based medicine eventually exerted an unparalleled influence on medicine, the representatives of its recent extension into the realm of patient choice are apparently facing an even more arduous journey than the pioneers of evidence-based medicine. Reasons for this state of affairs are diverse. Whereas many fear that

introducing unfettered choice may result in the slippery slope of unbridled and inappropriate consumer demand for health care and that the treatments that are demanded may overstretch agreed upon resources (Holmes-Rovner et al. 2002:271),⁶³ others acknowledge that clinical practice has proved to be very resistant to change and that the concept of patient choice might not have sufficient inherent force to overcome that resistance (O'Connor et al. 1999).

However, it is argued that in order to best move evidence-based patient choice into the mainstream of health care, a common set of minimum quality standards for decision aids should be incorporated into patient education materials designed to support evidence-based patient choice. To these belong elements such as proper treatment descriptions, outcomes and probabilities, value issues and health system policies (Holmes-Rovner et al. 2002:279). Furthermore, it is advocated that one way to promote evidence-based patient choice, is to teach critical appraisal skills to the public. It is now recognised that if the first encounter with shared decision making skills occurs when people are anxious about some major illness, it is far too late to expect of a patient to start deliberating carefully on information that may well be potentially disconcerting and complex. Skills such as these need to become part and parcel of patients' ability to deal with concepts such as uncertain outcomes and the benefits of taking an active role in clinical decision making and should be supplemented by a multi-faceted strategy to provide the public with an apriori understanding that budgets are limited and technologies are imperfect.

There are multiple opportunities that may be utilised to ensure that the key skills of evidence-based patient choice become embedded in the discourse of health care encounters. In this regard, it is proposed that the underlying mechanism that should be used to develop and promote evidence-based patient choice is the World Wide Web due to its unprecedented ability to link policy frameworks, consumers, patient groups and health care professionals with proper decision making skills based on validated evidence derived from empirical studies. The best way of introducing the evidence-based patient choice model among health care professionals, might be to utilise professional networks and short problem based workshops that previously have been so successful in disseminating evidence-based medicine among established health care professionals. Furthermore, while many curricula for the training of health care professionals already incorporate sections on communication skills, it is maintained that there are additional core and disease specific clinician skills in decision support that can be taught systematically (Holmes-Rovner et al. 2002:286).

⁶³ See also Wennberg et al, 1993; Holmes-Rovner et al. 1999.

As indicated in 3.2, evidence-based medicine was still based on a biomedical view of health care and therefore focused on improving the health care professional's use of evidence in order to determine the most appropriate treatment for a particular disease. However, as a further development and extension of evidence-based medicine, evidence-based patient choice has a different emphasis and is aimed at bringing the patient and his or her experience of disease to the fore. The distinguishing factor about evidence-based patient choice is thus about "health care professionals assisting patients to understand what is known about the benefits and harms of treatment options and to enable them to make the decision about how to proceed" (Rychetnik 2002:1). The proposed practice of evidence-based patient choice as partnership model in clinical decision making is therefore also directly related to its nature and can be conceptualised by means of four key decision making skills required from health care professionals to involve patients in clinical decision making. To these belong the skills of shared decision making, risk communication, decision analysis, and the use of decision aids which will be attended to in this paragraph.

3.3.1 Shared decision making

The concept of shared decision making is to be understood within the broader context of patient-centred medicine as promulgated from the late 1970s by authors such as McWhinney, Levenstein and Stewart and is according to Elwyn and Charles an issue of interest to a surprisingly diverse range of health related disciplines such as medicine, nursing, bioethics, health economics and medical sociology (Elwyn & Charles 2002:118).⁶⁴ While in medicine the issue is normally discussed within the larger context of the problem of a technological consciousness as represented in modern scientific medicine and the necessity to counter the dominance of this consciousness in order for medical care to become more humane, nursing focuses on the concept as a cornerstone of the profession.

Health economists again tend to view the treatment decision making process as requiring two components, namely technical information about available treatment including their benefits and risks and information about patient preferences and values. Due to the fact that the former emanates from the health care professional and the latter from the patient, the health economics challenge is to unite both these components in a single individual that would be able to make an informed choice with reference to the values of the patient. According to health economists, one way of achieving this could be to conceptualise the health care professional as the patient's agent who would utilise technical information in order to make a treatment decision that is supposed

⁶⁴ See for instance Mishler 1984; Ball et al. 2000; Gafni et al. 1998; Barry et al. 2000.

to be identical to the decision that the patient would have made, had he or she been in possession of the technical knowledge of the health care professional. It is however recognised that the perfect agent relationship between health care professional and patient only exists in theory and will be influenced by factors such as professional motivation and incentives in the health care system (Elwyn & Charles 2002:118).⁶⁵

On the other hand, medical sociologists increasingly typify the relationship between health care professionals and patients in making decisions on treatment as highly prone to conflict. This may arise, it is argued, from the different agendas each party brings to the encounter, the different types of discourse used by the respective parties to discuss health care concerns as well as the informational asymmetries between health care professionals and patients which may result in professional dominance of the encounter (Waitzken 1985:81). In view of these challenges, medical sociologists maintain that the only way to sustain patient autonomy is to ensure that health care professionals provide patients with information on treatment alternatives and to empower them to make informed choices that reflect their own preferences rather than those of the health care professional (Elwyn & Charles 2002:119).

The majority of these views thus employ the treating health care professional in some or other way in the role of the patient's agent and this perspective on the dilemma of partnership in clinical decision making is also evident in a conceptual framework developed and updated by Charles et al. that identifies the key characteristics of the paternalistic, informed and shared decision making approaches. These studies also indicate the different phases of the clinical decision making process, namely that of information exchange, the deliberation or discussion of treatment preferences and of deciding on the treatment that is to be implemented and explain

⁶⁵ The concept of the health care professional as the patient's agent is surrounded by various difficulties. Whereas the individualisation of health care information is aimed at the empowerment of the individual through the appropriation of aggregate data and the involvement of patients in clinical decision making remains dependant on the informed consent of the individual, both of these actions are autonomy driven and moreover inter-dependant and can therefore be regarded as two sides of the same coin. In thus addressing the matter of an adequate approach to the individualisation of the provision of information and the establishing and maintaining of patient autonomy in the involvement of patients in clinical decision making, attention has to be paid to both actions simultaneously. As a case in point, it is argued in the field of health economics that the informational asymmetries between "economic actors" are to be regarded as one of the main reasons why health care markets fail (Gravelle & Rees 1992). While in the normal economic environment, buyers and sellers have access to the same amount of information regarding the product in question, in health care the health care professional has to act as the patient's agent, since he or she has more information on the health care issue in question (Gafni et al. 1998:347-354). This scenario automatically puts the health care professional in a potentially powerful position and moreover in view of professionals' own objectives, opens the possibility of supplier induced demand (SID). It is therefore not only argued to be impossible to determine whether a health care professional acts as a patient's "best agent", but also to achieve this perfect agency: "If the agency relationship were complete, the professional would take on entirely the patient's point of view and act as if she were the patient ... The 'perfect agent' would need a split brain, one half advising the patient solely in the patient's interest, the other half reacting ... in a self-interested, own-welfare maximising way" (Evans 1984).

that while these are analytically separate, they are often woven together in an iterative process (Charles et al. 1997:681-692).⁶⁶

Utilising these phases as frame of reference, Charles et al. indicate that while the phase of information exchange refers to the type and amount of information exchanged between health care professionals and patients and whether the flow is one way or reciprocal, information exchange in the paternalistic approach is largely one way with the flow mainly from the health care professional to the patient. Of the health care professional is expected to at a minimum communicate legally required information about treatment to the patient and to obtain informed consent for the recommended treatment. However, beyond this it remains the health care professional's prerogative to determine what other, if any, information needs to be communicated to the patient (Charles et al. 1999b:652).

In the informed approach, they argue, information exchange largely remains one way with the flow of information from health care professionals to patients. With the health care professional's role as research transfer agent regarded as characteristic of this model, it is also considered his or her responsibility to communicate the information about the relevant treatment options, as well as their possible benefits and harms to the patient and to enable him or her to make informed decisions of their own.

On the contrary, the defining characteristic of the shared approach is its interactive nature with both the health care professional and the patient sharing information with each other. At a minimum, this approach requires of the health care professional to inform the patient of *all* relevant information that might be needed to make an informed decision and of the patient to reveal personal information on issues such as lifestyle, preferences and the quality of life. The intention is thus to enable both the health care professional and the patient to evaluate the various treatment options within the context of the latter's specific situation, needs and values.

With regard to the phase of deliberation or discussion of treatment preferences, Charles et al. state that in a pure version of the paternalistic approach, the health care professional will typically deliberate alone or at most with colleagues about the proposed treatment while either not soliciting or even overriding the patient's preferences in this regard. This approach is normally supported by the underlying assumption that the health care professional knows which treatment would be in the best interest of the patient and that patient input is therefore not required in the decisions being made (Charles et al. 1999b:655).

⁶⁶ See also Charles et al. 1999b:651-661.

In the informed approach, the patient is allowed to either alone or with family and friends, deliberate about treatment options. In a pure version of this approach, the health care professional functions as a true research agent, providing the patient with the most rigorous and current research findings, but is not expected to express treatment preferences or even opinions on the patient's treatment preferences, as it would be regarded as introducing an illegitimate professional bias into the decision making process rather than a furthering of patient sovereignty. In this approach the intention is thus to let the decision making process unfold through a division of labour in which health care professionals and patients have the specific, but separate tasks of providing information and of weighing the options and deciding on the preferred treatment.

In a shared approach to clinical decision making, both health care professionals and patients are considered to have a legitimate role in deliberation on treatment decisions. It is required of both parties to disclose preferences for a particular treatment scenario in order to enable them to either come to a consensus or negotiate a solution that will be acceptable to both. It should however be noted that these types of negotiations have the potential of escalating into a conflict and that in such a cases, health care professionals will have to decide whether they can support a patient's preference of treatment while considering another as more appropriate.

In the final phase of clinical decision making, namely that of deciding on the treatment that is to be implemented, the task in pure versions of both the paternalistic and informed approaches will be performed by the health care professional and the patient respectively and in the shared approach by both the health care professional and the patient working towards a consensus on the preferred treatment. The intention of a shared decision making approach is therefore to incorporate patient and provider preferences, as well as the principle of joint responsibility into decisions on treatment and thus represents a middle way between the paternalistic and informed approaches to clinical decision making. Moreover, it enables health care professionals to retain some influence on treatment decisions without dominating the encounter altogether and fosters patient participation to the preferred levels of patients without requiring them to bear full responsibility for decisions or engendering feelings of abandonment by their health care professionals (Charles et al. 1999b:658).⁶⁷

In connection to the different phases of clinical decision making, various research projects were initiated in order to determine the competences needed for successful shared decision making.

⁶⁷ Refer in this regard also to Quill and Cassel 1995:368-374.

In a study from 1997, Dowell and Dowie proposed a consultation method in order to achieve what they called a concordant therapeutic alliance and which drew on the concept of achieving concordance instead of compliance (which was deemed to have coercive overtones) in medical care (Elwyn & Charles 2002:134). The model starts with a perception of the problem and requires of a health care professional to identify, explore and address issues in terms of understanding and the acceptance of the experience of illness. The explanatory phase is then supposed to lead to an agreeing of goals, a negotiating of control, as well as an agreement on action and future appraisals (Blenkinsopp 1997).

Using the results of a literature search and semi-structured interviews with general practitioners, patients and patient educators, Towle and Godolphin in 1999 listed eight communication skills that could be regarded as essential competences for professionals in shared decision making (Elwyn & Charles 2002:134). They note that it is important to bear in mind that the practice of evidence-based patient choice is not just a matter of having positive attitudes towards patient choice and involvement in decision making, but requires good knowledge of a wide range of topics like treatment options, critical appraisal skills and sophisticated communication skills, such as the ability to elicit patients' preferences, present evidence-based choices and negotiate conflict. Furthermore, these knowledge, skills and attitudes need to be explicitly taught from medical school, through postgraduate training and even into continued medical education and should be based on a clear exposition of the competences needed to practice evidence-based patient choice. Based on the literature, interviews and focus groups, Towle and Godolphin defined the following set of informed shared decision making competences for health care professionals which they regard to be also applicable in the evidence-based patient choice context:

- Develop a partnership with the patient.
- Establish or review the patient's preferences for information (e.g. amount, format).
- Establish or review the patient's preferences for role in decision making (e.g. risk taking; degree of involvement of self and others) and the existence/nature/degree of decisional conflict (decisional conflict being a state of uncertainty about the course of action to take).
- Ascertain and respond to patients' ideas, concerns and expectations (e.g. about disease management options).
- Identify choices (including ideas and information the patient may have) and evaluate the research evidence in relation to the individual patient.

- Present or direct evidence, taking into account competences 2 and 3 and possible framing effects and help patients to reflect upon and assess the impact of alternative decisions vis-à-vis his or her values and lifestyles. Framing effects are said to occur when the presentation of the same information in different formats changes the decisions that people make.
- Make or negotiate a decision in partnership and resolve conflict.
- Agree upon an action plan and complete arrangements for follow-up (Towle & Godolphin 1999:766-771).⁶⁸

In 2000, yet another group of researchers undertook a research project using so called key informant interviews (Elwyn & Charles 2002:128).⁶⁹ The term key informants originated from anthropological studies undertaken by Crabtree and Miller and indicate a procedure in which informants are used to obtain opinions from specific contexts due to their special knowledge, status, skills or access to perspectives otherwise denied to researchers (Crabtree & Miller 1992). As informants, Elwyn et al. employed general medical practitioners with experience in assessing consulting skills competences and with educational involvement at undergraduate or post graduate levels in order to provide a bridge between theoretical ideas about the process of involving patients in clinical decision making and the practical problems met in actual practice. These practitioners deconstructed the concept of shared decision making and contributed to a process whereby a list of required competences in clinical decision making could be proposed, discussed and eventually agreed upon.

This list included the following nine competences in involving patients in health care decisions:

- Implicit or explicit involvement of patients in decision making process
- Agree and define problem that needs a decision
- Explore ideas, fears and expectations of the problem and possible treatments
- Portrayal of equipoise and options
- Identify preferred format and provide tailor-made information
- Checking process: Understanding of information and reactions
- Check that patients accept the process and decision making role preference

⁶⁸ With reference to competency 5, Sackett et al. suggested the following five phases: to formulate an answerable question for each chosen clinical problem; to search with maximum efficiency the medical literature and other sources of information pertaining to that specific question; to assess the validity (closeness to the truth) and usefulness (relevance to the problem) of the evidence identified; manage the patient accordingly; evaluate your own performance (Sackett et al. 1997).

⁶⁹ See also Elwyn et al. 2000:892-899.

- Make, discuss or defer decisions
- Arrange follow-up (Elwyn & Charles 2002:129)

However, despite the fact that these and other research projects contributed largely to a better understanding of the concept of partnership in clinical decision making, it became clear "that communication skills on their own cannot satisfy the demands of evidence-based patient choice and that a stripped down set of tasks and skills also fails to encompass the complexity of blending information with the degree of emotional support that is both necessary and a fundamental part of the clinical consultation" (Elwyn & Charles 2002:138). As indicated by Schneider, this is especially the case when patients are ill and anxious or, for whatever reason, lack the willingness to participate in rational models of decision making, such as those based overtly or covertly on decision analysis methods (Schneider 1998:75).⁷⁰ It is also evident that paternalism will no longer satisfy increasingly well informed consumers and that health care professionals urgently need new ways of communicating information. Since it is to be expected that current technological advances will strongly influence these developments, it is considered as highly likely that obtaining access, appraising and explaining data by employing well honed interpersonal skills will be the bedrock of future clinical practice (Elwyn & Charles 2002:139).

3.3.2 Risk communication

Apart from shared decision making, risk communication is also regarded as one of the key skills in attaining the goals of evidence-based patient choice. This perception is strongly related to the emergence in the late twentieth century of a society in which risk has increasingly become the focus of attention and the amount of literature on risk-related topics has risen exponentially (Skolbekken 1995:291-305). In this risk society, fields like economics, the environment, domestic life, litigation and in particular medicine and health care have to a large extent all come to be interpreted in terms of attached risks. In medicine and health care alone, there is an ever accumulating volume of literature on the issue of risk covering aspects as diverse as the perception, assessment and management of risk (Beck 1992).

While dangers of misunderstanding certainly exist when risks are communicated to patients, health care professionals nonetheless devote most of their time discussing the risks and benefits of treatments with their patients. This is normally done by either verbally describing the broad advantages and disadvantages of different options or involving the specific use of numerical data in decisions between forms of treatment (Edwards & Bastian 2002:144-145).

⁷⁰ See also Charles et al. 2000:1220.

However, there is conflicting evidence on whether verbal or numerical representations of the probabilities of risk are preferred by patients (Edwards & Bastian 2002:146). While the literature indicates that most people prefer numerical representations of information, it is also indicated that about one third of all patients prefer verbal to numerical descriptions of data. Moreover, people's understanding of numerical information may be affected by several factors such as age, educational level, health status, recent experiences of illness, as well as the severity and proposed outcome of the current illness. Also the values that people attach to different outcomes are likely to affect their use of risk information in addressing their risks (Mazur & Merz 1994:402-405).

In view of these challenges, there is a growing awareness that health care professionals engaged in risk communication need to go beyond an examination of the basic probabilities to also explore the effect of risk communication on individuals (Edwards & Bastian 2002:147). Many authors have therefore proposed that risk communication should both address the subjective probability or patient's perception of the actual probability of a specific event, as well as the outcome utilities or severity of the eventualities for that specific individual. Suggestions are thus that discussions of the benefits and risks of treatment options should be supplemented by discussions of patients' personal feelings about prescribed medications or treatments (Shiloh 1996:475-486).⁷¹

This emphasis on the need for individualisation in risk communication is also reflected in some of the definitions of risk communication. Ahl et al. for instance, defines risk communication as "the open two way exchange of information and opinion about risk, leading to better understanding and better risk management decisions" (Ahl et al. 1993:1045-1053). However, while this definition may be consistent with concepts like patient-centred care, it is regarded as too restrictive for health care in general, as much of the health care communication on risk does not take place in face-to-face encounters between health care professionals and patients (Edwards & Bastian 2002:147).

Another definition by Edwards et al. is more inclusive and typifies risk communication as "communication with individuals (not necessarily face-to-face) which addresses knowledge, perceptions, attitudes or behaviour relating to risk. The communication should include an element of weighing up risks and benefits of a treatment choice or behavioural risk-reducing change" (Edwards et al. 1998).

⁷¹ Refer also to Frets and Niermeijer 1990:295-306; Palmer and Sainfort 1993:275-294; Makoul et al. 1995:1241-1254.

To Edwards et al., the individualisation of risk communication, rather than detail of the patient or the health care professional or even the mode of risk communication, represents a characteristic of risk communication that proves to be most effective. Employing both treatment choice clinical topics and individualised risk estimates, their analysis indicated that individual communication interventions proved to be most effective and that interventions which used individually calculated risk estimates on average also effectuated an increase in adherence to treatment.

Risk communication represents an integral part of the practice of clinical decision making which is normally conducted in either a "faceless" or a "face-to-face" manner (Muir Gray 1996:202-203).

"Faceless" decisions are those in which decisions are based on either a specimen taken from or an image taken of a patient. Such decisions do not involve discussions with the patient or relatives and represent a clinician's interpretation of test results, samples or images. Being human, these decisions by a clinician will be influenced by the results, samples and images, but also by other factors such as the last patient, education, resources, evidence, previous experience and the threats of clinical audits and litigation. "Faceless" decision making will therefore always be characterised by inter and intra observer variabilities, such as different clinicians deciding upon a differing interpretations of the same material or the same clinician deciding upon a different interpretation of the same material.

On the contrary, the main characteristic of "face-to-face" decision making is the dialogue between health care professional and patient to which the patient brings his or her own set of beliefs, attitudes and values. Consequently, there are many more variables involved in this type of decision making which apart from resources and evidence may include other professionals, friends and family and even the media.

Furthermore, the dialogue in face-to-face decision making normally comprises of three elements, namely

- the provision of information by the clinician after a diagnosis has been made;
- the interpretation by the patient and
- the discussion between the clinician and the patient.

Moreover, it is regarded of great importance to note that for a patient to exercise choice based on the available evidence, all three elements have to be present in the process of decision making.

Within this framework, the provision of evidence-based information to patients is furthermore expected to include the following steps:

- the finding of all the available research evidence using the best possible searching techniques;
- the appraising of this evidence to identify the best available evidence;
- the calculation of the probability that the patient will benefit from the evidence;
- the calculation of the magnitude of the benefit;
- the calculation of the probability that the patient will suffer adverse effects of the treatment;
- the calculation of the magnitude of any adverse effects.

Many factors may however hamper the proper provision of information, as health care professionals are not always aware of the best available evidence and the latter is not always available in formats required by and useful to patients.

Regarding the interpretation of the patient, it is acknowledged that in general, patients are more averse to the risks of serious side effects than clinicians and are expected to consider:

- how the information provided would apply to their specific cases and
- what the effects of the outcomes will be on their values.

Concerning the discussion between the clinician and the patient, Muir Gray notes that the quality of the discussion is neither determined by the quality of the evidence, nor by the patient's knowledge of medical terms, but primarily by the relationship between the health care professional and the patient. If a patient feels powerless, the discussion will be inconclusive and unsatisfactory. If a patient on the contrary feels empowered to participate, a satisfactory discussion will take place. Moreover, attention has to be paid to the addressing of anxiety, as it might be experienced by both the health care professional and the patient. This implies a heavy burden on the health care professional, since the patient's ability to participate in the discussion and therefore also the success of the discussion is to a large extent determined by the input of the health care professional (Muir Gray 1996:210).

3.3.3 Decision analysis

Apart from shared decision making and risk communication, decision analysis is also regarded as an essential skill in attaining the goals of evidence-based patient choice.

It is a structured and systematic development of approaches to decision making and is aimed at examining potential outcomes under conditions of uncertainty. It is largely based on the theory of expected utility that was developed by Von Neumann and Morgenstern and which defines the concept of expected utility as "the product of the probability of an outcome (e.g. chance of avoiding a stroke by taking warfarin treatment for arterial fibrillation) and its utility or sense of worth, value and importance" (Elwyn et al. 2002:162). Based on the premise that a rational decision-maker normally opts for the plan of action with the greatest expected utility, this theory measures the valuation of outcomes in terms of both patient preferences and the probabilities of uncertainties and is usually portrayed in the form of a decision tree (Von Neumann & Morgenstern 1947).

Decision analysis is therefore conceptually quite different from other approaches such as shared decision making and risk communication, as these approaches usually entail a transfer of responsibility from the health care professional to the patient and either concern the skills to engage the patient more directly in clinical decision making or the nature of the information that may be most efficient. Decision analysis is different since it on the one hand prescribes the decision to be taken and on the other endeavours to assess the patient's values regarding the possible outcomes of treatment and integrate these with the health care professional's knowledge of the likelihood of these outcomes by means of simple mathematical procedures resulting in a prescribed decision independent of both parties (Elwyn et al. 2002:161).

The crux of the matter and the differences with other approaches to partnership in clinical decision making has been clearly defined by Gafni et al. who examined agency relationships in health care and described two key elements which are essential for good decision making, namely:

- information about the different outcomes of treatment options like benefits and harms and their likelihoods
- the patient's personal values about the significance and relative importance of these outcomes

According to Gafni et al., these elements open up a whole range of scenarios. At one end of the spectrum, the health care professional is typified as supporting patients to make their own decisions by providing them with the necessary information and allowing them to judge this information against their own values and concerns. At the other end of the spectrum, the health care professional may act as the patient's agent, deciding on what is considered to be the best options in the specific circumstances. In decision analysis, the responsibility of choices therefore

remains with the health care professional and the decisions are prescribed, while attention is also paid to a formal and explicit assessment of the patient's values or utilities to ensure a decision based on both information and values (Gafni et al. 1998:347-354).

Decision analysis has therefore been described as explicit, quantifying and prescriptive with the facts and the values going into making decisions being kept separate. In this way it is ensured that both the medical information and the patient's preferences are properly acknowledged and that both probabilities and patient utilities are quantified separately before being integrated. An optimum prescribed choice will therefore equal the decision outcome with the highest numerical score arrived at by multiplying a patient's utility for that specific event by its probability and is therefore also considered as a rational option (Elwyn et al. 2002:163).⁷²

In order to attain these goals, the practice of clinical analysis comprises of four principle steps, namely:

- to identify and bound the question
- to structure the decision over time in a logical sequence
- to obtain the necessary data
- to make the decision with the highest expected utility (Elwyn et al. 2002:165).

Of these four steps, the first is regarded as the most important, as the correct identification of the question at issue will affect the decisions to be made, as well as the outcomes that may arise for the patient. Moreover, this information needs to be contextualised together with a specification of all relevant aspects of the patient's health in order to address the probabilities of outcomes and utilities in relation to these issues.

The second principle requires the steps of a decision to be laid out in a logical order. Reference has earlier been made of the important role of decision trees in decision analysis and in the second step and bearing in mind that once a decision is taken, the outcome thereof is a matter of chance, these are utilised to indicate the decision to be made as a square node and the chance of an outcome as a circle with lines connecting these nodes representing the passage of time.

The third step of decision analysis requires the collection of two types of data for the decision tree, namely the probabilities of events at issue and the utilities placed on them by the patient, measured by methods such as the so-called time-trade-offs and standard gambles.

⁷² See also Weinstein et al. 1980.

Finally, a decision with the highest expected utility is to be made which is achieved by the calculation of the product of utilities and probabilities for each individual outcome at the end of the tree.

The decision analysis approach is thus not meant for obvious or even fairly obvious health care decisions, but most suited for situations of uncertainty, like drastic forms of treatment. Moreover, it remains dependent on the availability of the best quality data like randomised clinical trials or meta-analyses for the estimation of the probabilities and utilities of events and in order to reach a prescribed decision (Elwyn et al. 2002:166).

3.3.4 The use of decision aids

Apart from shared decision making, risk communication, and decision analysis, the use of decision aids is finally also regarded as an essential skill in attaining the goals of evidence-based patient choice. While shared decision making and risk communication were aimed at engaging the patient more directly in decisions about treatment and entailed a transfer of responsibility from the health care professional towards the patient, these skills still involved the health care professional in the act of clinical decision making. However, several decision aids have already been developed to supplement the existing communication between health care professionals and patients and are generally aimed at assisting patients to:

- understand the range of options available;
- understand the probable consequences of options;
- consider the value they place on the consequences;
- participate actively with their health care professionals in deciding about options (O'Connor & Edwards 2002:220).

With the aim of preparing patients to participate with their health care professionals in making deliberated and personalised choices about health care options, decision aids have been developed for a wide range of situations such as:

- medical therapies for arterial fibrillation, benign prostatic hypertrophy, low back pain, cancers of the breast and lung, leukaemia, lymphoma, circumcision and ischemic heart disease
- diagnostic tests such as amniocentesis and screening for colon and prostate cancers
- preventative therapies such as hepatitis B vaccine and hormone therapy at menopause

- clinical trial entry decisions
- end of life decisions such as resuscitation in seniors (O'Connor & Edwards 2002:221).⁷³

Of particular importance in this regard is the exclusion criterion for decision aids formulated by the Cochrane Collaboration in Australia that interventions designed to promote compliance with a recommended option rather than a choice based on personal values, do not qualify as decision aids.⁷⁴ This stipulation derives its inspiration from the international emphasis on patient autonomy and volutariness and is motivated by trends such as:

- the rise of consumerism with its emphasis on informed choice rather than informed consent;
- the evidence-based practice movement disseminating evidence to patients as well as to professionals;
- the use of patient-focused strategies to reduce regional practice variations;
- the identification of treatment decisions that are utility or value sensitive from decision analyses;
- related clinical practice guidelines which indicate that certain choices are sensitive to patient preferences and that patients should be involved in decision making;
- the proliferation of overviews and outcome studies which provide estimates of outcomes for use in decision aids;
- the evolution of patient preference-orientated health policy that reserves interventions for those individuals who consider the treatment benefits to outweigh the harms (e.g. reserving palliative surgery for those who consider symptom relief worth the surgical risks, rather than basing a surgical policy on the average patient's utilities) and
- the expansion of evaluation criteria by quality improvement groups to include the quality of counseling regarding options, such as the time of menopause (O'Connor & Edwards 2002:225).

⁷³ See also O'Connor et al. 1999a:67-80.

⁷⁴ Refer to the Cochrane Collaboration's definition of what decision aids include and do not include:

"Inclusion criteria: Interventions designed to help people make specific and deliberative choices among options by providing (at the minimum) information on the options and outcomes relevant to the person's health status. Additional strategies may include providing: information on the disease/condition; the probabilities of outcomes tailored to a person's health risk factors; an explicit values clarification exercise; information on others' opinions; and guidance or coaching in the steps of decision making and communicating with others. Decision aids are delivered using media such as decision boards, interactive videodiscs, personal computers, audiotapes, audio-guided workbooks, pamphlets, and group presentations.

Exclusion criteria: Passive informed consent materials, educational interventions that are not geared to a specific decision, or interventions designed to promote compliance with a recommended option rather than a choice based on personal values" (O'Connor et al. 1999b).

Against this background, it is argued that decision aids are most valuable in clinical practice to elicit patient preferences and enhance patient autonomy and voluntariness when options represent major differences in outcomes or complications, when decisions require trade-offs between short and long term outcomes, when a choice even has the slight potential of a grave outcome and when there are marginal differences in outcomes between options (O'Connor & Edwards 2002:225).⁷⁵

SUMMARY AND CONCLUSIONS

This chapter paid attention to the important political, economic and ethical developments that since the mid 1990s constituted the environment in which evidence-based patient choice developed as partnership model in clinical decision making. In addition it noted that evidence-based patient choice represents the sharing of good quality evidence-based information and respect for patient preferences and involvement in health care, is aimed at providing patients with evidence-based information in a way that enhances their ability to make choices and decisions about their health care and as such and brings together two important movements of evidence-based and patient centred medicine that have both developed as a critical response to what was perceived to be the excessive authority given to health care professionals in medicine. In the last paragraph it was argued that the practice of evidence-based patient choice is directly related to its nature and can therefore be conceptualised by means of four key decision making skills required from health care professionals to involve patients in clinical decision making, namely shared decision making, risk communication, decision analysis, and the use of decision aids. In addition, an exposition of the main elements of these key skills was undertaken.

From this discussion it became clear that individualism has indeed become an institutionalised concept and goes hand in hand with pressures towards a greater democratisation of society and the need to live in a more open and reflective manner than previous generations. It is therefore to be expected to also become a major force and influence in health care. Of importance was the observation that the end of the twentieth century also brought a new phase in the development of the medical profession with the introduction of the concepts of third party mediation and accountability through which doctors now became managed, appraised, investigated and directed by guidelines with their personal basis of expertise undermined by the World Wide Web as a ubiquitous source of information. Moreover, it was of importance to note that the credibility of medical practice was seriously undermined by studies of clinical practice and the delivery of information which indicated that the variation in the rate at which information is

⁷⁵ See Kassirer 1994:1895-1896.

provided or an intervention is used, is frequently far greater than can be explained by a variation in the incidence or prevalence of disease. It therefore also came as a tremendous shock to patients that the available clinical information was commonly not even employed by clinicians, or was often deficient. Whereas these developments necessitate a fresh approach to the involvement of patients in clinical decision making, it is clear that evidence-based patient choice has gained recognition as an approach aimed at providing patients with evidence-based information in a way that facilitates their ability to make choices and decisions about their health care. It is however also evident from the discussion in the chapter that the practice of evidence-based patient choice remains deprived of a proper embeddedness in a clear understanding of the human processes through which information is transformed into insight, knowledge and action and without which it remains impossible to tap into the real value of information resources and technologies. Furthermore, it was also clear that personal communication is still to be regarded as a major challenge in the provision of information, since the latter is still largely regarded as the responsibility of the health care professional and predominantly conducted in an objective and technical manner.

With regard to the aim of the study, namely to determine an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, it can further to the discussion in this chapter be concluded that any such effort would require a specific focus on the matter of the individualisation of the provision of information and that in this regard an embeddedness in the human processes through which information is transformed is indispensable and not negotiable. Furthermore it can be regarded as fortunate in such an endeavour that the medical profession has already entered a phase in its development that allows room for third party mediation, since the concept is of pivotal importance in this study.

CHAPTER 4

PATIENT AUTONOMY AND EVIDENCE-BASED PATIENT CHOICE: A CRITICAL EVALUATION

INTRODUCTION

Against the background of the discussion in Chapters 2 and 3, this chapter critically analyses evidence-based patient choice as partnership model in clinical decision making by evaluating it in terms of the ethical principle of patient autonomy as represented in the informed consent elements of competence, disclosure, understanding and voluntariness. It will be indicated that, judged against these elements and due to a wide variety of reasons that will be attended to shortly, none of the key skills of evidence-based patient choice can be regarded as completely adequate in honouring the principle of respect for autonomy in clinical decision making and that huge gaps therefore still exist between the ideal and current practices of evidence-based patient choice. It will also be shown that consequently these four key skills leave evidence-based patient choice with a challenge that needs to be addressed from another angle in order to establish and maintain patient autonomy in the involvement of patients in clinical decision making.

4.1 COMPETENCE AND SHARED DECISION MAKING

Acknowledging that specifically in medical contexts, a person would be regarded as competent if able to understand a therapeutic or research procedure, to deliberate regarding its major risks and benefits and to make a decision in the light of this deliberation (Beauchamp & Childress 2001:72), this paragraph would like to determine to what extent shared decision making as key skill of the evidence-based patient choice model succeeds in establishing and maintaining patients' competence in clinical decision making.

Adherence to the competences required from health care professionals in evidence-based patient choice should at first glance thus suffice in honouring the principle of respect for autonomy and in establishing and maintaining patients' competence in clinical decision making. However, evidence suggests that a huge gap still exists between the ideal and current practices of shared decision making in evidence-based patient choice.

While research on the concept of shared decision making is still evolving, a lack of proper communication is today widely recognised as a major challenge in the establishing of partnerships between health care professionals and patients in clinical decision making and as a root cause of numerous difficulties experienced in clinical settings and of the upward trend in the number of complaints and law suits by patients that are dissatisfied with treatment (Coulter 2002:308).

A mixed group of American health care professionals, patients and communication experts that convened in 1998 to devise a strategy for minimising the risk of conflict in the professional-patient relationship, stressed the need for openness and transparency in clinical decisions on the side of clinicians and listed four key skills to be employed in resolving communication difficulties in clinical settings (Coulter 2002:315).⁷⁶ While these components of good communication almost seem too obvious to be worth restating, research has shown that many consultations still fail to meet the standards of

- trying to understand patients' worries and concerns,
- expressing empathy,
- encouraging patients to take an active role in health care options and
- negotiating differences of opinion when necessary (Williams et al. 1998:480-492).

However, with average consultation times in general practices estimated at around eight minutes (Howie et al. 1999:738-743), and outpatient consultations being even shorter (Waghorn & McKee 1999:215-219), it is difficult to see how these basic communication skills can be accommodated without a fundamental change in the arrangement of health care.

Two recent papers in the *British Medical Journal* focussed on the type and frequency of communication misunderstandings experienced by general practitioners and patients in twenty English general practices. The prevalence of these misunderstandings among presumably well intentioned doctors and their patients proved to be alarming, particularly given their effects on subsequent patient behaviour. In the first paper the authors presented findings concerning communication misunderstandings associated with prescribing decisions. Fourteen categories of misunderstandings between doctors and patients were identified, each of which had the potential or actual adverse consequences for the taking of medicine. Moreover, all of these categories were associated with a lack of patient participation in decision making in terms of voicing

⁷⁶ See also Levinson et al. 1999:1477-1483.

expectations or preferences, or voicing responses to the doctor's advice (Britten et al. 2000:484-488).

In the second paper, the authors explored the agendas that patients bring for discussion in a consultation, including the aspects that they actually voiced, as well as the effects of unvoiced agendas on patients' subsequent behaviour. It was pointed out that most patients did not voice all their agenda items and that this led to specific problems such as unwanted prescriptions and non-adherence to treatment (Barry et al. 2000:1246-1250).

Other studies placed the reasons for the poor communication between health care professionals and patients within the wider context of interrelated factors such as the changing face of present day health care and conceptualisations of health and illness (Sines 1995:29). According to Clare, it was epidemiology that first drew attention to the implications that the dramatic changes in morbidity and mortality in Western Europe and the United States would have for primary health care. While in the nineteenth century, epidemics could still be controlled by vaccinations and antibiotics, today's medical challenges include diseases such as cardiovascular conditions, cancer, liver cirrhosis, depression and AIDS that cannot successfully be treated by the eradication of micro organisms, but rather by communicating with individuals in such a way as to bring about changes in values, attitudes, beliefs, and ultimately habits and lifestyles (Clare 1993:3).

While there thus is a wealth of evidence that health care professionals and patients do not communicate well and that health care professionals do not only provide insufficient information, but are also poor judges of the needs of patients, the scale of the dilemma and the difficulties related to the establishment and maintaining of competence in clinical practice only becomes evident once the phenomenon is studied in depth (Towle & Godolphin 2002:247-248).

Already in 1985, Waitzkin analysed 336 clinical consultations in the United States of America involving 34 health care professionals. His findings were that in encounters that averaged 16.5 minutes, health care professionals spent an average of 1.3 minutes or 9% on a range of 0 to 11.6 minutes of the interaction time on information giving, while patients spent an average of 8 seconds or 1% on a range of 0 to 97 seconds of the time on questioning behaviour. It was also indicated that doctors overestimated the amount of time allocated to the provision of information by an average of 7.6 minutes and that in 65% of the encounters health care professionals underestimated patients' desire for information (Waitzken 1985:81-101).

In 1995, Makoul et al. analysed the communication and decision making in prescribing medications in 271 consultations between 36 general practitioners and their patients in Oxford.

Once again, their findings were that health care practitioners overestimated the extent to which specific consultation tasks, such as eliciting a patient's opinion about prescribed medication, discussing a patient's ability to follow the prescribed treatment and the discussion of risks were properly accomplished. While health care practitioners estimated that they accomplished these tasks in 49, 49 and 42% of the consultations respectively, video tape analysis indicated that actual accomplishments only occurred in 34, 8 and 3% of the cases. Of particular importance to the practice of evidence-based patient choice, was the fact that side-effects, precautions and risks of treatment and medication were not even mentioned in 68% of the consultations and that moreover 23% of the patients left the consultation with the *illusion of competence* that the health care professional had fully explained the risks attached to treatment and medication (Makoul et al. 1995:1241-1254).

In 1999, Braddock et al. followed these studies up with an analysis of 1057 audio tape recordings of consultations with primary care physicians and surgeons in the United States of America. Their findings were that only 9% of the consultations met the general criteria of shared decision making with the nature of the intervention being discussed in 71% and an assessment of patient understanding undertaken in only 1.5% of the cases. Moreover, elicitation of patient's preferences took place in only 21% of the cases, discussions on alternative treatments and medication in only 11%, the weighing up of pros and cons in only 8%, the determining of patients' roles in decision making in only 6% and the sorting out of uncertainties about decisions in only 2% of the consultations. Further indications were that basic decisions, such as on laboratory tests, were "completely informed" in 17% of the cases, while no intermediate decisions, such as on new medication and only 5% of complex decisions on for instance procedures, were fully informed (Braddock et al. 1999:2313-2320).

However, a huge gap between the ideal and current practices of shared decision making in evidence-based patient choice is also evident when other than communication skills are examined.

In 1998, a study by McColl et al. among British general practitioners found that 40% knew about the Cochrane databases, but that only 5% made use of it (McColl et al. 1998:361-365). The same tendency was reflected in a study done by McAlister et al. in 1999 among 294 internists in Canada. This study indicated that only 11% of the practitioners always employed the principles of evidence-based medicine in their practices, while 59% reported that they often use these principles. However, only a minority admitted the regular use of evidence-based medicine related sources of information such as primary research studies (45%), clinical practice

guidelines (27%) and the Cochrane Collaboration Reviews (5%) and fewer than half of the respondents were confident in some of the basic skills of evidence-based medicine such as conducting a literature search (46%) or evaluating the methodology of published studies (34%) (McAlister et al. 1999:262-264). Also in 1999, a survey conducted by Young and Ward among 311 general practitioners indicated that while 22% of the practitioners were aware of the Cochrane Library databases, only 6% had access to it and only 4% had ever made use of it (Young & Ward 1999:56-58).

Thus, while the concepts of shared decision making and patient involvement may today be widely supported (Laine & Davidoff 1996:152-156),⁷⁷ decision aids and the implementation of decision making consulting styles have not yet seen widespread acceptance and implementation within clinical settings, but remained restricted to academic settings (O'Connor et al. 1999a:67-80).

In a recent study to evaluate the potential of shared decision making programmes (Holmes-Rovner et al. 2001), a health insurer (Blue Cross and Blue Shield of Michigan) introduced shared decision making in its fee-for-service hospital systems (Holmes-Rovner et al. 2002:275). With the objectives of providing a high quality and cost effective benefit to the insurer's members, improving quality of care and service satisfaction and assistance in managing health care costs, the study was aimed at evaluating two multimedia Shared Decision Making programmes employed in three hospitals in Michigan for the facilitation of patient choices in the treatment of early stages of breast cancer and moderate ischemic heart diseases.

Results indicated that the programmes were judged to be clear and accurate, contained the correct amount of information and were of acceptable duration. However, health care professionals were seemingly neutral about patients' desire to participate in decision making on treatment and seemed reluctant to add tasks that might disrupt the typical patient pathways, but were nonetheless happy to refer patients to the Shared Decision Making programmes. These results thus also emphasised findings indicating that the involvement of patients in decisions and the use of decision aids are still to be regarded as minority interests, mainly pursued in settings aimed at increasing patient autonomy (Holmes-Rovner et al. 2002:276).

The fact that involvement of patients in clinical decision making is still regarded as a minority interest in medicine was also emphasised by a survey done among 1248 general practitioners in British Columbia (Towle & Godolphin 2002:248). The survey indicated that gynaecological problems, chronic back pain, hypertension, ischemic heart disease and headaches belonged to

⁷⁷ See also Coulter 1999:719-720.

the top five topics of interest to these health care practitioners and that the only topic of interest not directly related to disease was the issue of "dealing with difficult patients" which was ranked thirteenth on the list for city practices.⁷⁸ Moreover, it was obvious that none of the typical evidence-based patient choice elements such as critical appraisal, assessment of therapeutic interventions, understanding and the avoidance of sources of bias appeared the top twelve of fifteen topics on any of the lists (Lirenman 1996).

Reasons for this attitude of complacency among health care professionals towards the involving of patients in clinical decision making are not only diverse, but also emphasise the fact that the implementation of decision making consulting styles have not yet seen widespread acceptance and implementation within clinical settings. Moreover, it provides compelling evidence of the difficulties related to the establishment and maintaining of competence in clinical practice.

Kaufman identifies several reasons why minimal communication with patients persists as an informal norm of professional practice and states that health care professionals are trained to assume authority and responsibility for the medical care of the patient and that the concept of responsibility is deeply ingrained in students throughout their clinical studies (Towle & Godolphin 2002:260). Within this context, effective communication requires that the student confronts his or her own feelings about the patient and the illness, as well as the uncertainties and ambiguities that are an unavoidable feature of the treatment process. Moreover, medical knowledge is seen as part of the professional property of the health care professional and a sharing of this information may therefore be construed as an undercutting of the status and authority of the professional in a treatment relationship (Kaufman 1982).

These reasons are echoed by Bellaby when he states that senior health care professionals have long been at the centre of power and that they from this position could afford to be quite complacent about the risks associated with their work. Defences for this attitude have always been derived from medicines moral authority as curer and from health care professionals' claims to be uniquely able to resolve the indeterminate questions of diagnosis and treatment and have also inspired professionals' efforts to keep collegiate control of audits of practice and disciplinary actions. Evidence-based medicine has therefore also been regarded as part of medicine itself, since it both provided a means by which health care could develop and a way in which a core group of health care professionals and scientists could retain control of the direction of this development. As such, evidence-based medicine represented yet a further specialisation of health care and another layer of technicality and as a result, the opportunity for

⁷⁸ The issue was not even raised among general practitioners in regional and rural practices.

patients or consumers to make a contribution to personal or societal decisions became even more remote.

According to Bellaby, a further way in which the authority of health care professionals is reinforced is by deflecting external threats. This is normally done by going on the offensive against issues like smoking which is perceived as self-inflicted illness from a medical point of view. With smoking unequivocally regarded as adverse in Britain and formally condemned by studies, British health care professionals themselves made a "heroic response" by remedying what used to be a widespread smoking habit among themselves. However, this moral crusade was renewed by assaults on issues such as tobacco advertisements, sales of tobacco to children and secondary smoking effects and in sociological terms became known as the "privatisation of risk" due to the increasing tendency towards the identification of risk factors and risk groups and the placing of blame on the individuals concerned (Bellaby 2002:90).⁷⁹

In addition, Mishler notes that doctors and patients talk to each other in different voices. The voice of medicine, he says, is characterised by medical terminology, objective descriptions of physical symptoms, and the classification of these within a reductionist biomedical model, while the voice of patients is characterised by non-technical discourse about the subjective experience of illness in the context of the patient's social relationships and everyday world. Furthermore, as a result of doctors having the control in structuring a consultation, patients may experience their voice as being overridden and silenced, or stripped of personal meaning and social context.

There are a number of ways, says Mishler, in which physicians use their position to control an interview during a consultation. They open each cycle of discourse with their request or question, assess the adequacy of the patient's response, close each cycle by using their assessment as a terminating marker and reopen the next cycle with another request or question. Through this pattern of opening and terminating cycles, physicians not only control the process of turn taking and decide when the patient should have a turn, but also control the content of what is to be discussed by selectively attending and responding to certain parts of the patient's statements and by initiating each new topic.

Moreover, his analyses indicated that there is a systematic bias to physicians' focus of attention in a consultation, since the patient's reports of how the problem developed and what effect it has in the life contexts of the symptoms are systematically ignored. Physicians instead direct their attention solely to the physical medical signs that might be associated with the patient's primary symptoms or to the further physical specification of the symbols (Mishler 1984:69-70).

⁷⁹ See also Wright Mills 1970 and Edwards et al. 1997:739-742.

These analyses by Mishler led to the depiction of a unit of discourse consisting of a three part utterance sequence, namely physician question - patient response - physician assessment/next question. In this sequence, physicians' second question served both to terminate the first unit and initiate the second and in this way produced a connected series of cycles that eventually constituted the entire interview. This complex unity of structure and function Mishler calls the voice of medicine which represents the normative order of the biomedical model in the discourse and which is in opposition to the voice of the life world or the patient's experiences of illness and treatment. Further analyses revealed that the voice of the life world occasionally found expression with patients sometimes talking about problems in their lives that were related to or resulted from their symptoms of illness. According to Mishler, the meanings expressed in this voice differed from those framed in the biomedical perspective and physicians therefore tended to treat these as non-medically relevant and in a typical interview quickly suppressed this voice in order to restore the voice of medicine to its position of dominance in the discourse (Mishler 1984:91).

Moreover, with regard to the limitations of the biomedical model, Kriel notes that although the clinical method provides health care professionals with a prescribed way of obtaining the required results and precise criteria for the validation of findings, the method remains strictly objective with the subjective world of the patient meticulously excluded. According to Kriel, the aim of the process is to diagnose disease and not to understand the patient and therefore the patient's agenda is overwhelmed by the doctor's objectively orientated agenda. This is due to the assumption that subjective processes do not contribute to biological disease and that an understanding of the psychological and subjective elements of health and disease is therefore irrelevant to the science and practice of medicine.

Due to being strictly objective, Kriel notes that the biomedical model therefore cannot deal with all the meaning problems related to illness. As an inherent part of being ill, illness represents a crisis in the self understanding of a patient, affects the whole person and requires a restoration of wholeness. While it is acknowledged that suffering can be endured if understood, the whole dimension of being human is excluded from the clinical method.⁸⁰ This inevitably leads to poor

⁸⁰ Compare Kriel's exposition of the clinical method: "The interaction between the scientific doctor and the patient is regulated by a specific method known as the "clinical method". According to this method, the doctor first systematically interrogates the patient regarding his or her symptoms. The symptoms are the subjective experiences of "being ill". Other information that may have a bearing on the still-to-be-diagnosed disease is then elicited such as family disease - history, work history, and social habits. This process of structured interrogation is known as "history taking". From this information the physician formulates a hypothesis regarding the organ system involved and the disease that may be affecting the organ, thus causing the symptoms. The history is said to access the subjective experience of being ill. However, the directed questioning enables the doctor to limit the interaction to symptoms that are known to be associated with, or are pointers to, possible organic disease. In this manner the

doctor-patient relationships, patient dissatisfaction, a move toward alternative medicine and an eventually an increase in litigation against health care professionals (Kriel 2000:36). The limitations of the traditional biomedical model that draws its inspiration from the natural sciences, are also increasingly being regarded as one of the important causes of the poor communication between health care professionals and patients (Kriel 2000:33). A broader model of science and an alternative understanding of reality and of human consciousness which can become the basis of a transformed clinical method that will accommodate interpersonal and societal influences, as well as the beliefs and predispositions of the individuals concerned, is therefore needed. However, a broader model of science would also demand changed views of health itself, from the mere absence of illness, to more positive, holistic and dynamic notions of optimising resources to maximise personal potential (Ewles & Simnett 1992).

Furthermore, Towle and Godolphin argue that education alone will not solve the problem (Towle & Godolphin 2002:249,260,261). They note that research indicates that practising health care professionals seem reluctant to participate in communication skills training and are also resistant to suggestions that they have deficiencies in their practice (Hulsman et al. 1999:655-668). Recent reviews have also shown the limitations of most continued medical education programmes in changing the behaviour of health care professionals and in improving care and patient outcomes (Oxman et al. 1995:1423-1431) and unveiled that in cases where health care professionals did decide to acquire new skills or knowledge in this regard, these decisions rose internally from curiosity and externally from problems encountered in everyday practice (Mann & Chaytor 1992:S4-S6).

Moreover, research indicates that communication skills teaching on decision making is inadequate, as most formal communication skills training occurs in the first year or two of medical training, while the emphasis remains on the first half of a consultation, namely the taking down of the history of illness in order to make a diagnosis (Elwyn et al. 1999:447-482).⁸¹

doctor is interested in shortness of breath as a pointer toward lung or heart disease, swelling of the ankles as possibly indicating right heart failure, and a pale colour of the stools as pointing toward obstructive jaundice. The history is followed by the physical examination in order to find physical signs that will confirm or disconfirm the hypothesis. Physical signs are "objective physical findings", for example, enlargement of the liver, signs of anemia, or the presence of abnormal heart sounds. This is usually followed by special investigations of, say, the blood or urine, or else X-ray examination. The aim is now finally to find objective laboratory evidence of abnormal physical processes. Without such objective evidence, there is no disease, regardless of the patient's story. If no objective evidence of disease is found, the concepts of neurosis or psychosomatic complaints are invoked. The disease label is the one that best links together the history, the physical examination, and the special investigations. This disease label is vital because it determines therapy" (Kriel 2000:22-23).

⁸¹ Refer also to the following findings by Maguire and Novack. Maguire et al. studied 40 young doctors of whom half had feedback training as part of training in interviewing skills as students five years earlier. All proved to be equally poor in providing information and advice and very few exhibited a sensitivity for patients' views and expectations. However, they all agreed that their poor performance was due to a lack of clear guidance on how to

Hargie et al. also pointed to a lack of good role models for professional-patient communication in general (Hargie 1998:25-34) and this tendency was confirmed by a study done at three Canadian medical schools which indicated that only 46% of students regarded their lecturers to be good role models in patient-centred medicine and only 53% regarded the lecturers as good role models in teaching the professional-patient relationship (Beaudoin et al. 1998:765-769). It was also pointed out by Burack et al. (Burack et al. 1999:49-55) that communication skills are rarely observed during undergraduate and even postgraduate clinical training in wards and that senior doctors did not explicitly pay attention to attitudes of compassion and respect and moral and professional norms in this regard (Towle & Godolphin 2002:256,258).

Furthermore, major sociological studies from the United States of America and the United Kingdom also suggest that the ability of students to communicate with patients deteriorates as they proceed through medical school and that medical school and teaching hospitals in general have de-humanising influences on medical students with detrimental consequences for their relationships with patients (Becker et al. 1961).⁸² It was also observed that doctors in training at the beginning of their studies were quite positive about the doctor-patient relationship and preferentially endorsed collegial models, but tended to endorse significantly fewer positive and more negative models of interaction with patients as their studies progressed (Sparr et al. 1988:1095-1101). Moreover, it has also been noted that the in-patient environment in hospitals where much of the clinical training takes place does little to support a patient-centred approach to communication, let alone ideas of patient autonomy and choice (Towle & Godolphin 2002:259-260).⁸³

The current state of shared decision making in the practice of evidence-based patient choice can therefore not be regarded as completely adequate in honouring the ethical principle of respect for autonomy and in establishing and maintaining patients' competence in clinical decision making. Moreover and due to the reasons for the lack of proper communication, the practice of shared decision making therefore still leaves evidence-based patient choice with the challenge of the separate worlds of doctor and patient.

give information and advice to patients, either while or since they were medical students (Maguire et al. 1986:1576-1578). Novack et al.'s survey of the state of medical interviewing and interpersonal skills teaching in US medical schools indicated that in introductory courses during the first two years, the main topics taught are the medical interview (83%), physical examination (46%), the professional-patient relationship (37%) and the medical record (25%). However, the survey indicated little co-ordination of skills teaching throughout the curriculum and also identified various barriers in teaching a progressive sequence of skills, such as a lack of curriculum time, trained faculty support and faculty interest (Novack et al. 1993:2101-2105).

⁸² Refer also to Mizrahi, 1986; Sinclair 1997.

⁸³ See also Thistlethwaite & Jordan 1999:678-685.

4.2 THE DISCLOSURE OF MATERIAL INFORMATION AND RISK COMMUNICATION

In recognition of the subjective standard of disclosure which judges the adequacy of information disclosure by reference to the informational needs of the individual person, rather than to that of the hypothetical reasonable person (Beauchamp & Childress 2001:83), the paragraph would like to establish whether risk management as a second key skill of the evidence-based patient choice model adequately provides for the disclosure of information to patients.

Adherence to the guidelines for face-to-face decision making required from health care professionals in evidence-based patient choice should once again at first glance suffice in honouring the principle of respect for autonomy and in establishing and maintaining the provision of an adequate disclosure of information to patients in clinical decision making. However, evidence suggests that also in this case a huge gap still exists between the ideal and current practices of risk communication in evidence-based patient choice.

This is due to the fact that the current practice of the individualisation of risk communication however constantly remains under the influence of a number of important factors (Edwards & Bastian 2002:150-154).

The concept of clinical equipoise is one such factor that may have a variety of influences on the practice of risk communication. Research indicates that risk communication has greater clinical effects in guiding treatment choices for conditions such as menorrhagia or prostatic symptoms than in prevention or screening programmes. According to Elwyn et al., this may be an indication of clinical equipoise due to health care professionals not having a clear preference about which treatment to choose (Elwyn et al. 1999a:753-756).

These indications however, seem to be in contrast to other studies aimed at behavioural changes such as smoking cessation and reduced alcohol consumption, since achieving such changes may clearly be interfered with by significant social and contextual influences. According to Sarfati et al, the absence of clinical equipoise may cause the professional goals of risk communication to become at odds with the spirit of partnership and in such cases not only influence the formation of genuine partnerships with patients, as the latter may have their own preferences and values, but also create ethical dilemmas (Sarfati et al. 1998:137-140).

The framing of information is another such factor, as the different ways of "framing" information in the discussion of risks can also have varying effects. Framing is normally defined as the presentation of logically equivalent information in a variety of ways (Wilson et al.

1988:1837-1847) and these different presentations may all have different motivational effects depending on whether individuals adhere to prescribed treatments or choose treatment options. Moreover, since people have different preferences in receiving and discussing information, the way facts and figures are conveyed, will often need to vary according to the needs of the individual patient. Also from a health care professional's perspective, a range of complementary formats such as descriptive, absolute and relative risk, "numbers needed to be treated" and graphical presentations may be more valuable, since such information will empower them to engage in proper partnerships with patients (Edwards et al. 1998:301-307).⁸⁴

The identification of the components of the most persuasive message however raises ethical concerns about the goal of risk communication - whether it is to achieve a desired behaviour change or to facilitate an informed choice with accompanying greater autonomy for the patient? Edwards et al. regard relative information as persuasive, but also prone to be over dramatic and thus potentially misleading when used on its own. They therefore suggest the use of absolute risk as the preferred format for the conveying of data, though people often make decisions on the basis of making comparisons which require relative risk data (Edwards et al. 1998:301-307).

However, combining absolute and relative risk information has the benefit of allowing patients to make informed decisions based on the "whole truth" rather than just the "truth". A further benefit of such an approach is its affinity to the principle of relationality proposed by Bottorff et al. This principle not only complements the standard ethical principles of patient autonomy, beneficence, nonmaleficence and justice, but also promotes the provision of accurate information in the context of the individual situation and incorporates ethics of care factors such as response, interpretation accountability and social solidarity.⁸⁵

The reasons for the discrepancy between the ideal and current practices of risk communication are therefore not only complex and diverse, but also provide compelling evidence of the difficulties related to the establishment and maintaining of disclosure in clinical practice.

According to Bellaby, the challenges faced in this regard could perhaps best be illuminated by an analysis of the concept of risk itself, which can be viewed from two sides: from science and from everyday life. In science, risk can be regarded as the product of the financial or human cost of a hazard and the likelihood of people or property being exposed to the hazard. Neither the hazard, nor its probability is thus completely independent of social relations, since in human

⁸⁴ The literature regards the type of risks discussed as crucial in ensuring an adequate match between the needs and expectations of patients and the information supplied by health care professionals (Edwards & Bastian 2002:152). For this reason it is regarded that precise information about for instance the absolute or relative risk of treatment indeed empowers health care professionals in engaging into partnerships with patients.

⁸⁵ For more information, see Bottorff et al. 1996.

populations, the magnitude of a hazard is directly linked to the proportion of the population exposed to the hazard. Moreover, the statistical concept of risk used by scientists, easily gives rise to misunderstanding by members of the public. It is a well established fact that the public tends to exaggerate risks when the hazard is great, but the probability of exposure is low and depreciate risks when the hazard is small, but the probability is high. Similar misunderstandings arise in health care when scientific knowledge is integrated in clinical practice and this may have far reaching implications for the involving of patients in clinical decision making (Bellaby 2002:79).

Bellaby notes that these realities are emphasised by Foucault who states that medicine two hundred years ago began to view the human body and disease in a different light (Bellaby 2002:87). Disease was now depicted as hidden from view, but possible to detect through signs and this view established the practice of classifying diseases according to symptoms that appeared on the surface of the body. While the previous approach could be described as holistic and viewed the patient as a participant in his or her health care, this new approach analysed and fragmented the human body and demoted the patient to a spectator in his or her health care with the doctor depicted as the person in charge of health care. This resulted in risks being conceived as internal and biological, health care professionals as the only people capable of addressing these risks, the consultation as the domain of decision making and hence in a complete abstraction of health care (Foucault 1975:88-192).

Early evidence-based health care descriptions regarding the involvement of patients in clinical decision making focused on what was seen to be new about the approach, namely the types of information that could influence clinical decisions about which tests, treatments and forms of care individual patients should or should not receive. Under this banner, the rather passive roles advocated for patients included:

- passively receiving and evidence-based justification for interventions given;
- asking questions that prompt health care professionals to search for research evidence;
- expressing preferences for particular interventions; and
- actively selecting a course of action after being given evidence-based information about the various options (Entwistle & O'Donnell 2002:35).⁸⁶

More recent writings by advocates of evidence-based health care (Sackett et al. 1997:163-170) have however emphasised that health care professionals' individual clinical expertise should not

⁸⁶ See also Evidence-Based Medicine Working Group 1992:2420-2425.

only be integrated with the best available evidence from clinical research and a more thoughtful and compassionate use of individual patients' predicaments, rights and preferences in making decisions about their care, but also with assessments whether the available research evidence suggests that treatments would do more good than harm from the individual's point of view and whether the patient's values and preferences would be satisfied by the treatment regimen and its consequences (Entwistle & O'Donnell 2002:36).

Reference was made in 3.2 to the five basic steps through which evidence-based decision making could be introduced in clinical settings.⁸⁷ These guidelines however also had a big influence on the involving of patients in clinical decision making, as it also unveiled some of the implications thereof. It modified the roles of patients to include more active elements such as assisting health care professionals in determining which health problems, interventions and outcomes are to be regarded as priorities and what the impact of research evidence could be on individual preferences (Entwistle & O'Donnell 2002:37).

This greater involvement of patients in clinical decision making however also inevitably involved them in an environment characterised by an overload of highly technical information (Entwistle & O'Donnell 2002:46). It soon became clear that patients' everyday lives differed considerably from the professional world of health care and that much of the information provided and shared with patients was not designed to support them in decision making and did not meet patients' own information needs. In similar vein, ill health itself tended to be viewed from different angles by patients and health care professionals - by the former as a personal experience depicted as illness and by the latter as a biological or psychobiological process called disease (Coulter et al. 1998:35).

The tensions created by the different worlds in which health care professionals and patients find themselves and the ways in which the constitution of meaning in illness is endangered in clinical practice are nowhere more obvious than in epidemiology. Epidemiology makes statistical estimates of disease in human populations and is aimed at identifying risk factors. Being based on aggregate data, the limitations of the epidemiological method are well understood by epidemiologists, with terms like predict and cause in principle being avoided (Bellaby 2002:80).

However, risks are not only assessed for the sake of knowledge, but also for the benefit of health and health care practice therefore also applies epidemiological knowledge in an effort to control disease in individuals. In the process it relies on aggregate data and employs these as guidelines

⁸⁷ To these belong (1) the asking of the right questions, (2) the finding of the relevant evidence, (3) the appraising of the evidence to select the best options, (4) decision making based on the evidence and (5) the storing of the evidence for future use.

to enable rational decisions on diagnosis and therapy. Risk estimates thus project from the known past into an uncertain future and in so doing conjecture that all parameters are known and that none will change. The dilemma with estimates of this nature is that each reflects a mean of a range of individual values which in principle could be narrowed down to smaller groups, but in practice will result in groups that will be too small to provide probabilities of any value at an individual level. While science and its applications traditionally represented the essence of modernity and have been dedicated to the identification and removal of the risks attached to humanity, mistrust in the ability of science to achieve this goal gradually emerged, as science now appeared to have become a major risk in its own right (Edwards et al. 1997:739-742).

Reference has earlier been made to the fact that risk can be regarded as the product of the financial or human cost of a hazard and the likelihood of people or property being exposed to the hazard and that neither the hazard, nor its probability is thus completely independent of social relations, since in human populations, the magnitude of a hazard is directly linked to the proportion of the population exposed to the hazard. The assessing of a risk is linked to practical action aimed at obtaining benefits for self and others. Medical science deals with aggregate data, but health care professionals have to apply these data in individual cases and make judgements that involve risks for individual patients. Risks are therefore never encountered on its own and never only involve an assessment of facts, but always also of values and rules of conduct. Thus, what health care professionals may regard as a risk from a medical point of view, may be regarded as a threat to personal values from another point of view (Shakespeare 1998:665-681). Judgements on risk therefore always represent a moral category and for this reason remain likely to be contested by parties with different values and interests (Bellaby 2002:81).⁸⁸

While in modern times relatively few natural threats still appear unpredictable and beyond control, many other risks arose such as the unintended consequences of individual actions. Reference has in 2.3 been made to the emergence in the late twentieth century of a society in which risk has increasingly become the focus of attention and the amount of literature on risk-related topics has risen exponentially. In this risk society, it was explained, fields like economics, the environment, domestic life, litigation and in particular medicine and health care have to a large extent all come to be interpreted in terms of attached risks. In medicine and health care alone, this is evident in an ever accumulating volume of literature on the issue of risk covering aspects as diverse as the perception, assessment and management of risk.

⁸⁸ See also Furedi 1997:45-60.

The fact that the consequences of individual actions became less predictable and controllable, also almost inevitably effectuated an escalation in the social interactions between parties involved. The phenomenon of globalisation multiplied these abstractions and caused a situation in which the risks of late modernity ceased to be local and under control and have become distant in source and remote in control. While there have been many attempts to order these somehow anarchic human chains of cause and effect, risks in late modernity have thus become the results of far reaching changes in social relations (Beck 1992).⁸⁹

The society that has emerged from modernity can therefore be characterised as fragmented rather than individualistic. Divisions in society have been accentuated and left both health care professionals and patients vulnerable to risks that have become remote and out of control. According to Bellaby, it is therefore not surprising that the concept of patient choice is emphasised in this climate or that it should coincide with a hierarchical approach to health care that bases practice on scientific knowledge. He however warns that this combination is unstable and that patients are less likely to understand and accept treatments grounded in evidence without the trust in a doctor that was typical of paternalism. Moreover, other health care professionals are now also more likely to contest the authority of medical knowledge and to bargain for their own claims of truth. The general public is thus more likely to perceive itself as vulnerable to threats which health care professionals may regard as spurious and although well informed, may choose treatments which evidence-based practice regard as ineffective and unnecessary. What therefore needs to be recovered is the sense that risks are localised rather than remote and can be co-operatively controlled by knowledge that all people value (Bellaby 2002:91). Risk has almost become an obsession in modern society and ways therefore have to be found of accommodating it rather than eliminating it, since risk is as much a social construct as it is a reality (Bellaby 2002:92).

Risk communication has thus been shown to be effective in terms of influencing consumer knowledge, anxiety, patient satisfaction, and certainty about making the best choices and adherence to treatments and other behavioural changes. However, while there seem to be small beneficial effects in clinical settings and also some inconsistency in evidence about the efficiency of risk communication in general, it proved to be most effective when using individually calculated risk estimates and in the contexts of patients making choices about treatment, rather than in screening or behavioural risk modification programmes. The practice of

⁸⁹ Refer in this regard also to Crozier who states that formal organisations such as hospitals, business firms, the welfare state and even the United Nations all aim to coordinate the different identities assumed by human actors and to minimise uncertainty (Crozier 1964).

risk communication also increasingly utilises specific packages containing information and approaches designed to facilitate discussion of reactions to the information and consumer values of different outcomes. These, however, need to be flexible enough to meet the needs of the individual patient, as well as the health care professional in need of different strategies to address the demands of the individual patient (Edwards & Bastian 2002:157).⁹⁰

The current state of risk communication in the practice of evidence-based patient choice can therefore not be regarded as completely adequate in honouring the ethical principle of respect for autonomy and in establishing and maintaining disclosure to patients in clinical decision making. Moreover and due to the complexity of the concept of risk itself, the practice of risk communication therefore still leaves evidence-based patient choice with the challenge of the constitution of meaning in illness.

4.3 THE UNDERSTANDING OF MATERIAL INFORMATION AND DECISION ANALYSIS

Employing the principle that persons understand if they have acquired pertinent information and have justified and relevant beliefs about the nature and consequences of their actions (Beauchamp & Childress 2001:88), this paragraph would like to inquire to what extent patients' understanding is facilitated by decision analysis as a third key skill of the evidence-based patient choice model.

Adherence to the four principle steps towards decision analysis required from health care professionals in evidence-based patient choice should once again at first glance suffice in honouring the principle of respect for autonomy and in establishing and maintaining adequate understanding of information by patients in clinical decision making. However, evidence suggests that despite the apparent advantages of the key skill of decision analysis in creating veracity and objectivity, some fundamental concerns arise when its principles are analysed in depth (Elwyn et al. 2002:167-172).

A first issue concerns the availability and accuracy of relevant data in the practice of decision analysis (Elwyn et al. 2002:167). It is pointed out by Walsh that even when apparently valid outcome information exists, it can be extremely difficult to populate decision trees with probability data, as outcome data from systematic reviews often derive from highly selected samples and therefore may not accurately reflect individual patient risk. In performing a decision analysis, a so-called sensitivity analysis is therefore included in the procedure which

⁹⁰ See also Holmes-Rovner et al. 1999:270-284.

repeats the calculation of the entire range of available data. While this notion may be difficult to convey to patients, it however can suggest further areas of research (Walsh 1993:1330-1332).

A further dilemma in this regard is that the quantification of probability, expressed as a percentage, is normally inserted into a decision tree as if representative of a mechanical factor. While patients' attitudes towards risk is according to Detsky et al. usually not explicitly sought, the determination of utility by standard gambling techniques may put patients at some risk, as it will assume that all people approach risk in the same manner (Detsky et al. 1997:123-159).

As argued by Vlek, this assumption is not tenable due to the fact that there may be important factors affecting a person's response to a perceived risk, such as the potential lethality, its controllability by safety measures, the number of people simultaneously exposed, personal familiarity with the side effects of the treatment and the degree of voluntariness of risk exposure (Vlek 1987:171-207). Elwyn et al. raise an even more fundamental concern by noting that people may simply not be able to assess utilities that are divorced from their probabilities, as these two components in the evaluation of risk is inextricably connected.

Another concern arising when analysing the principles of decision analysis in depth relates to problems of standardisation and the choosing of outcomes (Elwyn et al. 2002:168). Patient values or utilities in decision analysis are normally quantified in terms of strengths of preference towards outcomes as the possible consequences of choices. However, not all values can be elicited in terms of consequences and this is especially evident in the case of moral values. While biomedical outcomes are usually included in decision analysis, the more complex issues in decision making may not even feature when the relevant outcomes of decisions are defined too narrowly. According to Fitzpatrick et al., the options and outcomes portrayed in decision analysis frequently fail to reflect patients' personal concerns or the effect of the context and a standardised decision tree may therefore distort patients' decision making by not only limiting the available considerations, but by also manipulating it (Fitzpatrick et al. 1992:1074-1077).

Describing the outcomes is another concern that arises when the principles of decision analysis are analysed in detail (Elwyn et al. 2002:168). Once the relevant outcomes have been identified, the next important step in decision analysis is to define and describe the possible outcomes to enable patients to align their values to them. In practical terms and especially for research purposes, the standardisation of outcomes descriptions is therefore unavoidable, as outcomes are often portrayed by standardised vignettes which describe the possible health states the patient might experience. However, closer examination indicates that it is a daunting task prone to subjective bias. Choices have to be made, such as who to interview, what medium of language

to use and what level of the description to use and judgements are required at each stage of deciding. The variation in outcome descriptions therefore also raises issues concerning amongst others the objectives and interests of professionals and patients involved in the analysis (Wennberg et al. 1993:52-62).

Furthermore, also the measurement of utilities by numbers arises as a concern regarding the principles of decision analysis, as the quantification of patient utilities involves the assignment of cardinal numerical values in terms of natural numbers, such as 1, 2, 3 etc. (Elwyn et al. 2002:170). While patient utility is normally measured in terms of preference strengths and these are used to express individuals' evaluation of an outcome in terms of their moral and personal values, ordinal values, such as 1st, 5th and 10th etc. can be utilised to rank these preferences. Assessing utilities however require cardinal values which raises the question whether cardinal values indeed represent preference strengths?

In order to arrive at the multidimensional and complex prospect of a utility for a future health state, people have to weigh up the different dimensions of an outcome which is usually expressed as a value between 0 and 1.0, with 0 representing death and 1.0 perfect health. While these represent cardinal measurements, a lot of human options are weighed up without using cardinal measurements and trade-off techniques to ascribe numerical units to preferences can also be regarded as attempts to rationalise a more intuitive approach to choice.

In addition to the difficulties attached to the measurement of utilities by numbers, the heterogeneity of clinical conditions also raises concerns in the practice of decision analysis (Elwyn et al. 2002:170). Although complex and potentially of great value, decision trees remain fragile constructions and are most valuable in environments where probabilities are quantifiable.⁹¹ However, while decision analysis can be most helpful in clinical situations where legitimate treatment choices have to be made, clinical decisions are seldom typical and this could imply that although a decision tree might be developed for a specific scenario, it is unlikely to accommodate the heterogeneity of the clinical situation. For this reason, decision trees have proved more valuable in settings with limited variability, such as in secondary care. As Rosenberg points out, there is a degree of uniformity among patients attending a clinic in secondary care which makes it more feasible to construct decision trees accommodating a more limited variability in these patients (Rosenberg 2002:191-193).

The declared goal of decision analysis to value patients' views and involve them in clinical decision making however also raises some ethical concerns (Elwyn et al. 2002:171). Reference

⁹¹ A typical environment would be economics, where decision trees originated in the first place.

has already been made to the work of De Haes and Molenaar indicating that an increase in patient autonomy may not automatically lead to beneficence and may cause ethical conflicts to arise. This results from the fact that clinical decision analysis is based upon population data and the utilitarian principle of the greatest good for the greatest amount of people and is therefore not intended for individual application. The claimed enhanced autonomy may therefore be an illusion, particularly if the analysis is not performed to the highest level of rigour and may even undermine patient autonomy by influencing and restricting decisions due to the description of a too narrow range of outcomes or even by the way in which it is described (De Haes & Molenaar 1997:353-354).

According to Haynes et al., also the attitudes of clinicians are a serious source of concern in the practice of decision analysis (Elwyn et al. 2002:171). As indicated in an Editorial from the *Evidence-based Medicine Journal*, examples of decision analysis being routinely incorporated in clinical practice are scarce, though it is still not clear whether it simply has to be attributed to a lack of practical application or whether it reflects more fundamental concerns by health care professionals. As argued by Katz, doctors appear weary of exploring the inherent uncertainties of decision making in clinical practice (Katz 1988), but there may be other conceptual and ethical concerns about the claimed benefits of rational decision making (Haynes et al. 1996:196-198).⁹²

Though little has been published about the acceptability of the use of decision analysis to patients, it is argued by Guadagnoli and Ward that while factors such as age, educational levels and social class have been reported to have a significant effect on preferences for participation in clinical decision making, it is most likely that these factors could become more prominent once decision analysis is introduced into consultations (Elwyn et al. 2002:172). Moreover, due to the importance of the placing values on preferences and on the evaluation of complex decisions, there seems to be a real risk that the practice of decision analysis may be beyond the abilities of some patients and that once fully introduced in medical practice, may accentuate inequalities in health care (Guadagnoli & Ward 1998:329-339).⁹³

Finally, also the shortage of time in consultations is regarded as a source of concern in the practice of decision analysis (Elwyn et al. 2002:172). There is evidence that even a marginal increase in general practice consultation time has a positive effect on patient participation and even the ability to cope with an illness (Howie et al. 1998:165-171). However, with the current length of primary care consultations at around six minutes in the United Kingdom, it remains an

⁹² See also Edwards et al. 1998:296-300.

⁹³ Refer in this regard also Eysenbach and Jadad 2002:292-295.

open question whether the practice of decision analysis might benefit from extended consultation times?

It was indicated earlier that this paragraph would like to inquire to what extent patients' understanding, understood as having acquired pertinent information and having justified and relevant beliefs about the nature and consequences of their actions, is facilitated by decision analysis as a third key skill of the evidence-based patient choice model. According to Kassirer, decision analysis may be especially helpful in clinical situations when

- there are major differences in possible outcomes;
- there are major differences between treatments regarding the likelihood and impact of complications;
- choices involve a trade-off between short and long term outcomes;
- one of the choices can result in a small chance of a grave outcome;
- the apparent difference between options is marginal
- a patient is particularly averse to taking risks;
- a patient attaches unusual importance to certain possible outcomes (Kassirer 1994:1895-1896).

However, other researchers are more cautious for a variety of reasons (Elwyn et al. 2002:173). While Dowie suggests that the acceptability of decision analysis should first be cleared with patients (Dowie 1996:104-113) and Jungermann and Schutz warn that little research has been done to compare the quality of patients' decisions reached through decision analysis with those arrived at in normal practice (Jungermann & Schutz 1992:185-200), Ubel and Loewenstein note that decision making based on discussion is to be preferred to that based on numbers (Ubel & Loewenstein 1997:647-656).

In view of the preceding discussion and with O'Connor defining effective decisions as informed, consistent with personal values and acted upon (Elwyn et al. 2002:174)⁹⁴, it has to be concluded that the current state of decision analysis in the practice of evidence-based patient choice can not be regarded as completely adequate in honouring the ethical principle of respect for autonomy and in establishing and maintaining patients' understanding in clinical decision making. Moreover and due to the complexity of the analyses, the practice of decision analysis therefore

⁹⁴ See also O'Connor 1995:25-30.

still leaves evidence-based patient choice with the challenge of persisting abstractions in health care.

4.4 VOLUNTARINESS AND THE USE OF DECISION AIDS

Interpreting voluntariness such that a person acts voluntarily to the degree that he or she wills an action without being under the control of another individual's or some form of debilitating influence (Beauchamp & Childress 2001:93), this paragraph evaluates the extent to which the use of decision aids as a fourth key skill of evidence-based patient choice model succeeds in protecting patients against the influence of approaches such as paternalism.

Adherence to the four objectives in designing and utilising decision aids in evidence-based patient choice should once again at first glance suffice in honouring the principle of respect for autonomy and in establishing and maintaining adequate understanding of information by patients in clinical decision making. However, evidence suggests that despite the apparent advantages of decision aids, the protection of patients against informational manipulation and the meeting of the needs of the individual patient with a package developed for many remain a challenge.

Research has indicated that decision aids generally improve clinical decision making by:

- reducing the number of patients that are uncertain about what to do;
- increasing patients' knowledge of problems, options and outcomes;
- improving the match between choices and patient's values;
- reducing decisional conflict due to uncertainty, as well as the factors contributing to decisional conflict, such as feeling ill informed, unclear about values and unsupported in decision making and
- increasing participation in decision making without adversely affecting anxiety (O'Connor et al. 1999b).⁹⁵

However, according to O'Connor and Edwards, the evidence regarding the effects of decision aids on altering choices are less clear. Reasons for this lack of evidence are diverse, but include factors such as trials that have generally been underpowered, options that may have been under or over used and research that did not take variations in patients' responses into consideration.

⁹⁵ Refer also to O'Connor et al. 1999c:731-734; Molenaar et al. 2000:112-127. In this regard it is also argued by Clark et al. that the retention of information is only improved if the aid is used in conjunction with an interview (Clark et al. 1991:11-13).

Moreover, it was noted that patients generally became more cautious of suggested treatments and tended to opt for more conservative choices when provided with information and allowed the opportunity for involvement in especially major surgical decisions. In this regard and of particular importance for this study, research indicated that patients were on average 26% less likely to choose treatment in studies where information was provided and choices were offered (O'Connor & Edwards 2002:226).

More research is therefore needed for the development of decision aids and to determine which aids work best with which decisions and with which patients. In addition, the acceptability of decision aids to health care professionals and diverse groups and cultures, their impact on patient-professional communication and their effects on adherence to choices, health related quality of life, variation in practices and the use of resources also need to be evaluated.

There also remain questions about the composition of decision aids. Since decision aids have been fairly beneficial in normal practice, it has been noted that the difference between simpler and more detailed aids have often been quite marginal. However, while the simpler methods tended to result in similar effects in patients' knowledge and satisfaction and more intensive methods proved superior in terms of user acceptability, the clinical importance of these differences and the cost effectiveness of decision aids still need to be established. Up till now, most decision aids have made use of population data integrated into individualised counselling packages (Lerman et al. 1997:148-157), but in view of the fact that individually calculated risk information, compared to average or population data, has got the greatest influence on outcomes, more research is needed as to how this can be implemented in practice (O'Connor & Edwards 2002:227).⁹⁶ In this regard, O'Connor and Edwards therefore conclude: "The indications are that the implementation of decision aids in routine practice (away from the realms of the enthusiasts) is perhaps limited. Whilst some of the reasons for this are generic to the transfer of any research into practice, some more specific issues are also relevant. Developers of decision aids must continue to refine their methods and content. Meeting the needs of the individual patient with a package developed for many remains a challenge. However, if these needs continue to be addressed in the developing of future aids then there is great potential for the benefits currently shown in research to be available to patients across a wide range of settings and for a variety of health care choices. Decisions aids build on the conceptual frameworks of shared decision making and seek to implement effective risk

⁹⁶ Refer in this regard also to Edwards et al. 2000:290-297.

communication and values clarification. As such they offer a very practical way in which evidence-based patient choice can be facilitated" (O'Connor & Edwards 2002:238).

It can therefore be concluded that also the current state of the use of decision aids in the practice of evidence-based patient choice cannot be regarded as completely adequate in honouring the ethical principle of respect for autonomy and in establishing and maintaining patients' voluntariness in clinical decision making. Moreover and due to the indefinite and open-ended nature of the information provided by decision aids, the practice of the use of decision aids therefore still leaves evidence-based patient choice with the challenge of possible informational manipulation in health care.

SUMMARY AND CONCLUSIONS

This chapter was aimed at critically evaluating evidence-based patient choice as partnership model in clinical decision making by judging it in terms of the ethical principle of patient autonomy as reflected in the informed consent elements of competence, disclosure, understanding and voluntariness.

It was indicated that, judged in terms of these elements and due to a wide variety of reasons, none of the key skills of evidence-based patient choice can be regarded as completely adequate in honouring the principle of respect for autonomy in clinical decision making and that huge gaps still exist between the ideal and current practices of evidence-based patient choice. It was argued that the current state of shared decision making can due to a lack of proper and personal communication not be regarded as completely adequate in the establishment and maintenance of competence in clinical decision making and therefore leaves evidence-based patient choice with the challenge of the separate worlds of doctor and patient. Similarly, it was argued that also the current state of risk communication can as a result of the complexity of the concept of risk itself and the challenges attached to its application in medical practice, not be regarded as completely adequate in the establishment and maintenance of disclosure to patients in clinical decision making and still leaves evidence-based patient choice with the challenge of the constitution of meaning in illness. Moreover, it was indicated that the current state of the use of decision analysis in the practice of evidence-based patient choice can due to the complexity attached to analyses as such not be regarded as completely adequate in honouring the ethical principle of respect for autonomy and therefore also still leaves evidence-based patient choice with the challenge of abstractions in health care. In conclusion, it was shown that also the current state of the use of decision aids in the practice of evidence-based patient choice can due to the indefinite and open-ended nature of the information provided by decision aids not be regarded as

completely adequate in the establishment and maintenance of patients' voluntariness in clinical decision making and therefore still leaves evidence-based patient choice with the challenge of possible informational manipulation in health care.

These findings have also recently been emphasised by the Quality Enhancing Interventions (QEI) Review of patient-focused interventions regarding the improving of clinical decision making (Coulter & Ellins 2006:57).

This review indicates that while most patients expect to be given information concerning their condition and treatment options and moreover expect of clinicians to take their preferences into account, some seek to be actively engaged in the decision making process or even demand to take the decisions themselves. The desire to participate in the making of clinical decisions has however been found to differ according to age, educational status, the severity of the disease, cultural and ethnic matters and the preferred role of patients and thereby emphasised the importance of deliberation in clinical decision making.

The review however also indicates that proper shared decision making is not widely practiced and that doctors not only often neglect the exploration of patients' values and preferences, but also fail to adequately communicate risks to patients. The review therefore hints that training in communication skills should be the main mechanism through which health care professionals gain competencies in not only the principles, but also the practice of shared decision making.

Moreover, the review suggests the coaching of patients in communication skills, as well as the increased utilisation of decision aids, but then concludes: "In spite of policy commitments and evidence of benefit, initiatives to promote shared decision making, better risk communication and fully informed decision making have not been widely implemented. Well planned strategies are required which should include training for clinicians and high quality evidence-based decision aids for patients" (Coulter & Ellins 2006:57).

With regard to the aim of the study, namely to determine an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, it has to be concluded that although these key skills are aimed at enhancing patient autonomy, a mere recognition of this ethical principle simply remains inadequate. As observed in 1.1, the notion of "evidence-based patient choice" simply refers to the moral requirement that patients' treatment choices be based on adequate evidence that a certain line of treatment will be the most efficacious in the particular situation of the relevant patient. The issue therefore also is not simply that of a desirable choice in general, but a choice that is individualised for a particular patient in his/her particular circumstances. However, whereas

these key skills are intended to contribute to the individualisation of the provision of information, they predominantly are of an objective and technical nature and are therefore all deprived of a proper embeddedness in the human processes of sense making, knowledge creating and decision making without which it according to information science remains impossible to tap into the real value of information resources and technologies. Thus, in recognition of the fact that the individualisation of information requires the provision thereof in a manner that will facilitate patients' ability to make decisions about their health care and consequently also their autonomy in a sincere and credible way, a new approach to this challenging aspect of medical practice is needed. As anticipated in the second and third chapters and will be argued in the final chapter, such an approach will have to do justice to the fact that the concept of partnership in clinical decision making emerged in the context of the ethical principle of respect for patient autonomy and therefore has to be embedded in and developed within this particular context. Moreover, it will be required to address the matter of the individualisation of the provision of information in full recognition of the complexities attached to the contemporary understanding of the concept of personal identity and to the application of the ethical principle of respect for autonomy in medical practice. Whereas the contribution of the key skills of evidence-based patient choice to the provision of information in clinical decision making cannot be denied, it has to be recognised in any endeavour of this nature that it remains impossible to tap into the real value of information resources and technologies without a clear understanding and implementation of the human processes through which information is transformed into insight, knowledge and action. Whereas evidence-based patient choice is regarded as pointing the way to a potential future scenario of health care in which patients and professionals will operate as real partners, have shared goals and will make shared decisions on the best management of health care problems, it will be argued in the final chapter that this goal is to be achieved through the utilisation of the therapeutic value of information.

PART II

The Transformation of Evidence-Based Patient Choice to a Therapeutic Alliance in Health Care

INTRODUCTION

In view of the critical analysis of evidence-based patient choice conducted in Part I and drawing on its conclusions, Part II of the study is devoted to a further exploration of an adequate approach to the individualisation of the provision of information in health care and to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

In Part I it was concluded that whereas the concept of partnership in clinical decision making arose within the context of the development of patient autonomy, it needs to be addressed and further developed within this context and that a thorough and adequate understanding of the ethical principle of respect for patient autonomy as represented in the informed consent elements of competence, disclosure, understanding and voluntariness is therefore essential in the development of any new concept of patient-centred care. It was also noted that although evidence-based patient choice is claimed to not only ultimately rest on the two ethical principles of patient autonomy and patient benefit, but to also establish and enhance these principles, the practice of this partnership model remains deprived of a proper embeddedness in the context of the ethical principle of respect for patient autonomy. Moreover, it was argued that individualism has due to a variety of political and economical factors become institutionalised, goes hand in hand with pressures towards a greater democratisation of society and has therefore become non negotiable. This fact has at the end of the twentieth century also brought about a new phase in the development of the medical profession with the introduction of the concepts of third party mediation and accountability through which doctors now became managed, appraised, investigated and directed by guidelines with their personal basis of expertise undermined by the World Wide Web as a ubiquitous source of information. Moreover, the credibility of medical practice was seriously undermined by studies of clinical practice and service delivery which indicated that the variation in the rate at which a service is provided or an intervention is used, is frequently far greater than can be explained by a variation in the incidence or prevalence of

disease. It also noted that it came as a shock to patients that the available clinical information was commonly not even employed by clinicians, or was often deficient. It was also argued that although evidence-based patient choice is aimed at providing patients with evidence-based information in a way that facilitates their ability to make choices and decisions about their health care and this emphasis on patient choice is justified by three ethically inspired reasons, the practice of the provision of information remains deprived of a proper embeddedness in the context of the ethical principle of respect for patient autonomy. Personal communication is also still to be regarded as a major challenge in the provision of information with the latter largely regarded as the responsibility of the health care professional and predominantly conducted in an objective and technical manner. This implies, it was argued that the practice of evidence-based patient choice therefore remains deprived of a proper embeddedness in a clear understanding of the human processes through which information is used to construct meaning, create knowledge and make decisions. It was therefore also concluded that evidence-based patient choice is still faced by the challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and abstractions and informational manipulation in health care.

Drawing on these conclusions, Part II makes three recommendations to further explore the individualisation of the provision of information in health care and the involvement of patients in clinical decision making, namely to review and further develop the philosophical foundations of evidence-based patient choice, to consider continental philosophical perspectives on the challenges posed to evidence-based patient choice and to establish a practice in information therapy according to a broadened understanding of the generic concept of information therapy.

In this exploration it will be argued that a mere recognition of the importance of information and the provision thereof through predominantly technical means is inadequate and that the provision of information needs to be embedded in a clear understanding of the human processes through which information is used to construct meaning, create knowledge and make decisions and to transform information into insight, knowledge and action.

Furthermore, it will be argued that the employment of the therapeutic value of information will not only thoroughly individualise health care and consequently provide an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, but will also pave the way for a reconciliation of the opposing perspectives of patients and health care professionals in a therapeutic alliance against the common challenge of suffering in health care.

CHAPTER 5

FIRST RECOMMENDATION - TO REVIEW AND FURTHER DEVELOP THE PHILOSOPHICAL FOUNDATIONS OF EVIDENCE-BASED PATIENT CHOICE

INTRODUCTION

As a first recommendation for the transformation of evidence-based patient choice to a therapeutic alliance in health care, this chapter reviews and further develops the philosophical foundations of evidence-based patient choice. It is clear from the literature that, despite all the research conducted on evidence-based patient choice over the past two decades; such a review has never been undertaken. However, as will be evident from the following discussion, it is most rewarding, especially with regard to the illuminating of a particular aspect of the all important element of individualisation of the provision of information in health care in the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

The chapter traces the thought of John Locke that initiated the empirical tradition and indicates that the legacy of his distinction between the primary and secondary qualities of knowledge is still perceptible in not only the ontological and methodological assumptions of the natural science paradigm, but also in the formation of the clinical method. Similarly, it outlines the thought of Søren Kierkegaard who, with his emphasis on respect for the spirit, the whole person and the rights to individual self determination, argued for decision making as the most important human activity and also indicates that the traces of his thought are still to be found in not only the principles of patient-centred medicine and in clinical training, but also in the practice of evidence-based patient choice.

In addition, the chapter indicates that although the philosophical thought of John Locke and Søren Kierkegaard seem widely divergent, the concept of personal identity seems to have interested both and continues to analyse this shared interest in terms of an investigation of a significant feature of many contemporary Neo-Lockean discussions of the concept of personal identity.

With regard to this feature, namely the perceived dichotomy between the self understood as a human being with its various forms of physical, psychological and social continuity and history

and the self understood as the present locus of psychological experience, the chapter concludes that the threat of the bifurcation of self and person encountered in the thought of John Locke and Søren Kierkegaard is however not only a matter of academic interest, but is also perceptible in medicine in general and in the complexity of the contemporary understanding of personal identity in the practice of clinical decision making in particular.

5.1 JOHN LOCKE - INITIATOR OF THE EMPIRICAL TRADITION

In the sixteenth and seventeenth centuries, Western Europe experienced a change in world view of momentous proportions. The cosmology of Copernicus, the discovery and colonisation of up to then far away continents and the rise of Protestantism all contributed to the collapse of the Medieval world order and laid the foundation of modern science (McWhinney 1995:1). Whitehead described this new scientific order as a conjunction of on the one hand an interest in detailed facts and on the other a devotion to abstraction and generalization that gave European science its unique character (Whitehead 1985:3).

However, this devotion to abstraction and generalization of modern science has already been foreshadowed by medieval thought which Whitehead described as "one long training of the intellect of Western Europe in the sense of order ... an epoch of orderly thought, rationalist through and through" (Whitehead 1985:14). It was this sense of natural and moral order that became essential for the development of modern science, as it would have been fruitless to research the natural laws without a belief in the order of nature. The greatest contribution of the medieval world to the formation of modern science was therefore "the belief that every detailed occurrence can be correlated with its antecedents in a perfectly definite manner exemplifying general principles" (Whitehead 1985:15). This combined instinctive faith in rationality and interest in the simple occurrences of life was already discernable in early Benedictine life that was both spiritual and practical and thus paved the way for the alliance of science with technology by which learning was kept in contact with the "irreducible and stubborn facts" (Whitehead 1985:19).

The shared faith of the medieval church and science in reason and the orderliness of nature however did not prevent conflicts over the facts. While Galileo was interested in the way things happen, the church provided metaphysical explanations about why things happen, but in the process ignored the irreducible and stubborn facts of reality that was revealed by inventions such as the mechanical clock, telescope and compass and together with the generalizations behind them, led to the advent of modern science in the sixteenth and seventeenth centuries (Whitehead 1985:3). This era not only produced the towering figures of Galileo Galilei and

Isaac Newton, but also of René Descartes, Francis Bacon and John Locke who all contributed to the agenda of the Enlightenment, and laid the foundations of a completely new approach to scientific knowledge.

It was this interest in detailed facts, together with a devotion to abstraction and generalization that would structure the scientific thought of the sixteenth, seventeenth and eighteenth centuries in a decisive way. It provided science with an astoundingly efficient system of concepts for the organization of scientific research which has since become the guiding principle of scientific studies in the world. It furthermore established mathematics as the foundation of scientific thought with Descartes, Desargues and Pascal initiating the modern period in geometry and Fermat laying the foundations of modern analysis and all but perfected the methods of the differential calculus. This foundation not only enabled Newton and Leibniz to refine the differential calculus as a practical method for mathematical reasoning and as an effective instrument for application to all physical problems, but also enabled the appearance of the mathematical physicist who was to become the ruling mind in the scientific world of the eighteenth century.

The seventeenth century thus finally produced a scheme of scientific thought framed by mathematicians for the use of mathematicians and which had the capacity for dealing with abstractions and for eliciting clear cut demonstrative trains of reasoning from these abstractions (Whitehead 1985:70). According to Whitehead, the advantage of confining attention to a definite group of abstractions is that it confines your thoughts to clear cut definite things with clear cut definite relations. It provides you with a logical approach by which a variety of conclusions can be deduced from these abstractions and by which a variety of truths about nature can eventually be established. However, the disadvantage of exclusive attention to abstractions is that by the nature thereof, abstractions are obtained by means of selection. While it is impossible to think without abstractions, it remains of the utmost importance to critically revise your abstractions, as they might not be fit to deal with excluded elements that may be of importance in your experience. It is in this regard that philosophy has an important role in the health of societies, namely in criticizing abstractions and in liberating societies from the doom of sterility effectuated by abstractions (Whitehead 1985:73).

However, the enormous success of these scientific abstractions, yielding on the one hand matter with its location in space and time and on the other the mind with its functions of reasoning and perceiving, but not interfering, has according to Whitehead foisted onto philosophy the task of accepting them as the most concrete rendering of fact and has eventually led to the ruining of

modern philosophy: "Thereby, modern philosophy has been ruined. It has oscillated in a complex manner between three extremes. There are the dualists, who accept matter and mind as on equal basis, and the two varieties of monists, those who put mind inside matter, and those who put matter inside mind. But this juggling with abstractions can never overcome the inherent confusion introduced by the ascription of misplaced concreteness to the scientific scheme of the seventeenth century" (Whitehead 1985:70).

This new approach to scientific knowledge also had implications for medical science, with amongst others Bacon urging mankind to dominate and control nature, and in his *Advancement of Learning* providing a revival of the Hippocratic method of recording case descriptions with their course towards recovery or death, as well as a study of the pathological changes in organs with a comparison between these and the manifestations of illness during life (Faber 1923:5-6).

The intellectual climate of the 1600s also produced the first modern physician to use systematic bedside observations, namely Thomas Sydenham. Sydenham was a close friend of John Locke, also a physician, who took a great interest in his observations and sometimes accompanied him on visits to patients. Sydenham started describing the symptoms and courses of diseases without reference to speculative hypotheses based on unsupported theories and for the first time classified diseases into categories, believing that they could be classified by description in the same way as botanical specimens, and that once classified, remedies for the different 'species of diseases' could be determined. His great innovation, however, was to correlate his disease categories with their cause and outcome, thus giving them predictive value and making the prediction of syndromes like acute gout and chorea possible (McWhinney 1995:3).

Sydenham died in 1689 and although his work on classifying diseases was taken up by others like Sauvages of Montpellier and the Swedish physician Carl von Linné, it was of little practical value as the classifications were not correlated with the course and outcome of diseases and represented only random combinations of symptoms. However, the next great step and one that was to lay the foundations of the modern clinical method, was taken by French clinician-pathologists in the years immediately following the French Revolution. The Enlightenment ideas that brought about the political turmoil of the period, also found an application in the new clinical method described by Laennec, the greatest genius of the French school:

"The constant goal of my studies and research has been the solution of the following three problems:

1. To describe disease in the cadaver according to the altered states of the organs.
2. To recognize in the living body definite physical signs, as much as possible independent of the symptoms ...
3. To fight the disease by means which experience has shown to be effective ... to place, through the process of diagnosis, internal organic lesions on the same basis as surgical disease" (Faber 1923:35).

Clinicians could now for the first time examine their patients by using new instruments such as the Laennec stethoscope and combine two sets of data, namely signs and symptoms from the clinical data and the descriptive data of morbid anatomy. This provided medicine with a classification system based on the natural order of things and reflecting a correlation between symptoms, signs and the appearance of the organs and tissues after death. The system also proved to be of great predictive value and was further vindicated by clinical giants like Pasteur and Koch who for the first time pointed out that some of these entities had specific causal agents.

This classification system provided the foundation of the new clinical method which gradually developed during the nineteenth century and also became associated with a change in the perception of disease (Dubos 1980). Western medicine has since classical times used the ontological and physiological or ecological models of illness, which respectively viewed disease as an entity located in the body of the patient and therefore conceptually separable from the sick person or as the result of an imbalance within the organism and between the organism and its environment. In turn, these models became associated with two clinical methods: the ontological with the conventional and the physiological with the natural clinical method (McWhinney 1995:5).⁹⁷

However, the success of the new clinical method in the late 1800s soon resulted in the dominance of the ontological model. True to its origins in the Enlightenment, the new clinical method was analytic and impersonal with the feelings and experiences of the patient left aside. Whereas the term diagnosis formerly referred to the diagnosis of a patient, the objective of a diagnosis now became the identification of a disease. Diseases were now regarded as located in bodies and the categorization thereof as abstractions, which for the sake of generalization, omitted many features of being ill, such as the subjective experience of the patient. These developments furthermore resulted in physical and mental illnesses being classified separately, the distinguishing of somatic and psychotherapies and in the physician increasingly being

⁹⁷ See also Crookshank 1926:934-942.

viewed as a detached and impassive observer, utilizing the predictive and inferential power of the new clinical method to identify the patient's disease or rule out organic pathology. This dichotomy between the physical and the mental eventually also manifested itself in the organization of the profession with distinctions for instance being made between internal medicine and psychiatry and eventually also between different types of wards in medical institutions (Kriel 2000:22-27).

The central idea on which the modern clinical method was based came into being at a time when Enlightenment ideas had become the dominant worldview of the West. The human being had become the measure of all things, metaphysics was devaluated, tradition was weakened, progress was proclaimed, and knowledge was put to practical use for the benefit of mankind. Reason was enthroned, but it was a reason defined as formal logic and divorced from human experience. These developments not only resulted in moral relativism and a severance of culture from its traditions, but also led to a completely new paradigm of knowledge. Knowledge now became instrumental, defined and valued as a means to certain ends, but also impersonal, public, productive and empirically verified with personal, tacit, experiential and intuitive knowledge hardly recognized as knowledge anymore. According to McWhinney, these ideas can be traced back to John Locke who was a physician himself and is generally regarded as the father of empiricism and as the philosopher who laid the foundations for the features of the modern world (McWhinney 1995:3-7).

John Locke made huge contributions in two different areas of philosophy, namely in theory of knowledge and in political philosophy (Clapp 1996:489-498). In the former, he launched what is still regarded as his most important project, namely an inquiry into the limits of what might be intelligible to human beings. Up till then, people assumed that the limits of what could be known were set by the limits of what there is. However, Locke secularised these views and took it an important step further, namely to analyse man's own mental faculties and to, regardless of what happens to exist externally, determine what they are or are not capable of. For this reason, Locke also named his masterpiece *An Essay concerning Human Understanding* and proclaimed the purpose of the work "to inquire into the original, certainty, and extent of human knowledge, together with the grounds and degrees of belief, opinion, and assent" (Locke 1991:I.i.2).

The key term in Locke's *Essay* is idea, which he defined as "whatsoever is the object of the understanding when a man thinks, ... whatever is meant by phantasm, notion, species, or whatever it is which the mind can be employed about in thinking" (Locke 1991:I.i.8). What

Locke thus means by an idea, is simply anything that is immediately present to conscious awareness, be it sensory images, thoughts, feelings or memories (Clapp 1996:490).

Concerning the source of these ideas, it was Locke's central thesis that man gets all his ideas from experience and he therefore contended that there are no innate principles stamped upon the mind or brought into the world by the soul or principles to which all give assent. Locke allowed that the knowledge of some truths is in the mind very early, but indicated that observation shows that such truths are about particular ideas furnished by the senses. The senses first furnish man with particular ideas which the mind by degrees becomes familiar with, remembers and names. General ideas, words and the use of reason thus grow together and assent to the truth therefore depends on having clear and distinct ideas of the meaning of terms (Locke 1991:I.ii.1-27).

In similar fashion, Locke argued that man has no innate moral or practical principles, as there is no universal agreement about such principles and great varieties of human vice have at a time been considered as virtues. He also insisted that while all men have a desire for happiness and an aversion to misery, these inclinations do not produce knowledge or truth and that although some eternal principles of morality might be known through reason, it does not prove them innate (Locke 1991:I. iii.1-7).

With the possibility of innate ideas ruled out, Locke reiterated in Book II of the *Essay* that all ideas ultimately derive from experience in the form of either sensation or reflection and that man remains conscious of two things, namely the fact that he thinks and the ideas in the mind about which he thinks. Man's senses are affected by external objects and provide him with ideas such as yellow, white, heat, cold, soft, hard, bitter and sweet. With regard to the operations of the mind, man is furthermore furnished with ideas of perception, thinking, doubting, believing, reasoning, knowing and willing. The building blocks of knowledge are thus either the immediate objects of sense, such as colour or the direct awareness of acts such as knowing.

Locke's intention in describing the process of knowledge is clearly portrayed in his account of the concept of solidity. He maintained that we acquire the idea of solidity by touch as "that which hinders the approach of two bodies, when they are moving one towards another" (Locke 1991:II. iv.1). However, he sharply distinguished this sense from a purely mathematical use of the concept and stated that "if anyone asks me what this solidity is, I send him to his senses to inform him. Let him put a flint or a football between his hands and then endeavour to join them, and he will know" (Locke 1991:II.iv.6). Locke thus refers all philosophical and scientific discourse back to the experience or sensation encountered when something like a flint or a

football is held between the hands and all knowledge back to what is perceived (Clapp 1996:491).

On this foundation, Locke proceeded to distinguish between simple and complex ideas. A simple idea he defined as "nothing but one uniform appearance or conception in the mind, and is not distinguishable into different ideas" (Locke 1991:II.ii.1). To Locke, a colour seen, a sound heard or an odour smelled are all examples of simple ideas of sense. Thus, only those qualities in things that produce ideas can ever be imagined at all, which implies that human knowledge is therefore limited by the ideas furnished by experience. With regard to simple ideas, the mind is thus mostly passive with ideas simply acquired through experience.

However, once it is furnished with a number of simple ideas, the mind has the power to repeat, compare and unite these ideas in an almost infinite amount of combinations or complex ideas. Just as the mind observes that several combinations of simple ideas are found together, so too, it can by its own action voluntarily join several simple ideas together into one complex idea. To Locke there are moreover three categories of complex ideas, namely modes, substances and relations. To him modes are dependencies or affections of substances, with simple modes being variations on or different combinations of one simple idea and mixed modes representative of several distinct ideas joined together to form a complex idea. On the contrary, ideas of substances represent distinct particular things subsisting in themselves, while complex ideas of relation consist in comparing one idea with another (Clapp 1996:493).

In addition to the distinction between simple and complex ideas and of particular importance for the argument of the study, Locke made a second basic distinction between primary and secondary qualities. In this regard he noted that "whatsoever the mind perceives in itself, or is the immediate object of perception, thought, or understanding, that I call idea; and the power to produce any idea in our mind, I call quality of the subject wherein that power is" (Locke 1991:II.viii.8).

He argued that primary qualities are utterly inseparable from body and that they are known to be primary because sense experience constantly finds them there if body can be perceived at all and the mind by critical reflection finds them inseparable from every particle of matter. To Locke, concepts like solidity, extension, figure and mobility are thus all examples of primary qualities which are resembled in human ideas due to the fact that these qualities actually exist, whether they are perceived or not.⁹⁸

⁹⁸ Berkeley was to indicate that to speak of resemblance supposes that a comparison and an observation can be made.

On the contrary, Locke argued that secondary qualities were nothing but powers to produce various sensations. Bodies produce these sensations by the action of their bulk, figure and texture, as well as by the motion of their insensible parts on the human senses. These bodies somehow produce ideas such as colour, odour, warmth and smell which in no way resemble the qualities of bodies themselves, but remain signs of events in real bodies (Clapp 1996:492).

These considerations had far reaching implications for Locke's views on the essence of his theory of knowledge. As indicated earlier, Locke argued that there are only two sources of knowledge, namely sensation and reflection. He however also indicated that the ideas derived from reflection are in some important ways quite different from those derived from sensation. He asserted that "the mind turns its view inward upon itself and observes its own actions about those ideas it has (and) takes from thence other ideas" (Locke 1991:II.vi.1) and thereby meant that in reflection the mind observes its own action.

Against this background, Locke defined knowledge as "the perception of the connection and agreement, or disagreement and repugnancy, of any of our ideas" (Locke 1991:IV.i.2). To him, this agreement or disagreement is determined by four variables, namely identity and diversity, relation, coexistence or necessary connection and real existence. Perceiving agreement or disagreement is thus quite different from barely perceiving the ideas that are said to agree or disagree and implies that there can be no knowledge without judgement, since there can be no knowledge without a proposition, be it mental or verbal. Locke therefore also defined truth as "the joining or separating of signs, as the things signified by them do agree or disagree one with another" (Locke 1991:IV.v.2) and insisted that there exist two sorts of propositions, namely mental "wherein the ideas in our understandings are, without the use of words, put together or separated by the mind perceiving or judging of their agreement or disagreement" and verbal which represent propositions (Locke 1991:IV.v.5).

From this perspective, ideas not only represent the materials of knowledge and the terms of mental propositions, but due to its derivation from sensation and reflection, also the subject matter of reflection. Locke therefore argues that if perception of agreement or disagreement in identity and diversity represents the first act of the mind, then that act also represents a judgement. If for instance we infallibly know that the idea of white is identical with itself and different from that of red and that the idea of round is identical with itself and different from that of square, one has to distinguish between the bare having of these ideas and the knowledge of their identity and diversity. To Locke, the knowledge of their identity and diversity represents a judgement, as it is reflective and in the mind not only perceives its own action or operation, but

moreover leaves no room for a distinction between the judgement and the idea thereof. While one therefore may be uncertain as to how the mind makes judgements, what determines it to judge or in what kind of substance this power inheres, there may be certainty that in the actual making of a true judgement the mind perceives its own act.

In addition, Locke recognised two degrees of knowledge, namely intuition and demonstration. Of the two, he regarded intuition as more fundamental and certain since "the mind perceives the agreement or disagreement of two ideas immediately by themselves, without the intervention of any other" (Locke 1991:IV.ii.1). Such knowledge, Locke regarded as irresistible with no room for hesitation, doubt or examination, as the guarantee of all certainty and evidence in knowledge and as firmly anchored in intuition.⁹⁹ Apart from these two degrees of knowledge, Locke distinguished a third which is "employed about the particular existence of finite beings without us, which going beyond bare probability and yet not reaching perfectly to either of the foregoing degrees of certainty, passes under the name of knowledge" (Locke 1991:IV.ii.4). This degree of knowledge Locke called sensitive knowledge and grounded it in common sense since he always took sensory ideas to be representations of something beyond themselves.

Against the background of these distinctions, Locke asserted "that man's knowledge extends no further than his ideas and specifically no further than the perception of the agreement or disagreement of our ideas" (Locke 1991:IV.iii). He insisted that man cannot have knowledge of all the relations of his ideas or rational knowledge of the necessary relations between many of his ideas. To him, sensitive knowledge only goes as far as the existence of things and not as far as their real existence or reality. He for example argued that although we might have the ideas of circles, squares and equality, we may never find a circle equal to a square and know them to be equal. Similarly, he observed that even though we may have ideas of matter and thinking, we may never know whether mere material being thinks. However, while Locke noted that many relations of coexistence provide no certainty that it will continue to be the case, he seemed persuaded that the continued discovery of new knowledge suggests that there are vast horizons of reality that we may advance upon, but will never be able to reach (Clapp 1996:497).

Thus, to Locke the aspects of objects that science was able to deal with, were those that were independent of any individual observer and belonged to their measurable properties, such as their length, breadth, height, weight, position in space and velocity if in motion. Because of its independency of any observer, these properties could be regarded as objectively characterising an object and were therefore depicted as primary qualities.

⁹⁹ To Locke, this kind of knowledge is most evident in, but not limited to, mathematics.

On the contrary, the qualities that it was impossible for science to deal with were those which arose out of the interaction between the object and an observing subject and therefore contained a subjective element which could easily differ from observer to observer. According to Locke, these qualities had characteristics such as taste, smell and colour, belonged to objects in an ambiguous way, depended on being experienced by a subject and were therefore depicted as secondary qualities.

According to Magee, this distinction, having been written into philosophy's constitution by Locke, was never wholly departed from. According to him, an essential element in Locke's theory of knowledge is the view that due to the fact that we are able to observe only an object's observable characteristics and behaviour, we have no way of apprehending it independently of those characteristics. We in other words cannot have any knowledge of what the object is that exhibits those characteristics and behaves in that way.

To Locke, the thing in itself remains an invisible and metaphysical something which can be characterised as matter and material substance, but cannot be known apart from its characteristics and properties. Similarly, this also applies to the subject, since as subjects of knowledge and experience we can only find within ourselves the contents of our awareness and experiences. Accordingly, both the subject and the object of our knowledge remain in themselves unknowable and result in the domain of possible knowledge to entirely consist of transactions or possible transactions between these mysterious entities (Magee 2001:106).

Reference has earlier been made to the fact that the success of the new clinical method in the late 1800s soon resulted in the dominance of the ontological model and that true to its origins in the Enlightenment, the new clinical method was analytic and impersonal with the feelings and experiences of the patient left aside. It was indicated that whereas the term *diagnosis* formerly referred to the diagnosis of a patient, the objective of a diagnosis now became the identification of a disease. Diseases were now regarded as located in bodies and the categorization thereof as abstractions, which for the sake of generalization, omitted many features of being ill, such as the subjective experience of the patient. It was noted that these developments furthermore resulted in physical and mental illnesses being classified separately, the distinguishing of somatic and psychotherapies and in the physician increasingly being viewed as a detached and impassive observer, utilizing the predictive and inferential power of the new clinical method to identify the patient's disease or rule out organic pathology. This dichotomy between the physical and the mental eventually also manifested itself in the organisation of the profession with distinctions

for instance being made between internal medicine and psychiatry and eventually also between different types of wards in medical institutions.

The traces of John Locke's distinction between the primary and secondary qualities of knowledge are therefore still perceptible in not only the ontological and methodological assumptions of the natural science paradigm, but also in the constitution of the clinical method.

The ontological view of reality and of modern science according to Searle assumes that "we live in a world made up entirely of physical particles in fields of force. Some of these are organised into systems. Some of these systems are living systems and some of these living systems have evolved consciousness" (Searle 1995:7).¹⁰⁰ According to Kriel, the view that reality consists of material building blocks interacting according to timeless laws, determines in science which phenomena will be investigated, which methods will be used to investigate the phenomena and what types of explanations will be accepted by the scientific community.

Systems thus have a derived reality, with the parts thereof being ontologically prior to the systems. This implies a basic building-blocks view of reality, assuming that living matter is simply a more complex arrangement of the basic material building blocks and that living material systems do not require any other explanatory principles than those already available in physics and chemistry as the sciences by which non-living material systems are explained.

Kriel notes that within this scientific tradition, also conscious life is nothing but an even more complex arrangement of the basic building blocks, as consciousness will eventually purely be explained in terms of the laws of physics and chemistry, even though quantum physics and super computers may be invoked to do so. It is therefore due to the fact that reality is equated with basic material building blocks, that also consciousness is considered to be an epiphenomenon of material processes in the form of neurological activity (Kriel 2000:17).

To Kriel, the ontological assumptions and methodological beliefs of a paradigm form a mutually interactive network in which the methods must in some logical manner relate to the structure of the reality they are assumed to be able to access. This implies that the assumed structure of reality is established and even created by the methodological beliefs and vice versa. Among the ontological assumptions of the natural science paradigm which grew in sophistication over time, Kriel distinguishes dualism, materialism, reductionism, linear causality and determinism.

Descartes's dualism was fundamental in the development of science, as it dichotomised the material and immaterial worlds and permitted scientists to concentrate on those aspects of nature

¹⁰⁰ In similar vein, also Popper notes that, being a modern man, he shares "with old fashioned materialists the view that ... solid material bodies are the paradigms of reality" (Griffin 1988:19).

that are more readily subject to experimentation and quantification. However, while Descartes's dualism formed the essential background to empiricism, the immaterial gradually came to be regarded as a derivative of the material and eventually resulted in the dualism being replaced by a monistic materialism.

Regarding materialism, Kriel notes that the material world, as the domain of investigation of the natural sciences, is assumed to be a complex material whole composed of assembled atomic parts considered to be the fundamental building blocks of reality. Due to the fact that these building blocks, while interacting with sufficient complexity, constitute all the physical and biological systems encountered in the universe, only fundamentally material explanations can be considered as *true* explanations. The world view implied by the natural science paradigm thus presupposes what Foss and Rothenberg call a single fundamental material level of reality (Foss & Rothenberg 1988:52).

According to Kriel, the assumption of reductionism indicates the belief that complex wholes exist only in terms of their most fundamental parts, but also has the methodical implication that an acceptable explanation now becomes the process by which a complex whole is analysed into its constituent parts and its behaviour is explained only in terms of the interaction of those parts. Reductionism therefore also implies the existence of a unified physicalist language in whose vocabulary all physical, biological and mental events are ultimately expressible and which will represent the only type of discourse legitimated by the natural science paradigm.

Regarding the assumptions of linear causality and determinism, Kriel notes that in the explanatory framework of the natural sciences, all events are explained in terms of antecedent events which are organised in causal chains and networks, which can be characterised in terms of universal laws which make no reference to the causal efficaciousness of future events or higher levels of organisation and which demand determinate explanations. According to Kriel, this type of causal relationship in which the characteristics of the whole is determined by the behaviour of the parts, is often referred to as bottom-up causality and has due to the fixation on paradigmatic monism by the scientific community also been extended to biological, psychological and social phenomena.

The traces of John Locke's distinction between the primary and secondary qualities of knowledge is however also still perceptible in the methodological assumptions of the natural science paradigm. The standard view of science was first formulated by Francis Bacon in the sixteenth century and reached its culmination in the logical positivism of the Vienna Circle at the beginning of the twentieth century. As the first systematically formulated philosophy of

science, logical positivism is still accepted by most scientists and represents the view held by most medical practitioners and scientists in the world (Van Huyssteen 1986:16). According to Kriel, the basic tenets of the logical positivist approach to scientific methodology can be described in terms of the concepts of empiricism, verification, the unity of science, objectivity and the scientific method (Kriel 2000:14).

As a basic postulate of logical positivism, empiricism refers to the fact that all real knowledge is based on direct observation which also includes observation mediated through various forms of instrumentation. Moreover, the principle of empiricism postulates that theories can be based on theory-free observation which is able to facilitate an understanding of reality as it exists objectively or independently of the observer. Accordingly, methodological beliefs are considered to be self-evident truths, abstracted from the practice of physics as the most advanced of the physical sciences.

According to the principle of verification, propositions are considered meaningful and scientific only if it is possible to state which observations in reality could verify the proposition in question. In practice, it amounts to the fact that the only form of verification accepted and regarded as scientific by most natural scientists is that of nomological explanations and observations which are quantifiable and expressible in the form of causal laws.¹⁰¹

Regarding the concept of the unity of science, it is implied in the empiricist view of knowledge that all scientific disciplines must have the same epistemological structure and that all scientific knowledge should eventually be translatable to the language of the physical sciences in general and to that of physics in particular.

Also the concept of objectivity fulfils an important role in natural scientists' thinking about their practice, as objectivity within the logical positivist framework denotes knowledge obtained through the empirical method. Knowledge obtained in this way is considered to be free from any observer bias and regarded as a true and theory free representation of reality.

All of these concepts amount to the fact that scientific rationality is identified with a specific method, namely the method of physics or the scientific method. According to Foss and Rothenberg, this method became so successful that proceeding in accord with it came to be identified with proceeding in accord with the precepts of rational inquiry in general (Foss & Rothenberg 1988:45). Van Niekerk notes that also objectivity is guaranteed by this method as it amounts to a stabilised procedure which imposes a strict discipline on the researcher and

¹⁰¹ It is of importance to note that not even Popper's principle of verification is considered to change this underlying principle of empiricism.

legitimizes his work as scientific by delimiting the type of questions that may be asked, as well as the type of answers that can be given. As such, the scientific method ensures intersubjective validity, generates scientific knowledge, is used in the process of verification and is open to public scrutiny as it is known to others and potentially repeatable by them (Van Niekerk 1992:50).

Van Niekerk moreover characterizes the standard image of the scientific method in terms of concepts such as experimentation, inductive logic, verification and theory formation (Van Niekerk 1992:50-53).

Experimentation represents the strictly controlled, public and repeatable procedures whereby scientific knowledge is generated. In this regard, repeatable procedures refer to laboratory experiments under strictly controlled circumstances in which essential variables are limited to measurable ones and the scientist is thought to be a detached observer with no influence on the inexorable logic of the unfolding events.

Inductive logic represents the procedure through which the facts and regularities established in experiments are developed into generalised hypothetical statements.

Verification is the procedure through which the truth of the proposed hypothesis is established and is normally conducted by trying to find further experimentally controlled observations that could verify the claims of the hypothesis.

Theory formation represents a concept of fundamental importance in the natural science paradigm, as scientific theories are considered to be constructed on the secure foundation of objective and value-free facts obtained by factual and direct observation. Scientific knowledge thus grows by linear accumulation of factually true theoretical propositions, provides access to an objective reality and can be verified by reconstructing the observations on which the theoretical judgements rest and by reconstructing the logical arguments which motivate the deduced hypotheses and theories (Kriel 2000:15-16).

However, apart from the ontological and methodological assumptions of the natural science paradigm, the traces of John Locke's distinction between the primary and secondary qualities of knowledge are also still perceptible in the constitution of the clinical method and of biomedical research.

According to Kriel, the basis for the claim that clinical medicine represents a scientific practice is twofold. Clinical practice is firstly considered to be scientific due to the direct application of scientific medical knowledge in the clinical situation and in patient care. Clinical medicine is

thus assumed to be a direct application of a body of discipline-based natural-scientific knowledge through the central terms of medicine such as disease, therapy and the patient. Secondly, the analytic process through which clinical information leads to a diagnosis, is closely akin to the scientific method or the process through which experimentation leads to the discovery of new knowledge (Kriel 2000:22).

With regard to his exposition of the clinical method,¹⁰² Kriel systemises the impact of the natural science paradigm on the central concepts of medicine as follows (Kriel 2000:23-25).

With regard to the patient, he notes that he or she is regarded as biological organisms which, as Descartes put it, will continue to function normally even without a mind. The scientific framework of medicine thus simply cannot accommodate the reality of the psyche and of the realm of consciousness, even though Descartes's dualism has in the mean time been replaced by a materialistic monism.

According to Kriel, disease processes and causalities are conceptualised as purely physical or biological processes. If the patient is regarded as a machine, then disease represents a breakdown of the disease with the focus of the physician completely on the biological processes and not on the illness as experienced by the patient. This approach is also evident in medical research where the psychosocial aspects of disease are referred to as risk factors and are not considered as essential aspects of the disease itself. Reductionism presents itself in medicine in the dominance of molecular pathology as an explanatory framework for disease. While disease was initially in the seventeenth century defined in terms of organ pathology and in the nineteenth century as cellular pathology, it was ultimately in the twentieth century reduced to molecular pathology. A disease is therefore considered to be completely scientifically understood only when its molecular basis has been defined.

With regard to the concept of therapy, Kriel notes that because disease is conceptualized as a physical phenomenon, only physical treatment modalities such as drugs, surgery or radiation are considered part of scientific medicine. Diseases as described by medical science are considered to be real physical entities that exist free from any psychological or cultural influences of the patient or the doctor. The psychosocial needs of the patient are therefore recognised as perhaps important from a humanitarian point of view, while attention to these dimensions cannot be justified scientifically.

This approach to therapy also directly influences the doctor-patient relationship. Kriel notes that the clinical method which doctors are trained to use integrates the assumptions of biomedicine

¹⁰² See paragraph 4.1 for more detail.

and thus structures the clinical situation in such a way as to focus entirely on the biological aspects of the patient's complaints. The doctor's agenda is to diagnose a disease and not to understand the patient and the patient's personal agenda is therefore drawn into the reductionist, mechanistic and materialistic medical agenda in order to make a physical diagnosis and to prescribe physical treatment.

According to Kriel, the application of the natural science paradigm therefore almost inevitably led to the decline of humanistic medicine. In this regard, Kriel refers to Engel who comments as follows on the role of the natural science paradigm: "Developed as an approach to nature as it surrounds man, such a paradigm provides no means to accommodate human processes, and never was intended to ... Accordingly, the physician has come to be seen as operating scientifically and medicine judged to be properly scientific only when dealing with bodily processes, not when dealing with patients as people" (Engel 1988:118).

The result of this approach to medicine initially led to a distinction between laboratory-based medical science and the so-called art of medical practice. While the laboratory-based medical science concentrated on objective descriptions of disease processes and utilised universal laws which are mechanistic in nature, but exclude the human dimensions of being ill, the art of medical practice related to the patient as a human being and the application of the results of the laboratory-based medical science in a personalised and humane manner. A Cartesian-like body-soul distinction thus developed between medicine as a science and as an art which had the value that the humanity of the patient and of the doctor was for a time at least recognised as of clinical importance.

However, as the explanatory power and social status of the reductionist theories and their accompanying technologies increased, also the human dimension of the clinical encounter increasingly became regarded as subjective and due to it not being subject to measurement and verification, therefore also unscientific. The initial distinction between science and art therefore also disappeared and the clinical situation came to be interpreted almost exclusively in terms of the natural science paradigm initiated by John Locke in the seventeenth century.¹⁰³ Kriel notes that humanistic medicine is doomed in such a dichotomy, as the forces responsible for the ousting of human dimension of the clinical encounter will only grow more potent in future. This development was already foreshadowed by an Editorial in the *New England Journal of Medicine*

¹⁰³ See also the following comment by Schwartz and Wiggins: "As medical science makes rapid strides and as old forms of health care are replaced by newer, apparently less personal forms, humanistic medical practice grows even more problematic. Increasingly there seems to be a conflict between humanistic and scientific medicine" (Schwartz & Wiggins 1988:137).

from 1985 which stated: "It is time to acknowledge that our belief in disease as a direct reflection of mental state is largely folklore" (Kriel 2000:25).¹⁰⁴

5.2 SØREN KIERKEGAARD - DECISION MAKING AS MOST IMPORTANT HUMAN ACTIVITY

Reference has earlier been made to the fact that patient-centred medicine derives its inspiration from the thought of Søren Kierkegaard who with his emphasis on respect for the spirit, the whole person and the rights to individual self determination, argued for decision making as the most important human activity, since it is through choices that humans create their lives and become themselves.

By way of introduction it can be stated that Søren Kierkegaard's philosophy is commonly regarded as a reaction against the systematic philosophy of Hegel. According to Kierkegaard, Hegel's idealism was too abstract and general and had little regard for the real difficulties individuals have to face in their day to day lives. Kierkegaard was above all interested in the concrete or real living individual and argued that there are important aspects of human life such as existence in time and faith that lie beyond the scope of reason (MacIntyre 1996:336-340).

In Hegel's successive construction of philosophical systems, the linked development of freedom and reason was a logical one (MacIntyre 1996:337). Out of the most basic and abstract of concepts, namely Being and Nothing, Hegel developed the concept of Becoming, as well as the various phases of Becoming through which the Absolute Idea realises itself during the course of human history. In this development, each phase of history becomes the expression of a conceptual scheme in which the gradual articulation of the concepts leads to a realization of their inadequacies and contradictions. This scheme is however replaced by another higher and more adequate one, until finally Absolute Knowledge emerges and the entire historical process is comprehended as a single logical unfolding. To Hegel, it is this comprehension itself that forms the culmination of the process and he therefore stated in his *The Science of Logic* that he was setting out not merely his own thoughts, but the thoughts of God in the Hegelian conception of the Absolute.

Hegel regarded both moral and religious development as simply phases in this process and for instance in his *The Phenomenology of Mind*, described the moral individualism of the eighteenth century in terms of a logical process ranging from the hedonistic project of a universal pursuit of private pleasure, through the romantic of the idealisation of the noble soul to the Kantian

¹⁰⁴ See also Angell 1985:1570-1572.

scheme of duty. In terms of these views, Hegel regarded an individual as essentially a representative of his age with his personal and religious views just expressing his role in the total moral and religious development of mankind which was imposed on him by his place in the historical scheme. According to Hegel, an individual can therefore at best express, but never transcend his age.

To Kierkegaard, Hegel herewith dissolved the concreteness of individual existence into abstractions characteristic of the realm of concepts. To him, any particular conceptual scheme represents not an actuality, but a possibility. Regarding human beings, this implies that whether an individual realises this possibility and so endows it with existence, is determined by an individual's will and not by his or her understanding of concepts. While Kierkegaard in this regard invokes both Aristotle and Kant in support of his view that Hegel equalled concepts with individual existence, he in fact is more reminiscent of Tertullian or Pascal in his doctrine of the primacy of the will.

Kierkegaard supported his doctrine of the will with his view of the ultimacy of undetermined choice. He maintained that an individual constitutes himself or herself through his choices of one mode of existence rather than another. Christianity is therefore not to be regarded as yet another phase in the total development of man's religious and moral ideas, but rather represents a choice to accept or reject God's Word. To Kierkegaard, choice is however not restricted to supreme decisions such as these, but represents the core of all human existence. The Hegelian view that human existence develops within and through conceptual schemes, is therefore not only to be regarded as an intellectual error, but as an attempt to disguise the true facts, to cast off the responsibility of choice and to find an alibi for your choices. Moreover, to Kierkegaard, Hegel's speculative system building falsifies human existence by suggesting that, although those who lived prior to the construction of the system may have had to make do with a partial and inadequate view of reality, the arrival of the final system provides an absolute viewpoint. To Kierkegaard, human existence is thus irremediably finite and its standpoint incorrigibly partial and limited (MacIntyre 1996:337).

To Kierkegaard, the essence of this concept of choice is that it is criterionless, as any choices determined by criteria could not be regarded as self made. He argues that if somebody invokes criteria in order to make a choice, it would imply that he or she merely chooses the criteria. Similarly, if someone would justify his or her selection of criteria by an appeal to logically cogent considerations, it would imply that he or she has in turn chosen the criteria in the light of which these considerations appear logically cogent.

Thus to Kierkegaard, first principles have to be chosen without the aid of criteria, simply in virtue of the fact that they are first. Moreover, logical principles or even relationships between concepts can in no sense determine a person's intellectual positions, since it remains his or her choices that determine the authority thereof. In this regard Kierkegaard even excludes principles which enjoin consistency and prohibit contradiction, as even paradox challenges the intellect in such a way as to be a possible object of choice. While he is prepared to concede that the ordinary procedures of reason are legitimate in fields such as mathematics, the paradoxes he has in mind are those posed by religion and ethics and in this regard he contends that there are no objective standards where human existence is involved (MacIntyre 1996:338).

In *Either/Or 1*, Kierkegaard portrays what he calls the aesthetic life by means of the correspondence between a young man, A, who represents the aesthetic and a judge who represents the ethical point of view. A is a young man who does not like difficulties and would rather like to live a life of pleasure in which there is no need to think, choose or decide. He would prefer to just be instead of working towards some goal, but realises that this kind of life is not possible, except in art.¹⁰⁵ Thus, in order to make your life aesthetically or artistically pleasing, you should try to make it as interesting as possible and avoid all that might lead to boredom. To avoid being trapped in boredom, variety and freedom is essential which implies that you should therefore avoid commitments and entanglements of any kind, such as friendships, marriage or business. A also holds his Seducer's diary which describes the thoughts and plans of a young man setting out to make a girl fall in love with him, only to desert her when he has succeeded. While the seducer does not really want the girl for herself, he simply enjoys the plots and intrigues involved in conquering her and believes that in the end he has done her a favour by making her life more interesting and changing her from a naïve and innocent girl into a sophisticated woman. The aesthetic stage of life is therefore characterised by immediacy and temporality with little regard for actions that might have consequences in future. On the contrary, it supposes that nothing really matters due to everything eventually passing away and since nothing matters in the greater scheme of things, you might as well enjoy yourself while you can.

Either/Or 2 poses an alternative that, if not Kierkegaard's last word, marks a line behind which he is not willing to retreat in the further exploration of what it means to become an individual or the selves that we potentially are. This alternative is set out by a character called Assessor

¹⁰⁵ A admires Don Juan, the seducer of more than a thousand women and made famous by Mozart's opera *Don Giovanni*. Don Juan is a being of pure sensuality that perfectly embodies the philosophy of *living for the moment* (Kierkegaard 1987:87-103).

Wilhelm who is strictly speaking not meant as a pseudonym, but is more of a regular fictional character and is therefore far from simply being a mouthpiece of Kierkegaard's own views. However, at the same time this character presents ideas that anticipate or parallel those of other pseudonyms (such as the analysis of the concept of anxiety) or Kierkegaard himself (as in his criticism of the impatience of the aesthetic attitude). When the Assessor thus insists on the priority of what he calls the ethical, he also insists that the ethical has its source in a freedom that is not only manifested in the capacity for choosing between alternative goods, but also defines the self's way of being and its responsibility for the manner of its existence (Pattison 2005:91).

This insistence is in the second of the Assessor's letters to A focussed on the concept of choice. The slogan, either/or is already encountered in the early pages of *Either/Or 1* where it is used to indicate that there is no real significance attached to any of the choices we make in life, not to any of the attitudes we take to it, since all are equally meaningless (Kierkegaard 1987 1:38). In *Either/Or 2*, the Assessor responds by stating that choice is decisive for the content of the personality, since it is through choice that the personality immerses itself in what has been chosen and that should it not choose, it goes into a consumptive decline (Kierkegaard 1987 2:163).

In this approach, even non-choosing becomes a kind of choice due to the fact that our life in time implies that life itself moves forward despite hesitations to choose and that therefore our situation and even ourself becomes different from what it used to be. To Kierkegaard, the personality has an interest in the choice even before it is made and when it is postponed, it becomes an unconscious choice on the part of the personality or a choice on the part of the obscure powers at work within it (Kierkegaard 1987 2:164). Moreover and in response to A's spending a year and a half on thinking whether he should become a pastor or an actor etc., the Assessor indicates that this is not merely not choosing, but implies allowing one's life to be defined in a certain way and therefore amounts to a choice. In this regard the Assessor adds that it does not even matter so much when a person makes the wrong choice, as this is an indication of a readiness to accept responsibility. A therefore cannot escape responsibility for who he is by simply not choosing (Pattison 2005:92).¹⁰⁶

¹⁰⁶ "Therefore, even if a person chose the wrong course, he will nevertheless discover by virtue of the energy with which he chose, that he chose the wrong. For insofar as the choice is undertaken with all the inwardness of the personality, his being is cleansed and he himself is brought into an immediate relation to the eternal power that is all-pervasive throughout existence" (Kierkegaard 1987 2:167).

The Assessor however goes on to explain that the choices he is talking about are not these about good and evil and doing good instead of harm. While choice can always be explained retrospectively and can always be mediated, the outcome of choice and consequently its meaning for the chooser's life cannot be completely determined in the moment of choice. In making a decision, there always is the possibility of making a terrible mistake and for this reason choice can never solely depend on the motivating power of reasons. There has to be something more and for Kierkegaard this something more is freedom. The Assessor's argument is thus for the cause of freedom, the future and either/or which for him are three intimately connected and mutually reinforcing concepts.

What therefore matters is the activation of the freedom to choose, as well as the readiness to accept responsibility for the choice once made and since what is chosen is essentially the self or my self: "But what is it then that I choose; is it this or that? No, for I choose absolutely, and the absolute element in my choice is precisely that I am not choosing this or that. I am choosing the absolute, and what is the absolute? It is myself in my eternal validity. I can never choose anything external to my self absolutely, for then I am choosing something external, then I am choosing something finite, and therefore do not choose it absolutely" (Kierkegaard 1987 2:214).

With this argument the Assessor is not campaigning to envisage the self as the sole and absolute creative power in existence, but explains that there is in his view a significant difference between self-creation and self-choice. In choosing myself absolutely, I unconditionally accept that there is no alibi for being (Morson & Emerson 1990:31), since "I am who I am and as I am with no parallel universe in which to escape. I remain infinitely responsible for the self that I am with no one else who is or can be responsible for it in the same way" (Pattison 2005:93).

To Kierkegaard, this choice is however not without context. As an act of self-choice and not of self-creation, the self we become through choice is also a received self. Self-choice is always situated and occurs as the taking over of life possibilities that are given on the basis of a thrownness (Heidegger) or facticity (Sartre) that precede my taking over of these possibilities. In Kierkegaard, the concept of choice is hereby characterised by the fact that the one who chooses, acquires a history and accepts him or herself as the person they have become through the experiences that have brought them to that point. According to the Assessor, the act of choice can therefore also be described as repentance due to the fact that the awareness of self that accompanies the need for choice is always an awareness characterised by a sense of lack or inadequacy and a recognition of the fact that few if any actual human beings reach the point at

which they decisively choose themselves without having fallen short of the best standards of morality.

Thus, to choose or to accept myself absolutely is to recognize myself as someone who has lied a little, stolen a little, coveted a little, who has been a little idle and a little careless of others. However, even this little demands repentance and the Assessor therefore explains that someone who repents does so "back into the self, into the family, the race, until he finds himself in God" (Kierkegaard 1987 2:216). It is thus not only my own prehistory of moral failure that I repent of in choosing myself, but also the prehistory of both the immediate (family) and the general (race) human experience in which I participate as a non-negotiable condition of my being. Seen from this perspective, repentance implies that I cannot be a morally perfect being solely on the ground of my own good will while I am also the inheritor of a manifold history of failure and wrongdoing. While I as an individual did not choose that there should have been a slave trade or colonialism, these historical realities have shaped the world that I now inherit and therefore demand my repentance if I am to be the self that I historically am (Pattison 2005:94-95).

To Kierkegaard, choice is however not only about accepting the past, but is also inseparable from freedom and concern for the future. If the self chooses itself in its concretion, this also applies to its relation to the present and the future. The act of self-choice accepts the past as a task and as something that needs to be reshaped and to be ordered in terms of the archetype of human selfhood that we have got within ourselves. In ethical self-acceptance the individual is thus not only coming to terms with a past that is merely a collection of more or less arbitrary happenings, but is also committing himself "to the ideal of the transformation of the self into a universal individuality" (Kierkegaard 1987 2:256).

According to Kierkegaard, the universality of the ethical choice reveals itself in the individual's attitude towards society and an openness to commit him or herself to the obligations that might come their way as a member of a quite concrete social body. Moreover, this implies a willingness to work and engage in friendships and to allow the legitimate enjoyment of the aesthetic pleasures of a common cultural life. In terms of these distinctions it is clear that self-choice can only occur as a first-person free act of the person concerned and not as the result of the intervention of any external moral or social power and that although someone who for instance chooses to marry acquires a home and a position in society, these things do not constitute adequate reasons for getting married, but only provide the support and context for it (Pattison 2005:96).

Reference has earlier been made to the fact that patient-centred medicine derives its inspiration from the thought of Søren Kierkegaard who with his emphasis on respect for the spirit, the whole person and the rights to individual self determination, argued for decision making as the most important human activity, since it is through choices that humans create their lives and become themselves.

The traces of Kierkegaard's emphasis on respect for the spirit, the whole person and the rights to individual self determination are still perceptible in not only the principles of patient-centred medicine and in clinical training, but also in the practice of evidence-based patient choice.

Regarding the traces of Kierkegaard's thought in the principles of patient-centred medicine, it was noted that the dominance of the conventional approach in medicine has thus never been complete and that while Freud and others in the 1920s brought an awareness of the importance of the psyche, the costs of health care, coupled to an increasing awareness of the limitations of scientific medicine, brought about a growing appreciation of the psychosocial influences on health. This appreciation paved the way for Engel to propose the bio-psychosocial model for the practicing of medicine, which in turn led to the application of behavioural principles to health care problems and the emergence of new disciplines such as health psychology. Engel's model was widely welcomed by social scientists and those working in generalist clinical work, as it confirmed the importance of psychosocial factors and facilitated an expansion in bio psychosocial research.

It was within this context that the concept of patient-centred medicine emerged through the work of McWhinney and others. McWhinney in 1972 described a paradigm shift for clinicians working in primary care that acknowledged an understanding of the patient perspective on illness as the heart of the biopsychosocial model. In addition, analytic descriptions of the professional-patient relationship and the consultation process were published and gradually a patient-centred consulting style was described and promoted.

Patient-centred medicine thus emphasise the need of the professional to enter the world of the patient and to recognise that in clinical work, there needs to be an assessment of the disease (the biological dimension), as well as the illness (its effect on the patient). This implies a shift in the mind set of the clinician, as the historical hierarchical notion of a professional being in charge, and the patient being passive, is no longer valid. Moreover, it requires a renouncing of the control which has traditionally been in the hands of the professional and an enabling of the patient to share in the power in the relationship.

Within this broad framework, the patient-centred clinical method evolved over the past decades and had much in common with other therapeutic models focussed on the individual such as Rogers's psychotherapeutic concept of client centred therapy, Newman and Young's total person approach to patient's problems in nursing and Mattingly and Fleming's two-body practice. All of these conceptual models contributed to the evolution of the patient-centred clinical method by pointing at the importance of acknowledging a distinction between the clinician's theoretical understanding of the patient's disease and his or her personal experiences of the illness and patients' accompanying need for more than a scientific formulation and treatment of their medical problems and concerns. It became clear that patients generally want to feel understood and valued, become involved in addressing their health problems and also participate in the resolving thereof. Moreover, several key studies emphasised the many benefits of a more compassionate approach to patients, integrating the person in his or her social context and physical environment.

Regarding the traces of Kierkegaard's philosophy in clinical training, it can be noted that medical schools have traditionally emphasised a doctor-centred or disease-centred approach. This implied that a physician would ascertain a patient's complaints and then set off looking for information that would enable him or her to interpret the patient's illness from a physician's frame of reference, before diagnosing the disease and prescribing a treatment. Following from this, it is obvious that the success of an intervention in a doctor-centred or disease-centred approach would be determined by a precise diagnosis.

In contrast, the patient-centred clinical method is aimed at both a diagnosis of the disease and an understanding of the illness experience, as it recognises the fact that disease and illness are intertwined and can therefore not be artificially separated. While the term patient-centred medicine was first introduced in 1970 to contrast it with disease-centred medicine and to describe an understanding of the patient's complaints based on patient-centred thinking, the model was further refined and elaborated through feedback from participants to clarify the conceptual distinctions between disease as a pathological process and illness as a unique experience of feeling unwell, elucidate interviewing methods, describe an approach of finding common ground with patients, independently define a model for family practice and expand the model to include approaches to prevention, the doctor-patient relationship, and efficiency.

It was argued that these efforts resulted in a clinical method that despite its origins in family medical practice is highly relevant to all health professions and consists of six interconnected components. The first of these components involves an understanding of ill health as manifested

in disease and illness and thus requires the doctor to enter the world of the patient in order to explore both the disease and the illness experience.

The second component of the patient-centred clinical method is an integrated understanding of the whole person accumulated over time and going beyond diagnosing diseases or attending to illness experiences. It is argued that over time, doctors come to understand patients' diseases and experiences of illness in the context of their life settings and stages of personal development and as the serious illness of a family member may have an effect on the whole family system, an understanding of the whole person can indeed enhance a physician's interaction with a patient in a crisis and deepen a doctor's knowledge of the human condition and especially the nature of suffering.

However, also in the practice of evidence-based patient choice, the traces of Kierkegaard's emphasis on respect for the spirit, the whole person and the rights to individual self determination are clearly perceptible. In fact, Kierkegaard's idea of decision making as most important human activity runs like a golden thread through the practice of evidence-based patient choice.

With regard to the key skill of shared decision making, reference was made to the conceptual framework developed and updated by Charles et al. regarding the key characteristics of the paternalistic, informed and shared decision making approaches, as well as the different phases of the clinical decision making process, namely that of information exchange, the deliberation or discussion of treatment preferences and of deciding on the treatment that is to be implemented.

With regard to the exchange of information, it was noted that the defining characteristic of the shared approach is its interactive nature with both the health care professional and the patient sharing information with each other. At a minimum, this approach requires of the health care professional to inform the patient of all relevant information that might be needed to make an informed decision and of the patient to reveal personal information on issues such as lifestyle, preferences and the quality of life. The intention is thus to enable both the health care professional and the patient to evaluate the various treatment options within the context of the latter's specific situation, needs and values.

With reference to the phase of deliberation or discussion of treatment preferences, it was indicated that the shared approach to clinical decision making regards both health care professionals and patients to have a legitimate role in deliberation on treatment decisions. It is required of both parties to disclose preferences for a particular treatment scenario in order to enable them to either come to a consensus or negotiate a solution that will be acceptable to both.

It should however be noted that these types of negotiations have the potential of escalating into a conflict and that in such a cases, health care professionals will have to decide whether they can support a patient's preference of treatment while considering another as more appropriate.

In the final phase of deciding on the treatment that is to be implemented, the shared approach requires both the health care professional and the patient to work towards a consensus on the preferred treatment. The intention of a shared decision making approach is therefore to incorporate patient and provider preferences, as well as the principle of joint responsibility into decisions on treatment and thus represents a middle way between the paternalistic and informed approaches to clinical decision making.

With regard to the key skill of risk communication, reference was made of the fact that health care professionals devote most of their time discussing the risks and benefits of treatments with their patients and that this is normally done by either verbally describing the broad advantages and disadvantages of different options or involving the specific use of numerical data in decisions between forms of treatment.

It was also noted that there is a growing awareness that health care professionals engaged in risk communication need to go beyond an examination of the basic probabilities to also explore the effect of risk communication on individuals. Many authors have therefore proposed that risk communication should both address the subjective probability or patient's perception of the actual probability of a specific event, as well as the outcome utilities or severity of the eventualities for that specific individual. Suggestions are thus that discussions of the benefits and risks of treatment options should be supplemented by discussions of patients' personal feelings about prescribed medications or treatments.

As indicated, this emphasis on the need for individualisation in risk communication is also reflected in some of the definitions of risk communication. Ahl et al. for instance, defines risk communication as the open two way exchange of information and opinion about risk, leading to better understanding and better risk management decisions. However, while this definition may be consistent with concepts like patient-centred care, it is regarded as too restrictive for health care in general, as much of the health care communication on risk does not take place in face-to-face encounters between health care professionals and patients.

Another definition by Edwards et al. is more inclusive and typifies risk communication as communication with individuals (not necessarily face-to-face) which addresses knowledge, perceptions, attitudes or behaviour relating to risk. The communication should include an

element of weighing up risks and benefits of a treatment choice or behavioural risk-reducing change.

Thus, to Edwards et al., the individualisation of risk communication, rather than detail of the patient or the health care professional or even the mode of risk communication represents a characteristic of risk communication that proves to be most effective. Employing both treatment choice clinical topics and individualised risk estimates, their analysis indicated that individual communication interventions proved to be most effective and that interventions which used individually calculated risk estimates on average also effectuated an increase in adherence to treatment.

With regard to the key skill of decision analysis, it was noted that it represents a structured and systematic development of approaches to decision making and is aimed at examining potential outcomes under conditions of uncertainty. It is largely based on the theory of expected utility which defines the concept of expected utility as the product of the probability of an outcome, as well as its utility or sense of worth, value and importance. Based on the premise that a rational decision-maker normally opts for the plan of action with the greatest expected utility, this theory therefore measures the valuation of outcomes in terms of both patient preferences and the probabilities of uncertainties and is usually portrayed in the form of a decision tree.

It is therefore conceptually quite different from other approaches such as shared decision making and risk communication, as these approaches usually entail a transfer of responsibility from the health care professional to the patient and either concern the skills to engage the patient more directly in clinical decision making or the nature of the information that may be most efficient. Decision analysis is different, since it on the one hand prescribes the decision to be taken and on the other endeavour to assess the patient's values regarding the possible outcomes of treatment and integrate these with the health care professional's knowledge of the likelihood of these outcomes by means of simple mathematical procedures resulting in a prescribed decision independent of both parties. Furthermore, it was indicated that the crux of the matter and the differences with other approaches to partnership in clinical decision making are to be found in two key elements which are essential for good decision making, namely information about the different outcomes of treatment options like benefits and harms and their likelihoods and the patient's personal values about the significance and relative importance of these outcomes

These elements open up a whole range of scenarios. At one end of the spectrum, the health care professional is typified as supporting patients to make their own decisions by providing them

with the necessary information and allowing them to judge this information against their own values and concerns. At the other end of the spectrum, the health care professional may act as the patient's agent, deciding on what is considered to be the best options in the specific circumstances. In decision analysis, the responsibility of choices therefore remains with the health care professional and the decisions are prescribed, while attention is also paid to a formal and explicit assessment of the patient's values or utilities to ensure a decision based on both information and values.

Decision analysis has thus been described as explicit, quantifying and prescriptive with the facts and the values going into making decisions being kept separate. In this way it is ensured that both the medical information and the patient's preferences are properly acknowledged and that both probabilities and patient utilities are quantified separately before being integrated. An optimum prescribed choice will therefore equal the decision outcome with the highest numerical score arrived at by multiplying a patient's utility for that specific event by its probability and is therefore also considered as a rational option.

The traces of Kierkegaard's emphasis on respect for the spirit, the whole person and the rights to individual self determination are however also clearly perceptible in the key skill of the use of decision aids. It was noted earlier that while shared decision making and risk communication were aimed at engaging the patient more directly in decisions about treatment and entailed a transfer of responsibility from the health care professional more towards the patient, these skills still involved the health care professional in the act of clinical decision making.

However, several decision aids have already been developed to supplement the existing communication between health care professionals and patients and are generally aimed at assisting patients to understand the range of options available, understand the probable consequences of options, consider the value they place on the consequences and participate actively with their health care professionals in deciding about options.

With the aim of preparing patients to participate with their health care professionals in making deliberated and personalised choices about health care options, decision aids have been developed for a wide range of situations. Of particular importance in this regard is the exclusion criterion for decision aids formulated by the Cochrane Collaboration in Australia that interventions designed to promote compliance with a recommended option rather than a choice based on personal values, do not qualify as decision aids.

5.3 LOCKE, KIERKEGAARD AND THE PHENOMENOLOGY OF PERSONAL IDENTITY

While 5.1 and 5.2 have been devoted to a review of the two philosophical traditions which inspired evidence-based and patient-centred medicine, 5.3 would like to further explore the connections between them.

Broadly speaking, the philosophical thought of John Locke and Søren Kierkegaard seems widely divergent. It not only hails from different philosophical periods and different centuries, but has also come to represent completely different philosophical traditions. Although not recognised as the first empiricist in history, John Locke has since the seventeenth century been regarded "as the supreme liberal and chief founding father of the empirical tradition" (Magee 2001:102). On the contrary, Søren Kierkegaard is today recognised as an important forerunner of existentialism that was inspired by the idea "that the individual finds his own identity a problem and hopes to uncover meaning in life through investigating the mystery of his own existence" (Magee 2001:208).

However, the concept of personal identity seems to have interested both Locke and Kierkegaard.

Three years after the publication of John Locke's *An Essay Concerning Human Understanding*, his friend William Molyneux suggested that Locke recast the *Essay* as a scholastic textbook on the topics of logic and metaphysics with an additional volume dealing with human action and morality and specifically urged Locke "to insist more particularly and at large on *Æterna Veritates* and the *Principium Individuationis*".¹⁰⁷ Judging from these suggestions, both Locke and Molyneux were convinced that moral responsibility and therefore also the justice of moral sanctions depend on a persistent identity of the moral agent. However, while Locke in the first edition of the *Essay* denied that the personal identity of moral agents can be known inherently (Locke 1991:I.iii.3-5) and argued that the Cartesian dualism between body and soul does not adequately ground personal identity on the identity of the soul, the body or on a combination thereof (Locke 1991:II.i.11-12), Molyneux now requested him to incorporate their ideas into his concept of personal identity. This he did and a few months later he completed a draft on the concepts of Identity and Diversity that would become Chapter xxvii of Book II for the second edition of his *Essay*.¹⁰⁸

Similarly, Kierkegaard's headline categories such as subjectivity, the ethical, the self, passion and character suggest that he had important interests in at least one substantive philosophical

¹⁰⁷ Kemerling 1999-2002: <http://philosophypages.com/locke/g09.htm>

¹⁰⁸ Kemerling 1999-2002: <http://philosophypages.com/locke/g09.htm>

question, namely the question as to what it means to be a self or a person. While describing *personality* as a central element in Kierkegaard's philosophy, Hannay notes that it actually relates well to Kierkegaard's own intellectual context in which philosophers like Poul Martin Møller, F.H. Jacobi, the later Schelling and other antecedents of the later nineteenth century's philosophy of personalism participated (Hannay 2003:7-8). It however also relates to contemporary concerns to understand philosophy as requiring a concern for the virtuous or good life and even spirituality as a dimension that is more or less inseparable from even the most scholarly philosophy (Pattison 2005:8).

In a lengthy, but extremely fascinating argument, Stokes analyses this shared interest between Locke and Kierkegaard in terms of an investigation of a significant feature of many contemporary Neo-Lockean discussions of the concept of personal identity.¹⁰⁹ This feature is represented in the "perceived dichotomy between the self understood as a human being with its various forms of physical, psychological and social continuity and history and the self understood as the present locus of psychological experience" (Stokes 2008:645).

According to Stokes, the matter at issue in this distinction is the claim that the identity and persistence conditions of the human being that I am and the phenomenological self that I am are not necessarily coextensive and that this may lead to a failure of experiencing a sense of identity with the person we once were or will be. He notes that while some writers, such as Galen Strawson do not regard this dichotomy as a problem, others, such as Marya Schechtman, argue that it is at least psychologically desirable to extend our affective self-identification in order to experience as much as possible of our past and future life in a deep phenomenological sense.

However, while all agree that it remains an open question what such phenomenological identification might consist of, Stokes argues that Kierkegaard's elaborations on moral experience provide a compelling phenomenology of this link between the self as experiencing subject and the self understood as a human being and that his use of terms such as presence and contemporaneity, constitute a sort of phenomenal glue between the thinking self and its representations of itself in its remembered past and anticipated or projected future. To Stokes, these modes of self-reflexive vision provide at least part of an answer to a question identity theorists have long struggled with: "what, if anything, constitutes an identity-bearing psychological connection between the self that I experience myself as being right now with the

¹⁰⁹ Stokes's argument is not only extremely intricate, but also of cardinal importance for the study and is therefore almost rendered in full. I therefore, from the outset, acknowledge my indebtedness to the work of Stokes (Stokes, P. 2008). Locke, Kierkegaard and the Phenomenology of Personal Identity. *International Journal of Philosophical Studies* 16:645-672.

selves figured in my episodic memories, selves who can occasion my remorse, pride, embarrassment and sense of justification for present rewards and sanctions; and between myself now and those imagined future selves who are the subject of my self-interested concern, especially my concern for survival". Moreover, Kierkegaard's "glue", unlike many of the cognitive and/or affective psychological relations that identity theorists usually cite, "isn't normatively neutral, but it's presented to us in thoroughly ethical terms" (Stokes 2008:646).

The current problem of personal identity has its origins in English and Scottish Enlightenment thought and has been confined to a philosophical tradition quite different to that of Kierkegaard. Locke is only rarely mentioned in Kierkegaard's writings and there are no indications that Kierkegaard was familiar with Locke's chapter *Of Identity and Diversity*, which serves as inspiration for contemporary discussions of personal identity. However, Kierkegaard's conception of the problem of the self as a first-personal existential concern seems uniquely well-placed to contribute towards meeting the challenge posed to philosophy by Locke, namely to find a sameness of consciousness or a way of thinking through which we will be able to become a self to ourselves.

A key element in Locke's break with Rationalist views of identity is his insistence that the identity of the self or person is distinct from both the identity of the body or organism (man's identity in Locke's terms) and the identity of the thinking substance or soul. The person, according to Locke, has separate conditions of identity which are connected by a sameness of consciousness across time: "For as far as any intelligent Being can repeat the Idea of any past Action with the same Consciousness it has of it at first, and with the same Consciousness it has of any present Action; so far is it the same personal Self For it is by the Consciousness it has of its present Thoughts and Actions. that it is Self to it Self now, and so will be the same Self as far as the same Consciousness can extend to Actions past, or to come" (Locke 1991:II.xxvii.10).

Whereas Locke's concept of sameness of consciousness or that whereby the consciousness of our present thoughts and actions' is extended into the past and future, has traditionally been interpreted as memory, it has however been noted that memory taken as a criterion of identity appears to be circular. Since I can only remember things that happened to me, it means that to determine whether I remember something, I must have already identified with the self that had the past experience. This implies that if memory is taken as constitutive of identity, personal

identity will be confounded with the evidence which we have of our personal identity (Stokes 2008:647).¹¹⁰

Yet Stokes notes that accusing Locke of equating sameness of consciousness with memory might be too hurried. He refers to Schechtman who states that whereas it is clear that Locke regards memory as of central importance in the identity-preserving extension of consciousness over time, it is noteworthy that he always talks about extension of consciousness and never about memory connections (Schechtman 1996:107).¹¹¹ According to Schechtman, it is rather an appropriation of such memories and not a mere mental having of them, that is essential to the attainment of Lockean identity (Schechtman 1996:106).¹¹² To Locke, such appropriation is crucially linked to self-regarding concern: hence a body part belongs to a subject because he sympathises and is concerned for it, a state of affairs that ceases when it is severed. Locke apparently sees identity as the product of an active process of appropriative self-attribution, one driven by a Concern for Happiness, the unavoidable Concomitant of Consciousness. To Locke, this identity-producing *Concern* is not merely hedonistic, for Self and Person, which he regards as co-referent terms (corresponding roughly to a first-person and third-person perspective on the same object), are centrally ethical concepts; self is a Forensic Term appropriating Actions and their Merit. Thus, Locke's entire discussion of personal identity has an ethical motivation with even his Cobbler and Prince' body-swap thought-experiment "moving quickly into issues of accountability for past actions as central to the assignation of identity" (Stokes 2008:647). Stokes therefore also indicates that there are passages where Locke seems to suggest "that it is not so much that moral responsibility rests upon identity, as that identity itself is at least in part constituted by the process of assuming moral responsibility: This Personality extends it self beyond present Existence to what is past, only by Consciousness, whereby it becomes concerned and accountable, owns and imputes to it self past Actions, just upon the same Ground, and for the same Reason that it does the present" (Locke 1991:II.xxvii.26).

¹¹⁰ Stokes notes that Reid also raises the famous *problem of transitivity*: while Locke insists that *Distance of Time* is no impediment to identity holding between the present self and past person-stages, it implies that if an old man remembers events from his youth, and as a youth remembered events from his childhood that, as an old man, he has now forgotten, a strict memory criterion *would have the logically intolerable consequence that a man may be, and at the same time not be, the person that did a particular action*. As Reid also notes, sameness of consciousness can only mean that two episodes of consciousness are qualitatively similar, and this doesn't secure the sort of numerical identity apparently necessary to support most of our intuitions about why identity matters (survival etc.). Reid 1790:397. According to Stokes, this last objection also seems to apply to other forms of psychological continuity which neo-Lockeans have cited as identity conditions for persons, suggesting that twentieth-century attempts to circumvent the transitivity and circularity problems still do not succeed in securing personal identity in an intuitively adequate way. Stokes refers in this regard to Velleman suggesting that perhaps Locke gives a correct account of how memory recruits past selves for me by putting them within reach of subjectively reflexive thought, but then mistakes this for a metaphysics of personal identity (Velleman 2006:193).

¹¹¹ See also Schechtman 2005:12.

¹¹² See also Schechtman 2006:166-167.

This ethical understanding of selfhood has important implications for a metaphysical understanding of personal identity, since it violates the general presumption that once we get the metaphysics of the person straight, we must then accept whatever ethical and moral consequences follow (Rovane 1993:79). Stokes indicates that for Locke, the fact of personal responsibility is not something that gets appended to a morally neutral metaphysical fact of personal identity, but that we instead find ourselves to be diachronically extended selves insofar as we are beings sensible of Happiness or Misery. Furthermore, Locke introduces a curious eschatological note suggesting that this concern covers an entire life for which one is answerable in the great Day, wherein the Secrets of all Hearts shall be laid open. Stokes notes that whether we read this literally or figuratively, Locke here seems "to want extension of consciousness to secure responsibility-bearing identity in much the same way as the soul is taken to do in many religions, not so much by acting as a metaphysical pincushion holding together atomistic moments of consciousness and functioning as a sort of receptacle for moral worth accumulated over a lifetime" (Stokes 2008:649).

However, Stokes finds it necessary to indicate that the claim that our appropriative, concern-based identification extends across our entire lives, generates further dilemmas. He notes that according to Locke, our self extends exactly as far as it can appropriatively extend its consciousness. As indicated earlier, this has traditionally been understood to mean as far as the subject can remember. There are however also familiar cases where a person may have vivid memories of their past, or expectations of their likely future and yet still have a real sense that their present self is not identical with the person whose actions they recall/anticipate. A key example is Derek Parfit's *Nineteenth-Century Russian*, a young socialist who enlists his wife's help in attempting to frustrate the reactionary actions of his older, more conservative self: "I regard my ideals as essential to me. If I lose these ideals, I want you to think that I cease to exist. I want you to regard your husband then, not as me, the man who asks you for this promise, but only as his corrupted later self. Promise me that you would not do what he asks" (Parfit 1984:327).

In addition, Stokes also cites a past directed example from Schechtman to complement this future-directed one: a Serious Matron looking back at her former life as a carefree Party Girl. Though she remembers her past clearly, she no longer shares the affective responses of the self she remembers: she lacks what Schechtman calls empathic access with this past self. The Matron sees herself as the same person as the Party Girl in a fundamental sense, but her claims that she is no longer the same self are more than merely metaphorical or derivative: she

therefore "lacks a deep, phenomenological relation between different portions of a life that goes beyond mere memory" (Schechtman 2006:166).

Schechtman claims that two types of identity are in play here: the identity of what we might call the person (which encompasses both the Party Girl and the Matron and is connected to agency) and the self (something like the present mental entity discussed by Galen Strawson). According to Stokes, this bifurcation of person and self reflects various other distinctions to be found in literature, for instance the distinction between narrative and minimal selves, Strawson's me and me and practical and psychological identity and so forth. The identity and persistence conditions of the person and the self can be quite different and therefore represents something of a departure from Locke, who despite drawing crucial distinctions between animal, substance/soul and personal identity, still maintains the continuity of the experiencing subject that defines the persistence of the self as the precondition for the capacities that make someone a person (Stokes 2008:650).

Stokes notes that his is indeed quite far from the sort of identity Locke would like to ground in the extension of consciousness, as Lockean personal identity seems largely immune to the ravages of time, whatever changes these might have wrought on the person's dispositional and affective states: "Consciousness, as far as it ever can be extended, should it be to Ages past, unites Existences and Actions, very remote in Time, into the same Person, as well as it does the Existence and Actions of the immediately preceding Moment: So that whatever has the Consciousness of present and past Actions, is the same person to whom they both belong" (Locke 1991:II.xxvii.16).

Moreover, such identity is apparently not scalar, since Locke does not seem to allow degrees of identity and does not suffer transmission loss across time. To Stokes, this is important if identity is to carry the fairly heavy normative load Locke expects it to, since we are apparently responsible for all our consciousness can extend to and not just the actions that happened within affectively accessible sections of our psychological lives. In Locke's eschatological scenario, the Serious Matron will presumably still be called to account for any misdeeds of the Party Girl, even though she finds herself so affectively alienated from that past that these misdeeds may as well have been performed by another person. Moreover, there is nothing in Locke's picture to suggest that such affective alienation will mitigate this responsibility. The thought of Doomsday might of course itself give the Matron excellent grounds for concern about that past, whether she does care about it or not - but here again there is a schism between the person as object of moral responsibility and the self as a product of concern-based affective identification. Thus, while

Locke presumably does not address this bifurcation of self-identity and person-identity simply because he does not consider the possibility that they could fail to be co-extensive, it becomes difficult to ignore Locke's uncritical certainty on this point when cases such as the Nineteenth-Century Russian and Sober Matron are taken seriously.

An amended Lockean account of identity would therefore require that the person and the self be made co-extensive. What is needed is a sort of phenomenal glue to hold together the self that I am now and the selves I access in memory and anticipation, so that my person-identity and self-identity become coextensive. In order to let the neo-Lockean project succeed in its fullest sense, it is therefore necessary to identify a phenomenal experience of becoming self to oneself which features an appropriative form of consciousness that secures a non-scalar identity with all moments of my consciously accessible life in an intrinsically normative and even perhaps eschatologically normative way (Stokes 2008:651).

In order to find a psychological experience that could answer to this Lockean phenomenology of becoming self to oneself in such a way that the boundaries of self and person coincide, Stokes turns to Kierkegaard, a thinker for whom the motifs of self-presentation, appropriation and identification are even more important.

He begins by noting that the distinction between person and self discussed above closely reflects one found throughout Kierkegaard's writings. Its clearest articulation is to be found in his Concluding Unscientific Postscript where Johannes Climacus distinguishes between the self objectively understood as a human being in general (a term which maps onto the person-identity mentioned earlier) and the self as fully comprehended subjectively or with inwardness (corresponding to the self I affectively identify with). This contrast essentially exists in regarding oneself objectively (a view of oneself at least theoretically accessible to other people) and subjectively appropriating that same object of scrutiny. Stokes notes that for instance as a human being in general, I am mortal just like everyone else. Yet from my own subjective vantage point, I am not some thing in general as I perhaps am for others (Kierkegaard 1992:I.167).¹¹³ Thinking about my own mortality is a qualitatively radically different experience from thinking about the fact that human beings inevitably die. Climacus' point here is thus a diagnostic one: in the detached, objective, absent-minded way in which we normally think about our mortality, we think of ourselves merely as a human being in general and a token of a mortal species. Like Ivan Ilyich, we think of mortality as the product of the familiar syllogism without confronting the full force of the fact that I, the contemplating self, will die (Tolstoy 1960:137).

¹¹³ See also Kierkegaard 1997:7.155.

This further demonstrates that the self as locus of present subjective experience and the human being extended across time can and do come apart in precisely the way that Locke does not seem to anticipate.¹¹⁴

While we thus also meet with descriptions of agents who fail to identify with their past or (more commonly) future selves in Kierkegaard, he is uncommonly attuned to human evasion, self-delusion and sheer absent-mindedness as the strategies that we use to avoid responsibility of which we are only dimly aware. He also knows that reflection is not always a way out of such self-delusion, absent-mindedness or semi-wilful ignorance, but that it can instead be used to sustain them as reflection can distract us from the need to act or comfort us with flattering self-interpretations. It is perhaps for this reason that Kierkegaard does not present (non)identification with representations of oneself as a reflective process, but as a matter of vision (Stokes 2008:652).

According to Stokes, to identify yourself visually, means to recognise yourself and then refers to Kierkegaard who develops an account of a form of self-apprehension that is expressed in only partly metaphorical terms as self-recognition or a form of appropriative vision in which the self identifies with representations of their past and future selves. In Kierkegaard's thought, the pseudonym Anti-Climacus particularly refers to moral imagination as a mirror of possibility or a representation of ideal selves presented as a task for emulation. There are however certain conditions necessary for this mirror to function: "Even in seeing oneself in a mirror it is necessary to recognize (know) oneself, for if one does not, one does not see oneself but only a human being" (Kierkegaard 1980:50).¹¹⁵

¹¹⁴ To Stokes, cases such as the Sober Matron and the Nineteenth-Century Russian indicate that the self - the entity having this existence right now - can become so psychologically alienated from their own temporally distant person stages that they feel themselves to be a different self from the selves that inhabited (or will inhabit) those stages. In both instances, the experience of alienation and apprehension of non-identity turns on the presence or absence of some phenomenal quality of the experience of recollection or anticipation, but is also at least partly reflective: the Matron notes how inaccessible to her the feelings and concerns are that motivated the Party Girl she remembers, while the Russian identifies with his ideals and so disavows any future selves that does not share them.

¹¹⁵ In this regard, Stokes refers to Anti-Climacus who recounts the story of a peasant who goes into town with enough money to buy new shoes and socks and get drunk. On the way home he lies down in the middle of the road and when an approaching coachman warns the peasant that he'll run over his legs, the peasant, seeing the unfamiliar clothes, replies "go ahead, they are not my legs" (Kierkegaard 1980:56). To Stokes, this literal example of seeing a human being but not oneself, serves heuristically to clarify Anti-Climacus's distinction between different ways of seeing. In modes of imaginative activity such as idle fancy or fantasy, we can imaginatively represent future courses of action as possibilities for us without really identifying with the *us* in that representation on a subjective level, which eventually plays out phenomenally as a failure to recognize ourselves. Of course, in these cases (and unlike the unfortunate peasant) we no more see the self presented in imagination (or memory) as another person than our Sober Matron or Russian do, but we nonetheless do not fully identify with that self either. In some sense it is merely a representation of a human being and not of the self we experience ourselves as being right now. The same thought (though applied to moral exemplars and narratives that only implicitly contain the receiving subject rather than imaginative representations in which the subject is explicitly figured) is captured in another Kierkegaardian mirror-metaphor: looking into a mirror and seeing the mirror rather than oneself (Kierkegaard

According to Stokes, this phenomenal, pre-reflective experience of identification with remembered and imagined selves' sounds tantalisingly similar to Locke's talk of appropriating past and future actions to ourselves through sameness of consciousness. Moreover, Kierkegaard's mirror-metaphors exploit the same gap between the phenomenal experience of self-identity and cognitive awareness of person-identity that is operative in the Matron and Russian examples. Yet, while Schechtman can only point to psychological benefits (a 'richer and smoother' life) that may contingently follow from reunifying these two modes of identification, Kierkegaard presents these instances of non-recognition as moral failures. Specifically, the failures of recognition Kierkegaard describes are instances where self-experience does not map onto the full extension of the person as an object of responsible concern. Also the suggestion noted in Locke, namely that the self is constituted by moral responsibility rather than serving as its (morally neutral) basis, is also to be found here: not to identify with the ideal self figured in my imaginative projection is a failure to actualise oneself.

To Kierkegaard, the immediate person who lacks a moral sense of appropriation over his life as an agent, accordingly finds self-recognition to be problematic: "The question of immortality has often occupied him, and more than once he has asked the pastor whether there is such an immortality, whether one would actually recognize himself again - something that certainly must be of very particular interest to him, since he has no self" (Kierkegaard 1980:56). That *Anti-Climacus* raises an eschatological scenario at this point also echoes Locke's references to the great Day wherein each shall receive his doom with his conscience accusing or excusing him. To Kierkegaard, eschatologically qualified self-hood extends the moments of personhood that the self is responsible for to the greatest extent possible in that it demands one to identify with an unthinkable different self in the afterlife and a self that has undergone changes beyond anything found in the most extreme science-fiction scenarios in the neo-Lockean literature. It also invests each moment of the agent's life with equal importance, in that at each moment the self's eventual fate is equally at risk. Where identity is constituted by appropriative taking responsibility for such moments, there is no transmission loss in the sense mentioned above, as each moment is equally important and so equally of self-concern. To the extent that the Matron and the Russian disavow responsibility for their past and future actions they fall short of such phenomenal identification, even if they intellectually accept that they are the same person as their temporally distant person-stages.

1990:25). Stokes notes that in such a case, we see the image, but not our relation to it and again fail to see a connection between our current self and the self posited in such a representation (Stokes 2008:653).

In this regard Stokes refer to Schechtman who notes that the co-extensivity of self and person, which Anti-Climacus presents as normatively required, will have to consist in some sort of deep, phenomenological relation between different portions of a life. Kierkegaard's quasi-metaphor of recognition also serves to locate such experienced co-extensivity on the phenomenal rather than reflective or cognitive levels. Given the immediate, volitionally ambiguous character of vision, describing self-identification as self-recognition, indicates that such identification is something we experience and not something we reflectively deduce or infer. Kierkegaardian recognition, like the inwardness with which Kierkegaard invites us to think about our death, is precisely a phenomenological rather than reflective element in thought. However, Stokes concedes that a fuller picture is required in order to determine how this phenomenal experience of identification will differ from the sorts of affective accessibility that Schechtman posits or from other candidates for such a role such as sympathy, familiarity or the warmth and intimacy that James claims attaches to our memories, but not the memories of others (James 1950:331-336). To that end, Stokes turns to another aspect of Kierkegaard's phenomenology, namely the dialectic of presence and absence in recollection and anticipation (Stokes 2008:654).

According to Stokes, the phenomenology of subjective identification with one's remembered and anticipated selves are thrown into clearest relief by those who claim to have no such experience. Galen Strawson has argued that as an Episodic, he lacks a strong sense that the I that is a mental presence now was there in the past and will be there in the future (Strawson, G. 1999:109). Whilst Strawson is perfectly aware of the fact that he is a human being with extension across time and can access memories associated with that history, he does not find anything within those memories that would amount to a sense that his presently existing self, the entity having the experience in the present, is to be found in them. To Stokes this represents an extreme form of the bifurcation discussed earlier: the Episodic self experiences little or no overlap between the person and the self (in Schechtman's terminology) or the human being me and the self me (in Strawson's). Strawson admits that episodicity is scalar, but regardless of whether completely episodic individuals occur, the figure of such an Episodic provides a paradigm case of the separation of person- identity and self-identity.

In trying to describe the phenomenal quality of episodic self-experience, Strawson refers to not experiencing a sense being present in the past and future. In *Either/Or*, Kierkegaard's exhausted young aesthete A also describes ways in which the self can find itself to be present or absent in the past and the future: "The unhappy one is the person who is always absent from himself, never present to himself. But in being absent, one obviously can be in either past or future time" (Kierkegaard 1987 I:222). Stokes notes that this language of presence to oneself superficially

sounds like Locke's self to himself, but is interested in what it might mean in this case. A may regard it as obvious that one can be absent to oneself by being in either past or future time, but this seems less than perspicuous and his next comments hardly seem more illuminating: "There are the hoping and the recollecting individualities [...] strictly speaking, one cannot call an individuality unhappy who is present in hope or recollection. The point to stress here is that he is present in it" (Kierkegaard 1987 I:223).

In response, Stokes points out that in Kierkegaard's thought, being present to oneself in the past and the future is expressly linked to recollection and hope (Stokes 2008:655). Selves engaged in these activities are, apparently, present in the past or the future insofar as these activities posit them there, but this seems to add nothing more than that selves are posited in memory and anticipation. Stokes also consider the possibility that perhaps, the perspectival structure of episodic memory and anticipation means that these selves are, in Velleman's terms, figured in the notional first-person (Velleman 1996:193), but this again adds nothing about whether they are the same self as the self doing the recollecting or hoping. According to Velleman, these selves are my selves insofar as I can regard them as accessible to my first-person perspective without any further stipulations of identity and this will ultimately depend upon the causal history of the images themselves as that history would seem to circumscribe what can and cannot count as *real* memories. He furthermore also points to the fact that Kierkegaard too, speaks of a reality constraint with regard to memory and anticipation: "In order for the hoping individuality to become present in future time, it must have reality or more correctly, it must acquire reality for him; in order for the recollecting individuality to become present in past time, it must have had reality for him. But when the hoping individuality wants to hope for a future time that nevertheless can acquire no reality for him, or the recollecting individuality wants to recollect a time that has had no reality, then we have essentially unhappy individualities" (Kierkegaard 1987 I:223).

Thus, from this it seems that in order to become present in the past or future depends upon the reality of what is thereby envisioned and that if the past recollected had no reality or we hope for something that can have no reality in future, then we are not present in the past or future. To Stokes, this resembles a claim that presence or absence is determined or constrained by some sort of external actuality criteria, which, to be viable, would have to assume the identity of the rememberer/hoper and their remembered/anticipated selves. However, construed in this way, such presence could only serve as evidence of identity; to claim it as constituting identity would expose it to Reid's circularity objection and therefore this 'presence' in memory and anticipation,

whatever it is, apparently cannot be Lockean extension of consciousness if this is going to constitute identity (Stokes 2008:656).

However, this being Kierkegaard, Stokes points out that things are not that simple. The reality that A refers to is further qualified as a decisive reality, as agent-specific and as not restricted to events within the human life of the rememberer, as events long before his birth can acquire decisive reality while remembered events within his own life may not have it: "If, for example, an individual became absorbed in antiquity or in the Middle Ages or in any other time, but in such a way that it had decisive reality for him, or he became absorbed in his own childhood or youth in the way that this had had decisive reality for him, then, strictly speaking, he would not be an unhappy individuality. But if I were to imagine a person who had no childhood himself, since this age had passed him by without real meaning, but who now, for example, by becoming a teacher of children, discovered all the beauty in childhood and now wanted to recollect his own childhood, always stared back at it, he would certainly be a very appropriate example. He would discover backwards the meaning of that which was past for him and which he nevertheless wanted to recollect in all its meaning" (Kierkegaard 1997 2:218).

Accordingly, Stokes indicates that the reality constraint on presence in memory and anticipation therefore does not seem to be coextensive with facts about the biological life of the person. Moreover, the reality A is speaking of does not consist in facts about the person (which are presumably intersubjectively knowable and hold regardless of whether the subject knows them or not) but is rather reality for the subject. This seems to bring the argument closer to Locke again, for whom sameness of consciousness could theoretically make me the same person as one who saw Noah's flood, and for whom the extension of consciousness through time is always discussed as becoming self to oneself. Here, past and future events are presented to the self in a way that somehow gives them reality by virtue of their meaning to the subject (Stokes 2008:657).

An apparent asymmetry between recollection and hope may be evident here, in that one appears to be an affectively neutral exercise of memory while the other is affectively charged. I can remember eating breakfast this morning with no particular accompanying affect and I can imagine tomorrow's breakfast with similar unconcern. But to hope is something affectively richer than merely imagining.

However, to Stokes there is an important difference in the way Kierkegaard uses the verbs to remember and to recollect. In *Stages on Life's Way*, the pseudonym William Afham makes this distinction explicit: memory is immediate and is assisted immediately, while recollection can

only be assisted "reflectively" (Kierkegaard 1988:12); recollection is "ideality, but as such it is strenuous and conscientious in a way completely different from indiscriminate memory" (Kierkegaard 1988:10). Memory is indiscriminate in that it merely provides a mass of details which, rather than aiding, can actually distract recollection (Kierkegaard 1988:14). Whereas memory merely provides data, recollection is concerned with the essential and is conditioned not only by itself but also by its relation to the person concerned (Kierkegaard 1988:12). Recollection as a cognitive act thus involves a reflexive relationship to the person doing the recollecting, one that is lacking in the case of mere memory. The result is that while memory concerns mere facts, recollection is concerned with a specific task: "to maintain for a person the essential continuity of life and assure him that his earthly existence wants to remain *uno tenore* [uninterrupted], one breath, and expressible in one breath" (Kierkegaard 1988:10). To Stokes, a good episodic memory is therefore not a sufficient condition for recollection: indeed, Afham relates that many memoirs have no doubt been written that are products of memory but contain no recollection (Kierkegaard 1988:11). Such works would be like a notebook in which one scribbles anything that comes to mind or mere chronicles of the 'chatter' of events without any coordinating reference to the person who is once again understood in eschatologically normative terms: "The condition for mans immortality is that life is *uno tenore*. Strangely enough, Jacobi is the only one who, as far as I know, has commented on the terror in thinking oneself immortal. [...] However, as soon as one confuses memory and recollection, the thought is not so terrible - in the first place because one is bold, manly and robust, and in the second place because one is not thinking the thought at all" (Kierkegaard 1988:10-11).

To Stokes, recollection therefore differs from memory in that it reflexively refers back to the recollecting self. Recollection therefore does not merely reproduce self standing memories, but as Robert E. Wood puts it, ripens experience by bringing what is essential in the past into the present (Wood 2000:63). And what is essential is here constituted by its relation to the self as the subject of an eternal accounting: in the bookkeeping of recollection, a person draws on the eternal, which regards everyone as solvent. It soon becomes clear that Afham fails to live up to his own rather stringent conception of recollection, for like two figures in *Either/Or* (*A* as author of *The Rotation of Crops* and Johannes the Seducer), he seeks to elevate recollection to something like an aesthetic art, one that conjures away the present (Kierkegaard 1988:13) rather than situating the agent in the present. But the distinction between memory as the disconnected apprehension of past episodes and recollection as the reflexive relating of these episodes to a normatively emplaced, eschatologically qualified ethical subject nonetheless stands.

It's in this way that past events can present themselves to a subject in such a way that they acquire *decisive reality* for the subject. The apparent affective asymmetry between recollection and hope is thereby dissolved, because both are now shown to be reflexive in much the same way. Both are imaginatively mediated apprehensions of a distant point in time, but both also point back to the imaginer in a way that mere memory and idle fantasy do not (Stokes 2008:658).

Stokes however concedes that it is still unclear as to how this manifests on the phenomenal level and as an experience of presence in the past and future. He notes that unhelpfully, *A* says little about what it is to be present to oneself in past and future; like many of Kierkegaard's pseudonyms, he presents normative relations only in negative relief by sketching their corresponding mis-relations. The unhappy consciousness lacks presence in the past and future, because it suffers from a "misrelation in the self's temporal categories which results in an unquenchable desire for an absence impossible to make present" (McDonald 2003:68). In Kierkegaard, this temporal mis-relation consists in "hoping for that which should be recollected and in recollecting that for which [one] should hope, leaving the self turned the wrong way in two directions" (Kierkegaard 1987 I:225). Caught up in what George Connell describes as a complex temporal bi-directionality (Connell 2006:427), this self adopts attitudes towards the past and future that are incompatible with the temporal emplacement of the remembering/projecting subject. Through overleaping the future to turn back and recollect it in a mode of anticipatory recollection or hoping for events that are already in the past, the self flouts the directionality necessary for being an agent in time. Particularly in eschatological time, for a self concerned with salvation, however this is understood, is necessarily oriented towards some indeterminate future.

Torn out of the schematisation of temporality, the imagined/remembered selves we encounter cannot point back to us as concrete agents who must act in a unidirectional temporal context. They become like the chatter of memory or mere data devoid of a reflexive relation to the imaginer. Conversely, according to Judge William's response to *A*, "the healthy individual lives simultaneously in hope and in recollection, and only thereby does his life gain true and substantive continuity" (Kierkegaard 1987 II:142), appropriating memories and anticipations into his life as an ethical agent in the conative attitude appropriate to his current position in the stream of events. He thereby appropriates events encountered in memory and imagination to himself as events in his life as the self he is now. Stokes notes that this gives a better indication of what appropriative memory and anticipation will be like, but the question remains why should this be experienced as presence in the past and future? The Matron and Russian aren't

presented as hoping for the past or recollecting the future; they just experience non-identity with the past/future selves they remember/project. Thus, in order to bring the phenomenological character of presence in memory and anticipation in sharper focus, Stokes further explores Kierkegaard's writings (Stokes 2008:659).

In this regard, Stokes notes that the evocative, but somewhat unclear language of presence and absence in *Either/Or* needs to be further situated in the context of an important concept that is found throughout Kierkegaard's authorship and was also subsequently taken up by Bonhoeffer (Bonhoeffer 1966:32) and Gadamer. The Kierkegaardian concept of contemporaneity is primarily concerned with contemporaneity as a psychological feature of religious belief, with the believer enjoined to attain a state wherein they become contemporary with Christ. Such contemporaneity, according to Climacus, cancels the apparent epistemological advantage of Jesus contemporaries over historically later followers: "But what does it mean to say that one can be contemporary without, however, being contemporary, consequently that one can be contemporary and yet, although using this advantage (in the sense of immediacy) he a noncontemporary - what else does this mean except that one simply cannot be immediately contemporary with a teacher and event of that sort, so that the real contemporary is not that by virtue of immediate contemporaneity but by virtue of something else" (Kierkegaard 1997 4:268).

This something else is a quality of faith that overcomes the distance between the historical eyewitness and the later follower, removing any impediment to belief the latter might be taken to have by comparison. In Kierkegaard, the direction of the argument is twofold: insofar as the god [...] cannot be envisioned, the divinity of Christ cannot be discerned by direct inspection and accordingly being an historical contemporary is of no assistance in coming to believe therein. Equally, though, there is some quality of faith that amounts to a reconstitution of contemporaneity, whereby both the eyewitness and the later follower are contemporary by virtue of believing. In this way, according to the later *Book on Adler*, "the person who becomes a Christian in 1846 becomes that by being contemporary with Christianity's entry into the world in the same sense as the contemporaries were eighteen hundred years ago" (Kierkegaard 1995:38). In this regard, Stokes on purpose refers to Mark C. Taylor who summarises this in terms of all believers becoming equidistant from the event of incarnation (Taylor 1975:303), as he makes special use of the concept of distance in his further discussion.

That Climacus feels the need to reinstall contemporaneity as a condition or description of religious belief after having previously dismissed it as being of any help in acquiring faith,

suggests a new sense of contemporaneity that is in some way qualitatively distinct from the merely historical sense. For sound textual reasons, commentators have chosen to regard this second sense of contemporaneity as concerned with concrete action, choosing to live as if one were an historical contemporary. However, it is also worth attending to the phenomenological aspects of Kierkegaardian contemporaneity and especially what it experientially implies to become contemporary in the higher sense (Stokes 2008:660).

In further exploring the phenomenological aspects of Kierkegaardian contemporaneity, Stokes notes that in *Either/Or*, Johannes the Seducer regrets that however accurately he recollects his conversations with the object of his seductive intent, "he can never reproduce the element of contemporaneity, which actually is the nerve in conversation, the surprise in the outburst, the passionateness, which is the life principle in conversation" (Kierkegaard I:399). Here, contemporaneity apparently picks out a quality of direct experience, of being there that at least for Johannes cannot be reproduced in even the most accurate of memories. Such a quality must therefore be something beyond the sensory content common to both direct experience and memory. It's a quality that, according to Petrus Minor in *The Book on Adler*, allows events to really come to grips with us (Kierkegaard 1995:42). Its absence is often experienced when we see presentations of utterly extraordinary events in the theatre, the newspaper or on the pulpit without receiving such an impression, which according to Petrus happens, "because he in the first instance lacks imagination; in the last he lacks the inner experience for really becoming contemporary with what is depicted, because he thinks like this: it is, of course, many years since it happened" (Kierkegaard 1995:42). Here once again, presence becomes a key feature of contemporaneity, opposed this time to distance - the distance of 1,800 years which the believer uses to avoid confronting the full implications of belief. Whilst Anti-Climacus states that it is easy to believe that extraordinary things (such as the incarnation) happened in the distant past, the contemplation of such distance is actually a strategy for keeping the full force of what is contemplated, and the concomitant necessity of choosing to believe or disbelieve, at bay (in much the same way as we might discuss war casualties in abstract, numeric terms to avoid confronting the true horror of such losses) (Stokes 2008:661).

However, in contemporaneity no such evasion is possible. Phenomenologically, the encounter with what is imagined has a quality of direct presence, a quality as if what is being imagined is occurring right here and right now. This need not erase the knowledge that these events are in the past or future (as would be the ease in some types of flashback' to traumatic events or the reliving of past experiences by dementia patients), which would obviously hinder agency. Rather, these past/future events would be experienced with the same urgency as that presented

by features of the immediately present environment. Contemporaneity, then, is to be understood as a quality within the experience of memory and imagination that amounts to a synchronic experience of the past and present or future and present. However, Johannes the Seducer's inability to become contemporary despite his mastery of recollection and imagination and Climacus' claim that eyewitnesses have no advantage in becoming believers make it clear that contemporaneity is not to be understood as a function of some 'visual' quality of the representation itself as if contemporaneity were a quality memories had because they are unusually detailed or realistic. Whatever the phenomenal property of contemporaneity is, it can't just be vividness or realism. In *Practice in Christianity*, Anti-Climacus names the element missing in non contemporaneity: "The qualification that is lacking- which is the qualification of truth (as inwardness) and of all religiousness is - for you. The past is not actuality - for me. Only the contemporary is actuality for me. That with which you are living simultaneously is actuality - for you" (Kierkegaard 1991:64).

To Stokes this means that I can become contemporary with events insofar as I experience them as making a direct claim upon me. In the paradigm instance of contemporaneity with Christ, I can only achieve such a state insofar as I experience the imaginatively mediated events of the New Testament as speaking directly to me and calling upon me to make a response; in this sense I am - more than merely metaphorically - every bit as much present with these events as the eyewitnesses. What is at issue is a phenomenal, non-reflective quality of direct presence with the past (and future, as evidenced in Kierkegaard's non-pseudonymous discussion of presence with your own death in *At a Graveside*, where if you think earnestly about your death, then you are and death also is) (Kierkegaard 1997 5:446). Such co-presence, says Stokes, is constituted by a sense of normative obligation, a sense of being directly and personally claimed by what is experienced, an experience that what I imagine is something that I, the person I am right now, cannot be indifferent to.

On strength of these arguments Stokes notes that if this phenomenology of contemporaneity lives up to expectations, it has important implications for the sort of problems that have been under discussion. He has been looking for a quality of consciousness that can link our subjective sense of self to all moments encompassed within the bounds of our personhood, something that can overcome the radical changes in temperament, belief, values, projects, concerns and empathic access' that are characteristic of human lives. Kierkegaardian contemporaneity, which purportedly allows the subject to experience memories with a phenomenal quality as if they were happening here and now with, as Locke might say, the same consciousness - would seem to be precisely such a quality (Stokes 2008:662).

To become contemporary with one's remembered/anticipated person stages would according to this approach, be to reflexively relate that memory back to me as I am now in a way that is not frustrated by the discontinuities of character and affective access that prevent the young Russian and the Sober Matron from experiencing co-identity with their past and future selves. Schechtman's Matron may not be able to share the Party Girl's affective responses or concerns, but insofar as she directly experiences the Party Girl's memories as something she is responsible for, independently of facts about psychological similarity or difference, but instead on the basis of a holistic responsibility for the moral status of her entire life as a person, she can experience those past events as her experiences. She recollects rather than merely remembers, and thus, in Climacian terms, grasp them with the phenomenal *inwardness* that comes from regarding her past with a normatively qualified infinite, passionate interest. The same applies, *mutatis mutandis*, to Parfit's Russian.

A corollary of this way of viewing these examples of affective alienation is that the failure of identity they represent becomes in itself a moral failure and an attempt to evade responsibility for the past. In *Sickness Unto Death*, says Stokes, this evasion is diagnosed as despair or the condition of not wanting to be the self that one is (with its distinctive, concrete history and responsibilities) or wanting to be that self considered under one aspect to the exclusion of others. Anti-Climacus offers diagnoses that neatly fit the Young Russian and Sober Matron: "The youth despairs over the future as the present in futuro; there is something in the future that he is not willing to take upon himself, and therefore he does not will to be himself. The adult despairs over the past as a present in praeterito [in the past] that refuses to recede further into the past, for his despair is not such that he has succeeded in forgetting it completely, This past may even be something that repentance really should have in custody" (Kierkegaard 1980:59).

A lack of affective identification here is not a morally neutral psychological fact, but rather a symptom of a failure to take responsibility for the past or future. It points to an attempt to actively distance oneself from the past or future rather than a merely passive apprehension of distance. In trying to distance itself from the past, the self ultimately hopes for healing it by forgetting it and by making the self into a "receiver of stolen goods" (Kierkegaard 1980:60). In this regard Stokes concedes that it would be open to Strawson to simply to reject what amounts to a claim that Episodic self-experience is morally deficient, a charge voiced against Strawson several times from within the analytic tradition and which he has attempted to refute by claiming that diachronic self-experience is not necessary for moral responsibility. While he does not deal with the issue in this article, he acknowledges that the question will largely come down to how intuitively persuasive Kierkegaard's diagnosis of absent-minded remorse or guilt as lacking

something morally significant is and how compelling the description of contemporaneity as filling that lack will be (Stokes 2008:663).

In trying to bring his argument to a conclusion, Stokes also refers to the fact that it could also be objected that not all remembered or anticipated moments have any obvious normative claim attached to them. It's difficult to see how memories and anticipations of such ethically neutral activities as eating breakfast can make any particular normative claim on me, leading to the disquieting suggestion that I am the same self who incurred some terrible guilt twenty years ago but not the same self who had cornflakes for breakfast last week. A further objection is that the moral demands a given memory makes on me now can be quite different from those they made at the time the memory was formed. I may experience a moral claim when I look back upon my long-past failure to assist a person in immediate distress, but the prescriptive content of that claim is quite different from the claim operative upon me at the time the memory was formed. If sameness of consciousness consists in an apprehension of moral responsibility, we might worry that what I am conscious of in direct experience and subsequent recollection can be far from the same.

According to Stokes, both these objections can at least be partly answered by reiterating that Kierkegaard's thoroughly eschatological account of selfhood implies that all moments of existence are infused with equal, infinite importance. Insofar as I am subjective, with subjectivity essentially regarded as passion and at a maximum an infinite, personally interested passion for one's eternal happiness (Kierkegaard 1992 I:33), then this passion applies with equal *infinity* to all moments that count towards that eternal happiness. In this regard he also refers to one of Kierkegaard's favourite expressions, namely "that we are out on 70,000 fathoms of water at all times" (Kierkegaard 1988:444). Thus, just as the soul is sometimes envisaged as a container for all the moral guilt/worth accruing across a lifetime, so too for Kierkegaard eschatology brings every deed into the position of being judged: "The arrangement is such that through the conscience the report promptly follows each guilt, and the guilty one himself must write it. But it is written with invisible ink and therefore first becomes clearly legible only when it is held up to the light in eternity while eternity is auditing the consciences. Essentially, everyone arrives in eternity bringing along with him and delivering his own absolutely accurate record of every least trifle he has committed or omitted. Thus a child could hold court in eternity; there is really nothing for a third party to do, everything down to the most insignificant word spoken is in order" (Kierkegaard 1980:124).

Seen from this perspective, my salvation is thus no less at risk while eating cornflakes than when ignoring a plea for assistance. Stokes admits that this reply may seem implausible as I surely damage my soul more when behaving callously than when simply eating breakfast. However, relating this thought by appeal to our epistemic limitations, it could be asked how I could ever know with the certainty required as if my salvation depended on it that eating this specific cereal doesn't implicitly support some fundamentally exploitative business or economic system? Infinite concern would require that even these distant ethical possibilities would have infinite significance (Stokes 2008:664).

As to the second objection, Stokes notes that if sameness of consciousness is secured by an apprehension of past, present and future person- stages that I am responsible for, then this will be at least conceptually prior to any determination of the precise demands entailed by that responsibility. Hence in my experience of failing to render assistance and in later recalling this experience, the nature of what I am obligated to do right now will be different, but the experience that I am responsible for this event in my life will be the same. Moreover, he points out that it may be that we make a mistake when we try to cast 'sameness of consciousness' in tenseless terms, which may make the second objection moot.

Stokes commences the formulation of the implications and conclusions of his argument by reverting to his original problem statement, namely to identify some phenomenal property of consciousness that can serve to unify our awareness of ourselves as persons/humans with our subjective identification of our selves, to make person-identity and self-identity co-extensive. He proceeds by noting that what appeared necessary, especially with regard to Locke's picture of sameness of consciousness as securing sameness of self, is some quality of experience that appropriates past and future selves to myself in a way that is non-degrading across time (and apparently non-scalar) and not vulnerable to changes caused by alterations in character, concerns and emotions across time. Kierkegaard's reflexive contemporaneity appears to satisfy these demands as it seems to coincide with Schechtman's view that to experience a past event as belonging to myself, I do need to identify with it or care about it or take an interest in it. These events must condition the quality of present experience in the strongest sense, unifying consciousness over time through affective connections and identification. Stokes argues that the eschatological basis of Kierkegaard's account allows contemporaneity to constitute precisely such a strong form of experienced identification in ways that, unlike empathic access, are independent of facts about psychological change (Stokes 2008:665).

For Stokes it is important, however, to note the significant extent to which any Kierkegaardian account of personal identity emerging from that phenomenology will differ from that of Locke and his lineal descendants. Mainstream psychological identity theories see personal identity as inhering in the continuity of some form(s) of psychological property or state of affairs (such as appropriately caused memory) and try to find some such properties that are present in all but extreme cases such as radical amnesia, mind-swaps etc. Consequently, they seek a quality on the basis of which the self can be said to exist already. He notes that one of Kierkegaard's most original contributions to the discussion of selfhood, however, is his claim that the self is something that must be actualised and that it is easily lost: "The greatest hazard of all, losing the self, can occur very quietly in the world, as if it were nothing at all. No other loss can occur so quietly: any other loss - an arm, a leg, five dollars, a wife, etc. - is sure to be noticed" (Kierkegaard 1980:33).

Kierkegaard is quite clear that contemporaneity is not something automatically given, but is rather something that must - and that is also a normative must - be achieved and that it remains vulnerable (as the Russian and Matron examples also seem to demonstrate). What the Kierkegaardian approach suggests is that Locke was right to take self to be constituted by sameness of consciousness, but was wrong to see this as a mere description of a state of affairs that always already obtains. Hence cases of psychological change over time are not objections to Lockean selfhood, but are rather descriptions of cases where such selfhood has not been achieved. The descriptive account of selfhood is thereby replaced by a normative account - a move that, in some respects, contemporary personal identity theory has been moving towards for some time in the work of writers such as Christine Korsgaard (Korsgaard 1989).

In addition, Stokes notes that another point of departure from at least the more traditional versions of neo-Lockean identity theory is that these look for forms of psychological relatedness that hold across time. As a result, they cite continuity of one or more psychological properties or states as answering the question of how we reidentify selves. However, it is far from clear that the Kierkegaardian approach, which is fundamentally interested in the self as an object of existential/ethical concern, could answer that question. In Kierkegaard, presence or contemporaneity with one's past/future selves amounts to a form of synchronous experience in which the past and future are brought into the present, rather than extending the present self into the past and future. While contemporaneity might thus provide an answer to the question of what links me now to my past and future, it might not give an answer to this question in an untensed form. According to Stokes, this need not be a reason to throw the Kierkegaardian model out completely, as it just may be that the question of personal identity indeed is a

personal and existential one which can only be asked from the present and never from an atemporal nowhere. Should that be the case, says Stokes, then what secures persistence of selves across time and what secures my co-identity with my past and future selves are two different questions - and in the context of the existential problem of personal identity, Kierkegaard suggests that raising the impersonal question can only be a distraction from the requirement to deal with the personal one. The Kierkegaardian model thus suggests that there is something wrong with any attempt to envision selfhood from the outside, either outside of the individual subjectivity or outside of the present moment, as this would vacate the position of irreducibly existential moral concern that motivates the question in the first place (Stokes 2008:666).

Stokes thereby concludes his argument by stating that despite these concerns, "Kierkegaard's phenomenology of self-presence and contemporaneity in memory and anticipation seems to describe the reunification of phenomenally experienced selfhood and practical/moral person-identity that has eluded neo-Lockeans. It gives us a compelling phenomenological description of what it is to experience past and future selves as being us in a way that overcomes the bifurcation of self and person, and moreover, it reinstalls such a reunification as a properly moral concern" (Stokes 2008:667).

5.4 THE COMPLEXITY OF THE CONTEMPORARY UNDERSTANDING OF PERSONAL IDENTITY

The threat of the bifurcation of self and person encountered in the thought of John Locke and Søren Kierkegaard is however not only a matter of academic interest, but is also perceptible in medicine in general and in the practice of clinical decision making in particular and is to be understood within the larger context of a universal interest in the concept of the self.

The self has over centuries been a central focus of philosophers, phenomenologists, psychologists, literary scholars, linguists and semioticians who have all been intrigued with the nature of being - whether it is constant, performed at birth, created by God, present even before language, unitary or various, provable, transcendent or ever developing through actions (Charon 2006:68).¹¹⁶

Taylor captures something of the vastness of the question on the constitution of the self by stating: "Perhaps the best way to see this is the focus on the issue that we usually describe today as the

¹¹⁶ Charon's application in medical practice of the *threat of the bifurcation of self and person* encountered in the thought of John Locke and Søren Kierkegaard is decisive for the study. I therefore, from the outset, acknowledge my indebtedness to the work of Charon: Charon, R. (2006). *Narrative Medicine*. New York: Oxford University Press.

question of identity. We speak of it in these terms because the question is so often spontaneously phrased by people in the form: Who am I? But this can't necessarily be answered by giving name and genealogy. What does answer this question for us is an understanding of what is of crucial importance to us. To know who I am is a species of knowing where I stand. My identity is defined by the commitments and identification which provide the frame of horizon within which I can try to determine from case to case what is good, or valuable, or what ought to be done, or what I endorse or oppose. In other words, it is the horizon within which I am capable of taking a stand" (Taylor 1989:27).

Furthermore, scholars interested in the questions about identity also endeavour to answer them within the contexts of their respective disciplines. As such, psychologists for instance asked questions about the self in terms of interpersonal behaviour, sociologists in terms of individuals' social roles, literary scholars in terms of the texts that result from the search for identity, biologists in terms of the body and the brain that support and display whatever the self might turn out to be and philosophers in terms of concepts like autonomy and morality (Schafer 1992:21-35). What all these scholars have in common is to examine who they are, how they got to be that way and how many selves are still available to them. However, as such, their examination is simultaneously a demonstration, since it is in the very acts of discoursing about identity that they identify themselves (Charon 2006:69).¹¹⁷

Whereas today, the narrating of life stories has become a priority to many (Smith & Watson 2001), the study of especially autobiographies has become a useful way of coming to grips with the practice of relating about the self (Olney 1972).¹¹⁸ With regard to the writing of life stories, psychologist Jerome Bruner notes that "it is through narrative that we create and recreate selfhood ... If we lacked the capacity to make stories about ourselves, there would be no such thing as selfhood" (Bruner 2002:85-86). Thus, whether your life story is published or not, it is inspired by the same motives and it is aimed at delivering the same results. It endeavours to obtain clarity about the self which can only be attained through putting into language that which you sense about yourself and can therefore also be regarded as a plea for affirmation while it simultaneously puts into action an honest and sometimes even brutal, but always creative knowledge of oneself (Charon 2006:70).

The writing of an autobiography always creates a gap between the person doing the writing and the person on whom the autobiography is written, even though these two people are identical. This gap is commonly known as the autobiographical gap and not only refers to the space

¹¹⁷ See also Kerby 1991.

¹¹⁸ See also Eakin 1985; Eakin 1992.

between the narrator-who-writes and the protagonist-who-acts, but also to the very powerful distance of reflection without which it is impossible to consider your own actions, thoughts or life. It is within this reflective space that you behold and consider the self in a heightened way and reveal fresh knowledge about its coherent existence (Charon 2006:70).

The writing of a life story usually resists ordinary time and allows past and present to coexist not only in the mind of the author, but also in the forthcoming text and hereby facilitates a future that would be impossible without the writing of the autobiography. In this regard Pascal notes: "Autobiography is then an interplay, a collusion, between past and present; its significance is indeed more the revelation of the present situation than the uncovering of the past" (Pascal 1960:11). Sisson goes even further by noting: "Remembrance, reflection, and reconstruction are all indispensable elements of the enterprise, but (contrary to the usual perceptions) they are all aimed mainly at the life that lies ahead, not at the one already lived" (Sisson 1998:99).

Any autobiography can therefore not be considered apart from fundamental beliefs about the self which in turn are influenced by beliefs regarding the nature of elements such as language, thought, consciousness, time, memory and relation. To thus relate your life story is to ask intimate questions regarding aspects such as the reality of your memory, the authenticity of your self-regard or self-condemnation, the continuity or discontinuity achieved throughout your life, the relation of memory to experience and the relation between the writing of the self and being that self (Charon 2006:70).

These elements belonging to relating life stories are perceptible in the history of autobiographical theory as well, which also traces the evolving stages of our comprehension of what might constitute a self and what might constitute a life. In this history, St. Augustine's *Confessions* is not only commonly regarded as the first published autobiography, but also remains the touchstone for contemporary ideas of temporality and personal reflection. In this field, St. Augustine's view that the past as memory and the future as anticipation can only exist in the present, still represents the foundation of reflective life writing to this day.¹¹⁹

Until the mid-1950s, autobiographies were regarded by scholars as a marginal source of information for historians, literary critics and biographers (Charon 2006:71). This was due to the fact that autobiographies until then were used to stamp one version of a person's life as the authoritative and unquestionable one and to portray autobiographers as fully formed and autonomous selves who exerted power in the world and remained whole and unchanged throughout their lives. Inspired by anthropologist Georges Gusdorf, early students of

¹¹⁹ For a complete discussion of the concept of Augustinian temporality, refer to Ricoeur 1984-1988:Vol.1.

autobiography thus read autobiographies as straightforward and authoritative reports of a cohesive self (Gusdorf 1980:28-48).

However, from the 1960s, intellectual life came under the influence of French critical theory that amongst others asserted that the subject or the self is not contained within the person, but is instead socially constructed and to be regarded as an invention of language or culture and as stripped of any supremacy outside of the words it might produce. Once the author has been redefined as figural, functional, ventriloquistic or even dead by scholars such as Roland Barthes, Michel Foucault and Jean Paul Sartre, autobiographical reports on the self came under ironic critique.¹²⁰ Moreover, while psychoanalytic concepts of the unconscious had been an essential component of the belief in the autonomous self by providing a model of a self-contained, though layered, self, the French psychoanalyst, Jacques Lacan now reinterpreted Freud to suggest a textual unconscious self constituted through its relation with others (Charon 2006:71).

By the late 1960s French critical thought started challenging the then widely accepted belief in the autonomous individual who, within limits, was not only able to direct the course of his or her life, but also to talk about it.¹²¹ The concept of the self as intact and permanent was now replaced by a self conceptualised as a fragmented, ambiguous and ever-changing cultural construct that is fore-ever being created by subjective sensations, by power relationships over which there are no control and by evanescent changes in making sense of the world. Accordingly, the self now has to endure the contingency of never exactly knowing who he or she is, but also enjoys the freedom of creating that identity anew every day (Charon 2006:72).

However, these changes in perceptions about the self inevitably also changed the practice of autobiography. By the late 1970s, literary critics agreed that in writing your autobiography, "you do not report, but rather eavesdrop on yourself" (Jay 1984). In deconstructing the concept altogether, Paul de Man suggested that "autobiography, then, is not a genre or a mode, but a figure of reading or of understanding that occurs, to some degree, in all texts".¹²² Autobiography thus came to be regarded as a field in which conflicts among self, identity and discourse could be observed and as a source of evidence of the vortex of cultural, political, economic, artistic and intellectual forces that influence the situation of every person (Charon 2006:72).

These changes in perceptions about the self have practical implications for medicine in general and for the practice of clinical decision making in particular. It is to be expected that the classic

¹²⁰ Refer in this regard to Barthes 1988:142-148; Foucault 1979:141-160; Sartre 1988:21-245.

¹²¹ See Derrida 1978.

¹²² See De Man 1979 for a seminal treatment of the challenge to all notions of referentiality and the possible excision of the self from the task of writing about it and of declaring autobiography not as genre, but as a figural mode.

autonomous self will demand more control and less interference from outside than a postmodern and fragmented self realising that he or she reflects all the discontinuities and ambiguities of modern culture. Furthermore, research indicates that sick people and those caring for them react differently depending on their beliefs about the boundaries of and control over the self (Morris 2002:196-218). In this regard, Charon notes that in particular, three features of the contemporary understanding of the self are of great practical significance in understanding the events of illness and medicine. These features are represented in the concepts of narrativity, relation to others and the body, since today recognising or even being one's self unfolds in narrative language, but also includes attention to others and always takes account of the body (Charon 2006:73).

Narrativity has become the hallmark of postmodern theorising about autobiography due to the fact that identity is believed to be both declared and created through narrative (Charon 2006:73). In this regard, Eakin notes: "When it comes to autobiography, narrative and identity are so intimately linked that each constantly and properly gravitates into the conceptual field of the other. Thus, narrative is not merely a literary form, but a mode of phenomenological and cognitive self-experience, while self - the self of autobiographical discourse - does not necessarily precede its constitution in narrative" (Eakin 1999:100).

This point is further elaborated on by Ricoeur who notes that much of human knowledge exists in pre-narrative or quasi-narrative form and that in order to capture what you know about the self or anything else; this knowledge has to achieve the status of narrative language. Ricoeur's description of so-called untold stories forcefully brings home the realisation that our experience has a protonarrative or prefigured quality that only becomes detectable upon framing it in words: "Are we not inclined to see in a given sequence of the episodes of our lives (as yet) untold stories, stories that demand to be told, stories that offer anchorage points for narrative?" (Ricoeur 1984-1988:Vol.1:1:75). It is by recognising the narrative shadows of events that Ricoeur explains the relation between existing and knowing, since the story ultimately "told is in continuity with the passive entanglement of subjects that disappear into a foggy horizon" (Ricoeur 1984-1988:Vol.1:1:75). In adopting the image of the horizon, Charon notes that both Taylor and Ricoeur emphasise the fact "that it is only through narrative acts that our cosmic, physical and intersubjective orientation in the world occurs" (Charon 2006:74).

In addition to narrativity, our relation to others has become far more prominent in recent theories of autobiography and has today replaced the concept of the individually construed self with a realisation of the relationally created self. While autobiography is still recognised as an effort by a writer or narrator to reflect on, recapture, reinterpret and present the events of his or

her life to readers, the autobiographer is now also understood to be seeking and not merely repeating the grounds of meaning in life and to search not only among his or her own memories, but also among those of his or her intimates for that meaning. However, in these efforts by autobiographers, identity also declares itself in the differences among people. As powerfully stated by Derrida, "... a thing or a subject or a word or a text is itself to the extent that it differs in both space and time from not-self".¹²³ Applied in the context of identity, it enables the incorporation of an awareness of identity with an awareness of otherness and suggests that the individual is constituted in reference to the other, either in similarity or in contradistinction (Charon 2006:76).

In addition to narrativity and our relation to others, also the body has recently acquired great importance in understanding the self. The self has and is a body which not only is the exterior of the self, but also the interior thereof with the hidden functioning of the organs. Therefore all roads in contemporary autobiographical theory lead to the body whose corporeal evidence in the form of the face, the voice, the fingerprints and the DNA proclaims the individuality, authenticity and singularity of the self (Charon 2006:76). Philosophers and literary scholars have therefore also resoundingly dismissed Descartes' cogito that separated mind and body in order to embrace a far more complex understanding of the self's relation to the body (Kerby 1991).

These changes in perceptions about the body have also radically changed autobiography as an enterprise. In view of the body and contrary to the humanist tradition of the grand narrative of the self or the Augustinian confession of moral weakness and the boast of moral strength, autobiography cannot any more claim immortality, but has to succumb to temporality. It now refuses allegory for singularity, as there can be one body that is mine. It insists on intersubjective relation, since bodies have surfaces that require contact. Autobiography with the body in view, now has to concern itself with the actuality of its build and organic construction, but also opens areas of ethical duties unknown of in classical life writing (Charon 2006:77).

These intimate relationships between our bodies and ourselves, between brain and mind, perception and understanding, speech and language and consciousness and imagination are the object of study in fields as diverse as neurobiology and phenomenology. The classic question regarding the division or unity between mind and body is today still debated in order to come to grips with our mysterious simultaneous existence as material and metaphorical beings.

Regarding the interconnectedness of mind and body, Schlebusch notes that although suggestions of the influence of the relationship between mind and body on your health are abundantly found

¹²³ Quoted by Johnson 1980:51-52.

in ancient medical writings and philosophies, modern behavioural medicine and studies in psychoneuroimmunology have indicated scientifically that our minds and bodies are closely connected. In addition, it is now also a well established scientific fact that your behaviour can affect your health. If you therefore for instance want to deal with the ravages of stress, you need to be biologically, psychologically and socially healthy and it therefore makes little sense to separate these facets in total health care (Schlebusch 1999:43).

It is in the wake of these discourses about the body and the self that also medicine grapples with the relation between body and self in health and illness. While today much is done in medicine to acknowledge the privilege of touching another's body and to maintain the wholeness of the patient, illness intensifies the routine drives to recognise the self. Illness is therefore regarded as a problem of the total human being: "Illness is associated with the basic bodily needs of our existence which means that illness is, primarily an issue which affects the area of embodiment, i.e. the way we experience our uniqueness in our bodies. Man is a unity and a totality. He does not only have a body, but is a body. When our bodies become ill, it does not follow that we merely have an ailment or complaint. We do not only have an illness; we are sick. A disorder of bodily functions affects the entire person, as well as his feeling of identity. Because the body is the instrument through which we orientate ourselves in the world a sick body signifies a sick person. Thus, illness is a problem of the total person and affects the human self or ego most profoundly" (Louw 1994:34).

Illness thus creates a situation of conflict which initially takes place physically, since the afflicted part of the body becomes a threat to the rest of one's existence. This is due to the fact that the sick body or damaged tissue causes serious limitations in terms of freedom and living space and also emphasises your consciousness of transience and insignificance. Subsequently, illness creates a conflict in the human self-image, as the patient is compelled to anew answer questions regarding his or her identity, immediate responses to the illness and alternatives for the future.

In this regard and with specific reference to the phenomenon of pain, Degenaar argues that pain can be described in terms of physiology, consciousness and personhood and furthermore also in neurological, psychological and philosophical terms. In the biological context, pain can be seen as a sign of disharmony in the body. In the psychological context it functions as a symbol of disharmony in the mind. Philosophically speaking, it can be interpreted as a warning of disharmony in the moral order which calls the person to a conscious act of personal responsibility and involvement (Degenaar 1982:51).

Charon aptly summarises this intimate connection between the body and the self by noting that the body thus co-authors the story of the life being lived in it. Illness gives rise to the telling of two tales about the self at once - the one told by the person of the self and the other by the body of the self. However, the way in which the body relates its tale can be quite mysterious. While sometimes the signals are clear, like when a limb hurts, it can also be obscure, such as in a paralysis after a stroke. It is therefore of great importance to note that although the body is material, its communications remain representations that are mediated by sensations and the meanings ascribed to them. It therefore sometimes seem as if the body speaks a foreign language and relies on bilingual others in order to translate, interpret and make transparent what it is trying to communicate (Charon 2006:87).

The self thus firmly depends on the body for its presence and location, since it cannot be uttered and enter into relationships with other without the body. Without the body, the self remains an abstraction and yet the body itself can become invisible in its connectedness with the self. It is commonplace that we disregard our bodies until they cause us trouble.¹²⁴ Healthy people enjoying the silence of health¹²⁵ have little reason to dwell on their bodies or their bodies' relationship to the world. However, the observations of Murphy and others compel us to pay more attention to the messages from our bodies. Our bodies are the media through which we obtain sensory sensations and information and become aware of hunger, thirst, cold, heat, pain and pleasure. Moreover, it is at the same time controlled by its genetic inheritance, its environmental surrounds, its random hits and accidents and by the passage of time. I not only use this body to move through space and absorb information, but also use it to transmit my thoughts, feelings and desires to others. It is through the avenues of speech, gestures, expressions that I transmit what goes on inside my body into the world outside the body (Charon 2006:88, 90).

While the identity of a person is not determined by the state of his or her body, the way somebody experiences the world and accumulates and digests experiences depend directly on that person's body and its senses. The body defines the self from the inside, but not from the outside. There are thus two bodies: the one lived in and the one lived through with one body

¹²⁴ Compare the following quotation from the anthropologist Robert Murphy's book *The Body Silent*. Murphy experienced fleeting neurological symptoms of muscle spasms and numbness of his feet and eventually learned that a tumor had grown around his spinal cord from his neck to his chest, compressing the cord and eventually causing quadriplegia: "People in good health take their lot, and their bodies, for granted; they can see, hear, eat, make love, and breathe because they have working organs that can do all those things. These organs, and the body itself, are among the foundations upon which we build our sense of who and what we are, and they are the instruments through which we grapple with and create reality" (Murphy 1990:12).

¹²⁵ The moving phrase *the silence of health* is the subtitle of Felix Guyot's book, *Yoga: The Silence of Health* (Guyot 1937).

absorbing the world and the other emitting the self. The body as object is thus in a copulative position between world and self and is simultaneously a receiver with which the self collects all sensate and cognate information about what lies exterior to it and a projector with which the body declares the self who lives in it (Charon 2006:89).

These intimate relationships between our bodies and ourselves and especially the fact that the body simultaneously is and is not the self, have far reaching consequences for the clinical situation and clinical decision making.

Telling of the body in a doctor's surgery follows the rules of autobiographical telling or writing in general: the teller splits into a narrator and a protagonist, again creating the autobiographical gap that was referred to earlier. While the narrator normally tells what the protagonist has done in the past, one doubles the biographical charge when you tell of your own body, as the autobiographical gap is here accompanied by what can be called the corporeal gap. The teller of the self tells of the body of the self which momentarily separates the teller-who-reports from the body-that feels and this action calls upon the teller to become the voice of the body or the medium through which the body can convey its message to the listener (Charon 2006:90).

Moreover, the telling of the body uses the corporeal gap in a simultaneous gesture of avowal and disavowal. In order to emphasise this important point, Charon refers to the experience of the poet Lucy Grealy who was diagnosed with Ewing's sarcoma of the right lower jaw when she was only nine years old and who had to undergo fifteen operations and years of chemotherapy and radiation. Grealy reports that her life revolved around her face from school to adulthood and after another long graft operation for reconstruction noted: "When I woke I was in a lot of pain, but the pain was in my hip, where the graft came from, far away from my face, my self, so it was easier to deal with" (Grealy 1994:170).

Such experiences of fragmentation or dissociation recur in illness narratives as frightening, but also protective devices. It portrays living with a body that has temporarily abandoned its inhabitant and has turned against the self to turn the most basic actions into efforts. In allowing the body to separate from the person living in it, illness thus prompts conflict or struggle between them. The body can for instance keep secrets from the person who inhabits it and even from the person who takes care of it and this may not only be applicable to aspects that might be shameful to talk about, like bowel habits or sexual problems, but also to perfectly normal health issues (Charon 2006:91).

However, keeping secrets from one another is but one of the ways in which the body and the person who inhabits it can work at cross purposes. Charon notes that sometimes in especially

clinical settings, the body and the person who inhabits it actively disagree. They relate contradictory stories that either confuse the health care professional or make him or her take sides. In such cases the patient and the doctor struggle to identify the plot or the causality that brought the patient to the surgery in the first place and may even cause the physician to hear the body at the expense of the person, since the body has the material warrant and if the patient says otherwise, his or her word may be dismissed as untrue (Charon 2006:92).

To Charon, these lessons from the tales of illness have immediate and practical implications for routine medical care. Being a specialist physician herself, she notes that once we become aware of how the body and the person who inhabits it speak, we should endeavour to find the means to hear them both accurately and with professional skill. The body has various ways of communicating its messages. To these belong visible lesions of all kinds, physical examinations that suggest pathological states and measurements of substances in the blood that may signal disease. However, while the body through various avenues relate what might be wrong with it, the person inhabiting it feels out of the ordinary and needs to be taken seriously as well (Charon 2006:98).

If autobiographies tell truths about their writers of which they are unaware, then patients' narratives tell truths about themselves of which they are also unaware. Moreover, if patients' narratives bear any resemblance to life narrating in general, then the listening to these narratives is likely to be as demanding and daring and intersubjective as autobiography reading. Acknowledging that autobiographical narratives cannot solely be read as either factual truth or simple facts but, as an intersubjective mode, lies outside a logical or juridical model of truth and falsehood, also doctors according to Charon need to realise "that they are not only collecting and verifying facts, but are also creatively reaching for a mutual interpretation of all that the patient might disclose about the self". Narrative medicine therefore proposes "that health professionals, as a matter of routine, be equipped with the skills that allow them to competently and naturally absorb, recognize, interpret, and comprehend the value of all that patients tell" (Charon 2006:102-103).

However, Charon has to add that sadly, medical training enforces a method of listening to patients' narratives that is not conducive to these ideals. She notes that most North American medical schools teach doctors to report on a patient's history by means of a standard outline. This include aspects like the chief complaint, the history of the present illness, the past medical history, social history, family history, a review of the bodily systems, physical examination, laboratory test results, a formulation of the findings, an assessment and a plan of action.

Moreover, since many health care professionals are not comfortable with emotion and become uneasy when the medical interview is not evidently focussed on the physical problem at hand, they tend to structure the conversation as it unfolds by interrupting the patient and redirecting him or her to furnish only medically relevant information in the order dictated by the doctor's outline. According to Charon, doctors think that they are streamlining the process of telling of symptoms by asking for the history of the present illness first and then when they are ready, move on to the family history.

However, in all but the most mechanical and straightforward problems, this well meant streamlining sacrifices information of the most valuable sort, since it is only "if the health care professional listens stereophonically to what the person says and also to what the body says that he or she has the rare opportunity not only to hear the body out but also to translate the body's news to the person who lives in it" (Charon 2006:98-99).

SUMMARY AND CONCLUSIONS

This chapter was devoted to the formulation of a first recommendation for the transformation of evidence-based patient choice to a therapeutic alliance in health care and firstly reviewed and further explored the philosophical foundations of evidence-based patient choice.

It traced the thought of John Locke that initiated the empirical tradition and indicated that the legacy of his distinction between the primary and secondary qualities of knowledge is still perceptible in not only the ontological and methodological assumptions of the natural science paradigm, but also in the constitution of the clinical method.

It similarly outlined the thought of Søren Kierkegaard who argued for decision making as the most important human activity and also indicated that the traces of his thought are still to be found in not only the principles of patient-centred medicine and in clinical training, but also in the practice of evidence-based patient choice.

In addition, the chapter argued that although the philosophical thought of John Locke and Søren Kierkegaard seem widely divergent, the concept of personal identity seems to have interested both and continued to analyse this shared interest in terms of an investigation of the concept of personal identity.

With reference to this important concept, the chapter concluded by noting that the threat of the bifurcation of self and person encountered in the thought of John Locke and Søren Kierkegaard is however not only a matter of academic interest, but is also perceptible in medicine in general

and in the practice of clinical decision making in particular and is to be understood within the larger context of a universal interest in the concept of the self.

From the discussion of the thought of John Locke, it became clear that we cannot have knowledge of all the relations of our ideas or rational knowledge of the necessary relations between many of our ideas and that sensitive knowledge only goes as far as the existence of things and not as far as their real existence or reality. Moreover, it is important to note that the aspects of objects that science is able to deal with, are those that are independent of any individual observer and belongs to their measurable properties, such as their length, breadth, height, weight, position in space and velocity if in motion. This implies that the entities that it is impossible for science to deal with are qualities such as taste, smell and colour that belong to objects in an ambiguous way and arise out of the interaction between an object and an observing subject and therefore contain a subjective element which could easily differ from observer to observer. Thus, due to the fact that we are able to observe only an object's observable characteristics and behaviour, we have no way of apprehending it independently of those characteristics and in other words cannot have any knowledge of what the object is that exhibits those characteristics and behaves in that way. The thing in itself therefore remains an invisible and metaphysical something which can be characterised as matter and material substance, but cannot be known apart from its characteristics and properties. This also applies to subjects, since as subjects of knowledge and experience we can only find within ourselves the contents of our awareness and experiences and accordingly both the subject and the object of our knowledge remain in themselves unknowable and result in the domain of possible knowledge to entirely consist of transactions or possible transactions between these mysterious entities.

An important consequence of these findings was that the success of the new clinical method in the late 1800s soon resulted in the dominance of the ontological model and that true to its origins in the Enlightenment, it was analytic and impersonal with the feelings and experiences of the patient left aside. Whereas the term diagnosis formerly referred to the diagnosis of a patient, the objective of a diagnosis now became the identification of a disease, which was now regarded as located in bodies and the categorization thereof as abstractions that for the sake of generalization, omitted many features of being ill, such as the subjective experience of the patient. These developments furthermore resulted in physical and mental illnesses being classified separately, the distinguishing of somatic and psychotherapies and in the physician increasingly being viewed as a detached and impassive observer, utilizing the predictive and inferential power of the new clinical method to identify the patient's disease or rule out organic pathology. This dichotomy between the physical and the mental eventually also manifested itself

in the organisation of the profession with distinctions for instance being made between internal medicine and psychiatry and eventually also between different types of wards in medical institutions. Moreover, since disease became conceptualized as a physical phenomenon, only physical treatment modalities such as drugs, surgery or radiation became considered part of scientific medicine with the psychosocial needs of the patient recognised as perhaps important from a humanitarian point of view. This approach to therapy also directly influenced the doctor-patient relationship, since the doctor's agenda now amounted to the diagnosis of a disease and not to an understanding of the patient and the patient's personal agenda therefore got drawn into the reductionist, mechanistic and materialistic medical agenda in order to make a physical diagnosis and to prescribe physical treatment. The application of the natural science paradigm therefore almost inevitably led to the decline of humanistic medicine.

However, from the thought of Kierkegaard, it became clear that the ethical has its source in a freedom that is not only manifested in the capacity for choosing between alternative goods, but also defines the self's way of being and its responsibility for the manner of its existence. Choice is decisive for the content of the personality, since it is through choice that the personality immerses itself in what has been chosen and that should it not choose, it goes into a consumptive decline. Even non-choosing thus becomes a kind of choice due to the fact that our life in time implies that life itself moves forward despite hesitations to choose and that therefore our situation and even ourselves becomes different from what it used to be. In making a decision, there always is the possibility of making a terrible mistake and for this reason choice can never solely depend on the motivating power of reasons. What therefore matters is the activation of the freedom to choose, as well as the readiness to accept responsibility for the choice once made, since what is chosen is essentially the self.

A combination of the thought of Locke and Kierkegaard indicates that there exists a dichotomy between the self understood as a human being with its various forms of physical, psychological and social continuity and history and the self understood as the present locus of psychological experience. According to this intimate connection between the body and the self, the body thus co-authors the story of the life being lived in it which means that these intimate relationships between our bodies and ourselves and especially the fact that the body simultaneously is and is not the self, have far reaching consequences for the clinical situation and clinical decision making. Telling of the body in a doctor's surgery follows the rules of autobiographical telling or writing in general and often results in the teller splitting into a narrator and a protagonist, again creating the autobiographical gap. This implies that once we become aware of how the body and

the person who inhabits it speak, we should endeavour to find the means to hear them both accurately and with professional skill.

With regard to the aim of the study, namely to determine an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, it has to in addition to the discussion in this chapter and in anticipation of the discussion in the final chapter, be concluded that the above mentioned perspectives add a completely new dimension to the debate regarding evidence-based patient choice as partnership model in clinical decision making, as well as to the evidence-based patient choice challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and the dangers of abstractions and informational manipulation in health care. This dimension is represented in the complexity of the contemporary understanding of personal identity and is to be regarded as of pivotal importance in the transformation of evidence-based patient choice to a therapeutic alliance in health care. Whereas individualisation is recognised as the great challenge of evidence-based medicine and evidence-based patient choice is defined as "the use of evidence based information as a way of enhancing people's choices when those people are patients", this new dimension forcefully brings home the message of the complete inadequacy of any approach that aims to individualise health care, but fails to acknowledge the dichotomy between self and person and the resulting essence of an intersubjective and mutual understanding of all the patient has to disclose about the self in clinical decision making.

This new dimension to the debate regarding evidence-based patient choice as partnership model in clinical decision making therefore also demands a recognition of the fact that the body has various ways of communicating its messages. To these belong visible lesions of all kinds, physical examinations that suggest pathological states and measurements of substances in the blood that may signal disease. However, while the body through various avenues relate what might be wrong with it, the person inhabiting it feels out of the ordinary and needs to be taken seriously as well. If autobiographies tell truths about their writers of which they are unaware, then patients' narratives tell truths about themselves of which they are also unaware. Acknowledging that autobiographical narratives cannot solely be read as either factual truth or simple facts but, as an intersubjective mode, lies outside a logical or juridical model of truth and falsehood, also doctors need to realise that they are not only collecting and verifying facts, but are also creatively reaching for a mutual interpretation of all that the patient might disclose about the self. Moreover, these perspectives raise the important issue of the separate worlds of patients and health care professionals in health care and the resulting need for mediation in health care. As will be argued in the final chapter, the in principle inaccessibility of the world of

the other revealed by Locke, coupled to the ambivalence of and the difficulties attached to the constitution of a common communicative environment indeed create a major obstacle in health care in general and in the individualisation of the provision of information in particular. Considered together with the challenges attached to the complexity of the contemporary understanding of the concept of personal identity, the difficulties related to the in principle inaccessibility of the worlds of the other not only demand a new approach to the bridging of these divides, but also a new agent to serve as mediator between these separate worlds. The end of the twentieth century also brought a third phase in the development of the medical profession with the introduction of the concepts of third party mediation and accountability. Mediation refers to a resolution in which a third party mediates in the relationship between the producer and the consumer and defines both the needs and the manner in which the needs are to be met. As such, it can thus also be regarded as fortunate that these developments have indeed paved the way to a new approach to the individualisation of the provision of information that will be argued in the final chapter.

CHAPTER 6

SECOND RECOMMENDATION - TO CONSIDER THE RELEVANCE OF CONTINENTAL PHILOSOPHICAL PERSPECTIVES ON THE CHALLENGES POSED TO EVIDENCE-BASED PATIENT CHOICE

INTRODUCTION

As a second recommendation for the transformation of evidence-based patient choice to a therapeutic alliance in health care and in view of the dimension of the complexity of the contemporary understanding of personal identity added to the challenges of evidence-based patient choice, this chapter considers the relevance of continental philosophical perspectives for the challenges posed to evidence-based patient choice. The chapter therefore in succession considers the perspectives of Edmund Husserl, Jean-Paul Sartre, Maurice Merleau-Ponty and Jürgen Habermas on the challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and of abstractions and informational manipulation in health care. This consideration is conducted against a discussion of the background of the central position of the self in continental philosophy and in the Phenomenological method and will be concluded by an analysis of the complexity of the application of the ethical principle of respect for autonomy in medical practice.

6.1 THE SELF IN CONTINENTAL PHILOSOPHY

Whereas the pivotal role of the self in medical practice can in view of the preceding discussion not be denied, the concept of the self also in continental philosophy not only became the focus of attention, but the entire subject matter thereof.

The term continental philosophy can at least be traced back to 1840 when John Stuart Mill used it in his essay on Coleridge to contrast the Kantian-influenced thought of Continental philosophers with the empiricism of the eighteenth century and of Bentham in particular.¹²⁶ This idea became prominent in the early 1900s when on the one hand figures such as Bertrand

¹²⁶ Wikipedia Encyclopedia 2009: http://pediaview.com/openpedia/Continental_philosophy. See also Mill 1950:104, 133, 155.

Russell and G.E. Moore developed the philosophical school of logical positivism and on the other, Brentano, Husserl and Reinach advanced the philosophical method that would become known as phenomenology. Heidegger added new dimensions to this approach and his ideas were after the Second World War expanded by Jean Paul Sartre into Existentialism. These developments were in the 1960s followed by the emergence of Structuralism which was later succeeded by Poststructuralism.

The concept continental philosophy reappeared among English speaking philosophers in the 1970s and today refers to a whole range of philosophical traditions outside the analytic movement, such as German Idealism, Phenomenology, Existentialism, Hermeneutics, Structuralism, Poststructuralism, French Feminism and the Critical Theory of the Frankfurt School.¹²⁷

Continental philosophy has responded in various ways to a world increasingly dominated by technocracy, the positive sciences and the threat of totalitarian control of human intelligence. To continental philosophers, new models of understanding were required, as the question of meaning could no longer be taken for granted. In this endeavour, Phenomenology and Existentialism attempted to relocate the origins of meaning in our concrete lived experience prior to the impersonal objectivism of a narrow scientific attitude. Structuralism emphasized the hidden structures of language which underpin our current established discourses, while Critical Theory developed the insights of Hegel and Marx into a radical interrogation of the ideologies at work in advanced industrial societies.

Continental philosophy thus testified to a sense of imposing crises. There was a common feeling that the classical systems of ideas which had a place for everything and had everything in its place, no longer sufficed. Moreover, the sacrosanct notion of one philosophical mind for Europe had lost its credibility, while the accompanying collapse of a globally accepted system of social, political and religious values seriously undermined the ideal of a Western rational tradition destined to historical progress and unity (Kearney 1991:1).

Though the term continental philosophy lacks clear definition and may merely mark a family resemblance between disparate philosophical views, the following common themes that typically characterise continental philosophy can be identified.¹²⁸

Firstly, continental philosophers generally reject the scientific view that the natural sciences are the best and most accurate way of understanding reality. The upshot of positivism has been to

¹²⁷ Wikipedia Encyclopedia 2009: http://pediaview.com/openpedia/Continental_philosophy

¹²⁸ Wikipedia Encyclopedia 2009: http://pediaview.com/openpedia/Continental_philosophy

reduce the life of ideas to a cult of verifiable certainty and this reductionist fixation on objective facts was accompanied by a total ignorance of ulterior human, historical and structural factors which in the final instance determine the meaning of such facts. Continental philosophers have therefore often argued that science is dependant upon a pre-theoretical substrate of experience and that scientific methods therefore remain inadequate to fathom such conditions of intelligibility (Critchley 2001:115). While positivism regarded truth exclusively in terms of a one-dimensional surface observation, Continental philosophy opened up other dimensions of meaning concealed behind the empirical manifestation of things, such as the intentional activities of consciousness in Phenomenology and the historical strategies of domination and liberation in critical theory (Kearney 1991:2).

Secondly and with reference to the aforementioned conditions of intelligibility, continental philosophers moreover often regard these conditions of possible experience as liable to change and at least partly influenced by factors such as context, space and time, language, culture or history. Continental philosophy thus tends towards historicism and typically suggests "that philosophical arguments cannot be divorced from the textual and contextual conditions of its historical emergence" (Critchley 2001:57).

Thirdly, continental philosophy typically holds that conscious human agency can change these conditions of possible experience by arguing that "if human experience is a contingent creation, it can be recreated in other ways" (Critchley 2001:64). Continental philosophers thus tend to take a strong interest in the unity of theory and practice and as a result consider their philosophical activities closely related to personal, moral or political transformation.¹²⁹

Fourthly, continental philosophers share a common conviction that philosophy needs new methods of enquiry that are more accurately attuned to the particular circumstances of modern Western culture. In continental philosophy such innovations in methodology mark a transition from the traditional philosophy of substance (which assumed that the truth of a being exists in itself prior to its relationship to other beings) to the modern philosophy of relation (which argues that the truth of a being is only constituted in and through its relationship to beings or to systems of meaning other than itself). This transition is characterised by a specific choice of method, corresponding to a specific category of relation in each of the continental philosophical traditions. So for instance, the Phenomenological method favours the intentional relation of consciousness to meaning in the world, while the method of critical theory highlights the social

¹²⁹ Wikipedia Encyclopedia 2009: http://pediaview.com/openpedia/Continental_philosophy

relation of the human subject to the historical conditions of production or alienation (Kearney 1991:2).

It is important to note that fundamentally, the forementioned distinctive themes derive from the broadly Kantian thesis that the nature of knowledge and experience is bound by a variety of conditions not directly accessible to empirical investigation. Continental philosophers have therefore usually identified such conditions with the transcendental subject or the self.¹³⁰ In this regard, Solomon notes: "It is with Kant that philosophical claims about the self attain new and remarkable proportions. The self becomes not just the focus of attention but the entire subject matter of philosophy. The self is not just another entity in the world, but in an important sense it creates the world, and the reflecting self does not just know itself, but in knowing itself, knows all selves and the structure of any and every possible self" (Solomon 1988:6).

These themes are particularly evident in the philosophical traditions of phenomenology and critical theory that are in focus in this study.

Phenomenology was committed to a new form of concrete thinking. The Phenomenological method was developed by Edmund Husserl at the turn of the twentieth century and claimed to redeem philosophy from its academic abstractions by enabling us to return to the origin of ideas in our concrete lived experience of the things themselves. In his *Being and Time*, Martin Heidegger proclaimed that the phenomenological method permitted modern man to retrieve the fundamental question of the meaning of Being by relating it to the concrete concerns, moods and projects of our lives. Phenomenology, he argued, at last provided the philosophical means for understanding Being in terms of man's everyday being-in-the-world. Merleau-Ponty insisted that Phenomenology is not some speculative system with ready made solutions, but a unique style of thinking which must be experienced by each questioning person for himself. It was also because of this openness of appeal that the phenomenological method lent itself to multiple interpretations and Heidegger could apply it to the question of being, Merleau-Ponty to the question of our bodily relationship to the world and Sartre to the question of human freedom (Kearney 1991:3).

Critical Theory provided a radical stimulus to a new generation of continental philosophers by combining the dialectical methods of Hegel and Marx. This gave rise to a distinctive brand of socially committed analysis often described as Hegelian or humanist Marxism. While philosophers such as Georg Lukács and Herbert Marcuse were prominent in this tradition, Walter Benjamin, Ernst Bloch and Jürgen Habermas developed the dialectical method of

¹³⁰ Wikipedia Encyclopedia 2009: http://pediaview.com/openpedia/Continental_philosophy

humanist Marxism in its dual capacity as a critique of ideology and a project of emancipation. What all these thinkers had in common, was a basic debt to Marx's original recognition "that it is only by combining our practical and reflective abilities that we may effectively combat the prevailing forces of domination" (Kearney 1991:5).

6.2 THE SELF IN THE PHENOMENOLOGICAL METHOD

Reference has earlier been made to the fact that the foregoing distinctive themes of continental philosophy derive from the broadly Kantian thesis that the nature of knowledge and experience is bound by conditions that are not directly accessible to empirical enquiry and that continental philosophers have therefore usually identified such conditions with the transcendental subject or the self. It was noted that it was with Kant that philosophical claims about the self attained new and remarkable proportions and the self became not just the focus of attention, but the entire subject matter of philosophy. Nowhere in the vast spectrum of continental philosophy are these accents more evident than in the discipline of phenomenology.

Phenomenology is the study of phenomena or the appearances of things as they appear in our experience or in the ways we experience things. Phenomenology thus studies experience as experienced from a subjective or first person point of view. What makes an experience conscious is a certain awareness one has of the experience while living through or performing it. This form of inner awareness has been a topic of considerable debate since the issue arose in Locke's notion of self-consciousness on the heels of Descartes's sense of consciousness.¹³¹

It was mentioned earlier that the Phenomenological method was developed by Edmund Husserl at the turn of the twentieth century and claimed to redeem philosophy from its academic abstractions by enabling us to return to the origin of ideas in our concrete lived experience of the things themselves.¹³² In thus providing a phenomenological description of experience, a phenomenologist departs from what presents itself to consciousness in immediate experience in order to clarify the constitutive activity of consciousness and the sense-structure of experiencing. It has therefore been one of the primary characteristics of the phenomenological

¹³¹ Smith 2008: <http://plato.stanford.edu/entries/phenomenology>. See also Chalmers 2002:33.

¹³² Also with regard to the Phenomenological method, it should be noted that in Husserl's work there is an important distinction between psychological and transcendental phenomenology. Both these forms of phenomenology involve Husserl's concept of phenomenological reduction, but apply it on different levels. The level of psychological phenomenology involves the suspension of belief in the outer world in order to make explicit the field of consciousness, represented in what Husserl called the noetic (the intentional act which represents the thing as meant) and the noematic (the thing meant). The transcendental level involves a further reduction which not only brackets out the outer world, but also individual consciousness in an attempt to disclose the ultimate structure of consciousness (Toombs 1993:121). I also, from the outset, acknowledge my indebtedness to the work of Toombs: Toombs, S.K. (1993). *The meaning of Illness: A Phenomenological account of the Different Perspectives of Physician and Patient*. Dordrecht: Kluwer Academic Publishers.

method to let the given appear as a pure phenomenon and to then describe the invariant features of such a phenomena (Toombs 1993:xi). In this regard Casey notes that "no matter how something came to be in the first place, what is of crucial concern to the phenomenologist is a detailed description of the phenomenon as it now appears" (Casey 1976:8-9).

Husserl further elaborated on the concept of immediate experience by contrasting it with the world derived from science and by making a distinction between the natural and naturalistic attitudes to experience (Husserl 1970:321, 379). He regarded the natural attitude as prior to any scientific intent or activity and described it as taking the existence of the world for granted and acting in a pragmatic way according to your subjective and selective interests. On the contrary, the aim of the naturalistic or scientific attitude is to grasp the nature of reality and to describe this reality in terms of some objective description which will accurately describe the thing-in-itself apart from your experiencing thereof (Toombs 1993:13-14).

In order to determine the invariant features of phenomena, phenomenologists used the method of imaginative free variation (Husserl 1962:181 ff.). In this regard Toombs notes that free phantasy variation differs from empirical generalization in that, in the former, one explicitly endeavours to consider a range of actual and possible affairs as examples of some kind or sort in order to determine which characteristics intrinsic to the range of variations are invariant (Toombs 1993:123). With reference to Husserl's method of imaginative free variation, Zaner notes that "it is never a matter of trying to generalise ... it is rather a question of trying to determine what is invariantly common to or exemplified by every actual and possible example of the kind in question" (Zaner 1981:193).

Moreover, the Phenomenological method involves a type of radical disengagement or distancing from our immediate ongoing experience in order to make the nature of such experience and especially the essential intentional structures that determine the meaning of such experience explicit (Toombs 1993:xi). The structure of these forms of experience typically involves what Husserl called intentionality or the directedness towards things in the world and the property of consciousness that it is a consciousness of or about something. According to classical Husserlian phenomenology, our experience is directed or intended toward things only through particular concepts, thoughts, ideas and images which make up the meaning or content of a given experience and are distinct from the things they present or mean.¹³³

¹³³ Refer to the following quotation from Husserl: "In unreflective consciousness we are directed upon objects, we intend them; and reflection reveals this to be an immanent process characteristic of all experience, though infinitely varied in form. To be conscious of something is no empty having of that something in consciousness. Each

As such, phenomenology is a thoroughly reflective enterprise with the common sense world and our experiencing thereof being the focus of our reflection (Toombs 1993:xi). In this regard, Zaner points out that our attention shifts from that of engagement in the world to that of concern for the meaning of the engagement itself. Rather than a straightforward and unreflective view of the objects of experience, a phenomenological approach therefore encompasses reflection upon experience itself with the task of making clear the taken for granted assumptions of everyday life and of one's consciousness in the world. It is in this bringing to the surface of the intentional structures of our consciousness that phenomenological reflection thematises the meaning of experience (Zaner 1970:51).

However, in Phenomenology, the task of elucidating and rendering explicit all the taken for granted assumptions of everyday life and of one's consciousness in the world, is intimately related to the concepts of bracketing or phenomenological reduction (Toombs 1993:xii). In order to describe phenomena as they present themselves to consciousness, a phenomenological approach attempts to bring about a systematic neutrality by temporarily bracketing our taken for granted suppositions about the nature of reality and our commitments to certain habitual ways of interpreting the world and in particular sets aside any theoretical commitments derived from the natural sciences in order to describe what presents itself directly to consciousness and to prevent you from using any judgement that concerns spatio-temporal existence (Husserl 1962:100).

As noted by Natanson, what is thus disclosed in phenomenological reduction is the field of intentionality or the conscious processes of experiencing (the noetic) and the objects of experience (the noematic): "To bracket the world is neither to deny its reality nor to change its reality in any way; rather it is to effect a change in my way of regarding the world, a change that turns my glance from the real object to the object as I take it, treat it, interpret it as real. Within the natural attitude I attend to the object; in the phenomenological attitude I attend to the object as known, as meant, as intended ... The object continues to be in the real world as I do, but what now interests me, phenomenologically, is my awareness, my sense of its being in the real world. The object I reflect upon in the reduced sphere is the real thing as I've taken it to be real. Thus 'the world' is replaced by 'my world', not in any solipsistic sense, but only in the sense that 'mine' indicates an intentional realm constituted by my own acts of seeing, hearing, remembering, imagining, and so on" (Natanson 1968:58-59).

Of importance is that phenomenological reduction does not deny the existence of the physical, social and cultural world, but rather "reveals the prejudices and taken for granted

phenomenon has its own intentional structure, which analysis shows to an ever widening system of individually intentional and intentionally related component" (Husserl 1929:699-702).

presuppositions which are not explicitly recognized in our spontaneous and unreflective experience" (Toombs 1993:xii). As stated by Merleau-Ponty, it indeed alone discloses the setting of the world which is presupposed in every moment of our thought: "The philosopher, as the unpublished works declare, is a perpetual beginner, which means that he takes for granted nothing that men, learned or otherwise, believe they know. It means also that philosophy itself must not take itself for granted, in so far as it may have managed to say something true; that it is an ever-renewed experiment in making its own beginning; that it consists wholly in the description of this beginning, and finally, that radical reflection amounts to a consciousness of its own dependence on an unreflective life which is its initial situation, unchanging, given once and for all. Far from being, as has been thought, a procedure of idealistic philosophy, phenomenological reduction belongs to existential philosophy: Heidegger's 'being-in-the-world' appears only against the background of phenomenological reduction" (Merleau-Ponty 1962:xiv).

With its emphasis on firsthand or direct description, phenomenology thus provides a way of bringing to the fore the domain of the unreflective and often taken for granted lived experience and as such provides an intricate account of the way in which we interpret the world of everyday life or our lifeworld,¹³⁴ as well as an explication of the fundamental distinction between scientific conceptualisation and lifeworld interpretation. In particular, the Phenomenological method indicates that meaning is constituted by certain invariant intentional structures which characterise consciousness and should be recognised if one is to give an account of meaning (Toombs 1993:xiii).

6.3 EDMUND HUSSERL AND THE CHALLENGE OF THE SEPARATE WORLDS OF DOCTOR AND PATIENT

Edmund Husserl never commented on the issue of separate worlds of doctor and patient, but became famous for his depiction of the inescapable reality of the different worlds we as human beings inhabit. Therefore and with regard to the evidence-based patient choice challenge of the separate worlds of doctor and patient referred to at the end of 4.1 and against the Continental philosophical background of his work, this paragraph considers Husserl's perspectives on the different worlds we live in.

6.3.1 Continental philosophical background

Edmund Husserl (1859-1938) began his career in mathematics, but after a brief assistantship to the noted mathematician Karl Theodor Weierstrass, moved to Vienna where he from 1884-1886

¹³⁴ Husserl termed the world of everyday experience the *lifeworld* to distinguish it from for example the world of science (Husserl 1970:379-383).

attended the lectures of Franz Brentano and decided to devote himself to philosophy. To Husserl, philosophy was not just his occupation, but a matter of the utmost seriousness. He regarded it first and foremost a science and although his conception of this philosophical science changed more than once, he never wavered in his conviction that only a body of indubitable and objective truths deserves to be called science and that the truths he was looking for were these on which all other human knowledge rests (Schmitt 1996:96-98).

Devoted to this pursuit with a moral fervour, his search was for the unshakeable foundation of human knowledge which he often referred to as the Archimedean point. His requirement that philosophy be scientific is specified in several imperatives for philosophers. A philosopher must endeavour to find apodictic certainty in at least the starting points of his inquiry and must be radical in the sense of taking nothing for granted. Philosophy should therefore ideally be conducted without presuppositions, with no statements admitted as true without scrutiny and with no conception used without examination.

In his conception of philosophy as a science, Husserl departed from the view of philosophy as a division of empirical natural science to establish philosophy as an a priori and autonomous science. This science Husserl called phenomenology and in his earliest writings identified it with descriptive psychology despite his earlier polemic against psychologism. However, he soon realised it to be a mistake to typify what he was doing as psychology, but continued to insist that phenomenology is descriptive in nature. This, he believed, "distinguished the phenomenological method from the established practice of philosophy which deduces what ought to be regarded as truth from prior assumptions instead of looking at the world itself and discovering what it is like" (Schmitt 1996:97).

In order to distinguish phenomenological from psychological descriptions, Husserl introduced the concept of transcendental-phenomenological reduction as a methodological device as a prerequisite of phenomenology. As such, this concept roughly indicated a transition from an ordinary and straightforward to a reflective attitude towards the world. Husserl claimed that once we perform the reduction, we discover what he called the transcendental ego or pure consciousness through which we discover that whatever exists in the world exists as an object of our pure consciousness. He thus ascribed the task of the description of the workings of this pure consciousness to the phenomenologist and now also characterised phenomenology as the exploration and description of a realm of being which was previously unsuspected, but represents the absolute foundation of the experienced world. This realm, he said, is not

accessible to empirical observation, but only to phenomenological description and to what he called eidetic intuition.

Husserl's use of the concept of an indubitable transcendental ego served both to distinguish phenomenology from the empirical sciences and to provide the Archimedean point from where to commence phenomenological activities. He regarded this transcendental ego as distinct from the self which is to be regarded as the object of my empirical self-observations or the observations of a psychologist. This made it sound as if a human being had two selves, namely the familiar empirical one and another transcendental and generally unknown one. However, Husserl regarded objections of this nature only as indications that the descriptions given to the transcendental ego until then were inadequate and had to be replaced by better ones.

In his later work, he still held that the transcendental ego exists absolutely and that all other things exist relative to it, but in the lectures he delivered in 1935, the transcendental ego was said to be correlative to the world and had thus lost its absolute status. Equally important in the lectures was his view that the world is no longer said to be a world for any transcendental individual, but for an intersubjective community of individuals.

These distinctions also changed the concept of phenomenology in an important way. Phenomenology was no longer regarded as a separate realm of being, but rather as a reflection on and description of the ways in which our communal experience comes to be and what the criteria for the coherence and adequacy of the different sorts of experiences are. Phenomenology thus no longer differed from the empirical sciences due to a different subject, but because it dealt with the world in a reflective way and reflected not on matters of fact, but on the necessary conditions for the coherence and adequacy of experience.

These views thus marked a major change in the conception of phenomenology. While phenomenological reflection earlier had to provide the foundations of scientific knowledge by reflecting on scientific knowledge, Husserl now sharply distinguished between the world as known to science and the *Lebenswelt* in which we live. He now contended that scientific knowledge can only be understood once we understand the *Lebenswelt* and that the study of the *Lebenswelt* and of our experience thereof amounts to the first task of phenomenology (Schmitt 1996:98).

6.3.2 Edmund Husserl and the separate worlds we live in

Against this background and as indicated in 6.2, Husserl paid specific attention to the way in which the individual experiences the world and thereby analysed experience in terms of the

structuring activity of the human consciousness (Toombs 1993:1-7). His analysis also revealed an essential correlation between the perceiver and the object that is perceived and demonstrated that immediate experience is therefore necessarily to be regarded as unique.

Husserl's concern in emphasising the direct exploration of experienced phenomena was the fact that we tend not to reflect consciously upon the way in which we experience reality and simply take the objectivity of the everyday or lifeworld for granted. This naïve and unreflective experiencing of the world Husserl called the general thesis of the natural standpoint or the natural attitude and describes it as follows: "I find continually present and standing over against me the one spatio-temporal fact-world to which I myself belong, as do all other men found in it and related in the same way to it. This 'fact-world' as the world already tells us, I find to be out there, and also take it just as it gives itself to me as something that exists out there. All doubting and rejecting of the data of the natural world leaves standing the general thesis of the natural standpoint. 'The' world is a fact-world always there; at the most it is at odd points 'other' than I supposed, this or that under such names as 'illusion', 'hallucination', and the like, must be struck out of it, so to speak; but the 'it' remains ever, in the sense of the general thesis, a world that has its being out there" (Husserl 1962:96).

Husserl thus called for a suspension of this unreflective acceptance of the lifeworld through the act of phenomenological reduction or bracketing and in the course of his analysis of experiencing, identified certain invariant intentional structures which characterise consciousness in general.

A first of these invariant structures of consciousness is that of directionality or focusing. Husserl noted that the way in which an object is experienced is strictly correlated to the way in which consciousness directs itself to that object. The activity of consciousness thus not only renders the object thematic, but also makes certain aspects of the object explicit (Husserl 1970:108).

To Husserl, also temporality represents a fundamental feature of consciousness (Husserl 1962:215-220). To him each particular consciousness of something exhibits a temporal structure and temporality also links all experiences into a single stream of experience, which means that every present moment also has a fringe of experiences which are part of the present consciousness of the object (Husserl 1962:218-219). Moreover, he regards the temporal aspects of the noetic-noematic distinction as crucial in the constitution of the meaning of an object and especially in the constitution of intersubjectivity and therefore distinguishes between internal time (an aspect of the noetic) and immanent temporality (an aspect of the noematic) through which whatever is experienced is temporally ordered (Husserl 1982:39-43).

Apart from directionality and temporality, Husserl also regards the horizontal structure of experience as an invariant feature of consciousness. By this he meant that we encounter everything in a context and that this context can be temporally, spatially, socially and historically determined. The horizon of experience is thus not restricted to perceptual experiences, but also extends to former experiences preserved in memory and therefore implies that the meaning of a particular object cannot be separated from the global field of meaning from the subject's world (Husserl 1962:91-93).

According to Husserl, individuals thus find themselves located in a lifeworld of immediate experience which needs to be interpreted in terms of a meaningful structure imposed on reality in order to make it comprehensible. This is done through the act of intentionality by which we attend to aspects of our experience against the background of a unique biographical situation. However, since all experience represents a correlation between experiencing and that which is experienced and since the locus of meaning is grounded in the intentional activity of consciousness, the Other's experiences are not immediately accessible. Husserl therefore also notes that the contents of another's world are therefore only available to me in an indirect manner (Husserl 1982:113 ff.).

It can therefore be concluded that whereas each individual retains the essential core of experiencing as a constituted world, things in this world are not the in-themselves-existing things of nature or of the exact sciences with the distinctive properties which alone are recognised by science, but are instead experienced as intentional objectivities of the personal consciousness.

6.4 JEAN-PAUL SARTRE AND THE CHALLENGE OF THE CONSTITUTION OF MEANING IN ILLNESS

With regard to the evidence-based patient choice challenge of the constitution of meaning in illness referred to at the end of 4.2, this paragraph considers Jean-Paul Sartre's perspectives on the issue of the distinct levels of constitution of meaning in illness.

6.4.1 Continental philosophical background

Jean-Paul Sartre (1905-1980) was born in Paris and became a professional teacher of philosophy. In 1938 he published a novel under the title of *Nausea* which in fact turned out to be a phenomenological account of a mind in the process of disintegration. It was followed in 1940 by his first important work of directly written philosophy called *The Psychology of Imagination*. However, World War II completely changed Sartre's life. After joining the French army he was

captured and imprisoned by the Germans and in prison studied Heidegger's philosophy and also wrote his first play. On his release he returned to Paris where he wrote his most important philosophical work, namely *Being and Nothingness* in 1943 (Olafson 1996:287-291).

Sartre's philosophical culture appears to have been formed almost entirely within the tradition of Continental rationalism and idealism ranging from Descartes to Kant and from Hegel to the twentieth century phenomenology of Husserl and Heidegger. Although a great deal of Sartre's work has been devoted to often extremely violent criticism of the various forms of dualism and idealism that are peculiar to the Cartesian tradition, his leading ideas bore the mark of their derivation from the philosophers he attacked. At different stages of his career therefore his thought seems to have been strongly influenced by Husserl, Heidegger, Hegel and Marx, as well as by extra philosophically disciplines like psychology and sociology.

Despite the great diversity of his writings which ranged from ontology to political journalism and films, the central theme of his work has been his passionate interest in human beings. It is argued that although he sometimes expressed his sense of the primacy of human existence in rather exaggerated ways, there can be no doubt of the profoundly moral and humanistic character of his philosophy. However, his deep interest in individual human beings and his effort to understand them and to form a general concept of human being, has been heavily dependent on a number of other such conceptions which emanated from amongst others the Christian, Cartesian and Hegelian theories of man. While he rejected all of these for some or other reason, they in his view expressed a fundamental aspiration of human beings, namely to establish one's own individual being in a rational necessity of some sort. Sartre's entire philosophy can therefore be seen as an attempt to describe a mode of human being which finds its essence in this fundamental aspiration of human beings and his combination of a rejection of all forms of rationalism with a recognition of the permanent validity of the demand they reflect thus not only reflects the most characteristic feature of Sartre's thought, but also holds the key to his moral philosophy and to the fundamental imperative of the recognition of this irresolvable contradiction that defines human nature (Olafson 1996:288).

There can be little doubt that Sartre's *Being and Nothingness* owes more to the thought of Martin Heidegger than to any other philosopher. While in many respects his account of the human reality represents little more than an amplified restatement of the views of Heidegger in *Sein und Zeit*, there are however also important differences. Unlike Sartre, Heidegger has never been interested in a detailed analysis of the structure of consciousness, but instead described the ontic counterparts of these intentional structures and thereby tried to convey the special character of

human being by indicating what its world is like. However, in Sartre's view such a description of the human world must be supplemented by an account of the structure of the consciousness that establishes this world. While he therefore repeatedly criticised Heidegger for having suppressed consciousness, Sartre was on the contrary unequivocally committed to the use of his ontological apparatus in order to generally clarify the human predicament. As reflected in the subtitle of *Being and Nothingness*, namely *An Essay on Phenomenological Ontology*, Sartre explained that his kind of ontology is like phenomenology, purely descriptive in nature and therefore does not undertake to explain human experience by reference to extra phenomenal realities in the manner of Descartes or Kant (Olafson 1996:290).

Sartre therefore in the Introduction to *Being and Nothingness* firstly takes up the claim of contemporary phenomenism to have overcome the traditional duality of appearance and reality by joining both the *physical* and the *mental* under the concept of appearances that is neutral with respect to the distinction. He regarded this joining of concepts as entirely justified insofar as it denied that there is any screen of sensations or mental contents behind which reality may lurk. To Sartre, Being itself appears and he therefore insisted that being is completely independent of the fact of its appearing and is transcendent in the sense that it can never be exhausted by any finite set of appearances. However, this view raised the question of the nature of this appearing and of the relationship between the being of things and the being of their appearance - a question that constitutes the problem statement of the book in general (Sartre 1956:xxi-xliii).

In order to inquire into this question, Sartre however had to depart from Husserl on several points. Most importantly, he drastically reinterpreted the Husserlian notion of intentionality. While for Husserl intentionality referred to an internal structure of mental states by virtue of which they were directed towards objects, Sartre added the stipulation that these objects had to be independent of consciousness, since objects would otherwise owe their being to consciousness, which he regarded as impossible. He argued that since objects are never exhaustively given to an instantaneous intuition, a constitutive consciousness as conceived by Husserl could only reproduce this central feature of our consciousness of objects by intending the infinite series of appearances that compose the object and at the same time not intending all those that are not presently given. The fact that this cannot be done, Sartre argued, would establish the transcendence of objects (Sartre 1956:171-216).

In the same way as Sartre presented the transphenomenality of objects as the background against which they appear, he also argued that the being of consciousness is transphenomenal and not dependent on its appearing to itself in an explicit and reflective self awareness. On the contrary,

this reflective self-consciousness is said to presuppose the antecedent existence of a prereflective consciousness in much the same way as consciousness of objects presuppose their transphenomenal status. To Sartre, the main characteristic of this being of consciousness is its activity, since it is incapable of being acted on from without and consists in and is exhausted by its own intentional and meaning conferring acts. On the contrary, the being of things is characterised in terms of a complete incapacity for any relationship to itself. Having established these two radically different types of being and by rejecting both the idealistic and the realistic accounts of their rapport, Sartre submitted himself to the obligation to provide a more satisfactory account of the relationship between being-in-itself and being-for-itself and of the relationship of both to the generic concept of being (Sartre 1956:73-106).

In an attempt to thus describe conscious being, Sartre took his cue from the human ability to ask questions and receive negative answers. To him, negative judgements require an ontic counterpart which is non-being and he therefore had to ask what the origin of this non-being might be. In developing his argument, he rejected the Hegelian view that being and non-being are logically interdependent in favour of Heidegger's notion of non-being as a kind of circumambient medium in which medium is contingently suspended (Sartre 1956:3-16).

However, he at the same time criticised Heidegger for not indicating how non-being can appear in a local form in the world and argued that this would only be possible if there is a being that is or generates its own nothingness. To him, this being turns out to be human consciousness whose distinguishing feature he regarded as the ability to constitute itself in contrast to its physical milieu, its body, its past or everything whatsoever. By its self-detaching activity, human consciousness thus creates a hole in being-in-itself, while the latter, as the horizon that surrounds its focus of negation, becomes a world. Human consciousness thus apprehends itself as a bridge between the actual and the possible and as having to determine which of these possibilities are to be realised and can thus be regarded as free, since it is forced to think of itself as other than the world and unincorporable into any causal sequence existing in the world. To Sartre, the human feeling of anguish is therefore to be regarded as our experience of this freedom (Sartre 1956:433-556).

In the face of this freedom, says Sartre, human beings can adopt either of two fundamentally different attitudes. They can attempt to conceal their freedom by for instance a belief in some form of psychological determinism. However, all these attempts are doomed to failure, since human beings can try to conceal their freedom only to the extent that they recognize it. To Sartre, the attempt succeeds only in producing a paradoxical internal duality of consciousness in

which consciousness thinks of itself as a thing at the same time that it gives covert recognition to its freedom. Such a state he calls bad faith and poses as its antithesis an acceptance of one's own freedom, as well as a recognition that human beings are the absolute origin of and solely responsible for their own acts (Sartre 1956:47-67). The contrast between these two possible attitudes to life not only forms the basis of Sartre's ethic, but also to his definition of human being as precisely this self-contradictory effort to achieve the status of a thing while remaining a consciousness that contemplates itself as a thing. However, to Sartre, this effort has to fail, since while human beings are absolutely responsible for their choices, their existence is not a result of a choice, but simply a fact (Olafson 1996:291).

6.4.2 Jean-Paul Sartre and the distinct levels of the constitution of meaning in illness

Against this background, Sartre analyses pain and illness in *Being and Nothingness* by identifying four distinct levels of constitution of meaning in illness, namely pre-reflective sensory experience, suffered illness, disease and the disease state. To him, the first three represent the way in which the patient experiences illness, while the fourth represents the physician's perception thereof (Toombs 1993:31-32).

At the pre-reflective level, the body is not explicitly thematised as body, as in the normal course of events I do not experience my lived body as a biological organism (Sartre 1956:401-402). My lived body is essentially that which is perpetually forgotten or surpassed in carrying out my projects in the world (Sartre 1956:429-430). In for instance writing a letter, I am not explicitly aware of the neurophysiological mechanism which controls the movement of my hand and the grasping of the pen. Thus, while the lived body is present in every action, it is invisible. What Sartre would like to emphasise is that at the level of the lived body, every consciousness of the body is a non-thetic consciousness. Since I am my body, in that I am an embodied subject, it takes an act of reflection to let my body stand out as a body (Sartre 1956:425-427).

Sartre argues that the fundamental level of the constitution of illness is that of pre-reflective sensory experience (Sartre 1956:436-438). At this level, the immediate pre-reflective experience is a manifestation of the way consciousness exists in the body. A pain in the eyes is therefore not immediately experienced as an object pain which is located in the eyes, but rather is the eyes at this particular moment. One experiences the eyes-as-pain or vision-as-pain for instance as an act of reading which manifests itself in terms of the blurring of the words or the inability to concentrate on what is being read.

However, Sartre says, when I start reflecting on my pain and try to apprehend it, the pain ceases to be lived pain and becomes object pain (Sartre 1956:440-441). As lived pre-reflectively, the

pain is the body, but in the reflective act, the consciousness of pain is transcended by a psychic object, namely suffered illness, becomes a psychic object outside your immediate subjectivity and manifests itself as for instance a pain in the eye. Thus, in reflective consciousness, illness becomes distinct from the body and takes on its own form. Sartre compares this with individual notes that form part of a melody. Each concrete pain, he says, is like a note in a melody; it is at once a moment in the melody, as well as the whole melody. With each pain you apprehend the illness and yet it transcends them all, for it is the synthetic totality of all the pains, the theme which is developed by them and through them (Sartre 1956:442).

In addition, Sartre distinguishes yet another level of reflection in which one starts apprehending your illness as disease (Sartre 1956:466). While in its immediacy, illness is not experienced as disease, but rather as the body painfully lived, illness at this level represents an objective disease, such as an ulcer of the stomach which is identified by means of bits of knowledge acquired from others. Of importance to Sartre, is the fact that in the normal course of events I do not experience my body as a neurophysiological organism, but when I conceive of my body as an object or a being for others, I apprehend it as a malfunctioning physiological organism. To him, disease represents such an objectification, as he notes: "I know that it has the shape of a bagpipe, that it is a sack, that it produces juices and enzymes, that it is enclosed by a muscular tunica with smooth fibres, etc. I can also know - because a physician has told me - that the stomach has an ulcer, and again I can more or less clearly picture the ulcer to myself. I can imagine it as a redness, a slight internal putrescence; I can conceive of it by analogy with abscesses, fever, blisters, pus, canker sores, etc. All this on principle stems from bits of knowledge which I have acquired from Others or from such knowledge as Others have of me. In any case all this can constitute my illness, not as I enjoy possession of it, but as it escapes me" (Sartre 1956:466).

To Sartre, the fourth level of constitution of meaning is the disease state which represents the physician's conceptualisation of the patient's illness. On this level, illness is identified with a pathoanatomical or pathophysiological fact which conceives of illness as a question of bacteria or of lesions in tissue (Sartre 1956:466).

6.5 MAURICE MERLEAU-PONTY AND THE CHALLENGE OF ABSTRACTIONS IN HEALTH CARE

With regard to the evidence-based patient choice challenge of abstractions in health care referred to at the end of 4.3, this paragraph considers Maurice Merleau-Ponty's perspectives on the issue of the transcendental role of the body in human existence.

6.5.1 Continental philosophical background

Maurice Merleau-Ponty (1908-1961) was born in Rochefort-sur-mer and studied at the *École Normale Supérieure* in Paris where after he taught at a number of *lycées* and at the *École Normale* itself. After serving in World War II as an army officer, he was appointed as professor first in Lyon and later at the Sorbonne in Paris (Olafson 1996:279-281).

Merleau-Ponty's career had two principle aspects. He was first and foremost a professional philosopher and teacher of philosophy and worked mainly in the fields of philosophical psychology and phenomenology. In addition, he was a man of letters and wrote extensively on especially political and aesthetic subjects while also actively taking part in the intellectual life of his time.

Like Sartre, Merleau-Ponty's philosophical development was dominated by a strong reaction against the Cartesian tradition and in particular the critical idealism of thinkers such as Léon Brunschvieg. His main objection to their philosophy was that by treating the objects of knowledge as completely susceptible to a residueless conceptualization, it reduced the world to the status of a term of thought and, in effect, assimilated it to the knowing mind. To Merleau-Ponty, idealism produced a harmonious and logical systematisation of experience, but failed to do justice to the fundamental discontinuities between consciousness and the world and between consciousness and the other. Though Merleau-Ponty remained a lifelong student of Descartes and his entire philosophy can be regarded as a radical reinterpretation of the Cogito, it were exactly these discontinuities that he came to regard as fundamental to an understanding of human subjectivity and that inspired him to work out a theory of mind that would do justice to the contingent and non-conceptual character of our encounters with the world and with other conscious beings.

In constructing his theory of mind, Merleau-Ponty drew on two completely distinctive bodies of thought, namely scientific psychology and the phenomenology of Edmund Husserl. The psychological theory to which he owed the greatest debt, was the Gestalt theory, but gave its perception of conceptual wholes a much wider range of application. Similarly, he recognised behaviourist's identification of mental activities with the functioning of the physical organism, but strongly denied that a causal or quantitative analysis could do justice to these dimensions of bodily activity.

However, Merleau-Ponty's relation to Husserlian phenomenology is even more complex. While he derived the idea of philosophy as a descriptive account of the structures of consciousness from Husserl, he never accepted Husserl's theory of phenomenological reduction which required

the world as a phenomenon for consciousness to be bracketed off from any transcendent being. While Merleau-Ponty thus agreed with Husserl that there can be no knowledge of things-in-themselves, but only as they are accessible to human consciousness, he insisted that all perceptual experience brings with it an essential reference to the world that transcends consciousness. To Merleau-Ponty, this transcendent reference can itself be made a theme for explicit reflection and in that sense be reduced to its being for consciousness, though this reduction involves no attempt to create an independent world of phenomenal immanence. Phenomenological description, as conceived by Merleau-Ponty, does not alone deal with sense data or essences, but also undertakes to present the self transcending and referential character of our experience by virtue of which it differs from conceptual thought. It was therefore because he believed that the nexus of conceptual thought and the world is not affected by means of a deduction, but through a perceptual encounter, that Merleau-Ponty regards the primacy of perception as a mode of access to the real.

Merleau-Ponty derived some of the principle guidelines for his account of what he called the perceptual milieu from Husserl's last period. It was in Husserl's *The Crisis of European Science* from 1936 that he argued that the modern scientific world view that had developed since the seventeenth century had in effect resulted in a kind of systematic obliviousness to the familiar perceptual world from which the mathematico-physical sciences of nature took their departure and on which they remained dependent for any final interpretation. While Husserl called this perceptual world the *Lebenswelt*, Merleau-Ponty in his major works, elaborated in great detail and amid a wealth of supporting psychological evidence on this conception of an original and unique perceptual relationship to the world that is on the one hand presupposed by all scientific activity, but on the other cannot be retroactively explained or even described by means of the categories of the natural sciences. To Merleau-Ponty, it in particular was the distinctively human mode of being-in-the-world that accordingly cannot be understood in terms of the traditional dualistic model that presents perceptual experiences as effects produced in the mind by the action of extra phenomenal physical causes. He therefore emphatically affirmed the reality of a world that transcends our consciousness thereof, but held that all our scientific and other attempts to conceptualise the world remain dependent for their sense on that primordial perceptual milieu (Olafson 1996:280).

In his major work, *Phenomenology of Perception*, Merleau-Ponty continued his critique of psychology, but also laid the foundation of a general theory of human subjectivity that closely compared to the ontologies of Heidegger and Sartre. In constructing his theory, he objected to the sense-datum theory of perception because it, as a primary condition, represents experience

composed of sensations that are stripped of any transcendent reference to objects and to the world. Like Bergson, Merleau-Ponty regarded sensations as the products of intellectual analysis and argued that it is impossible to reconstitute our experience of the world by means of artificial units that have been abstracted from the intentional structure of consciousness.

In addition, Merleau-Ponty also developed his highly original theory of the role of the body in perception and argued that the body is neither just an object among objects, nor just a contingent fact that our perceptual experience is conditioned by, but represents the locus of consciousness in the world that determines the perspectivistic and uncompletable nature thereof. The functioning of the human body can therefore only be understood at its higher levels if the intentional structures that Sartre would reserve for pure consciousness, is attributed to it.

In the concluding chapters of *Phenomenology of Perception*, Merleau-Ponty presented an account of human liberty and its development in historical action as part of his general theory of human subjectivity. Like Sartre, Merleau-Ponty viewed liberty as implicit in the capacity of human consciousness for objectifying its situation and setting it within a context of possible courses of action. However, unlike Sartre, he denied that this liberty can ever be total, due to the fact that although we create moral beings through our choices, it is done progressively and remains dependent on the collectively accepted meanings by which our world is pre-evaluated. Merleau-Ponty regarded this stratum of funded meanings as of great importance and as the intermediate term between pure individual subjectivity and the blank opacity of things in the world. As such, he did not regard it as an obstacle to individual moral autonomy, but rather as an indispensable precondition for the exercise of freedom (Olafson 1996:281).

6.5.2 Maurice Merleau-Ponty and the transcendental role of the body in human existence

Against this background, Merleau-Ponty reflects on the transcendental role of the body in perception in *Phenomenology of Perception* by analysing the lived body and the body as object in the world.

The phenomenological analysis of body provided by Merleau-Ponty reveals a fundamental distinction between the lived body as it is immediately experienced in a non-reflective or pre-reflective way and the objective or the physiological body. This analysis particularly reveals that at the pre-reflective level (1) the body is not explicitly thematised *as* body and not apprehended as a physiological body or material object among other material entities within the world; (2) the relation with the lived body is an existential, rather than an objective relation, since I do not have or possess a body, but am my body; (3) there is thus a fundamental identification with the body with no perceived separation between body and self and (4) the lived body exhibits certain

features that are essential to embodiment, such as being in the world, bodily intentionality, primary meaning and body image (Toombs 1993:51-57).

With regard to the concept of the lived body, Merleau-Ponty notes that we always find our self as embodied selves within the world and amidst an environment. I am embodied, not by possessing a body, but by being a body. This means that rather than being an object of the world, my body represents a particular point of view on the world (Merleau-Ponty 1962:70-72). He notes that it is indeed by means of my body that I have access to the world in the first place, as sensory experience after all represents the sole means by which the environing world is disclosed to me. As my locus of orientation in the world, my body through my senses both orients me to the world around me and positions the environing world in accordance with my bodily placement and actions. Thus, from the point of view of my experience of the world, to perceive something is necessarily to be related to it by means of my body (Merleau-Ponty 1962:92).

With regard to being in the world as a feature of embodiment, Merleau-Ponty notes that my bodily engagement in the world is an active one. That means that rather than an exclusively physical entity devoid of intentionality, the lived body is an embodied consciousness which both engages and is engaged in the surrounding world.¹³⁵ I constantly find myself within the world, but also continually move towards the world and organise it in terms of projects, etc. It is in this respect, says Merleau-Ponty that sensory perception is neither a purely mechanical or physiological process, nor a purely psychological one. Sensing rather exhibits a bodily intelligence and affectivity and implies that the function of the lived body can only be understood insofar as the lived body is a being in the world whose global presence gives meaning to sensory stimuli and causes them to acquire importance, value and existence for the organism (Merleau-Ponty 1962:79-80).

Due to it being a practical field of significance, the world according to Merleau-Ponty arouses in the lived body certain habitual intentions and consequently, objects are apprehended as manipulatable by the body (Merleau-Ponty 1962:81-89). It is in this directedness towards the world that the body thus exhibits a bodily intentionality and body parts may be regarded as intentional threads linking the body to the world surrounding it. To Merleau-Ponty, embodied consciousness is thus not in the first place a matter of I think or I can, as in the action of the hand reaching for a pen, a reference to the object is already contained as something at which action is directed. This implies that every formula of movement presents itself to the body as a

¹³⁵ With regard to the body as a unique vehicle of one's agency and one's primordial means of contact with the world, see also Husserl 1989:159-160.

practical possibility and a sphere of action (Merleau-Ponty 1962:138) and that every geographical setting contains a system of meanings through which the individual organises the given world (Merleau-Ponty 1962:106-112).

Accordingly, Merleau-Ponty argues that the primary introduction of meaning is that which is afforded by the body through what he calls physiognomic perception (Merleau-Ponty 1962:132). By this concept he meant that there is a primary knowing which is knowing through the body as for instance demonstrated by an infant who first understands the world through the experiences of sense perception and bodily action and only subsequently by means of the development of rational and conceptual thought. Moreover, he pointed out that we do not experience the world in terms of pure and isolated sensations, but as an experience of a host of impressions and that implicit in any concrete situation is a set of meanings whose reciprocities, relationships and involvements do not require to be made explicit in order to be exploited (Merleau-Ponty 1962:129).

To Merleau-Ponty, the lived body is thus experienced as an integrated system of coordinated bodily movements which are spontaneously distributed among the various body segments and is most of the time not conceived as such by an individual. He notes that I do not bring together one by one the parts of my body, but that this translation and unification is performed once and for all within me; they are my body itself (Merleau-Ponty 1962:148-153). Furthermore, he says, I do not perceive the relations between the parts of my body as a spectator, but rather know where my limbs are through a body image in which all are included. My body image represents the total awareness of my posture or form in the intersensory world. However, this form is dynamic and my body thus appears to me as an attitude directed towards a certain existing or possible task. Moreover, the body is experienced not only in terms of its present set of positions, but also as an open system of an infinite number of equivalent positions directed to other ends. To Merleau-Ponty, this implies that body image is not only to be regarded as an experience of my body, but also as an experience of my body-in-the-world (Merleau-Ponty 1962:100-147).

With regard to the concept of the body as object and over against his views on the lived body, Merleau-Ponty argued that there thus is a fundamental ambiguity in the structure of the lived body, since while the lived body is that which is most intimately me or mine, it is yet an object for others and at the same time the expression and the expressed of my existence (Merleau-Ponty 1962:194-199). As noted earlier, also Sartre regarded the apprehension of one's body-as-object as revealed in the experience of being-for-the-other and that one first experiences your body-as-object in the gaze of the Other (Sartre 1956:445-461). In the experience of being looked

at, I recognise not only my being-as-object for another subject, but also the brute fact of my being as material and physico-biological stuff.

6.6 JÜRGEN HABERMAS AND THE CHALLENGE OF INFORMATIONAL MANIPULATION IN HEALTH CARE

Jürgen Habermas never specifically addressed the issue of informational manipulation in health care, but became famous for his views on the elimination of paternalism/authoritarianism in society. Therefore and with regard to the evidence-based patient choice challenge of possible informational manipulation in health care referred to at the end of 4.4 and against the continental philosophical background of his work, this paragraph considers Habermas's perspectives on the elimination of paternalism/authoritarianism in society.

6.6.1 Continental philosophical background

Jürgen Habermas (1929-) was born in Düsseldorf in 1929 and after the World War II studied at Göttingen, Zürich and Bonn before becoming the assistant of Theodor Adorno at the Institute of Social Research in Frankfurt. After habilitating at the University of Marburg in 1961, he taught philosophy and sociology at the Universities of Heidelberg and Frankfurt and became co-director of the Max Planck Institute in Starnberg. He returned to the University of Frankfurt in 1983 where he worked as professor of philosophy until his retirement in 1994 (McCarthy 1996:227-228).

Habermas's life remained deeply influenced by the traumatic events of his youth under National Socialism in Germany and from the time of his involvement with the German student movement in the 1960s became one of Germany's most prominent intellectuals speaking out on issues ranging from violations of civil liberties to the attempted historicising of the Holocaust. His scholarly work therefore ranged across many of the humanities and social sciences and aspires to a comprehensive Critical Theory. His *The Structural Transformation of the Public Sphere* from 1962 was a historical, sociological and philosophical account of the emergence and transformation of the liberal public sphere as a forum of public critical discussion of matters of general concern. While the historical structures of that sphere reflected the particular interests that gave rise to it, the idea it claimed to embody, namely that of legitimating political authority through rational discussion and reasoned argument, remains central to democratic theory. In 1992, Habermas returned to these themes in his *Between Facts and Norms* where he applied the idea of justification by appeal to generally acceptable reasons to the deliberations of free and equal citizens in a constitutional democracy. In this work he argued that the primary function of

the system of basic rights is to secure personal and political autonomy and regarded the institutionalisation of the public use of reason in the legal-political domain as the key to the establishing thereof (McCarthy 1996:227).

Habermas's extensive writings in the intervening decades can be regarded as an examination of the cultural, psychological and social preconditions of the barriers to the accomplishing of this goal. His essays in the early 1960s introduced the idea of studying society as a historically developing whole with the purpose of enlightening political consciousness and guiding political practice. The methodology and epistemology behind this approach he worked out in his *On the Logic of the Social Sciences* from 1967 and *Knowledge and Human Interests* from 1968. Both works had as principle target the neopositivist thesis of the unity of scientific method and in particular the claim that the logic of inquiry in the human sciences is basically the same as in the natural sciences. His *On the Logic of the Social Sciences* was therefore devoted to an examination of the nature and role of *Verstehen* in social inquiry and argued that access to symbolically prestructured object domains calls for interpretative procedures designed to grasp the meanings on which social interactions turn. Moreover, he argued that intersubjective meanings constitutive of sociocultural lifeworlds can neither be wholly objectified, as supposed by positivism, nor simply reappropriated, as proposed by hermeneutics. On the contrary, he noted that Psychoanalysis suggests an alternative approach in which explanatory and interpretative procedures are combined with a critique of ideology in a historically orientated theory with practical intent.

In his *Knowledge and Human Interests*, Habermas undertook a historical and systematic study of the prehistory of modern positivism in an attempt to free the ideas of reason and rationality from what he regarded to be a 'scientistic misunderstanding'. By tracing the development of the critique of knowledge from Kant through German idealism to Marx, as well as its transformation into the methodology of science in early positivism, he established his own position in critical encounters with three classic attempts to overcome positivism from within methodology, namely the reflections of Peirce on natural science, of Dilthey on cultural inquiry and of Freud on self-reflection. In each of these cases he examined the roots of cognition in life and argued for an internal connection of knowledge with 'anthropologically deep-seated' human interests. A key feature of this 'quasi-transcendental' theory of cognitive interests was the basic distinction between the interest in prediction and control of objectified processes and the interests in mutual understanding and distortion free communication with speaking and acting subjects (McCarthy 1996:228).

These works were followed by a series of studies of basic structures of communication which he arranged as a three-tiered research program. The ground level consisted of a general theory of communication in natural languages which he typified as 'universal pragmatics'. This theory also served as the foundation for a general theory of socialisation in the form of a developmental account of the acquisition of communicative competence. Progressing from here, Habermas sketched a theory of sociocultural evolution as the historical development of forms of communicative interaction and mutual understanding. These accounts of communication, socialisation and social evolution enabled him to anchor moral theory in his theory of social and communicative action. Arguing that our basic moral intuitions are caused by something deeper and more universal than contingent features of particular traditions, his Discourse ethics therefore endeavoured to reconstruct the intuitive grasp of the normative presuppositions of social interaction possessed by competent social actors in general.

Habermas's work of the 1960s and 70s culminated in his monumental *The Theory of Communicative Action* from 1981 in which he developed a concept of communicative rationality freed from the subjectivistic and individualistic premises of modern social and political theory, together with a two-level concept of society which integrated the competing paradigms of lifeworld and system. On this basis he designed a critical theory of modern society that focused on "the colonisation of the lifeworld" by forces emanating from the economy and the state and represented in systematic mechanisms such as money and power drive processes of social integration and symbolic reproduction out of domains in which they cannot be replaced. To Habermas, this relentless attack on the communicative infrastructure of society can be contained only by a countervailing expansion of the areas of life coordinated via communication and in particular by the subordination of economic and administrative subsystems to decisions arrived at in open and critical public debate. Habermas's critique of modernity is therefore typified by an unflinching defense of Enlightenment rationality that emphasises the ongoing and unfinished character of the project of enlightenment (McCarthy 1996:228).

6.6.2 Jürgen Habermas and the elimination of paternalism/authoritarianism in society

According to Habermas, Weber, Adorno and Horkheimer neglected the communicative essence of rationality in favour of a purely instrumental rationality that eventually led to the 'Dialectic of Enlightenment'. Habermas's reformulation is based on the two insights that (1) rationality is inherently linguistic and discursive; and (2) discourse requires that interlocutors assume the possibility of sincere and truth governed speech. To him, this means that participants in discourse cannot regard all of discourse as merely a matter of power and self-interest.

Consequently, Habermas denies the pessimism of Adorno and Horkheimer, as well as the postmodern denial of the transcendence of norms due to the fact that there remains a moment of unconditionality and of truth and freedom in human relations despite the inroads of the late modern system of money and power. He therefore also laments the traditional dependence of both modernism, as well as its postmodern critics on a subjectivist and non-social conception of rationality (Cahoone 1997:589).

He acknowledges that Foucault indeed provided an illuminating critique of the entanglement of the human sciences in the philosophy of the subject by indicating that these sciences try to escape from the aporetic tangles of contradictory self-thematisation by a subject seeking to know itself, but in the process becoming all the more deeply ensnared in the self-reifications of scientism. However, he notes that Foucault did not think his approach through well enough to realise how his theory of power was overtaken by a similar fate than that of the human sciences rooted in the philosophy of the subject (Habermas 1997:590).

Hence, Habermas regards it a good idea to once again return to the unmasking of the human sciences through the critique of reason, but then in full awareness of an important fact that the successors of Nietzsche stubbornly ignored. This fact, he contends, is the philosophical counter discourse which from the start accompanied the philosophical discourse of modernity as initiated by Kant and which already postulated an alternative for subjectivity as the principle of modernity.¹³⁶ While the basic conceptual issues of the philosophy of consciousness have already been analysed by thinkers as diverse as Schiller, Fichte, Schelling and Hegel, their solutions failed to provide a way out of the dilemma and therefore behooves a retrace of the path of the philosophical discourse of modernity back to its starting point. To Habermas, the paradigm of the philosophy of consciousness has become exhausted, but the symptoms of this exhaustion should dissolve with a transition to the paradigm of mutual understanding (Habermas 1997:591).

Contrary to the objectifying attitude in which the knowing subject regards itself to the surrounding world, the performative attitude of participants in interaction who coordinate their plans for action by coming to an understanding about something in the world, has become fundamental to the paradigm of mutual understanding. In this regard Habermas notes that when an ego carries out a speech act upon which an alter takes up a position with regard to it, the two parties enter into an interpersonal relationship which is structured by the system of reciprocally interlocked perspectives among speakers, hearers and non-participants who happen to be present at the time.

¹³⁶ Refer in this regard to the unique lecture delivered by Michel Foucault in 1983 (Foucault 1984:32-50).

This attitude of participants in linguistically mediated interaction, says Habermas, enables a completely different relationship of the subject to itself from the sort of objectifying attitude that an observer assumes towards entities in the external world. To him, the transcendental-empirical doubling of the relation to self is only unavoidable when there is no alternative to the observer perspective and the subject views itself as the dominating counterpart to the worlds as a whole or to an entity appearing within it. In such a case, no mediation is possible between the extramundane stance of the transcendental I and the intramundane stance of the empirical I.

However, when linguistically generated intersubjectivity gains primacy, this alternative no longer applies, since the ego then stands within an interpersonal relationship that allows him to relate to himself as a participant in an interaction from the perspective of alter. This reflection undertaken from the perspective of the participant, says Habermas, escapes the kind of objectification which is inevitable from the reflexively applied perspective of the observer. Everything now gets frozen into an object under the gaze of the third person, which can be inwardly or outwardly directed. The first person, who turns back upon himself in a performative attitude from the angle of vision of the second person, can now *recapitulate* the acts it just carried out which means that we now have a recapitulating reconstruction of knowledge already employed instead of reflectively objectified knowledge (Habermas 1997:592).

This implies that, says Habermas, the intuitive analysis of self-consciousness that was earlier relegated to transcendental philosophy, now gets adapted to the circle of reconstructive sciences that endeavour to make the pre-theoretical grasp of rules on competently speaking, acting and knowing subjects explicit from the perspective of those participating in discourses and interactions. Due to the fact that such reconstructive attempts are no longer aimed at the realm of the intelligible beyond that of appearances, but at the actually exercised rule-knowledge deposited in correctly generated utterances, the ontological separation between the transcendental and the empirical is no longer applicable.

To Habermas, the same holds true for the doubling of the relation to self in the dimension of making the unconscious conscious. According to Foucault, the thought of subject philosophy here oscillates back and forth between heroic exertions bent on reflectively transforming what is in-itself into what is for-itself and on the recognition of an opaque background that stubbornly escapes the transparency of self-consciousness. However, if we make the transition to the paradigm of mutual understanding, these two aspects of self-thematisation are no longer incompatible. When speakers and hearers straightforwardly achieve a mutual understanding about something in the world, says Habermas, they move within the horizon of their common

lifeworld as an intuitively known, unproblematic and unanalysable holistic background. The speech situation, he notes, is the segment of a lifeworld tailored to the relevant theme, since it both constitutes a context and furnishes resources for the process of mutual understanding. The lifeworld, he says, thus forms a horizon and at the same time offers a store of things taken for granted in the given culture from which communicative participants draw consensual interpretative patterns in their efforts at interpretation (Habermas 1997:593).

However, Habermas concedes that making such statements require a change in perspective. What is needed is a theoretically constituted perspective to be able to treat communicative action as the medium through which the lifeworld as a whole is reproduced. Within such a perspective, participants no longer appear as originators who master situations with the help of accountable actions, but as the products of the traditions in which they stand, of the groups to which they belong and of the socialisation processes in which they grow up. The lifeworld therefore reproduces itself to the extent that the propagation of cultural traditions, the integration of groups by norms and values and the socialisation of succeeding generations are fulfilled.

Whoever thus wants to become reflectively aware of the individual totality of any individual biography or of a particular way of life has to give up the intention of rational reconstruction and recur to the perspective of the participants by simply proceeding historically. According to Habermas, also narrative tools, for which the analytic conversation between doctor and patient offers a suitable model, can be stylised into dialogically conducted self-critique that is related to the narratively recollected entirety of a course of life.

To Habermas, the two heritages of self-reflection that manage to get beyond the limits of the philosophy of consciousness have different aims and scopes. While rational reconstruction subscribes to the program of heightening consciousness, but is directed towards anonymous rule systems and therefore does not refer to totalities, methodically carried out self-critique is related to totalities and yet in the awareness that it can never completely illuminate the implicit, the prepredicative and the not focally present background of the lifeworld. However, as is evident from psychoanalyses, the two procedures can still be brought together in the same theory and as two aspects of self-thematisation by the knowing subject, are not irreconcilable.

Habermas thus regards the following as the most important aspects of his theory of communicative action (Habermas 1990:133). Communicative action is firstly characterised by an orientation toward success versus an orientation towards reaching understanding. To him, the question in social theory on what makes social order possible, has a counterpart in action theory, namely in the question how at least two participants in interaction can coordinate their plans in

such a way that alter is in a position to link his actions to ego's without a conflict arising or at least without the risk that the interaction will be broken off? If the actors are solely interested in success and the consequences or outcomes of their actions, they will try to reach their objectives by influencing their opponent's definition of the situation and therefore his decisions and motives by using external means such as weapons or goods or threats or enticements. Such actors treat each other strategically and the degree of cooperation is determined by the interest positions of the participants. On the contrary, he speaks of communicative action when actors are prepared to harmonise their plans of action through internal means and committing themselves to pursuing their goals only on the condition of an agreement about definitions of the situations and prospective outcomes. He notes that in both cases the teleological structure of action is presupposed, inasmuch as the actors are assumed to have the ability to act purposively and have an interest in carrying their plans out. However, they differ in that for the model of strategic action, a structural description of action directly orientated towards success is sufficient, while the model of action orientated towards understanding must specify the preconditions of an agreement to be reached communicatively and that will allow alter to link his actions to ego's (Habermas 1990:134).

To Habermas, communicative action is also characterised by reaching agreements as a mechanism for coordinating actions. He notes that the concept of communicative action is set out in such a way that the acts of reaching understanding that coordinate the action plans of several actors, cannot in turn be reduced to teleological action. This is due to the fact that the kind of agreement that is the goal of efforts to reach understanding depends on rationally motivated approval of the substance of an utterance. Agreement can therefore not be imposed or brought about by manipulation of your partner in interaction, since something that patently owes its existence to external pressure cannot even be considered as an agreement. Habermas therefore also notes that the generation of convictions can be analysed in terms of the model of taking a position on the offer contained in a speech act. Accordingly ego's speech act can be successful only if alter accepts the offer contained in it by implicitly taking an affirmative position on a claim to validity that is in principle criticisable.

In addition, Habermas also regards action situation and speech situation as characteristic of communicative action. He notes that if we define action in general as mastering situations, then the concept of communicative action highlights two aspects of this mastering, namely the teleological one of implementing an action plan and the communicative one of arriving at a shared interpretation or consensus on the situation. To Habermas, a situation denotes a segment of a lifeworld that has been delimited in terms of a specific theme and a theme arises in

connection with the interests and objectives of actors. As such, it defines the range of matters that are relevant and can be thematically focused on. In turn, individual action plans help put a theme in relief and determine the current need for consensual understanding that has to be met through the activity of interpretation. It is in this sense that the action situation is at the same time a speech situation in which the actors take turns in playing the communicative roles of speaker, addressee and even bystander. To these roles, says Habermas, correspond first- and second person participant perspectives as well as the third person observer perspective from which the I-Thou relation is observed as an intersubjective complex that can thus be objectified (Habermas 1990:135).

However, the system of speaker perspectives is intertwined with a system of world perspectives which motivates Habermas to also regard the lifeworld as background as characteristic of communicative action. Communicative action, he says, can be understood as a circular process in which the actor represents two things in one, namely an initiator who masters situations through actions through which he is accountable and a product of the traditions surrounding him, of groups to which he belongs and of processes of socialisation in which he is reared. The actor, says Habermas, finds himself face to face with that situationally relevant segment of the lifeworld that impinges on him as a problem that must be resolved through his own efforts. However, in another sense, the actor is carried or supported from behind by a lifeworld that not only forms the context for the process of reaching understanding, but also furnishes the resources for it. The shared lifeworld therefore offers a storehouse of unquestioned cultural givens from which those participating in communication can draw agreed-upon patterns of interpretation for use in their interpretative efforts. It has to be noted though that these ingrained cultural background assumptions represent only one component of the lifeworld and that for instance the solidarity of groups integrated through values and the competences of socialised individuals may also serve as resources for action towards reaching understanding.

Moreover, Habermas also regards the process of reaching an understanding between world and lifeworld as characteristic of communicative action. As mentioned, the lifeworld offers both an intuitively pre-understood context for an action situation and resources for the interpretative process in which participants in communication engage as they strive to meet the need for agreement in the action situation. However, participants in communicative action have to reach understanding about something in the world if they would like to carry out their action plans on a consensual basis. In this action, they presuppose a formal concept of the world as the reference system in the context of which they have to decide what is and what is not the case. According to Habermas, the depiction of facts is however only one among several functions of the process

of reaching understanding through speech, as speech acts not only serve to represent an objective world of states and events, but also to produce a social world of interpersonal relationships. Furthermore, they serve to express the process of self-representation in which case the speaker may refer to something in the subjective world to which he has privileged access. To Habermas, this reference system of three worlds represents the basis on which communicative actors strive to reach understanding and on which agreement is reached through intersubjectively shared propositional knowledge, normative accord and mutual trust (Habermas 1990:136).

In addition, Habermas also regards relations to the world and claims to validity as an important characteristic of communicative action. To him, a measure of whether or not participants in communication reach agreement is the yes or no position taken by the hearer whereby he accepts or rejects the claim to validity that has been raised by the speaker. In order to reach understanding, a speaker raises with every utterance the claim that the utterance is true, that the speech act is right in terms of a given normative context and that the speaker's manifest intentions are meant in the way they are expressed. Thus, when someone rejects what is offered in an intelligible speech act, he denies the validity of an utterance in terms of at least three respects, namely truth, rightness and truthfulness. A person's no signals that the utterance has failed to fulfill at least one of its three functions due to the fact that the utterance is not in accordance with either the world of existing states of affairs, our world of legitimately ordered interpersonal relations or each participants own world of subjective lived experience.

Finally Habermas also regards world perspectives as characteristic of communicative action. He notes that against the background of the previous discussion, the options of a competent speaker can now be identified. Provided that the foregoing analysis is correct, a speaker essentially has the choice between a cognitive and interactive and an expressive mode of language use. To these modes, says Habermas, corresponds three different classes of speech acts, namely the constative, the regulative and the representative which permit the speaker to concentrate, in terms of a universal validity claim on issues of truth, justice or taste. This implies that he has a choice among three basic attitudes with each entailing a different perspective on the world. In addition, says Habermas, the decentred understanding of the world enables him to confront external nature in not only an objectivating attitude, but also in a non-conformative and expressive one, to confront society not only in a norm-conformative attitude, but also in an objectivating or an expressive one and to confront inner nature not only in an expressive attitude, but also in an objectivating one (Habermas 1990:137).

Habermas worked out the implications of this formal pragmatics in a number of different ways. Firstly, he thought, that at the level of language itself, it may be possible to examine the systematic distortion of communication, since such distortions characteristically result from unresolved external conflicts which impinge on the communicative encounter. Secondly and much more controversially, Habermas, along with his associate Karl-Otto Apel, developed a discourse-based or communicative ethical theory. He believed that the agreements aimed at in speech not only concern matters of fact, but also of morality. Contra to a tradition of thought which is still influential in especially the English speaking countries, he maintained that moral judgements are not merely expressions of preference or prescriptions based on an ultimately arbitrary choice between alternative values. Instead, he argued that we can distinguish between ethical dilemmas related to concrete ways of life and core moral questions to which our reasoning must take a universalistic approach. His discourse ethics thus steers a path between the formal and communitarian traditions of ethical thought, since he contended that moral judgements are neither just expressions of social conventions, nor reached deductively by individuals who are in principle isolated from one another and alone with their consciences. The agreement, he stated, must be one which is or could have been reached in discussion (Outhwaite 1996:12).

Jürgen Habermas and Karl-Otto Apel began reformulating Kant's ethics by grounding moral norms in communication - a venture to which Habermas referred as discourse ethics. However, this venture has to be understood against the background of Hegel's critique of Kant. Among the many criticisms leveled against Kant by Hegel, Habermas singles out four which he regards as the most incisive. The first of these is Hegel's objection to the formalism of Kantian ethics. Since the categorical imperative as moral principle requires that the moral agent abstract from the concrete content of duties and maxims, Hegel argues that its application necessarily leads to tautological judgements. The second is Hegel's objection against the abstract universalism of Kantian ethics. He argues that due to the fact that the categorical imperative enjoins separating the universal from the particular, a judgement considered valid in terms of that principle necessarily remains external to individual cases and insensitive to the particular context of a problem in need of a solution. The third criticism is Hegel's attack on the importance of the mere ought. Hegel argues that since the categorical imperative enjoins a strict separation of is from ought, it necessarily fails to answer the question of how moral insight can be realised in practice. Fourthly, Hegel objected to the terrorism of pure conviction. Since the categorical imperative severs the pure postulates of practical reason from the formative process of spirit and its concrete historical manifestations, it necessarily recommends to the advocates of moral

worldview a policy that aims at the actualisation of reason and even sanctions immoral deeds if they serve higher ends (Habermas 1990:195-196).

In defining discourse ethics, Habermas notes that Kantian moral philosophy can be described as deontological, cognitivist, formalist and universalist. Wanting to limit himself strictly to the class of justifiable normative judgements, Kant was forced to choose a rather narrow concept of morality. While classical moral philosophies dealt with all the issues of the good life, Kant deals only with problems of right or just action. To him, moral judgements merely serve to explain how conflicts of action can be settled on the basis of rationally motivated agreement and to justify the validity of norms in terms of principles worthy of recognition. In short, thus, the basic phenomenon that moral philosophy must explain is the normative validity of commands and norms of action. To Habermas, that is what is meant by saying that a moral philosophy is deontological, since a deontological ethics conceives the rightness of norms and commands on analogy with the truth of an assertoric statement.

Habermas however notes that it would be erroneous to equate the moral truth of normative statements with the assertoric validity of propositional statements. While this mistake is often made by intuitionism and by value ethics, he acknowledges that Kant does not make this mistake and does not confuse theoretical with practical reason. However, concerning his own position, he contends that normative rightness must be regarded as a claim to validity that is analogous to a truth claim. To him, this notion is captured by the term cognitivist ethics that is intended to answer the question regarding the justification of normative statements. He notes that although Kant opts for the grammatical form of an imperative (Act only according to that maxim by which you can at the same time will that it should become a universal law), his categorical imperative in fact plays the part of a principle of justification that discriminates between valid and invalid norms in terms of their universalisability to the effect that what every rational being must be able to will, is justified in a moral sense.

Discourse ethics, however, reformulates the Kantian categorical imperative in terms of intersubjectivity and by a procedure of moral argumentation. The principle of this procedure, which Habermas typifies as (D), postulates that only those norms may claim to be valid that could meet with the consent of all affected in their role as participants in a practical discourse (Habermas 1990:66). While thus broadly retaining the categorical imperative, Habermas scales it down to the principle of universalisation (U). In practical discourse, the principle of universalisation plays the part of a rule of argumentation: for a norm to be valid, the consequences and side effects of its general observance for the satisfaction of each person's

particular interests must be acceptable to all (Habermas 1990:197). To these two principles, Habermas adds a third, namely that consensus can only be achieved if all participants participate freely, as we cannot expect the consent of all participants to follow unless all affected can freely accept the consequences and the side effects that the general observance of a controversial norm can be expected to have for the satisfaction of the interests of each individual (Habermas 1990:93).

In order to circumscribe such discourse more precisely, Habermas takes up the rules first proposed by Robert Alexy as the rules of reason (Alexy 1990:165-167). These rules are the following:

1. Every subject with competence to speak and act is allowed to take part in a discourse.
- 2a. Everyone is allowed to question any assertion whatever.
- 2b. Everyone is allowed to introduce any assertion whatever into the discourse.
- 2c. Everyone is allowed to express his attitudes, desires and needs.
3. No speaker may be prevented by internal or external coercion from exercising his rights as laid down in 1 and 2 (Habermas 1990:89).

These rules are meant to circumscribe the ideal speech situation, namely one which emphasises equality and freedom for each participant, in particular freedom to participate in a discourse in a critical way so as to express your own attitudes, desires and needs and freedom from coercion of several sorts.¹³⁷

Finally, Habermas acknowledges that these procedural rules need to be complemented by a sense of solidarity between participants. To him, such solidarity involves concern for the wellbeing of both one's fellow human beings and of the community at large. In Habermas's account, solidarity is the other side of justice and a complementary perspective to that of equal treatment (Habermas 1990:xi-xii). He writes in this regard: "Under the pragmatic presuppositions of an inclusive and noncoercive rational discourse among free and equal participants, everyone is required to take the perspective of every one else, and thus project herself into the understandings of self and world of all others; from this interlocking of perspectives there emerges an ideally extended we-perspective from which all can test in common whether they wish to make a controversial norm the basis of their shared practice; and this should include mutual criticism of the appropriateness of the languages in terms of which

¹³⁷ Cavalier et al.: <http://caae.phil.cmu.edu/Cavalier/Forum/meta/background/HaberIntro.html>

situations and needs are interpreted. In the course of successfully taken abstractions, the core of generalisable interests can then emerge step by step" (Habermas 1995:117-118).

On the matter of what moral intuitions discourse ethics conceptualise, Habermas notes that moral intuitions are intuitions that instruct us on how best to behave in situations where it is in our power to counteract the extreme vulnerability of others by being thoughtful and considerate. Put into anthropological terms, morality is a safety device compensating for a vulnerability built into the sociocultural form of life. To him, the basic facts are that creatures that are individuated only through socialisation are vulnerable and morally in need of considerateness. Linguistically and behaviourally competent subjects are constituted as individuals by growing into an intersubjectively shared lifeworld and this lifeworld of a language community is in turn created through the communicative actions of its members. To Habermas this explains why the identity of the individual and that of the collective are interdependent, since they form and maintain themselves together.

However, built into the consensus-orientated language use of social interaction there exists an inconspicuous necessity for participants to become more and more individuated, while everyday language is also the medium through which the intersubjectivity of the shared world is maintained. This implies that the more the subject becomes individuated, the more he becomes entangled in a densely woven fabric of mutual recognition, but also of reciprocal exposedness and vulnerability. Thus, unless the subject externalises himself by participating in interpersonal relations through language, he becomes unable to form that inner centre that is his personal identity. To Habermas, this also explains the almost constitutional insecurity and chronic fragility of personal identity (Habermas 1990:199).

Moral philosophies of sympathy and compassion have therefore discovered that this profound vulnerability demand some guarantee of mutual consideration. In this regard, Habermas notes: "The profound vulnerability that makes necessary an ethical regulation of behaviour as its counterpoise is rooted, not in the biological weaknesses of humans, not in the newborn infant's lack of organic faculties and not in the risks of a disproportionately long rearing period, but in the cultural systems that are constructed as compensation. The fundamental problem of ethics is guaranteeing mutual consideration and respect in a way that is effective in actual conduct. That is the core of truth in any ethics of compassion" (Habermas 1983:120).

Whereas no one can maintain his identity by himself, says Habermas, this considerateness has the twofold objective of defending the integrity of the individual and of preserving the vital fabric of ties of mutual recognition through which individuals reciprocally stabilise their fragile

identities. Morality therefore always has to solve two tasks at once. On the one hand, it has to emphasise the inviolability of the individual by postulating equal respect for the dignity of each individual and on the other it has to also protect the web of intersubjective relations of mutual recognition through which these individuals survive as members of a community. To these two complementary aspects, says Habermas, correspond the principles of justice and solidarity respectively, since the first postulates equal respect and equal rights for the individual, whereas the second postulates empathy and concern for the wellbeing of the other. While justice in the modern sense of the term refers to the subjective freedom of inalienable individuality, solidarity refers to the wellbeing of associated members of a community who intersubjectively share the same lifeworld. However, to Habermas, both principles have one and the same root, namely the specific vulnerability of the human species which individuates itself through association. Morality thus cannot protect the rights of the individual without also protecting the wellbeing of the community to which it belongs (Habermas 1990:200).

While in the past the principles of justice and solidarity served as core elements of two contrary traditions in moral philosophy, Habermas maintains that the fundamental motif of an ethics of compassion unifies these two moral principles. Theories of duty, he says, have always centred on the principle of justice, whereas theories of the good have always emphasised the common weal. However, Hegel was the first philosopher to argue that the basic moral phenomenon is misperceived when the aspects of justice and solidarity are isolated and opposite principles are assigned to each. Hegel's own concept of ethical life implies an implicit criticism of two kinds of one-sidedness. He on the one hand opposed the abstract universality of justice as manifested in the individualist approaches of the modern age, in rational natural right theory and in Kantian moral philosophy and on the other the concrete particularism of the common good that pervaded the work of Aristotle and Thomas Aquinas.

To Habermas, the uniting of the principles of justice and solidarity is not that remarkable when it is borne in mind that discourses represent a reflective form of communicative action. Linguistically mediated interaction remains both the reason for the vulnerability of socialised individuals and the key resources they possess to compensate for that vulnerability. The common core of all kinds of morality, says Habermas, can therefore be traced back to the reciprocal imputations and shared presuppositions actors make when looking for understanding in everyday situations (Habermas 1990:201).

On strength of its pragmatic features, Habermas concedes that practical discourse or moral argumentation serves as a warrant of insightful will formation and as insurance that the interests

of individuals are given their due without cutting the social bonds that unite them intersubjectively. As a participant in argumentation, everyone is both on his own and yet embedded in a communication context. To Habermas, the agreement made possible by discourse thus depends on two things, namely the individual's inalienable right to say yes or no and his overcoming of his egocentric point of view. The implication hereof is that without the individual's unfringeable freedom to respond with a yes or no to criticisable validity claims, consent remains merely factual rather than truly universal. Conversely, says Habermas, without empathetic sensitivity by each person to the other, no solution deserving universal consent will result from the deliberation. He therefore concludes by noting: "These two aspects - the autonomy of inalienable individuals and their embeddedness in an intersubjectively shared web of relations - are internally connected, and it is this link that the procedure of discursive decision making takes into account. The equal rights of individuals and the equal respect for the personal dignity of each depend upon a network of interpersonal relations and a system of mutual recognition" (Habermas 1990:203).

6.7 THE COMPLEXITY OF THE APPLICATION OF THE PRINCIPLE OF RESPECT FOR AUTONOMY IN MEDICAL PRACTICE

The respective perspectives of Edmund Husserl, Jean-Paul Sartre, Maurice Merleau-Ponty and Jürgen Habermas on the evidence-based patient choice challenges of the separate worlds of patients and health care professionals, the constitution of meaning in illness and the dangers of abstractions and informational manipulation in health care on the one hand forcefully illuminate the complexity of the application of the principle of respect for autonomy in medical practice, but on the other also provide valuable clues for an adequate approach to the application of the principle of respect for autonomy in medical practice.

In this regard, Husserl's perspectives on the reality of the separate worlds we live in firstly emphasise the complex reality of incommensurability in epistemology in general.

Bioethics and contemporary philosophy of science are two fields in which the issue of incommensurability in epistemology and especially in science has been debated in the past twenty years. In this regard, the questioning of a physician's authority to make medical decisions on behalf of a patient has been one of the persistent themes in contemporary bioethics. Scholars initially challenged the view that the physician could determine which outcomes were best for patients, as the moral principle of autonomy provided a foundation for the claim that patients had to play an active role in deciding on which outcomes were worth pursuing. Moreover, this view was compatible with the view that physicians should ideally strive to present value and

concept free information upon which patients could make their choices. However, in later stages scholars started questioning whether it was at all possible to determine any medical facts in a value and concept free manner (Veatch & Stempsey 1999:99-103).

Also contemporary philosophy of science as represented in the work of scholars like Popper, Kuhn, Hanson, Feyerabend, Lakatos, Quine, Winch, Rorty, Fleck and Laudan has struggled with similar epistemological problems. It was argued that science operates within social constructs called paradigms or thought collectives or worldviews that provide broad cultural frameworks for doing science and that the work done in one of these paradigms is incommensurable with that done in another due to the fact that concepts have different meanings, questions are formulated differently, evidence is processed differently and success is measured differently in different paradigms. It is therefore probably not by accident that the challenges to physician's authority in bioethics and these to scientific positivism in contemporary philosophy of science occurred at roughly the same time.

The net effect of these deliberations on the topic of incommensurability in science was that although there might still be controversy about the exact extent to which commensurable concepts exist across paradigms and worlds, there is consensus that postmodern science necessarily relies on conceptual and evaluative conventions which imply that any scientific statement accepted by those working in one scientific paradigm would have different meanings and validity for those working in another. Due to the fact that paradigms or world views in science may only be partially overlapping with only some degree of shared conceptualisations, value systems and metaphysical beliefs, they can never be regarded as fully commensurable. It is therefore to be expected that the work of those practicing science will be influenced by the specifics of their respective paradigms.

With regard to medicine, there are at least four ways in which these normative and conceptual commitments to a paradigm determine the practice thereof. Medical scientists themselves will inevitably perform their work under the influence of their own world views. In turn, clinicians, receiving the results of medical science, will shape or frame their understanding of these results according to their own worldviews. When these data is communicated to patients, their understanding may subject the data to yet another recodification. Finally, clinician and patient values and beliefs will come into play in the eventual decision on the clinical course to pursue (Veatch & Stempsey 1999:99-103).

In addition, Husserl's perspectives on the reality of the separate worlds we live in however also emphasise the complex reality of communication in the application of the principle of respect for autonomy in medical practice.

Although others' experience of the world therefore largely transcends our possible comprehension, some elements thereof nevertheless become available by means of bodily gestures and linguistic expressions through which a shared world of meaning and a common communicative environment is constituted (Toombs 1993:8). It is due to their location in this intersubjective world that individuals not only remain subjects among other subjects, but also become objects to others. This location in a historical, social and cultural environment therefore entails that an individual's unique biographical situation and the typifications through which his or her world is rendered comprehensible, to some extent represent a shared reality (Schutz 1962a:313-315).

In everyday life, a common world is normally established through the constitution of a common communicative environment which is made possible by certain constructs of common sense thinking and factors such as shared typifications and congruent interpretational schemes (Toombs 1993:25). For the communication process to be successful, it thus presupposes a certain taken for granted congruence between the interpretational schemes of the communicators (Schutz 1962a:327) and has to involve a set of common abstractions or standardisations.¹³⁸

The dilemma in communicating about illness is however that patient and physician often assume that they are discussing a shared reality or a common object (Toombs 1993:23). This assumption is made on the basis of what Schutz calls the two idealisations of the general thesis of reciprocal perspectives, namely the idealisations of the interchangeability of standpoints and of the congruency of the system of relevances. Through an idealisation of the interchangeability of standpoints, individuals take for granted that the difference in perspectives originating in the unique biographical situation is irrelevant for the purpose at hand and that both partners have selected and interpreted common objects in an identical manner. In the clinical situation, the patient may therefore take for granted that the physician recognises the illness as essentially a

¹³⁸ With regard to the requirements of communication, Shutz notes that "(1) since the sign used in communication is always preinterpreted by the communicator in terms of its expected interpretation by the addressee, communication presupposes that the interpretational scheme which the communicator relates and that which the interpreter will relate to the communicative sign in question will substantially coincide; (2) full identity of the interpretational schemes of communicator and interpreter is impossible (because such interpretational schemes are determined by the unique biographical situations of each of them). Successful communication is, therefore, possible only between persons who share a substantially similar system of relevances. The greater the differences between the systems of relevances, the fewer are the chances for successful communication; (3) to be successful the communicative process must involve a set of common abstractions or standardisations. Typification is a form of abstraction which provides the basis for standardisation within common sense thinking. Typification occurs within the prepredicative sphere of experience" (Schutz 1962a:322-323).

threat to his or her personal being and the physician may assume that the patient understands the disease in terms of objective clinical data (Schutz 1962b:11-12).

However, in the patient-physician encounter it often happens that the doctor and patient do not communicate on the basis of a shared set of typifications. It often happens that whereas the doctor interprets the patient's illness as a typified instance of a particular disease state, the patient encounters the disorder as a unique personal event. Furthermore, the impact on the life of the patient may be such that he or she finds it difficult to readily incorporate the experience into the flow of everyday existence, especially when the illness commences unexpectedly or appears to be serious (Toombs 1993:20).¹³⁹

Husserl's fundamental phenomenological insight that there is an essential correlation in the constitution of meaning between the experiencer and that which is experienced, therefore underscores the absolute necessity of considering the manner in which each patient constitutes the meaning of his or her personal experience of illness. Since no two patients will assign exactly the same meaning to their disorder, it is of vital importance to consider the horizon of the patient's world in terms not only of a unique biographical situation, but also in terms of the wider social meanings which are a function of particular ethnic and cultural backgrounds (Toombs 1993:26).

Moreover, the phenomenological analysis of the constitution of meaning discloses the validity of the patient's subjective experience of illness. While criticisms of modern medicine indicate that the subjective experiences of patients are often discounted as unreliable and treated as soft data to be essentially ignored in favour of the hard objective and quantitative data of laboratory tests, x-rays, etc., it has to be emphasised that the patient's experience must be taken into account, since lived experience represents the reality of the patient's illness (Toombs 1993:26).

The failure of the interchangeability of perspectives is therefore not simply a matter of completely different interpretations of a common object, but on a more fundamental level indicates that the lived experience of illness is such that it cannot represent a common object. It

¹³⁹ Refer also to the following striking quotation from Heidegger: "In the publicness with which we are with one another in our everyday manner, death is known as a mishap which is constantly occurring - as a case of death. Someone or other dies, be he neighbour or stranger ... People who are no acquaintances of ours are dying daily and hourly. Death is encountered as a well-known event occurring within-the-world. As such it remains in the inconspicuousness characteristic of what is encountered in an everyday fashion ... The analysis of the phrase 'one dies' reveals unambiguously the kind of Being which belongs to everyday Being-towards-Death. In such a way of talking, death is understood as an indefinite something which, above all, must duly arrive from somewhere or another, but which is proximally not yet present-at-hand for oneself and is therefore no threat. The expression 'one dies' spreads abroad the opinion that what gets reached, as it were, by death is the 'they'. In Dasein's public way of interpreting it, it is said that 'one dies', because everyone else and oneself can talk himself into saying that 'in no case is it I myself'" (Heidegger, 1962:296-297).

is a reminder that illness is first and foremost a subjective experience and as such represents an inner rather than an outer event which to a large extent cannot be shared with another. This in principle unshareability of illness furthermore not only results in the failure of the interchangeability of perspectives, but also in incongruence in the appresentational schema of patients and health care professionals. For the patient, language is intended to relate the inner event of illness, while for the physician language provides a description of the disease concealed by the patient's subjective experience (Toombs 1993:23-24).¹⁴⁰

The difference in perspectives between physician and patient is therefore not simply a matter of varying levels of knowledge, but is rather grounded in the phenomenological distinction between lived experience and scientific conceptualizations and abstractions (Foucault 1975:8). While the patient necessarily experiences illness in its immediacy, the extent to which the physician conceives of illness as a pure scientific construct, he or she moves away from the patient's immediate experience and thereby opens a decisive gap in communication between them (Toombs 1993:26). It is therefore only by understanding what it is that keeps them apart, "that physician and patient may take concrete steps to build bridges between their separate worlds" (Toombs 1993:29).

In turn, Sartre's perspectives regarding the distinct levels of constitution of meaning in illness not only reveals the enormous complexity of the meaning of illness, but also underscores the philosophical importance of the distinction between meaning which is grounded in lived experience and meaning which represents an abstraction from lived experience.

According to Sartre, the disease state, interpreted according to Husserl's naturalistic attitude (Husserl 1970:5-7), represents a theoretical abstraction which is distinct from and not identical with the patient's experience. However, illness in its complexity cannot be reduced to a pathoanatomical and pathophysiological fact. This implies that if one is to alleviate a patient's suffering, it is of importance to pay attention not only to the patient's sensory experience of illness, but also to his or her apprehension of illness at the reflective level (Toombs 1993:42).

In this regard Kriel notes: "This insight into the nature of scientific knowledge emphasizes the necessity for an interdisciplinary approach. To understand a phenomenon such as illness in its

¹⁴⁰ Refer to the following quotation from Elaine Scarry regarding the unshareability of the experience of pain: "When one speaks about 'one's own physical pain' and about 'another person's physical pain', one might almost appear to be speaking about two wholly distinct orders of events. For the person whose pain it is, it is 'effortlessly grasped' (that is, even with the most heroic effort it cannot not be grasped); while for the person outside the sufferer's body, what is 'effortless' is not grasping it (it is easy to remain wholly unaware of its existence: even with effort, one may remain in doubt about its existence or retain the astonishing freedom of denying its existence; and finally, if with the best effort of sustained attention one successfully apprehends it, the aversiveness of the 'it' one apprehends will only be a shadowy fraction of the actual 'it')" (Scarry 1985:4).

true complexity, we require more than anatomical, physiological, and molecular knowledge. We require the insights of the natural, the human, and the social sciences, as well as other forms of knowing ourselves and the world, such as are given in philosophy, literature, art, and religion. The philosophical method known as phenomenology was developed specifically to enable us to get a grasp on a phenomenon in its concreteness, to understand it as it reveals itself in concrete experience prior to our metaphysical (and scientific) theories (Kriel 2000:54-58).

In this regard and of particular importance for the study, it is important to emphasise that there is a distinction between suffering and clinical distress (Toombs 1993:42). Suffering is experienced by persons and not merely by bodies, occurs at the reflective level and is intimately connected to the meaning a patient assigns to pre-reflective sensory experience. The significance of unusual sensory experience will therefore vary according to the particular patient's life situation (Cassell 1982:639-645).

Thus, since suffering is closely connected to the way in which illness is perceived by a patient, it is evident that the alleviation thereof will require recognition of the various meanings patients attach to illness. Moreover and due to the fact that suffering is not identical to clinical distress and it could be argued that illness is therefore not identical to the disease state, suffering is therefore also not necessarily alleviated when attention is only paid to illness at the level of the disease state (Toombs 1993:43). In this regard, it is important to note that only the patient will be able to judge whether a medical intervention has the potential of causing personal suffering. While a physician may consider a particular treatment to be relatively innocuous, a patient may find it unacceptable in terms of the resulting disruption of daily living in the context of his or her particular lifeworld (Mishler 1984:82-89).

Moreover, since changes in meaning can mitigate or exacerbate suffering, it is important to understand the meaning a diagnosis might have for a particular patient. With regard to the possible impact of a diagnosis, the failure to acknowledge illness as a disease state may also constitute a source of suffering to the patient. While the biomedical model today requires that a patient's complaints be correlated with demonstrated pathoanatomical and pathophysiological findings in order to be recognized as bona fide illnesses, a scientific diagnosis thus validates a patient's experience. However, a lack of a diagnosis suggests that such an experience is not to be taken seriously and not to be regarded as a medical problem. Patients with recurring non-specific complaints which are not easily accommodated in the biomedical model are numerous in general practice and for such patients to be dismissed as not really ill or to be told that it's all in your head, can become a serious source of suffering (Toombs 1993:45).

The phenomenological analysis of the meaning of illness thus indicates that at the level of disease, the patient assigns explanatory meaning to his or her experience. It is therefore vital for a physician to understand a patient's explanatory model of illness which consists of notions that patients, families and even practitioners have about specific episodes of illness. While patients' explanatory models may include issues such as the nature of the illness and desired treatment, it is important for the practitioner to clearly communicate his or her explanatory model of the illness to the patient, as a failure to ensure that the patient incorporates this model into his own, may result in appropriate treatment being ignored (Toombs 1993:46).

An important element which further contributes to the unshareable nature of illness is the incommensurability of inner and outer time. A patient lives through his or her illness in inner or lived time, but has to describe the illness in outer or objective time. The physician, on the contrary, uses the objective time scale to measure the physical events and biological processes which defines the patient's illness as a disease state. Toombs notes that also in this regard the analysis of pre-reflective sensory experience, suffered illness, disease and the disease state elucidates the different ways in which patients and physicians constitute the temporality of illness (Toombs 1993:47).

At the levels of pre-reflective sensory experience and suffered illness, a patient lives through his or her illness in inner time. However, at the level of disease, a patient in objectifying the body and in assigning explanatory meaning to the experience of illness, reflects upon, rather than lives through his or her illness. Furthermore, in describing disease to the physician, a patient makes use of narrative history and is thereby obliged to recollect past events and in fact relive illness, not in its immediacy, but in an as-if presentation. The temporality of the level of disease can therefore differ considerably from the temporality of pre-reflective sensory experience or suffered illness (Toombs 1993:48).

However, at the level of the disease state, the physician understands the patient's illness as a temporal process wholly according to the units of the objective time scale (Toombs 1993:49). It should however be noted that although the physician interprets the disease state in terms of an objective causal chain, the events identified in this chain may not and almost certainly do not coincide with the events identified by the patient. An explicit awareness of the temporal dimension of illness is thus essential in creating a shared world of meaning between physician and patient. While it can be extremely difficult for patients to measure their immediate experience of disorder in terms of the objective time scale, such difficulties in communication

should be recognised as a function of temporal experiencing, rather than as an indicator of unreliability in the patient's narration of his or her illness story (Cassell 1985:18-31).

As already indicated by Sartre, the objectification of illness as disease inevitably results in a sense of alienation from one's body (Sartre 1956:466). The movement from the temporality of inner time at the level of lived experience to a reflective description in terms of outer time transforms illness into an objective entity which is transcendent to subjective consciousness. The further one moves away from lived experience, the greater the sense of alienation from one's body becomes (Toombs 1993:49).

With regard to the aim of the study, it is thus important to recognise that the meaning of illness is constituted by the patient at both the pre-reflective and reflective levels. The fundamental level is that of pre-reflective sensory experience at which your immediate experience is such that it leads you to become aware of some disruption in the way you exist in your body. At this level, some unusual sensory experience such as pain or weakness causes the patient to shift attention from ongoing involvement in the world to a disruption of his or her bodily functions. Once the immediate experience of disruption is thematised at the reflective level, it may be apprehended as suffered illness. Suffered illness is to be conceived as a synthetic totality that incorporates the immediate bodily sensations as parts of a larger whole. In particular, the unusual sensations are now interpreted as symptoms which point to a more complex entity, namely illness. Furthermore, at this reflective level, the disruption is identified and located in a specific part of the body and as in the case of pre-reflective experiences, still represents a lived experience. It is however only at a further interpretative level, that the patient starts apprehending suffered illness to be disease. The lived body becomes objectified to a neurophysiological organism and the immediate sensory disruption is apprehended as a particular illness (Toombs 1993:38).

In addition, Merleau-Ponty's perspectives regarding the transcendental role of the body in illness contribute largely to the illumination of the particular aspect of the impact of the body in the complexity of the application of the ethical principle of respect for patient autonomy in medical practice.

Further to the perspectives of Merleau-Ponty, Toombs notes (Toombs 1993:59) that according to Gallagher, the body suddenly appears in the field of consciousness when the organism loses or changes its rapport with the environment in certain limit situations such as illness or pain or even in such positive experiences as sport, dance or sexual excitement (Gallagher 1986:148-149).

Also Zaner observes that to experience one's body as Other, is to experience the own body as weird. He furthermore argues that there can be four senses in which the body can be experienced as weird, namely (1) the inescapable/the limitation; (2) chill and implicatedness; (3) hidden presence; and (4) alien presence (Toombs 1993:60). Regarding the first sense, he argues that while it is inescapable that I am embodied, this embodiment carries with it certain radical limitations. The second sense indicates that since I am affected by whatever happens to my body, bodily experiences are experiences of corporeal implicatedness. In addition, the body is experienced as a hidden presence in that, as a biological organism, it includes structures and processes of which I have no awareness and over which I have no control. Finally, the body manifests itself as other through its essentially alien presence and with its own nature and biological rhythms (Zaner 1981:48-55).

From this it follows that the objectification of the body at the reflective level involves a disruption of the unity of lived body. At the reflective level the body becomes an object for me as subject, since I now explicitly recognise this body as *my* body in a sort of owned recognition. However, while recognising my body as a material and physical object, I at the same time apprehend the body as Other-than-me and this may bring about a sense of alienation (Toombs 1993:61).

However, while the objectification of the body at the reflective level involves a disruption of the unity of lived body, the experience of illness at the prereflective level usually results in the disruption of the features that are essential to embodiment. The implication is that fundamental features of embodiment such as being-in-the-world; bodily intentionality, primary meaning and body image are all disrupted in a variety of ways.

The very nature of body as being-in-the-world is transformed by representing a disability or inability to engage in the world (Louw 1994:34-44).

A headache is therefore not only experienced as a pain in the head, but also as an inability to concentrate on the activity I am busy with at the moment. However, in illness, also bodily intentionality is frustrated, since objects that were formally grasped as utilisable and were therefore largely taken for granted, now present themselves as problems to the body. Thus for example, for a person suffering from angina a flight of stairs that previously just had to be climbed, may now present an obstacle to be prevented or even feared (Toombs 1993:62).

In addition, also the primary meaning provided by the body may be disrupted. The visually impaired person who trips on the stairs may indeed find his or her body's intuitive sense ineffective and even deceptive. Also body image changes, not only in terms of elements such as

posture, but especially in terms of the sense that the possibilities for action shrink. The surrounding world looks and feels different, accompanied by a disruption of the complexity of mind, body and world interaction (Toombs 1993:63).

Illness therefore also affects the body's gestural play. It not only affects changes that may be perceived by others in the look of the sick person, the grimace of pain and the stoop of the shoulders, but also impairs the various forms of social interaction and expression like standing facing one another and shaking hands in greeting that are normally taken for granted (Toombs 1993:64). In this regard, Zaner suggests that the upright posture itself has particular significance as a gestural display (Zaner 1981:61). To be able to stand on your own feet is directly related to autonomy, while there is more than metaphorical significance to expressions such as to look up to someone or down at somebody. In hospital settings the patient more often than not is in bed and have to look up to the doctor who stands talking and looks down on the patient. In looking up to the doctor and being looked down on, the patient is on an unequal footing with the doctor and therefore concretely experience diminished autonomy (Myerscough 1992:15-18).

Thus, while in the normal course of events locomotion continually opens up space, illness and debility exert a centripetal force anchoring you in the Here and engendering a heightened sense of distancing between oneself and surrounding things (Toombs 1993:67). This sense of distancing is not only exhibited in the experience of objects and locations as far that used to be near, but also in the fact that the range of possible actions becomes severely circumscribed with space encountered as a restriction of possibilities, rather than an arena of possible action (Zaner 1981:97).

However, the disruption of lived spatiality is also reflected in a change in temporal experience. Just as lived spatiality is characterised by an outward directedness and intention, time is experienced as a moving towards the future. In illness, the future perspective suddenly appears irrelevant and out of reach, since you find yourself preoccupied with the demands of the here and now and confined to the present moment. The effortful nature of everyday existence engendered by illness thus has a significant impact on the subjective experience of time of past, present and future. While the past may take on a threatening character and the present may be forfeited and transposed into an imagined future, the real future may disappear completely (Toombs 1993:69).

As referred to earlier, the body under normal circumstances appears as an object both in the experience of being an object for another and in certain limit situations in which the body is apprehended as a material and physical entity. It was noted that such objectifications separates

self from body and depending on the circumstances, may result in a deep sense of alienation from one's body. Illness represents such a limit situation in which the body is apprehended both as material and physical entity and as a being-for-the-Other (Toombs 1993:70).

As such, the disruption of the lived body through illness causes the patient to explicitly shift his attention and attend to his or her body as body, rather than simply living it. The body is thus transformed from lived body to object body, with the objectification resulting in the apprehension of the corporeal nature of the body as a physical encumbrance and an oppositional force (Toombs 1993:71).¹⁴¹

While apprehending the body as a material and physico-biological thing employed in actions in the world, the patient perceives the dysfunction of the body as a defective physico-biological thing and as such objectifies the body not only as a physiological organism, but as a malfunctioning physiological organism. Moreover, the malfunctioning body is apprehended in terms of its mechanistic nature as being a machine like entity comprising of organ systems and parts that can break down, but can also be repaired, removed or even technologically supplemented (Kriel 2000:23-29).

In addition to the shift of attention, the corporeal nature of the malfunctioning body is made obvious through the body becoming an oppositional force in illness. The concrete experience of the increasing weakness of the body impedes your interaction with a world providing inert and overt resistance, even without explicit reference to any pathoanatomical concepts. Furthermore, the objectification of the body as a malfunctioning physiological organism contributes to a sense of bodily alienation and in particular the experience of the body as weird (Toombs 1993:72). According to Cassell, this experience is often reflected by patients who express their awareness of their bodies as an alien presence by using impersonal pronouns (the breast instead of my breast) as a means to avoid contact with an intrusive reality (Cassell 1985:55-56).

The prolonged attention to the body which occurs in chronic illness therefore easily engenders a kind of metamorphosis. The lived body is transformed into a new entity, namely the diseased body which with its ongoing demands necessarily stands in opposition to the self. The bodily metamorphosis which occurs in chronic illness therefore indeed incorporates a type of Gestalt switch in that the experience of bodily disruption becomes a normal expectation while non-disruptive moments appear as somewhat fleeting anomalies (Toombs 1993:76).

However, the shift of attention which renders the body thematic in illness is necessarily a part of the clinical encounter, for in order to cooperate with the doctor, the patient must explicitly attend

¹⁴¹ See also Pellegrino and Thomasma 1981:107-108.

to his or her body as object. Moreover, in the clinical encounter the body is not only objectified as a material or physical entity, but also as a being-for-the-Other. It is under the gaze of the physician that the patient perceives his or her body as an object of scientific investigation. In the experience of being looked at by the physician, one recognises not only your being-an-object for the Other, but also the fact of the ambiguity of your own body. It is at the level of disease that the patient apprehends illness as a being-for-the-Other in that disease is known to the sick person by means of physiological and pathological concepts derived from others (Mishler 1984:103-112).

With regard to the body as scientific object, it has been mentioned that the patient's lived body assumes the status of a scientific object under the gaze of the physician. The human body as presented to the doctor in the clinical encounter is understood as a strictly biological entity that is ultimately explainable in purely physical terms and by means of the categories of natural science. This means that the particular body presented to the physician simply represents an exemplar of the human body and may as such be viewed independently from the person whose body it in fact is. The mechanical workings of this particular human body is thus objectified in such a way as to make the subjective experience of the particular patient explicable in terms of a general and theoretical account of the causal structure of such experience (Toombs 1993:77). Already Husserl has noted that the goal of natural science is to explicate reality in terms of universal and causal laws which are objective and therefore valid for all (Husserl 1970:315-383).

In this regard also Foucault noted that according to the modern scientific understanding of disease, the gaze of the physician transforms the body-as-scientific-object from the lived body to an anatomical body and as such lets it assume the guise of a corpse (Foucault 1975:111). The developments in the science of pathoanatomy in the nineteenth century relocated the primary focus of medicine inside the body and disease thus became identified with anatomical pathology lesions or pathophysiological disturbances. It is important to note that the body-as-scientific-object no longer represents the totality of body in situation as in the case of the lived body, but is taken purely in terms of its mechanistic nature and therefore no longer in situation (Toombs 1993:78).

While it is clear that illness is fundamentally experienced by the patient as a disruption of lived body, it cannot simply be regarded as a physical dysfunction of the mechanistic and biological body. The body represents the patient's particular embodiment and as such, this embodiment bears important relations to a particular world and to a unique self. The paradigm of lived body

also situates illness in the particular patient in a very explicit way, which implies that the biological body cannot be conceived apart from the person whose body it is. As stated, the patient does not simply possess a body, but is his or her body (Kriel 2000:135-137).

However, as indicated by Pellegrino and Thomasma, the goal of medicine is primarily the relief of a perceived lived bodily disruption and the restoration to a former or better state of perceived health or well-being.¹⁴² This action may include, but is not limited to the cure of organic dysfunction (Toombs 1993:82). In order to address a patient's experience of disorder, attention should not only be paid to the physical manifestation of a disease state, but especially in the case of chronic illness, also to the changing relations between body, self and world. The recognition of the impact of illness on the essential features of embodiment and on lived spatiality and temporality should therefore be taken into consideration in medical practice (Pellegrino & Thomasma 1981:72).

According to Toombs, such recognition holds the key to the mitigation of some of the dehumanising aspects of medical care (Toombs 1993:86). Conceiving the body as an exclusively biophysiological mechanism, medicine effectively abstracts the body from the person inhabiting the body and with the primary focus on the physical disease process and a concurrent de-emphasis on the disorder of self and world, the person may then well be regarded as a well-controlled diabetic or an interesting carcinoma rather than a person suffering from illness. Therapeutic interventions that are thus only concentrated on the dysfunction of the biological body with little attention being paid to the disturbance of lived body, may cause patients to feel reduced to the status of physical objects and as a result dehumanised. In addition, the devaluation of subjective experience in favour of an exclusive preoccupation with objective quantitative clinical data, further adds to a patient's loss of personhood.

Reference has earlier been made to the distinction between suffering and clinical distress and the fact that suffering is experienced by persons and not merely by bodies. It has also been mentioned that suffering appears when the impending destruction of the person is perceived. It can consequently be stated that suffering not only relates to the loss of intactness of the biological body, but also to the loss of integrity of the interrelationships between body, self and world and that if suffering is to be alleviated, such disruption of embodiment should be addressed urgently (Toombs 1993:86).

¹⁴² Refer in this regard also to the WHO definition of health as a state of complete physical, mental and social well-being. Consider also Daniels's view that disease and disability can be regarded as departures of species-typical normal functional organisation and functioning (Daniels 2009:37).

In response to the illumination of the complexity of the application of the principle of respect for patient autonomy in medical practice enabled by the perspectives of Edmund Husserl, Jean-Paul Sartre and Maurice Merleau-Ponty, the application of Jürgen Habermas's views on discourse ethics provide valuable clues to an adequate approach to the application of the principle of respect for autonomy in medical practice.

Employing Habermas's views with regard to discourse ethics as a means of establishing and maintaining patient autonomy in the involvement of patients in clinical decision making, Keller et al. note that today, the doctor/patient relationship ought to be a participatory and personal relationship, forming the basis of a therapeutic alliance and that an egalitarian interaction which is not primarily based on hierarchy can lay the groundwork for mutual respect and autonomy (Keller et al. 2006:99).¹⁴³

Referring to Donald A. Schon (1930-97), Keller et al. argue that the central problem in biomedicine is the failure of the technical and purely rational approach and that a reflection-in-action approach is therefore required from medical professionals in view of the fact that the provision of medicine to a patient is dependent on both knowledge and values. Scientific knowledge therefore has to be harmonised with what individuals prefer and since ethics has a role in almost all medical action, practical medicine is in need of a new method in order to solve the inherent conflicts arising from the fast growing medical knowledge and technologies on the one hand and the increasing individual and group values on the other. In their article, they therefore endeavour to indicate to what extent the increasing problems in medical practice may be regarded as a result from both the inherent complexity of medical science and from the simple fact that treating a patient is a relational encounter with the inscrutable "Other" (Levinas 1906-95).

In view of the fact that discourse ethics has been proposed by Jürgen Habermas as a means of handing autonomy, initiative, and responsibility back to people and not to institutions or to the systems represented by anonymous elites, Keller et al. suggest that discourse ethics as a procedural model for communicatory action may have an essential role as a mediator and an integral component in practical medicine. Since shared responsibility and reciprocal autonomy have become essential to the modern doctor/patient relationship, a discourse based on equality and reciprocity may moreover facilitate both autonomy and responsibility.

¹⁴³ Keller et al.'s argument as an effort to a practical application of the ideas of Habermas is of cardinal importance for the study and is therefore almost completely rendered. I therefore, from the outset, acknowledge my indebtedness to the work of Keller et al. Keller, F., Allert, G., Baitsch, H. and Sponholz, G. (2006). Discourse ethics in practical medicine. *J Med Ethics; Medical Humanities* 32:99-103.

As a background to their argument, Keller et al. present a routine clinical case to exemplify the applicability of discourse ethics as a procedural method for case based diagnosis and treatment. The real-life case presented indicates how the clinical treatment failed and also technical rational approaches would not help, because the failures in the process were mainly due to failures in communicative action: "A 63 year old woman was admitted to the gynaecology department with impaired renal function. She had an inoperable carcinoma of her uterus three years previously, which was treated by palliative radiotherapy. Instead of consulting a nephrologist, an intravenous urogram was ordered. This caused a further increase in serum creatinine level and complete anuria. After this iatrogenic complication, the nurses refused to place a urinary catheter, as the patient had already experienced misplacement during radiotherapy. The conflict escalated and the urologist was phoned, but he judged that this was the terminal stage of the patient's disease and that the best solution for her would be to die of uraemia. The gynaecologist who had ordered the urographic investigation with contrast media, however, consulted and argued with the nephrologist. In view of the diagnosis, the nephrologist thought that it would be pointless to start renal replacement therapy. The gynaecologist and the nephrologist discussed whether they should talk again with the nurses or with the urologist. However, they finally agreed to talk with the patient, intuitively following a discursive approach" (Keller et al. 2006:99).

When the nephrologist visited the patient, she was in unexpectedly good physical and mental condition. The gynaecologist and the nephrologist discussed the options with the patient at her bedside and all three consented to start haemodialysis immediately. The urologist was willing to install a urinary catheter the next day and, as often happens, the patient's urine output resumed. However, a week later a diagnosis of peritoneal carcinoma was confirmed, upon which the standard course of chemotherapy was ordered with a high dose cyclophosphamide and epirubicin. The patient was discharged after two weeks, but once at home, her condition deteriorated quickly and she passed away one month later.

Looking at the results objectively, Keller et al. contend that this patient's course of treatment can be described by terms such as incompetence and malpractice (intravenous urography), negligence and mismanagement (no catheter placement), overtreatment (haemodialysis) and also futility (chemotherapy). To them, shortcomings emerge from the urologist's rule based approach of the disease in general terms instead of visiting the patient, talking to her and taking a look at her as an individual. Furthermore, they note that haemodialysis prepared the way for the ordering of chemotherapy without discussing other options and this resulted in the point being missed at which it would have been best to reduce treatment and start palliative care. In addition

they note that one event, namely renal impairment, led to a cascade of subsequent procedures, namely urography, haemodialysis, and chemotherapy which all from the logic of if you say A, then you must also say B, or from the law of all-or-none.

However, Keller et al. concede that when looking at each discrete action, the patient's welfare was primarily in mind and the ordering of urography, for example, could be regarded as equivalent to taking over responsibility. Moreover, the decision to carry out dialysis was made easier in view of the fact that presumably contrast nephrotoxicity would resolve. After high tech dialysis, the urologist agreed to place a simple catheter and also chemotherapy was ordered to provide her with all possible chances. They however contend that what was done, should have been done in a more communicative way, although this again raises the question whether it would have amounted to a more scientific approach or to more than common sense?

In further deliberation on the issue, Keller et al. continue to consider whether and to what extent any of the algorithm-like methods developed to deal with complex clinical situations may have improved the treatment of this patient with cancer (Keller et al. 2006:100).

1. They note that in the patient's course of treatment, a simple intervention (urography) led to an unpredictable cascade of actions. While one may be inclined to model the unpredictable decision making process on the chaos theory, it has to be admitted that chaos theory does not provide a description of unpredictability.
2. Whereas a tree for decision analysis could have been constructed in order to determine the best possible solution in the circumstances, the necessary data to quantify the different options in this case were however lacking.
3. With regard to the assessment of quality-of-life, Keller et al. note that the mortality from uraemia contrasts with the discomfort caused by haemodialysis, but that it has to be recognised that different qualities such as mortality or discomfort are subjective judgements and furthermore depend on non-uniform cultural mores, traditions and standards that are resistant to harmonisation and therefore cannot be evaluated on the same scale.
4. They also note that predictive score models, such as the Acute Physiology And Chronic Health Evaluation (APACHE) Score, can be developed from accumulated clinical observations for making predictions about patient survival in an intensive care unit, but that it was not possible to make use of this type of model, since these or a comparable system (for example, acute tubular necrosis ATN-ISS Score) that would be needed for a decision to withhold dialysis, was not calibrated for their hospital.

5. They also indicate that while priorities can be chosen by fuzzy-set analysis based on cost effectiveness and cost utility in healthcare, counting values on an ordinal scale by modern computer methods may be valuable in deciding whether a hospital should, in the long run, be equipped with dialysis facilities, but does not solve the actual conflict in the patient with cancer.
6. In addition, Keller et al. note that a stage further from generalisation to individualisation may be achieved by applying Bayes's theorem. It is known, they say, that patients with advanced cancer do not usually benefit from dialysis, but that in the case described earlier, the conditional probability that renal function would recover was higher than the primary probability without the history of radiocontrast investigation. However, the bayesian approach requires an assumption of conditional independence and a priori knowledge for advanced statistical calculations, which could not be established with certainty in the case of the particular patient.
7. They also mention that artificial neural networks are a kind of case based learning by doing employing multivariate statistics and used to predict from different previous cases what will happen to a prospective patient. However, neural networks are restricted to making proposals, while all people participating must take responsibility for the decision and the patient has to consent to the proposal.
8. Keller et al. however note that the models to which they refer are not designed to take the time dependent sequence of momentary actions into account. For the patient, the open course of discrete moments was different from the fatal final event which was death. The temporality of clinical processes therefore needs a special kind of reasoning that would require, for example, the application of Petri nets instead of linear first order logic, which unfortunately was not at hand.
9. In conclusion, Keller et al. note that although the theory of the four bioethical principles does not depend on numerical or mathematical models, the clinical application thereof also has to be considered as a rule based method. Though these principles do not try to give ultimate reasons, but are rather middle-level principles, they are not yet applicable by themselves. Autonomy can for instance be in conflict with justice and beneficence with maleficence. While medical practice is influenced by the four bioethical principles, it is also influenced by several medical virtues, such as prudence, courage, responsibility, self-control, discretion, and veracity. They therefore suggest that the communication of information between patients and health care professionals should be disseminated between

more agents, since there no longer exists a binary, but a multi-actor scenario that needs to communicate on how to act.

According to Keller et al., the obvious discrepancies between the nine algorithms and the case of the patient with cancer may allow some general conclusions to be drawn. Whereas in scientific medicine, knowledge is generated by statistically integrating the observations made in a group of patients, practical medicine has to provide a knowledge based answer that is simultaneously influenced by pending options and value based judgements. Treating a patient thus amounts to action that should not be objectified, but personalised.

With regard to the case of the patient with cancer, knowledge and principles do not have to be created, but instead applied. Most of the problems with modern clinical medicine may result from the need to individualise the available knowledge and to make it applicable to the individual patient. The patient has to participate as an autonomous subject in this process, but the autonomy of the patient is based on informed consent and the patient thus participates in a communicatory act with the gynaecologist, nephrologist, and oncologist (Keller et al. 2006:101).

Moreover, it has to be noted that in contrast with classical physics (where one body is, no other can be) and in line with modern relativistic thinking, diverging possibilities such as death and dialysis apply simultaneously in clinical medicine. The etymology of *medi-cina* indicates that the golden mean holds true more than the principle of either right or wrong with no third way. The chronology of medical decision making therefore demands a chronological or temporal logic for the case based process. Temporal logic seems to be constitutive to the theory of action as every following decision is dependent on what has been previously decided. Premises and decisions are referential, as are prognosis and treatment, which implies that treatment can change a prognosis, while a prognosis can also influences the treatment. If a decision is made (urography), the assumptions - true or false - result in actions (haemodialysis) and create new conditions (pushing chemotherapy). Every decision selected out of several possibilities is usually irreversible and therefore the chronology of events brings the temporality of the logic to factual perception.

With regard to the specific case, a scientific true or false testing could not be applied to the haemodialysis treatment, since it was rather a more or less right answer and a decision of now, later, or never. Temporal logic obviously applies to clinical medicine, as one main reason for starting dialysis was to gain time. However, clinical problem solving is a process with multivalent logic as time and values can both have an influence. The logical structure of medical practice is analogous to the logic of ethical reasoning and ethical deliberations are constitutive to

the logic of practical medicine. Clinical medicine and applied ethics are thus both analogous and complementary, since both are looking for a solution that is individualised from general knowledge and normative presumptions. The application of medical science should therefore be based on ethical reasoning to fit the temporality and individuality in the doctor/patient relationship and a universal model is needed for the individualised proceeding and communicatory action.

In this regard, the case of the patient with cancer is a clear illustration of the temporal mode of medical logic. In this case a discourse approach would have come closer to the temporal logic than any of the other nine algorithms discussed above. The discursive approach may therefore not only be the most fitting type of action, but also the ethical approach needed in this case.¹⁴⁴

Discourse ethics emerged as a universal approach to address the loss of a metaphysical foundation in philosophical ethics and in postmodern societies. It works as a procedural model for finding a consensus, where a plurality of traditional, religious, moral, cultural, philosophical, political and juridical values, norms, and principles are in conflict. In postmodern ethical theory, a universal and simultaneously fundamental foundation of ethics is regarded as no longer possible or desirable (Keller et al. 2006:101). Even the purely rational foundation of ethics must be doubted after the trolley experiments disclosed the strong emotional engagement influencing moral judgement. According to newer concepts of ethics, they maintain, all people have some ethics - otherwise it cannot be evoked - although some personal ethics may differ. For postmodern cultures, moral authority primarily derives from the actual consent of those concerned. Also, the modern theory of science is more influenced by the discursive consent model than by the traditional congruence concepts of truth (Charles S Peirce, 1839-1914). The discourse model thus stands for both rational reasoning in and the practical application of ethics (Keller et al. 2006:102).

With regard to the case of the patient with cancer and although it might have been time consuming, early communication and consultation with the nephrologist could have avoided contrast nephrotoxicity. In this case, fundamental, but conflicting values (beneficence versus non-maleficence) were in competition when the urologist and the nurses were made responsible for placing a urinary catheter. However, moral obligations become relative through the dialogue with the patient and ethical reasoning on preferences. The discourse model allows the expert (urologist) to change his mind without losing authenticity and represents a case based dialogue

¹⁴⁴ In this regard, they quote Christine K Cassel who writes: "Communicative ethics says ... that striving for the best among imperfect results is admirable, especially when strict adherence to principles does not allow for negotiation and compromise essential to the sharing of power and the framing of decision" (Cassel 1994:332-343).

implicitly or explicitly applying ethics and which does not affect the validity of personal ethics or medical expertise. The discourse also corresponds to the temporality and individuality of medical practice.

As a universal model for non-dominated communicatory action, discourse ethics represents a sharing of power. The gynaecologist could not order, but could ask for dialysis; the nephrologist could not refuse dialysis, but he could argue. The patient, gynaecologist, nurses, urologist, nephrologist and oncologist could therefore communicate, since everybody has ethics and no expert, mediator, or ethics committee was in fact needed. Discourse is therefore both a method and a target, since for practical medicine, the discourse is both a way to proceed to consent and a mode to import ethical principles such as respectful reciprocity.

Discourse admittedly depends on a set of conventions such as equality and reciprocity and on rules to be followed, such as argumentation and listening. However, whereas discourse is both a rule based procedure and a case based ethics, it is also learning by doing and aimed at bringing general principles and values about in practice. The discursive dialogue has to be learnt and taught and has the potential of changing the mind and educating the participants. Equal rights are the specific prerequisite of the discourse process, since domination-free communication between the people specifically forming part of the discourse may increase the chance that a creative and adequate solution can be found. It defines the aim of ethics, as the procedural rules promote mutual respect and the communicative rules establish reciprocal equity. Respect and reciprocity may be seen as both the procedural means and the ethical ends of the discourse process (Keller et al. 2006:102).¹⁴⁵

¹⁴⁵ With regard to objections to the use of a discourse ethical approach in medical practice, Keller et al. note that although the treating of patients involve the solving of problems, an obvious asymmetry exists in the doctor/patient relationship in the patient having a problem and the doctor holding the solution. Due to the fact that the principle of reciprocity also influences this asymmetry and the solution has to fit both the doctor and the patient, the objection is made that discourse ethics resemble only an arbitrary, ephemeral and decisionistic counting of votes (Moreno 1991:393-408). What happens if people are unable or unwilling to participate in the discursive process of arguing, if it is not the better argument, but the higher status or the more eloquent rhetoric that prevails? It is also argued that people could consent to something very stupid and irrational. Keller et al. however argue that such a failure of the discourse process applies only to the momentary action and when no objection is raised, experts too can make foolish decisions (intravenous urography in renal failure). The discourse provides a good chance of determining which decision needs the expert with medical knowledge (type of chemotherapy) and which needs communicatory seeking for the best solution in a special situation (any chemotherapy?). Moreover, as compared with deterministic or authoritarian decisions, the discursive arguing process may also be more scientific in terms of theoretical fallibility and practical testability. While major objections have been made against discourse ethics, Keller et al. regard it of importance to discuss some of these objections in the light of the logic of medical action. In discourse ethics, the universal ability to generalise the reasoning must be demanded for the theoretical discourse, whereas adequacy must be demanded for the practical discourse process applied in an individual case.

It is often objected, say Keller et al., that medical decisions must be made on a basis of equity and this cannot happen if each case is settled on its own merits. With reference to John Rawls, they reply that equity indeed comes first, but that individuality in addition makes for better decisions as formal justice must be made factual by a concrete action (Rawls 1971). In addition, they note, it is objected that medical decisions must be made

In conclusion, Keller et al. maintain that discourse ethics may be the most generic way of applying ethics as all those concerned can participate in the discourse process. Other forms of ethics (deontological, utilitarian, principled or communitarian) may be required and should be considered in more complex problems, such as decisions on embryonic stem cell research or euthanasia.

However, in medicine, a new method for case based proceeding is needed. Such a method should use everyday speech more than complicated rule based algorithms. Communicatory action in clinical medicine is learning by doing, guided by a structured proceeding and ethical reasoning. As such, clinical ethics resembles a time dependent process in three sequential stages. Firstly, clinical problems pose diverse external or internal moral dilemmas that may be related to the conflict of ethical principles, medical knowledge, as well as to professional or individual values. Secondly, in the process of ethical reasoning, every person participating has expertise, is guided by private values and has to accept professional and personal responsibility. Thirdly, conflicting values and intentions should result in concrete action, as it is instrumental in finding a solution between irreconcilable medical experts and it integrates ethics as a constituent in the individual treatment. Clinical ethics is therefore to be regarded as a pragmatic seeking for the best thing to do now and in this respect, discourse ethics applies especially well to procedural logic in clinical medicine. Moreover, given the generalisation achieved by medical statistics in the last 50 years, an additional and complementary way of accomplishing individualisation in health care is needed for the future and according to Keller et al., discursive ethics may just support this addition to clinical medicine (Keller et al. 2006:103).

impersonally and professionally and that this cannot happen if decision making is seen as a unique personal encounter between doctor and patient. However, with reference to Emmanuel Levinas, they argue that medical professionalism is not impersonal and that besides cognitive factors, also emotional factors, which enhance and reaffirm the patients' expectations, will make the doctor/patient relationship more successful, even in therapeutic terms. The discourse model permits personal distance and as the doctor is responsible for and face to face with the patient, the discourse also calls for personal empathy (Thomas Percival, 1740-1804). It is also often objected, say Keller et al., that medical decisions must be made transparent and presented in a way that is publicly defensible. They however reply that discretion stands before publicity and that transparency of medical decision making can be better established by all those concerned than by one paternalistic and solipsistic decision maker. It is also objected by some that the method advocated by discourse ethics is subjective and arbitrary. To this Keller et al. respond that strictly speaking, there is no objective decision, since all action must be taken by subjects. After discursive seeking of consent, such a decision must have a reason and is no longer arbitrary with regard to the individual case. A last objection is that discourse ethics suggest no clear method of decision making at all. Their reply is that the discourse process does not replace the will to act, but helps in finding the way to decide. To fears that the discourse may result in never ending deliberations, Keller et al. respond that if the patient needs more time to decide, the staff have to accept this. The more the course of the disease needs an immediate treatment, the more it remains to the treating doctors to make the decisions to the best of their knowledge, virtue, and responsibility, though such pressure often also needs to be communicated retrospectively.

SUMMARY AND CONCLUSIONS

This chapter was devoted to a discussion of the respective perspectives of Edmund Husserl, Jean-Paul Sartre, Maurice Merleau-Ponty and Jürgen Habermas on the evidence-based patient choice challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and of abstractions and informational manipulation in health care. These discussions revealed a number of important implications of their thought for the issue of the dichotomy between person and self and of the need for an intersubjective and mutual understanding of the patient in particular.

A first of these implications is that due to the reality of incommensurability in epistemology in general, any statement used by those working in one paradigm would have different meanings and validity for those working in another. The incongruence between the typificational, interpretational and appresentational schema of doctor and patient present particular difficulties for the establishment of a shared world of meaning and have serious implications for medical practice. The fundamental phenomenological insight that there is an essential correlation in the constitution of meaning between the experiencer and that which is experienced, therefore underscores the centrality of individualisation in health care and the absolute necessity of considering the manner in which each patient constitutes the meaning of his or her personal experience of illness. The difference in perspectives between physician and patient is therefore not simply a matter of varying levels of knowledge, but is instead related to the phenomenological distinction between lived experience and scientific conceptualizations. Whereas the subjective experience of patients are often discounted in modern medicine as unreliable and treated as soft data to be ignored in favour of the hard objective and quantitative data, it has to be emphasised that the patient's account must be taken into account, since lived experience represents the reality of the patient's illness and it is only by understanding what keep patients and doctors apart, that bridges can be built between their separate worlds.

With regard to the constitution of meaning in illness, it has to be emphasised that the disease state as fourth level of the constitution of meaning in illness represents a theoretical abstraction which is distinct from and not identical with the patient's experience and that since suffering is intimately connected to the way in which illness is perceived by a patient, it is evident that the alleviation thereof will require specific attention to the meanings patients attach to illness. Due to the fact that suffering is not identical to clinical distress and illness is not identical to the disease state, suffering is therefore also not necessarily alleviated when attention is only paid to illness as a disease state. In this regard, it is important to note that only the patient will be able to

judge whether a medical intervention has the potential of causing personal suffering. It is moreover important to recognise that the meaning of illness is constituted by the patient at both the pre-reflective and reflective levels. The fundamental level is that of pre-reflective sensory experience at which your immediate experience is such that it leads you to become aware of some disruption in the way you exist your body. At this level, some unusual sensory experience such as pain or weakness causes the patient to shift attention from ongoing involvement in the world to a disruption of his or her bodily functions. Once the immediate experience of disruption is thematised at the reflective level, it may be apprehended as suffered illness. Suffered illness is therefore to be conceived as a synthetic totality that incorporates the immediate bodily sensations as parts of a larger whole. In particular, the unusual sensations are now interpreted as symptoms which point to a more complex entity, namely illness. Furthermore, at this reflective level, the disruption is identified and located in a specific part of the body and as in the case of pre-reflective experiences, still represents a lived experience. It is however only at a further interpretative level, that the patient starts apprehending suffered illness to be disease. The lived body becomes objectified to a neurophysiological organism and the immediate sensory disruption is apprehended as a particular illness.

Moreover, it has to be borne in mind that the body suddenly appears in the field of consciousness when the organism loses or changes its rapport with the environment in certain limit situations such as illness or pain. The very nature of body as being-in-the-world is transformed by representing a disability or inability to engage in the world. With regard to the body as scientific object, the patient's lived body assumes the status of a scientific object under the gaze of the physician. The human body as presented to the doctor in the clinical encounter is understood as a strictly biological entity that is ultimately explainable in purely physical terms and by means of the categories of natural science. According to the modern scientific understanding of disease, the gaze of the physician transforms the body-as-scientific-object from the lived body to an anatomical body and as such even may let it assume the guise of a corpse.

Thus, whereas the goal of medicine is primarily the relief of a perceived lived body disruption and the restoration to a former or better state of perceived health or well-being, this action may include, but is not limited to the cure of organic dysfunction. In order to address a patient's experience of disorder, attention should not only be paid to the physical manifestation of a disease state, but especially in the case of chronic illness, also to the changing relations between body, self and world. Such recognition holds the key to the mitigation of some of the dehumanising aspects of medical care. Treating a patient thus amounts to action that should not be objectified, but personalised. Most of the problems with modern clinical medicine result from

the need to individualise the available knowledge and to make it applicable to the individual patient. The patient has to participate as an autonomous subject in this process, but the autonomy of the patient is based on informed consent and the patient thus participates in a communicatory act with the health care professional.

With regard to the aim of the study, namely to determine an adequate approach to establishing and maintaining patient autonomy in the involvement of patients in clinical decision making, it can in addition to the discussion in this chapter be concluded that in postmodern ethical theory, a universal and simultaneously fundamental foundation of ethics is regarded as no longer possible or desirable. In addition, the purely rational foundation of ethics must even be doubted, since according to newer concepts of ethics, all people have some ethics and according to postmodern cultures, moral authority primarily derives from the actual consent of those concerned. Also, the modern theory of science is more influenced by the discursive consent model than by the traditional congruence concepts of truth.

As a universal model for non-dominated communicatory action, it can be concluded that discourse ethics represents a much needed sharing of power which allows an expert to change his mind without losing authenticity and represents a case based dialogue implicitly or explicitly applying ethics which does not affect the validity of personal ethics or medical expertise. While also corresponding to the temporality and individuality of medical practice, discourse ethics admittedly depends on a set of conventions such as equality and reciprocity and on rules to be followed, such as argumentation and listening. It is thus both a rule based procedure and a case based ethics and as such represents a pragmatic approach of learning by doing how to bring general principles and values about in practice. This has the important implication that the discursive dialogue therefore has to be learnt and taught, but also has the potential of changing the minds of and educating the participants therein. It moreover, as an egalitarian interaction which is not primarily based on hierarchy, has the implication that the doctor/patient relationship ought to be a participatory and personal relationship, forming the basis of a therapeutic alliance in health care.

While thus reflecting both the relevance and complexity of the application of the ethical principle of respect for autonomy in the context of the individualisation of the provision of information and thereby also in that of the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, these perspectives pave the way for a discussion of a postmodern approach to these matters in the final chapter.

CHAPTER 7

THIRD RECOMMENDATION - TO ESTABLISH A PRACTICE IN INFORMATION THERAPY IN HEALTH CARE

INTRODUCTION

As stated in Chapter 1, this study is aimed at determining an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

In this regard, it was argued in Part I that although evidence-based patient choice is considered as a significant contribution to the debate regarding partnership in clinical decision making and as pointing the way to a potential future scenario of health care in which patients and professionals will operate as real partners, have shared goals and will make shared decisions on the best management of health care problems, none of its key skills can be regarded as completely adequate for the individualisation of the provision of information in health care and consequently for the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making. Moreover, it was argued that evidence-based patient choice is faced by a number of serious challenges that defeat its objectives and which all amount to the challenge of the individualisation of the provision of information in health care.

On the basis of this analysis and drawing on its conclusions, the study in Part II continued its determination of an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making by further exploring the challenge of the individualisation of the provision of information in health care. This exploration revealed the following important aspects.

Devoted to a review and further development of the philosophical foundations of evidence-based patient choice, Chapter 5 disclosed the centrality of the concept of personal identity in these foundations, as well as the complexity of the contemporary understanding thereof.

Chapter 6 elaborated on this theme by considering continental philosophical perspectives on the autonomy related evidence-based patient choice challenges of the separate worlds of patient and health care professional, the constitution of meaning in illness and of the danger of abstractions

and informational manipulation in health care discussed in Chapter 4 and in turn revealed the complexity of the application of the principle of respect for autonomy in medical practice.

In response to these findings, the study regards a broadened understanding of the concept of information therapy as an adequate approach to the complexity of the individualisation of the provision of information in health care and therefore also to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

In explicating this broadened understanding and with regard to the evidence-based patient choice insistence on unprecedented access to information as one of, if not the most important influence in the attainment of its goals, the study will in 7.1 argue that, from an information science perspective, it is regarded as impossible to tap into the real value of information resources and technologies without a clear understanding of the human processes involved in the transformation of information. It will moreover be argued that therefore the mere recognition of the central importance of information and the provision thereof through predominantly technical means in evidence-based patient choice is inadequate. Instead, the study will argue that the provision of information in health care needs to be individualised by embedding it in the human processes through which information is transformed into insight, knowledge and action. Moreover, it will be argued that this employment of the therapeutic value of information will also reveal why it is considered impossible to tap into the real value of information resources and technologies without a clear understanding of the human processes involved in the transformation of information into insight, knowledge and action (Chun Wei Choo 1998).

This discussion will in 7.2 be followed by the description of the recommended profile of an information therapist as a postmodern ethics consultant. It will be argued that the application of the concept of information therapy in medical practice and therefore also the profile of an information therapist, is to be understood within the context of applied ethics in general and of recent developments in the field of ethics consulting in particular and furthermore as a response to the complexities attached to the individualisation of health care.

In 7.3 the study will argue that a broadened understanding of the concept of information therapy will not only provide an adequate approach to the individualisation of the provision of information and consequently also to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, but will also pave the way for a reconciliation of the opposing perspectives of patients and doctors in a therapeutic alliance and for the establishment of an ethics of responsibility in health care. In this regard, it will be argued that the human processes through which information is transformed into insight, understanding

and action are closely related to other human activities such as intentionality and therefore extends and renders explicit the mysterious human processes through which the lifeworld is constituted. It will be argued that it is this extension of and explication of acts of consciousness that enables shared meanings in health care and a scenario in which patients and health care professionals can operate as real partners, have shared goals and will make shared decisions on the best management of health care problems.

7.1 INFORMATION THERAPY AS AN APPROACH TO THE ESTABLISHMENT AND MAINTENANCE OF PATIENT AUTONOMY

In view of the complexities attached to the individualisation of the provision of information in health care, the study regards a broadened understanding of the generic concept of information therapy as an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

The concept of information therapy is an already established and generic health care term describing the timely prescription and availability of evidence-based information in order to meet the specific needs of individuals and in the process support sound decision making. Unlike free floating health care information on the Web that anyone can access at will, information therapy works through involving consumers in the process of care and providing patients with information that is relevant for a specific need. It can be clinician, system or even consumer prescribed. It is therefore asserted that while visits to clinics, medical tests and even surgery can be preceded and/or followed by information therapy prescriptions, the latter can also be directly communicated to patient portals to ensure continuity in care.¹⁴⁶

Whereas information therapy has in the past often been delivered by the random distribution of health care information, the advent of new technologies have recently enabled clinicians and health care institutions to deliver information therapy more efficiently by means of a variety of media. To these media belong modern technologies such as electronic medical record systems, order entry systems and the use of personal digital assistants (PDA's) to which so-called "information triggers" can be attached to ensure that tailored and customised information prescriptions are automatically sent to either a patient's email address or to a secure patient portal. It is envisaged that these options will also empower patients to immediately

¹⁴⁶ Wikipedia Encyclopedia 2006: http://en.wikipedia.org/wiki/Information_Therapy

communicate new symptoms to their health care providers and stay on top of new and useful information with regard to their respective conditions.¹⁴⁷

However, while information therapy has recently been hailed as "as important as other medical treatment" by Don Kemper, CEO and Founder of Health wise and Chairman of the Information Therapy Commission in the United States¹⁴⁸ and is regarded as of value for amongst others medical clinics and health plans, the current understanding of this concept seems to have serious limitations with regard to two aspects, namely a recognition of the importance of the role of persons in health care and an embeddedness in the ethical context in which deliberations on the empowerment of patients in clinical decision making are normally conducted. With regard to the role of persons in the practice of information therapy, the concept of information therapists apparently does not even yet exist, despite the fact that a number of fairly new job descriptions already appear in the field of the management of health information.¹⁴⁹ Similarly, whereas serious attention is paid in the current practice of information therapy to the ethical rule of confidentiality, recognition of the ethical principle of respect for patient autonomy and of the elements of informed consent is virtually absent.

In therefore selecting the generic concept of information therapy to enable a new approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, the study on the one hand strongly identifies with the concept of the therapeutic value of information¹⁵⁰ and the timely prescription and availability of evidence-

¹⁴⁷ Wikipedia Encyclopedia 2006: http://en.wikipedia.org/wiki/Information_Therapy

¹⁴⁸ Medical News Today 2006: <http://www.medicalnewstoday.com/articles/38391.php>

¹⁴⁹ Entwistle et al. for instance refer to the concept of health information professionals and argue that if this new category of professionals is to play an important role in both informing patients and health care professionals, they will have to become skilled in assessing the quality of health care information. In this regard the DISCERN instrument (Charnock 1998) is suggested to help achieve this, since it both provides a method of judging the quality of written consumer health information on treatment choices and highlights the issue of whether information is based on high quality evidence-based medicine (Entwistle et al. 1998:212-225). Also with regard to a possible bridging of the gaps in health care, Muir Gray refers to the concept of the information broker and notes that the traditional role of the librarian is changing and in the twenty first century will become that of an information broker who facilitates the interchange between those who need and those who provide information (Muir Gray 1996:65). Refer also to the concept of a knowledge broker (KB) as a popular knowledge translation and exchange (KTE) strategy emerging in Canada to promote interaction between researchers and end users, as well as to develop capacity for evidence-informed decision making (EIDM). Dobbins et al. 2009: <http://www.implementationscience.com/content/4/1/23>

¹⁵⁰ With regard to the therapeutic value of information, it is broadly acknowledged that the looking for explanations does not begin with a question requiring an explanation, but rather with what leads to the posing of the question and that there therefore is an important therapeutic link between exigence and explanation. An answer is pragmatically considered an explanation when it not only provides a description, but also information that allows you to act in such a way that the exigence which leads to the looking for explanations may be overcome. Faye aptly summarises this therapeutic connection between exigence and explanation by writing: "If the answer provides the person with information upon which he can act, create, construct, take precaution, intervene, move around, etc., it will be considered relevant ... A true explanation will, indeed, allow for a successful action under practically realizable circumstances, whereas a false explanation will result in an unsuccessful one. In both cases, however, the information has established the possibility of some action" (Faye 1999:74).

based information in order to meet the specific informational needs of individuals and in the process support sound decision making, but on the other also argues in favour of the broadening thereof by embedding it in the human processes through which information is transformed into insight, knowledge and action.

In thus broadening the generic concept of information therapy, the study in the following discussion embeds it in the human processes of meaning construction, knowledge creation and decision making through which information is transformed into insight, knowledge and action and which are exclusively conducted in the human arenas of sense making, knowledge creating and decision making (Chun Wei Choo 1998:3).¹⁵¹

The human process of sense making (Chun Wei Choo 1998:xiv)¹⁵² is normally precipitated by a change in the environment of a person that creates a discontinuity in the flow of experiences (Weick 1979). These discontinuities provide the raw material from the environment that has to be made sense of through the enactment, selection and retention (Weick 1995). In enactment, people typically respond to the discontinuities in their environment in order to distil data to be interpreted. In selection, past experiences of sense making are identified to be utilised as overlays in making sense from discontinuities in the environment. In addition, the human activity of retention stores the results of successful sense making for future reference. Furthermore, whereas the human process of sense making may be belief or action driven, people might conduct their sense making processes by starting from an initial set of sufficiently clear and plausible beliefs and employ them as nodes in connecting more information into larger structures of meaning, or start from their actions and develop their structures of meaning to benefit their actions (Weick 1995).

On the contrary, the human process of knowledge creation is normally precipitated by situations that reveal gaps in existing knowledge which may hamper problem solutions (Chun Wei Choo 1998:xv).¹⁵³ People, however, have at their disposal three kinds of knowledge that can be tapped into in order to address such challenges and to create new knowledge, namely tacit knowledge that is embedded in the experience and expertise of individuals, explicit or rule-based knowledge that is codified in routines and procedures and cultural knowledge that is used by people to assign significance to new information (Nonaka & Takeuchi 1995). By tapping into

¹⁵¹ Chun Wei Choo's book, *The Knowing Organization*, is of crucial importance to the final recommendations of the study. I therefore, from the outset, acknowledge my indebtedness Chun Wei Choo (1998). *The Knowing Organization-How Organizations Use Information to Construct Meaning, Create Knowledge and Make Decisions*. New York: Oxford University Press.

¹⁵² See also Chun Wei Choo 1998:65-104.

¹⁵³ See also Chun Wei Choo 1998:105-154.

these kinds of knowledge, new knowledge is created by means of the human activities of knowledge conversion, knowledge building and knowledge linking. In the activity of knowledge conversion, people continuously create new knowledge by converting between the personal and tacit knowledge of individuals and the shared and explicit knowledge of routines and procedures. In this activity, tacit knowledge becomes shared and externalised through dialogue and the use of metaphors and analogies and in the process creates new knowledge that is justified and evaluated. In addition, the human activity of knowledge building involves shared problem solving through the research and implementation of new processes, tools and techniques. Once new knowledge has been created, it can also be shared with others and transformed into value through the human activity of knowledge linking.

Whereas the human process of sense making is precipitated by a change in the environment of a person and that of knowledge creation by gaps in existing knowledge, the human process of decision making is precipitated by a choice situation in which a person is expected to select a course of action (Chun Wei Choo 1998:xvi).¹⁵⁴ It therefore involves rational decision making through the identification of alternatives, the projection of the possible outcomes of each alternative and the evaluating of the alternatives and their projected outcomes according to known preferences and objectives. However, this is also the process that could be beyond the capabilities of an individual and would require interventions from outside (March & Simon 1993).

In addition, the therapeutic value of the human processes through which information is transformed into insight, knowledge and action is represented in the cognitive, affective and situational or environmental dimensions of the use of information (Chun Wei Choo 1998:41-50).

In the environment of information utilisation it is argued that information is fabricated by individuals who continuously cut new cloth from the fabric of past experiences and fashion it according to the exigencies of particular situations. The user of information is therefore to be regarded as a sentient person, incorporating the thoughts, feelings, actions and the environment attached to the use of information and participation in a social and dynamic process extending over space and time. Information, insight and knowledge are thus created in the hearts and minds of individuals through a dynamic and disorderly social process that unfolds in layers of cognitive, affective and situational contingencies (Chun Wei Choo 1998:40).

¹⁵⁴ See also Chun Wei Choo 1998:155-205.

Since information and eventually also insight and knowledge are constructed in the minds of individuals, cognitive needs and abilities are of particular importance in the search for and use of information. In the process of sense making, a person is continuously taking new steps in space and time while making sense of his or her environment. However, from time to time this movement is obstructed by a perceived discontinuity in the form of a cognitive gap which demands the determination of the nature of the gap and the steps to be taken in the creation of new sense (Chun Wei Choo 1998:42-44). In thus addressing the questions on the nature and effect of the obstruction, as well as the required interventions to be taken, a person is finally enabled to cross the bridge constructed through the cognitive process of sense making and to continue the journey of life (Dervin & Clark 1987).

Cognitive needs are however always draped in affective responses, since they are as much felt as they are thought about (Chun Wei Choo 1998:44-47). Recent research in neurobiology indicates that emotions play a crucial role in the use of information due to the intimate connections between the searching for and the risks involved in the use of information (LeDoux 1996). It is therefore also recognised that people in the act of seeking information experience various emotional stages ranging from uncertainty to relief, satisfaction or even disappointment. Whereas the process of looking for information is thus driven by efforts at closing the cognitive gap or eliminating uncertainty, these efforts are all accompanied by distinct emotional states. In the early stages, uncertainty or a lack of understanding may cause affective symptoms of anxiety, confusion, frustration and doubt. In later stages, these emotions may shift towards increased confidence and even satisfaction. However, of importance to the study is the fact that these affective states motivate and direct individuals' information searches and influence and are influenced by the user's ability to construct meaning, focus on the search, balance valuable and redundant information and above all manage moods and expectations.

It is moreover considered as fortunate that the environment in which individuals look for information, is also populated with other people who share assumptions about the use and value of information and whose work is concerned with solving informational difficulties (Chun Wei Choo 1998:47-50). As people interact with one another, they draw upon the information resources from their environment which is both a resource and a product of people looking for information (Taylor 1991).

A broadening of the generic concept of information therapy, by embedding it in the human processes of the construction of meaning, the creation of knowledge and the making of decisions therefore not only thoroughly individualises the concept and as such makes a substantial

contribution to the individualisation of the provision of information in health care, but also provides an adequate approach to establishing and maintaining patient autonomy in the involvement of patients in clinical decision making.

It radically acknowledges information, insight and knowledge as created in the hearts and minds of individuals and the user of information as a sentient person, incorporating the thoughts, feelings, actions and the environment attached to the use of information and participation in a disorderly social and dynamic process extending over space and time. Moreover, a broadened understanding of the generic concept of information therapy recognises that the concept of partnership in clinical decision making originally emerged in the context of the development of the ethical principle of respect for autonomy and to this day remains closely connected to the elements of informed consent.

Acknowledging that specifically in medical contexts, a person would be regarded as competent if able to understand a therapeutic or research procedure, to deliberate about its major risks and benefits and to make a decision in the light of this deliberation, a broadened understanding of information therapy will create an environment in which individuals will have the opportunity of participating in the activity of knowledge conversion whereby people through deliberation continuously create new knowledge by converting between the personal and tacit knowledge of individuals and the shared and explicit knowledge of routines and procedures in order to make informed decisions.

In recognition of the subjective standard of disclosure which judges the adequacy of information disclosure by reference to the informational needs of the individual person, rather than to that of the hypothetical reasonable person, a broadened understanding of information therapy will allow people to conduct their sense making processes by starting from an initial set of personal and sufficiently clear and plausible beliefs and employ them as nodes in connecting more information into larger structures of personal meaning.

Employing the principle that persons understand if they have acquired pertinent information and have justified and relevant beliefs about the nature and consequences of their actions, a broadened understanding of information therapy will encourage rational decision making through the identification of alternatives, the projection of the possible outcomes of each alternative and the evaluation of the alternatives and their projected outcomes according to known preferences and objectives.

Interpreting voluntariness such that a person acts voluntarily to the degree that he or she wills an action without being under the control of another individual's or some form of debilitating

influence, a broadened understanding of information therapy will empower people to personally respond to the discontinuities in their environment by personally distilling the data to be interpreted, employ past experiences in making sense from discontinuities in the environment and store the results of successful sense making for future reference.

Moreover, the broadening of the generic concept of information therapy acknowledges and accommodates the autonomy related complexities of the contemporary understanding of personal identity and of the application of the principle of respect for autonomy in everyday medical practice by involving and accommodating individuals with their unique make-up in every aspect of the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

According to complexity theory, complex systems consist of a great number of dynamically interactive elements which influence and are influenced by an indeterminate number of other elements in a variety of ways.¹⁵⁵ Of particular importance in complex systems, is the fact that the interactions between elements are non-linear, which implies that the components of a non-linear system cannot simply be added and that there is little centralised control possible in such systems. Furthermore, complex systems remain open and irreconcilable with equilibrium, since it is powered by a constant evolution of new possibilities and thus possesses a history that can be regarded as a frame of reference for current issues.

In this regard, De Roubaix and Cilliers note that contemporary human society displays many of these characteristics, since it can also be understood as a system of individuals and groups of individuals as the elements of a complex system in which information is constantly exchanged between subjects on a high level of interaction (De Roubaix & Cilliers 2007:88-111). In this system, human elements in themselves represent heterogeneous systems, but are also constituted in a system of differences in which each person finds him or herself fragmented into a variety of potentially conflicting interests which in turn result in internal uncertainty and conflict. This implies that in contemporary society, also moral decisions are always provisional and subject to circumstance and new answers are constantly needed in response to constantly changing environments.

Applied to the complexities attached to the contemporary understanding of the concept of personal identity, a broadened understanding of the generic concept of information therapy with its recognition of the fact that information, insight and knowledge are created in the hearts and minds of individuals through a dynamic and disorderly social process that unfolds in layers of

¹⁵⁵ For a detailed discussion of the characteristics of complex systems, see Cilliers 1998.

cognitive, affective and situational contingencies, provides an adequate approach to the aforementioned complexities attached to the dichotomy between person and self and the inescapable fact that illness occasions the telling of two tales about the self at once - the one told by the person of the self and the other by the body of the self.¹⁵⁶

Similarly, a broadened understanding of the concept of information therapy will acknowledge and accommodate the complexity of the application of the principle of respect for autonomy in medical practice through its recognition of the fact that in postmodern cultures, moral authority primarily derives from the actual consent of those concerned and that the doctor/patient relationship therefore ought to be a participatory and personal relationship, forming the basis of a therapeutic alliance.

Finally, the broadening of the generic concept of information therapy also reveals why it is regarded in information science as impossible to tap into the real value of information resources and technologies without a clear understanding of the human processes involved in the transformation of information into insight, knowledge and action (Chun Wei Choo 1998:1). With reference to for instance the key skills of evidence-based patient choice referred to earlier, it is remarkable that the essence of the latter is represented in the human processes of sense making, knowledge creating and decision making and that none of these key skills can according to these processes be employed in isolation, or independent of the overall human frame of reference according to which the experiencing of a need for information leads to the looking for and the eventual use thereof.¹⁵⁷

¹⁵⁶ Refer in this regard to the following statement by Charon: "The body, as my story about the patient convinced he had pancreatic cancer demonstrates, coauthors the story of the life being lived in it. Illness occasions the telling of two tales of the self at once, one told by the 'person' of the self and the other by the body of the self. How the body communicates its tale is very mysterious. Sometimes its signals are very clear - my left knee hurts since I ran 13 miles or my period is coming and giving me cramps. Sometimes its signals are obscure, like the paralysis suffered by Freud's hysterical patients. Even though the body is material, its communications are always representations, mediated by sensations and the meanings ascribed to them. It is sometimes as if the body speaks a foreign language, relying on bilingual others to translate, interpret, or in some way make transparent what it means to say" (Charon 2006:87).

¹⁵⁷ Whereas shared decision making elements such as a clear understanding of the problem, an implicit or explicit involvement of the patient, an exploration of ideas, fears and expectations about the problem and possible treatments, a clear portrayal of options and the identification of a preferred format for the provision of information are well represented in all three processes, elements of risk communication such as the incorporating of the subjective probability or patient's perception of the actual probability of a specific event, as well as the outcome utilities or severity of the eventualities for that specific individual are salient characteristics of the processes of knowledge creating and decision making.

Similarly, key elements of decision analysis such as the provision of information about the different outcomes of treatment options and the incorporation of a patient's personal values about the significance and relative importance of these outcomes are to be found in the human processes of knowledge creating and decision making, while also the use of decision aids in the empowering of patients are represented in the process of decision making. However, since none of these human processes can be regarded in isolation, or detached from the dynamic and disorderly social process that unfolds in layers of cognitive, affective and situational contingencies, any provision of

Whereas a broadened understanding of the generic concept of information therapy thus indeed thoroughly individualises the concept, as such makes a substantial contribution in addressing the individualisation of the provision of information in health care and consequently also provides an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, the administering thereof however requires an agent of particular description. As noted, the human processes through which information is transformed into insight, knowledge and action are intersubjective and demand the interventions of an agent to facilitate the effective functioning thereof. Moreover, a broadened understanding of information therapy relies on the fortunate fact that the environment in which individuals look for information, is also populated with other people who share assumptions about the use and value of information and whose work is concerned with solving informational difficulties. The next paragraph is therefore devoted to the description of an agent for the administering of information therapy that will fit the bill.

7.2 THE INFORMATION THERAPIST AS A POSTMODERN ETHICS CONSULTANT

The administering of the concept of information therapy in medical practice and therefore also the profile of an information therapist, is to be understood within the context of applied ethics in general and of recent developments in the field of ethics consultation in particular and furthermore as a response to the complexities attached to the individualisation of health care.

Although the concept of applied ethics has proved difficult to define, it is widely accepted to denote the application of general ethical theories to urgent moral problems with the objective of providing guidance to the solution of these problems (Beauchamp 1996:31). The difference between theoretical and applied ethics is, particularly, that in the case of the latter, the problems are urgent in the sense that action has to be taken sooner rather than later and the luxury of prolonged, unhurried reflection on a problem that might last a lifetime is not available. Among the methods used for achieving this goal, a version of the coherence theory, called reflective equilibrium connected to the so-called common-morality theory, today enjoys considerable prominence in the field of applied ethics (Beauchamp & Childress 2001:397-408).

The concept of reflective equilibrium is inextricably linked to the name of John Rawls who used the term to refer to his influential statement of this method (Rawls 1999:40-45, 508-509). Rawls views justification in ethical deliberations as a reflective testing of our moral beliefs, principles

information should be embedded in a clear understanding of the human processes through which information is transformed into insight, knowledge and action.

and theoretical postulates in order to make them as coherent as possible (Beauchamp & Childress 2001:398). According to Rawls, method in ethics properly begins with our considered judgements, or the moral beliefs in which we have the highest amount of trust and believe to have the lowest level of bias. It may for instance include judgements about the wrongness of racial discrimination, religious intolerance and political repression. These considered judgements occur at all levels of generality in moral thinking and whenever some feature of a moral theory conflicts with one or more of these judgements, one or the other should be revised to again achieve equilibrium (Rawls 1974:8).

Even these considered judgements are thus liable to revision and it remains the goal of reflective equilibrium to match, prune and adjust our considered judgements in order to render them coherent with the premises of our most general moral commitments. This process normally starts with paradigm judgements of moral rightness and wrongness and then proceeds to the construction of more general and more specific accounts that are as consistent and coherent with these paradigm judgements as possible. These results then have to be evaluated for incoherencies and readjusted if necessary (Beauchamp & Childress 2001:398).

A completely stable equilibrium can therefore never be assumed, but is dependent on a continuous harmonising of diverse moral commitments and of an evaluation of these results against all other moral commitments. Rawls emphasises the ideal, though not utopian, character of this procedure by stating that no matter how wide the pool of beliefs, there can be no reason to anticipate that the process of pruning, adjusting and to rendering moral beliefs coherent will ever come to an end or be perfected. A moral framework is henceforth to be regarded as more of a process than a finished product and moral problems as considered projects in need of continual adjustment by reflective equilibrium (Rawls 1999:171-176).

All organised sets of moral belief thus remain somewhat indeterminate and unable to eliminate contingent conflicts among principles and rules and might even require so-called wide reflective equilibrium in order to evaluate the strengths and weaknesses of all plausible moral judgements, principles and relevant background theories. Moral views that may come under scrutiny in wide reflective evaluations might therefore include beliefs about particular cases, rules and principles, virtue and character, the moral standing of foetuses and animals and the role of moral sentiments (Beauchamp & Childress 2001:399).

From this perspective, moral thinking is analogous to hypotheses in science that are tested, modified and even rejected through experience and experimental thinking. Though we start in ethics with a set of considered judgements that are initially accepted without augmentative

support and these judgements may have a history rich in moral experience, any moral certitude associated with these norms should derive from beliefs that are acquired, tested and modified over time (Beauchamp & Childress 2001:399-400).

In applying general ethical theories to everyday moral dilemmas, the key role of considered judgements in reflective equilibrium also has important connections to common-morality theory. While there exist more than one theory of common morality (Ross 1930), common morality theories share several features, such as being pluralistic, relying on ordinary, shared moral beliefs as points of departure, making no appeals to pure reason, rationality, natural law or a special moral sense as well as a suspicion about any ethical theory that cannot be made coherent by means of pre-theoretical commonsense moral judgements. Common morality thus represents a pre-theoretic point of view that transcends local customs and attitudes and for this reason makes it more suitable to play a foundational role in bioethics than code like ethical theories such as utilitarianism and Kantianism (Beauchamp & Childress 2001:403). This is due to the fact that far more social consensus exist about principles and rules obtained from the common morality than from ethical theories, that the common morality is capable of providing both the starting point and the constraining framework for innovation in ethics and that morality is to be regarded as the anchor of theory and not the other way round (Beauchamp & Childress 2001:404-405).

Considered judgements thus have their origin in common morality and no more basic moral data exist than principles requiring that we respect persons, take note of their well-being and treat them fairly. This means that the more general (principles, rules and theories) and the more particular (case judgements, feelings, perceptions, practices, parables, etc.) moral categories are integrally linked in our moral thinking and that neither should have priority over the other. It is also because of the fact that in everyday moral reasoning, we effortlessly blend appeals to principles, rules, rights, virtues, passions, analogies, paradigms, narratives and parables, that, according to Beauchamp and Childress, we should be able to do the same in biomedical ethics (Beauchamp & Childress 2001:408).

The current field of bioethics arose in the mid 1960s as a response to wrongdoings and potential wrongdoings by doctors and biomedical scientists (Martensen 2003:99-122). The Harvard specialist Henry Beecher blew the whistle in 1966 on doctors and biomedical scientists who were experimenting with patients without their consent (Beecher 1966:1354-1360) and this was followed by amongst others the exposure of the injection of cancer cells into elderly patients of the Jewish Chronic Disease Hospital in Brooklyn in 1963 and of the Tuskegee Syphilis study in

1972. Around the same time medicine's growing technical abilities started triggering the public's anxiety that doctors might be in a position to decide who will live and who will die and this made ethicists assume the role of protecting patients from the doctor/scientist and intervening on the side of the patient in an adversarial relationship between doctor and patient. Hence, many of the early concerns of bioethics like informed consent and patient autonomy were powered by the suspicion that doctors, left on their own, could exploit and even harm patients (Charon 2006:204).

The accompanying assumption that the doctor-patient relationship is of an adversarial nature, therefore also seems to have governed the bioethics agenda over the past decades (Charon 2006:205). The current bioethical focus on patient autonomy can only be understood if the doctor is seen as poised to take advantage of a patient and as a result, doctors and patients found themselves at opposite poles of interest. The middlemen and women who came to populate the bioethical field between doctor and patient have until recently therefore also tended to be trained in either law or juridical moral philosophy and even physicians and scientists who worked as ethicists came to be seen as "strangers at the bedside" which posed a fundamental challenge to the until then uncontested authority of doctors (Rothman 1991:4, 94).

Once the doctor-patient dyad was conceived as an adversarial one, contractual safeguards emerged to protect the one party from the other. Ethics therefore became governed by negotiated instruments like advance directives, informed consent processes and conflict of interest disclosures. Ethicists now joined licensing boards, policy makers, insurance company functionaries and hospital admission privilege overseers in building a tort-based, law-enshrining enterprise of controlling doctors and protecting patients. Bioethics thus suffered a restriction of its vision and influence when it often implicitly and seemingly unconsciously accepted the assumption that patients had to be protected from their doctors. The example of autonomy is again most telling, for in their zeal to protect patients' autonomy, some ethicists designated as paternalism any expression of personal opinion on the side of health professionals (Charon 2006:206).

Against this background, discussions in ethics consultation were from the mid 1970s to the mid 1980s largely occupied with what the ethicist knows.¹⁵⁸ It portrayed the ethicist as a logical superintendent who sharpens concepts, upholds standards of rigorous argument and polices fallacious thinking and regarded ethicists as the moral engineers needed to service the engines of

¹⁵⁸ Two interesting exceptions to this are Churchill LR, *The Ethicist in Professional Education*. Hastings Center Report. 1978; 8(6):13-15; and Ruddick W. *Can Doctors and Philosophers work together?* Hastings Center Report. 1981; 11(2):12-17.

ethics through purely conceptual maintenance routines (Walker 1999:354). This conception of ethics therefore also became known as the engineering model (Caplan 1982:1-18) and not only remained the prevailing definition of philosophical ethics for most of the twentieth century, but also became thoroughly embedded in medical ethics. It viewed moral theory as not merely a comprehensive, reasoned and reflective account of morality, but as a highly specific one where moral judgements come from and as a compact code of very general (law like) principles and procedures which, when applied to cases appropriately described, would yield completely impersonal justified judgements about what any moral agent under such circumstances should do (Walker 1999:348).

However, since the mid 1980s concerns about what the ethicist does moved to the fore (Jennings 1984:205-217). The importance of this shift is reflected in the prominence now allocated to matters such as the different institutional functions of ethicists, the differing kinds of responsibility, authority and accountability that should accompany them, where the ethicist fits into the relationships with health care providers, patients, families and caretakers and how moral deliberation within health care institutions connects to larger social arenas of moral consensus and conflict (Hoffmaster et al. 1989).

This shift also coincided with a growing awareness of the principles of the European Ethical and Legal Culture which, apart from autonomy, also emphasise the importance of the principles of dignity, integrity and vulnerability in the protection of the private sphere of human beings (Rendtorff 1998:2-16; Kuhse 1977).

The Stoics already pointed to the *dignitas* of man as an essential contribution to the human being and the concept undergone further development in the Renaissance in the thought of Pico della Mirandola (Della Mirandola 1998). It became an important element in Immanuel Kant's categorical imperative (Kant 2004) and through the work of philosophers such as Jean-Paul Sartre (Sartre 1943), Gabriel Marcel (Marcel 1963) and Simone de Beauvoir (De Beauvoir 1949) developed into an essential element of the foundation of the development of human rights as a legal instrument for the protection of the human person. Integrity is a philosophical concept that according to the Danish philosopher Logstrup concerns that untouchable core of the human personality that should never be subject to external intervention (Logstrup 1971). It was the French philosopher Emmanuel Levinas that regarded human vulnerability as the foundation for morality, as morality is a compensation for man's vulnerability (Levinas 1969).¹⁵⁹

¹⁵⁹ With regard to the meaning Levinas attaches to the concept of human vulnerability as the foundation of morality, refer to the following quotation by Benaroyo: "Now what do Levinas' fundamentals of an ethics of

Reasons for this shift in ethics consultation included the questioning of the assumption that morality is best represented by code-like theories and that moral competence equals an intellectual mastery of code-like theories and law-like principles (Baylis 1989:98-99). It furthermore included suspicions about a lack of skills of attention and appreciation, of the wisdom of a broad life experience and of the role of feelings in guiding one's views among ethicists. Doubts also emerged about the ability of philosophers to bring their abstract constructions into a sensitive and useful contact with the problems of often extremely busy clinics, and this was accompanied by a growing awareness of the social embeddedness of all moral understandings (Walker 1999:348).

Efforts were also made to bring morality to bear upon particular instead of general occasions (Walker 1999:349) and these were linked to an acknowledgement of the often constructive nature of moral deliberation as is evident from the fact that communities, relationships and moral ideas are often renewed and revised as the process of interpersonal negotiation and interpretation in moral terms continues (Edel 1984:317-335). The period after the mid 1980s therefore also saw the emergence of the idea that deductively modelled theories and applications in ethics should give way to a narrative understanding of moral problems and moral deliberation.

Emphasis on narrative as the pattern of moral thinking is first of all an acknowledgement that morally relevant information is always set in particular episodes of deliberation - that history is the basic form of representation for moral problems and that an ethicist needs to know who the parties are, how they understand themselves and each other, what terms of relationship have brought them to the particular morally problematic point and by which social and institutional frames their options are shaped. A narrative approach does not spurn general rules or broad ideals, but treat them as markers of moral relevance, as guidelines to the typical moral weight of certain acts or outcomes, as necessary shared points of departure and as continuing shareable points of reference and reinterpretation (Walker 1999:350).

response mean in the realm of clinical activity? Following Levinas thought, it means that the physician's first order responsibility consists in patiently accepting the 'visitation' of his patient, without too hastily closing the encounter of a specific rational and technical kind. In other words, it means that the physician's first ethical task is to accept the extraordinary 'otherness' of the ill person who is in front of him, that is expressed by this vulnerable face, and that constitutes an ethical call for help and care. To better understand the depth of Levinas' insight, let us now look what the expression 'vulnerable' means in this context. In Levinas's thought, vulnerability does not mean frailty, dependency or loss of social autonomy. Vulnerability, that is increased suffering, is for him intimately tied to 'sensibility'. In turn, sensibility does not mean reception of information or knowledge. Rather, sensibility is a kind of signifying. That is an opening to others, a nearness, the one-for-the-other, precisely vulnerable to others" (Benaroyo 2007:5).

Narratives in moral thinking therefore come before, during and after moral generalities and permit and invite full exploration of what is often neglected or devaluated in the engineering model, namely specific histories of individual commitment, of relationship and responsibility and of institutional practices and evolving moral traditions. While the need to apply principles in code like moral theories tends to dispose of complicating and possibly irrelevant detail, narrative is focused on the enrichment of context and detail. Specific personal, religious, professional or cultural values and commitments may be of crucial importance to the keeping up of individuals' maintaining of integrity and coherent moral self understanding and could necessitate a grasp of the history of trust, expectation and agreement that constitute particular relationships (Walker 1987:171-185).

A narrative approach furthermore regards moral generalities as ingredients of a process rather than axioms to steer by and as ingredients to stories that reveal how problems have become the problems they are, that imagine possible solutions or outcomes and that contemplate the moral influence on the people involved as well as the values at stake. In addition to this, narrative also highlights a situation's dynamic potential. Narratives are furthermore built or constructed and remain open to further additions of information through elaboration, continuation and revision (Walker 1999:352).

Narrative approaches in the resolution of a moral problem are therefore often more like the outcome of a negotiation than the solution of a puzzle and address the question of how values and obligations can guide people in finding morally justifiable solutions to complex problems. Moreover it keeps people involved in moral deliberation morally accountable to one another and is followed in order to act justifiably to the other and to acknowledge the fact that imperfect understandings, conflict and incomprehension often provide opportunities for critical and constructive moral reasoning. For these reasons, moral narratives are ideally authored and judged by those whose stories they reflect and invoke shared moral resources not only to achieve solutions, but to achieve solutions that at the same time protect, refine and extend those very moral resources themselves (Walker 1999:353).

Due to the fact that principle governed bioethics arose to deal with oppositional clinical relationships, it has over the past decade been argued that conventional bioethics has struggled to find its way among its chosen principles and has been found inadequate to address the actual value conflicts that arise in illness (Dubose et al. 1994). It for example became clear that although a principle governed bioethics might be equipped to adjudicate appropriate surrogacy

for the incapacitated terminally ill patient, it is ill equipped to help a paediatrician to talk with parents about the meaning of their child's autism (Charon 2006:208).

A number of alternative approaches in addressing the current ethical problems in health care, like feminist, communitarian, liberation and care ethics have since all started to alter the conceptual geography of bioethics.¹⁶⁰ With their foundations no longer in law and principle governed moral philosophy, but in the particularities of individuals and the singularity of beliefs, all these approaches share a commitment to narrative truth and the power of telling and listening. They share a realisation that meaning in human life emerges not from rules given, but from lived, thick experience and that determinations of right and good by necessity arise from context, perspective, culture and time (Charon 2006:208-209).

These approaches are furthermore all grounded in narrative orientated theory and practice ranging from literary studies and liberation theology to human phenomenology. They also do not assume that patients must be protected from their doctors, but locate them and their loved ones close to those who care for them. Rather than emphasising the divides between doctors and patients, these approaches are aimed at congress between human beings all identified by culture, revealed in language, but also marked by suffering and limited by mortality (Charon 2006:209). While it is not a case that some are sick while others are well, but that all will die, it is argued that to at least provisionally address the ethical conflicts of our day, the ethicist will need the means to probe, honour, represent and live in the face of temporality, singularity, subjectivity and contingency (Charon 2006:212).

These developments remodelled the ethicist's role to that of a facilitator in an inherently social process of moral inquiry by which norms and problem solving plans of action that evoke shared and stable social commitments could be identified (Ackerman 1989:141-160). It also added the responsibility to create and keep moral reflective spaces in institutional life open, accessible and active where sound and shared processes of ethical deliberations and negotiation can take place. Expectations were especially high for the establishment and maintenance of these moral reflective spaces in busy, bureaucratised acute care settings where ethics consulting, whether by committee or individual, should serve the ends of clarifying the responsibility and accountability

¹⁶⁰ For some seminal texts in this vast territory, see Walker MU. *Moral Understandings: A Feminist Study in Ethics*. New York: Routledge; 1998; Holmes HB, Purdy L, editors. *Feminist Perspectives in Medical Ethics*. Bloomington: Indiana University Press; 1992; Noddings L. *Caring: A Feminist Approach to Ethics and Moral Education*. Berkeley: University of California Press; 1984; Tronto J. *Moral Boundaries: A Political Argument for an Ethics of Care*. New York: Routledge; 1993; Pellegrino E, Thomasma D. *For the Patient's Good: The Restoration of Beneficence in Health Care*. New York: Oxford University Press; 1988; Macintyre A. *After Virtue: A Study in Moral Theory*. Notre Dame, Ind: Notre Dame University Press; 1984; Jonsen AR and Toulmin S. *The Abuse of Casuistry: A History of Modern Reasoning*. Los Angeles: University of California Press; 1988.

of patients, proxies and professionals without pre-empting, erasing or diluting that responsibility and accountability (Walker 1999:354-355).

The new approach also witnessed the enlivening of a process in which the ethicist is no longer regarded as a virtuoso of moral theory, but one among other participants in a process in which common moral concerns stay in focus, while differences are recognised and, ideally, mediated (Walker 1999:355). With the concept current in the reflective social dialogue embodied in a myriad of academic journals, books, newsletters, government publications and public discussions, this development was furthermore accompanied by an urgent need for a historically and sociologically informed understanding of the community's moral resources and the current state of discussions within institutions and outside them, as well as the employment of a narrative approach as the key element in all moral deliberations (Ackerman 1989:156).

The reframing of bioethics through narrative therefore focuses attention on the process of interpretation, negotiation, construction and resolution required by any complex deliberation, as well as of the roles of the deliberators. It furthermore typifies the ethicist within a moral space as a kind of mediator, actively participating in a situation of potential conflict with the primary commitment to a fruitful resolution. Walker also compares this profile with that of an architect who does have technical expertise, but must also involve social, psychological and aesthetic elements in order to relate structure and function in a workable and satisfying way (Walker 1999:356-357).

With regard to the reference in 3.1 that the end of the twentieth century brought about a third phase in the development of the medical profession with the introduction of amongst others the concept of third party mediation, the study regards this profile of an ethics consultant functioning in postmodern fashion as fitting for the description of an information therapist as agent for the administering of information therapy amid the complexities attached to the contemporary understanding of the concept of personal identity and the application of the principle of respect for autonomy in medical practice discussed in paragraphs 5.4 and 6.7 respectively. Moreover and in addition to the complexities attached to the contemporary understanding of personal identity and the practical application of the ethical principle of respect for autonomy, the administering of information therapy will be of benefit to patients and health care professionals in both primary and secondary health care.¹⁶¹

¹⁶¹ Evidence-based patient choice is considered to be of value in both primary and secondary health care. Refer in this regard to Schofield 2002:181 and Rosenberg 2002:191. As a transformed version of evidence-based patient choice, it is therefore argued that information therapy will be amenable to both primary and secondary health care.

With reference to the complexities attached to the contemporary understanding of the concept of personal identity and the proposed benefit of the administering of information therapy to individuals, it is common knowledge that patients for various reasons experience an urgent need for reliable information, particularly once an unexpected or drastic diagnosis has been made. Prognosis is a fundamental, though often implicit, basis for many theoretical and practical decisions in medical care and prognostic uncertainty may therefore affect and complicate such decisions considerably. Moreover, the determining of a prognosis and death are tightly interwoven and profoundly affect decisions to initiate, withhold, or terminate life support to critically ill patients. Therefore, prognosis remains a key element in the shared decision making process, especially with respect to end-of-life care (Richter 2007:331).

However, as patients proceed through the known phases of dealing with a prognosis,¹⁶² they often and despite a preference that their health care professionals should make the decisions on their behalf and even the provision of information by the latter, experience uncertainty and an urgent need for clarification of the possible causes and nature of the condition, treatment options and possible second opinions. Since there is in such cases obviously something lacking in the provision of information, these information needs often direct people affected by illness to the Web, although it has been indicated that web surfing is, due to various reasons limited in its potential and may even result in negative psychological reactions in patients.¹⁶³

Cognisant of the complexities attached to the contemporary understanding of personal identity, the administering of a broadened understanding of information therapy will benefit the individual patient in a number of ways. It will foremost create the environment in which discontinuities in experience can be analysed and identified, alternatives to treatment can be explored and actions can be taken. Moreover, it will allow individuals the support of an intersubjective and personalised approach to the clarification of uncertainty and access to an institutionalised service in this regard. Whereas the use of treatment protocols is rapidly gaining ground in medicine, it could be utilised in information therapy to alleviate many of the difficulties experienced by individuals in this regard.¹⁶⁴

¹⁶² Refer to the seminal work of Kübler-Ross in this regard. Kübler-Ross, E. (2003). *On Death and Dying*.

¹⁶³ According to the Washington Post (11/10), Microsoft researches who studied the use of the Web found that people can Google themselves into a state of "cyberchondria" due to the turning of a Web search on a single symptom into a panic over an array of serious diseases. It was also found that two in five people surfing the Web for health information found that it made them feel more nervous about a perceived medical condition.

¹⁶⁴ Coiera notes that many regard the unfolding of protocol based medicine as a vital cultural change in clinical practice that will allow the design of useful clinical information systems. Whereas it was regarded as inappropriate for the designers of early computer systems to regularise clinical practice in order to suit the nature of the systems, the advent of evidence-based medicine amongst others also paved the way for health care professionals to utilise standard assessment and treatment protocols. Thus, whereas the ultimate goal of protocol based decision support

Furthermore, with regard to the complexities attached to the practical application of the ethical principle of respect for autonomy in medical practice and the proposed benefit of administering information therapy to health care professionals, it is recognised that the performance of these ethical duties implies a daunting and almost humanly impossible task to health care professionals due to time and economic constraints, insufficient training and no existing codes for the claiming of remuneration for ethical consultations in the current health care remuneration systems.

According to the guidelines of the Health Professions Council of South Africa,¹⁶⁵ the ethical duties of doctors, dentists and medical scientists include duties towards patients, colleagues and other professionals, health care professionals themselves, society, the medical profession and the environment. While the ethical duties of doctors, dentists and medical scientists to patients include aspects like the patient's wellbeing, respect for patients, informed consent, patient confidentiality and patient participation in own health care, the guidelines of the Health Professions Council of South Africa regard the effective communication of information as the key to the fulfilling of this obligation. It furthermore states that appropriate steps should be taken to determine what patients want and ought to know concerning their condition and treatment, that patients have the right to information, that the amount of information might vary according to factors such as the nature of the condition, the complexity of the treatment, as well as the wishes of the patient and that care should be taken in the provision of information to determine the influence of a patient's beliefs, culture, occupation, and other factors on reaching a decision.

As mentioned earlier, the performance of these ethical duties implies a daunting and almost humanly impossible task to health care professionals due to time and economical constraints, insufficient training and unclarity about remuneration for ethics consultation and information therapy. However, the guidelines of the Health Professions Council of South Africa make provision for ethical tasks of health care professionals to be delegated, provided that the person to whom it is delegated is suitably educated, trained and qualified, has sufficient knowledge of the proposed investigation or treatment and understands the risks involved and acts in accordance with the guidance in this part.

systems is to provide a set of tools that would allow a clinician to access up to date guidelines and apply these in treating patients, it could also prove to be an essential element in the provision of information by information therapists outside a consultation (Coiera 1995:1381-1387).

¹⁶⁵ Medical and Dental Professions Board of the Health Professions Council of South Africa. Handbook - Guidelines for Good and Ethical Practice in Medicine, Dentistry and the Medical Sciences. Pretoria: October 2002.

In this regard, the study argues that the administering of a broadened understanding of information therapy will benefit health care professionals in a distinct way. By employing the services of an information therapist to enhance the provision of information according to the human processes through which information is transformed into insight, knowledge and action, it will allow health care professionals the opportunity of having their ethical duties properly attended to while having the time to focus on their core business.

As such, information therapists will represent an important link in the information chain in health care. They will admittedly find themselves in the "no-man's-land" between patients and health care professionals, but rather than representing another version of patient advocacy, they will endeavour to understand who the parties are, how they comprehend themselves and each other, what terms of relationship have brought them to the particular morally problematic point and by which social and institutional frames their options are shaped. This information will enable them to respond to the informational needs of the respective parties and to enhance a relationship of trust between them.

Properly trained and equipped information therapists would therefore be in a perfect position to intersubjectively and through dialogue employ the human processes through which information is transformed into insight, knowledge and action in not only addressing patients' fears and anxiety regarding prognosis and treatment and health care professionals' concerns about treatment options and the communicating thereof to patients, but in uniting these parties in a therapeutic alliance against the common challenge of illness and the mysterious and inescapable reality of suffering. While the latter aspect will be attended to in the next paragraph, it is clear that the therapeutic value of interventions of this nature can hardly be overestimated. As indicated in 4.1, the divides between patients and health care professionals have reached the stage where fourteen categories of misunderstandings between the respective parties, all resulting from hidden agendas on both sides, have been identified. However, the fact that these divides are often regarded as a given and is to a certain extent tolerated by patients and health care professionals alike, does not diminish the suffering resulting from an inability to communicate your innermost feelings. Therefore, rather than emphasising the divides between patients and health care professionals, approaches in information therapy will be aimed at congress between human beings all identified by culture, revealed in language, but also marked by suffering and limited by mortality (Charon 2006:212).

This study therefore argues for a position that wishes to combine the notion of information therapist and ethics consultant. The information therapist is the person that mediates relevant

and significant - and, may it also be asked, true! - information between the medical professional and the patient. But the information therapist should also be able to act as an ethics consultant. The mediation of information is an *ethical* act. "Information" that is relevant and true for the patient must, after all, be distinguished from "brute facts". Brute facts are not necessarily the truth of the relevant information for the patient. To "speak the truth" is not only an epistemological undertaking, but first and foremost an ethical undertaking. The opposite of "conveying facts", is a *mistake*. The opposite of speaking the truth, is a *lie*. Whereas a "mistake" is not an ethical category, a "lie" is indeed. One "speaks the truth" when one is truthful yourself, when "the facts" are so conveyed that the integrity of the relationship between communicator and addressee is not violated. One also "speaks the truth" when the communication is not a monologue, but a dialogue in which the needs and fears of the patient are acutely registered and respected, and in which the autonomy and integrity of the receiver of information is taken seriously. The conveyance of "true" information therefore requires the commitment of the entire person and the establishment of a relationship of truthfulness that requires time and patience. These kinds of considerations emphasise the need to attune information therapy and ethics consultation with one another.¹⁶⁶

The administering of a broadened understanding of information therapy to the complexities attached to the contemporary understanding of personal identity and the practical application of the ethical principle of respect for autonomy in medical practice will however imply the provision of information outside the clinical consultation. Whereas such a concept might appear outrageous to some, it is increasingly being argued that if patients are to be truly empowered, they will need access to information independently of health care professionals (Entwistle et al. 1998:212-225).¹⁶⁷ These sentiments are echoed by writers who argue that a substantial component of a decision making process can or even should take place outside the face-to-face consultation, since it may indeed relieve the time constraints under which health care professionals have to work and could liberate them to attend to their first obligations (Elwyn et al. 2002:174). Others link the concept of the provision of information outside the clinical consultation with the challenges encountered in searching for information. In this regard, it is noted that apart from cardiac information, there is a shortage of high quality evidence on which to base clinical decisions and that the available evidence is often not suitable to the needs of health care decision-makers. This is reflected by a legacy of years of research which indicates that there are relatively few papers written about common conditions, whereas numerous papers

¹⁶⁶ For an excellent analysis of the ethical dimension of "speaking the truth", see Rossouw, H.W. (1982). Waarheid en siekte. In De Villiers, D.W. en Anthonissen, J.A. (Eds.). *Dominee en dokter by die siekbed*: 97-107.

¹⁶⁷ Refer in this regard also to Blanchard et al. 1988 and Beisecker and Beisecker 1990.

on relatively uncommon conditions exist. This situation is aggravated by a large amount of useful, but unpublished evidence, the limitations of electronic databases and the inadequate indexing of research (Muir Gray 1996:59-64).

Southern Africa is facing various ethical challenges in health care. At patient care level, professional-patient relationships and issues like confidentiality and trust, respect for autonomy and informed consent are still regarded as ethical dilemmas. At the institutional level, issues like the search for equity, resource allocation and priority setting and the withholding and withdrawal of treatment are still being debated. At national level, decisions regarding the HIV/AIDS pandemic and the health budget remain high on the agenda. However, it is envisaged that a national capacity to deal with these social and ethical dilemmas could amongst others be created by an interdisciplinary approach in health care and by promoting a global health ethics (Benatar 2005).

In addressing these challenges, ethics consulting in the guise of a broadened understanding of the concept of information therapy, inspired by the coherence and common-morality theories, as well as by a narrative approach in bioethics and the work of philosophers like Edmund Husserl (Husserl 1962), Jean-Paul Sartre (Sartre 1956), Maurice Merleau-Ponty (Merleau-Ponty 1962), Paul Ricoeur (Ricoeur 1992), Emmanuel Levinas (Levinas 1969) and Jürgen Habermas (Habermas 1990), has already proved to be of great value to patients, health care professionals and Medical Aid schemes in the Namibian context and also holds great potential for the official creation of moral reflective spaces for addressing the ethical demands faced by medical practitioners and medical clinics.

With regard to the support of patients and Medical Aid Schemes and by utilising the therapeutic value of information (Ricoeur 1980), substantial progress has already been made in the establishment of an engaged, contextual and compassionate approach to health care in Namibia. This was largely achieved by honouring the care ethics principle of attachment and by establishing and maintaining personal contact with the patient, employing of a contextual approach in health care and by approaching the patient within his/her personal situation and through the implementation of traits valued in intimate personal relationships such as empathy, compassion, fidelity, discernment and love (Gilligan 1985).

It is also envisaged to extend this information therapy support to more specialised services rendered not only to patients and Medical Aid Schemes, but also to health care professionals and medical clinics. With the aim of officially creating moral reflective spaces to address moral dilemmas as they present themselves from day to day and with respect to for instance the

bioethical principle of respect for patient autonomy, such services could include the acknowledgement of people's rights to hold views, make choices and take actions based on personal values and beliefs, the pursuit of the bio-ethical obligation to build up or maintain others' capacities for autonomous choice as well as assistance to allay fears and other conditions that disrupt autonomous actions, as well as the enhancement of understanding and the capacity for autonomous choice and informed consent and assistance in the disclosure of health care information.

Concerning the ethical principles of beneficence and nonmaleficence, information therapy services could for instance include the facilitation through consultation of conflicts between beneficence and autonomy, consultations on the balancing of benefits, costs and risks in health care, deliberations on the value and quality of life, deliberations on end-of-life care and the protecting of incompetent patients by means of the facilitation through consultation of advanced directives and surrogate decision making. Even the bioethical principle of justice could be addressed through deliberations on the concept of fair opportunities, consultations on the allocation of health care resources and the rationing of scarce treatments to patients and support of all those harmed in the execution of health care.

An information therapist therefore indeed has to display the traits of a commitment to narrative truth and the power of telling and listening, of a realisation that meaning in human life emerges not from rules given, but from lived experience and that determinations of right and good by necessity arise from context, perspective, culture and time. He or she will need the mental make-up to function in the face of temporality, singularity, subjectivity and contingency and assume a role among other participants in a process in which common moral concerns stay in focus, while differences are recognised and, ideally, mediated. Moreover, information therapists will have to accept the responsibility to create and keep moral reflective spaces in institutional life open, accessible and active where sound and shared processes of ethical deliberations and negotiation can take place. In these environments, they should assume the role of a mediator,¹⁶⁸ actively

¹⁶⁸ Refer in this regard to the seminal work of Reuven Feuerstein. Feuerstein identified ten criteria or types of interaction which he believes to be fundamental in mediation. Though he regards mediation as a dynamic and open process that should not be rigidly applied, he considers the first three of these criteria to be necessary and sufficient for an interaction to be regarded as mediation, while the remaining seven serve to balance and reinforce each other and may function where and when appropriate. The first of these criteria is Intentionality and Reciprocity and occurs when on the one hand a mediator deliberately guides an interaction in a chosen direction by means of selecting, framing and interpreting specific stimuli in order to focus attention on the stimuli and on the other when there is responsiveness from the learner or mediatee as an indication of being receptive to and involved in the learning process. The second criterion is Meaning which occurs when a mediator conveys the significance and purpose of an activity by showing interest and emotional involvement, discusses the importance of the activity with the mediatee and furthermore elicits an understanding of why it should be done. In addition, Feuerstein describes the third criterion of the mediated learning experience as Transcendence, which occurs when interaction goes beyond the

participating in a situation of potential conflict, but with the primary commitment to a fruitful resolution.

7.3 INFORMATION THERAPY AS AN APPROACH TO THE ESTABLISHMENT OF A THERAPEUTIC ALLIANCE IN HEALTH CARE

A broadened understanding of the concept of information therapy however does not only provide an adequate approach to the individualising of the provision of information in health care and to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making, but also paves the way for a reconciliation of the opposing perspectives of patients and health care professionals in a therapeutic alliance and for establishing an ethics of responsibility in health care. The human processes through which information is transformed into insight, understanding and action in a broadened understanding of information therapy, are closely related to other human activities such as intentionality and therefore also extends and renders explicit the mysterious human processes through which the lifeworld is constituted in order to establish shared meanings in health care. As such, a broadened understanding of the concept of information therapy, as envisaged with regard to the future of evidence-based patient choice, indeed enables a scenario in which patients and health care professionals can operate as real partners, have shared goals and will make shared decisions on the best management of health care problems.

These statements are to be understood within the context of on the one hand, the various references already made in the study to the limitations imposed by the immensity of reality on mans' knowing abilities and knowledge and on the other, the potential of a broadened

immediate need and thereby diversifies the need system of the mediatee and is responded to by promoting the acquisition of principles, concepts or strategies that may be generalised to issues beyond the present. This criterion is followed by that of Competence which occurs when a mediator assists a mediatee to develop confidence in order to successfully engage in a given act and which is not necessarily to be regarded as an outcome of success, but rather of the mediatee's perception thereof. The fifth criterion of a mediated learning experience is that of Self-Regulation and Control of Behaviour which occurs when a mediator intervenes in order to make a mediatee conscious of the need to monitor and adjust behaviour and the rapidity and intensity of the mediatee's mental activity is modified according to characteristics of the stimuli and the circumstances. This is followed by the sixth criterion of Sharing Behaviour which relates to the interdependence of mediator and mediatee and of individuals in general which is reflected in a mutual need for cooperation at a cognitive and affective level and which develops empathy through social interaction. The seventh criterion of a mediated learning experience is that of Individuation which occurs when a mediator fosters a sense of uniqueness and difference in a mediatee, encourages autonomy and independence from others and celebrates the diversity of people. This is followed by the eighth criterion of mediated learning, namely Goal Planning which occurs when a mediator, by making the process explicit, guides and direct a mediatee through the phases involved in setting, planning and achieving goals. The ninth criterion is that of Challenge which occurs when a mediator instils in a mediatee a feeling of determination and enthusiasm to cope with novel and complex tasks by identifying the steps involved in achieving success in further challenges. According to Feuerstein the final criterion of a mediated learning experience is that of Self-Change and occurs when a mediator encourages a mediatee to also be aware of the dynamic potential of change and to recognise the importance and value thereof (Feuerstein 1980).

understanding of the concept of information therapy in establishing shared meanings in health care.

With reference to the thought of John Locke, it was noted in Chapter 5 that man cannot have knowledge of all the relations of his ideas or rational knowledge of the necessary relations between many of his ideas and that sensitive knowledge only goes as far as the existence of things and not as far as their real existence or reality. Consequently, the study noted that the aspects of objects that science is able to deal with, are those that are independent of any individual observer and belongs to their measurable properties, such as their length, breadth, height, weight, position in space and velocity if in motion. The implication of this reality, it was argued, is that it is impossible for science to deal with qualities such as taste, smell and colour that belong to objects in an ambiguous way and arise out of the interaction between an object and an observing subject and therefore contain a subjective element which could easily differ from observer to observer.

Moreover, it was noted that due to the fact that we are able to only observe an object's observable characteristics and behaviour, we have no way of apprehending it independently of those characteristics and therefore cannot have any knowledge of what the object is that exhibits those characteristics and behaves in that way. The study thus contended that the thing in itself remains an invisible and metaphysical something which can be characterised as matter and as a material substance, but cannot be known apart from its characteristics and properties.

This, it was argued, also applies to subjects, since as subjects of knowledge and experience we can only find within ourselves the contents of our awareness and experiences and accordingly both the subject and the object of our knowledge remain in themselves unknowable and result in the domain of possible knowledge to entirely consist of transactions or possible transactions between these mysterious entities.

The study furthermore maintained that the success of the new clinical method in the late 1800s soon resulted in the dominance of the ontological model, which true to its origins in the Enlightenment, was analytic and impersonal with the feelings and experiences of the patient left aside.

It was noted that whereas the term diagnosis formerly referred to the diagnosis of a patient as a person, the objective of a diagnosis now became the identification of a disease which was now regarded as located inside bodies and the categorization thereof as abstractions that for the sake of generalization, omitted many features of being ill, such as the subjective experience of the patient. These developments furthermore resulted in physical and mental illnesses being

classified separately, in the distinguishing of somatic and psychotherapies and in the physician increasingly being viewed as a detached and impassive observer, utilising the predictive and inferential power of the new clinical method to identify the patient's disease or rule out organic pathology.

The study furthermore contended that this dichotomy between the physical and the mental eventually also manifested itself in the organisation of the health care profession with distinctions for instance being made between internal medicine and psychiatry and eventually also between different types of wards in medical institutions. Due to the conceptualisation of disease as a physical phenomenon, also only physical treatment modalities such as drugs, surgery or radiation became considered part of scientific medicine with the psychosocial needs of the patient recognised as perhaps important from a humanitarian point of view.

As could be expected, this approach to therapy also directly influenced the doctor-patient relationship, since the doctor's objective now was to diagnose a disease and not to understand the patient. The patient's personal agenda therefore got drawn into a reductionist, mechanistic and materialistic medical agenda in order to make a physical diagnosis and to prescribe physical treatment which almost inevitably led to the decline of humanistic medicine.

In the discussion in Chapter 6 of the complexities attached to the application of the principle of respect for autonomy in medical practice, the study from the angle of Phenomenology and with reference to Husserl noted that individuals always find themselves located in a world of immediate experience and that in order to render this world comprehensible, it is interpreted in terms of a meaningful structure imposed on reality. It is by means of intentionality and directedness of acts of consciousness and against the horizon of a unique existence in the world that we perceive our experience. It is therefore also due to the fact that experience always represents a correlation between experiencing and what is experienced and that the locus of meaning is to be found in the intentional activity of consciousness, that the content of another's experience and world is not directly accessible to us. Each individual thus retains an essential core of experience as a constituted world that is to be distinguished from the world in itself as studied by the exact sciences.

Although others' experience of the world therefore largely transcends our possible comprehension, elements thereof nevertheless become available by means of bodily gestures and linguistic expressions through which a shared world of meaning and a common communicative environment is constituted. It is through their location in this intersubjective world that individuals not only remain subjects among other subjects, but also become objects to

others. This location in a historical, social and cultural environment thus entails that an individual's unique biographical situation and the typifications through which his or her world is rendered comprehensible, to some extent represent a shared reality.

This shared reality and the establishment of a shared world of meaning is however often accompanied by the idealisations of the interchangeability of standpoints and of the congruency of the systems of relevances which Schutz called "the general thesis of reciprocal perspectives" and which can be regarded as typifying constructs of objects of thought that supersede the private thoughts of individuals. A common communicative environment is thus made possible through the interpretation of the familiar world by means of typifications that are socially and culturally derived according to the general thesis of reciprocal perspectives. Moreover, any communication therefore presupposes a certain congruence between the participants, since it is taken for granted that the intentions and perceptions of the respective participants will substantially coincide. Moreover, since full identification with the interpretational schemes of communicative partners remain impossible, communication as such demands a substantially similar system of relevances and to be successful, a set of common abstractions or typifications.

However, it was noted that in the patient-professional encounter it often happens that due to a variety of reasons, patients and health care professionals do not communicate on the basis of a set of common abstractions or typifications and that as a result illness is represented as two distinct realities instead of a shared reality between the parties.

Due to the fact that in general an individual's perception of something is directly related to the manner in which it is experienced, this attentional focus also determines the meaning of illness. Patients interpret illness in the context of their lived experience and therefore essentially in terms of its effect upon everyday life. On the contrary, physicians are trained to essentially perceive illness as a manifestation of physical signs and symptoms which eventually determine a specific disease state. As a result of the fact that the world is foremost experienced in its immediacy and only upon reflection becomes thematised in terms of theoretical and scientific constructs and that immediate experience therefore enjoys a certain precedence over the derivative world of science, a decisive gap often results between the immediate experience of the patient and the derived scientific views of the health care professional. Moreover, this gap might even result in a conclusion that no bona fide illness exists, while the patient might still experience him or herself as sick.

It was furthermore noted that these potential pitfalls regarding attentional focus in the patient-professional encounter are also evident in the discrepancies arising from the distinction between

the natural and naturalistic attitudes in medicine and the different perceptions of temporality and relevance in the clinical situation. Contrary to patients' natural attitude to illness, health care professionals' commitment to an accurate diagnosis provide them with a naturalistic attitude in which the patient's illness is conceptualised in terms of objective and scientific constructs.

Similarly, patients experience illness in a subjective manner as an ever present and enduring consciousness of disorder, while health care professionals utilise an objective time scale in order to conceptualise the physical events and biological processes that constitute a disease state. These realities are also reflected in the fact that whereas the relevance of illness for a patient is determined by the effect upon daily life, a health care professional adopts a view of relevance that is dominated by the scientific determinants of the illness. Whereas patients therefore experience a disorder as a unique and personal event, health care professionals interpret the same disorder as a typified instance of a particular disease state. Moreover, while a patient might find it difficult and in some cases even impossible to incorporate the reality of illness into his or her everyday existence, health care professionals simply interpret a disorder as yet another scientific typification.

Although patients and health care professionals thus share some common abstractions and prescientific typifications on the basis of which descriptions of a physical experience and diagnostic processes are undertaken, much of what is happening in the clinical situation is based on the assumption of the discussion of a shared reality as reflected in the two idealisations of the interchangeability of standpoints and of the congruency of the systems of relevances referred to earlier. In a typical clinical situation, the patient therefore takes for granted that the health care professional acknowledges a disorder as essentially a threat to personal being, while the health care professional in turn assumes that the patient, though incompletely, understands the disease in terms of objective clinical data and may even go to great lengths to explain the intended interventions. As a result, the constructs of common sense thinking, rather than facilitating communication between patients and doctors, have instead deepened the divides between the respective worlds.

However, it was indicated that this failure of the common understanding between patients and health care professionals on central issues in health care is fundamentally to be attributed to the fact that the experience of illness is foremost a subjective experience which cannot be represented as a common object and represents an inner rather than an outer event that is essentially unshareable. It is also evident that the incongruence in the interaction between patients and health care professionals is precipitated by the essentially unshareable nature of

illness which also renders a complete identity between the interpretational schemes of the respective parties in principle impossible.

Up till now, these divides between the separate worlds of patients and health care professionals have been readily acknowledged, but mostly cited as justification for the different perspectives of patients and health care professionals and for inequalities in health care in general. It has therefore also been addressed by means of models such as evidence-based and patient centred medicine and evidence-based patient choice, which have all developed as a critical response to perceived inequalities in medicine and by ways of minimising the unshared aspects of illness, such as the use of narratives.¹⁶⁹ However, almost all of these efforts were characterised by an emphasis of the inequalities in power and knowledge between patients and health care professionals and therefore either resulted in efforts at empowering patients against doctors or in adding responsibilities to doctors that had significant time and cost implications. Whereas the empowering of patients furthermore almost always entailed technical assistance by means of the Internet or packages such as risk communication and decision analysis, it was expected of health care professionals to undergo training in communication and utilise aids such the key skills discussed earlier.

Although these models and approaches have all made valuable contributions to the involving of patients in clinical decision making, none of them have managed to enter the mainstream of medical practice, but have instead somehow deepened the divides between patients and health care professionals due to perceptions that doctors' knowledge bases are being undermined and their authority challenged, complacency among health care professionals in getting involved in efforts at involving patients in clinical decision making, resistance to training in this regard and the lack of training, time and remuneration for ethical counselling.

What is thus obviously required, is to not further widen these divides between patients and health care professionals by introducing yet another instrument of patient advocacy, but to regard illness as not only attached to a patient or perceived by a health care professional, but as an entity or a challenge somewhere between patients and health care professionals. Moreover, it needs to be recognised that not only patients are in need of empowerment in the clinical situation, but also doctors and that both parties therefore not only share the challenge of full identification with the interpretational schemes of communicative partners in general and of the unshareability of illness in particular, but also find themselves challenged by a reality so immense that it cannot adequately be addressed within the current parameters of the clinical

¹⁶⁹ Refer in this regard also to the efforts of Mishler (Mishler 1984), Kriel (Kriel 2000), Toombs (Toombs 1993), Charon (Charon 2006) and Richter (Richter 2007) at addressing these issues.

situation and therefore demands an approach to clinical decision making that will be capable of establishing shared meanings between patients and health care professionals and will do justice to not only the autonomy of patients, but also to the interventions of health care professionals.

However, while the essentially unshareable nature of illness as a subjective experience continues to pose a challenge to the establishing of a common communicative environment in health care, a broadened understanding of information therapy with its emphasis on the accommodation of the individual and the shared creation of meanings between individuals exhibits the potential for reconciling the opposing perspectives of patients and health care professionals in an approach of illness as a shared reality and in creating a therapeutic alliance in health care.

Whereas health care is challenged by the in principle inaccessibility of the respective worlds of patients and health care professionals and remains subject to the ambivalence of human gestures and linguistic expressions and the failure of the idealisations of the interchangeability of standpoints and the congruency of the systems of relevances, a broadened understanding of information therapy is primarily focused on the establishment of shared meanings. As such, all the human processes through which information is transformed into insight, knowledge and action are joined in a continuous cycle of learning and adaptation and solely aimed at the creation of shared meanings between the participating individuals (Chun Wei Choo 1998:18; 241-242; 247-249).

Through a dynamic and disorderly social process that unfolds in layers of cognitive, affective and situational contingencies, streams of experience are continuously and intersubjectively bracketed, labeled and connected in the process of sense making aimed at developing shared interpretations on the reasons for changes in the environment and discontinuities in the flow of experience. Should the results of sense making indicate that more knowledge is required to properly respond to changes in the environment or discontinuities in the flow of experience, knowledge creation is again intersubjectively achieved by converting between the internal, tacit knowledge held by individuals and the external, explicit knowledge codified in routines and procedures and by means of the intersubjective and social processes of socialisation, externalisation, combination and internalisation. Once new knowledge has been created, also the process of decision making is aimed at establishing shared meanings between participating individuals in selecting a pattern of action through invoking the appropriate routines and procedures.

As argued in 7.1, all these processes remain intimately attached to the fact that the user of information is a sentient person that incorporates the thoughts, feelings, actions and the

environment attached to the use of information, that participates in a social and dynamic process extending over space and time and that therefore, information, insight and knowledge are created in the hearts and minds of individuals. This implies that the human processes through which information is transformed into insight, knowledge and action and which constitute and are constituted by human acts of consciousness, are closely related to other human activities such as intentionality and therefore not only extends, but also renders explicit the mysterious human processes through which the lifeworld is constituted.

As such, the human processes through which information is transformed into insight, knowledge and action indeed exhibits the potential of reconciling the opposing perspectives of patients and health care professionals in an approach of illness as a shared reality and in creating a therapeutic alliance in health care. Through its involving of the most basic acts of human consciousness in intersubjective processes of problem solving, a broadened understanding of the concept of information therapy in the provision of information renders explicit some of the content of another's experience and world and thereby not only constitutes the possibility of access to that world, but also of the establishment of shared meanings and of a therapeutic alliance in combating a common challenge.

Reference has in 7.2 been made to the responsibility of information therapists to create and keep moral reflective spaces in institutional life open, accessible and active where sound and shared processes of ethical deliberations and negotiation can take place. Also with reference to Habermas's insistence on the need for the institutionalisation of moral action,¹⁷⁰ the study would like to close by pointing to the change in approach to illness that will be enabled by a broadened understanding of the concept of information therapy.

¹⁷⁰ Habermas's views on the need for the institutionalisation of discourses are to be understood within the context of his principle of universalisation. In this regard he notes that it is important to recognise that discourses take place in particular social contexts and are moreover subject to the limitations imposed by time and space. Moreover, their participants are not to be equalled with Kant's intelligible characters, but are real human beings that are also driven by other motives than that of the search for truth. In this context, topics and contributions, as well as the opening, adjournment and resumption of discussions have to be arranged. It is due to all these factors, says Habermas, that institutional measures are needed in order to sufficiently neutralise the empirical limitations and avoidable internal and external interferences and to ensure that the idealised conditions that are normally presupposed by participants in argumentation can at least be adequately approximated. He therefore continues to argue that the discursive justification of norms does not provide any guarantee for the actualisation of moral insight, as discourse in itself cannot ensure that the conditions required for an actual participation of all involved are met: "Often lacking are crucial institutions that would facilitate discursive decision making. Often lacking are crucial socialisation processes, so that the dispositions and abilities necessary for taking part in moral argumentation cannot be learned. Even more frequent is the case where material living conditions and social structures are such that moral-practical implications spring immediately to the eye and moral questions are answered, without further reflection, by the bare facts of poverty, abuse, and degradation. Wherever this is the case, wherever existing conditions make a mockery of the demands of universalist morality, moral issues turn in issues of political ethics. How can a political practice designed to realise the conditions necessary for a dignified human existence be morally justified. The kind of politics at issue is one that aims at changing a form of life from moral points of view, though it is not reformist and therefore cannot operate in accordance with existing laws and institutions" (Habermas 1990:209).

The rendering explicit of the content of another's experience and world through a broadened understanding of the concept of information therapy will however not only reveal the uncertainties and anxiety of patients and the question marks of health care professionals, but through its emphasis on "situationally based responses" (Allmark 1995:20) and the importance of social, cultural and even political factors in the provision of information, also pave the way for an ethics of responsibility in health care.

An ethics of responsibility is a model in which people accept responsibility for all their actions rather than hiding behind rules, codes and conventions, recognise that they are morally accountable in terms of a universal moral claim, exhibit a moral responsibility toward future generations, have to come to terms with moral ambivalence and empower people to accept their responsibilities (Van Niekerk 2002b:35-43). In medical ethical contexts, it therefore obliges people to accept responsibility for the creations of science and technology and denies that morality is exclusively determined by rules, codes and laws. It however emphasises the accountability to the unconditional claim of others to, irrespective of their reciprocity, always act with their best interests in mind. Furthermore, an ethics of responsibility recognises the fallibility of human insight and therefore no longer restrict the ethical debate to the realm of "ethical specialists", but extend it to include all involved in decision making (De Roubaix & Cilliers 2007:105).

With regard to the individual patient, the mediation of the radically individualised human processes of sense making, knowledge creation and decision making will indeed instill the Kierkegaardian inspired recognition discussed in 5.3 of the need to, through the concept of contemporaneity, take responsibility for past and future actions in the present as an adequate approach to the complexities attached to the dichotomy of person and self in personal identity. Such an approach to illness will allow patients personal equilibrium in dealing with their illness and the accompanying ability to deal with the matters at hand.

Similarly, in the broader health care context, the administering of the thoroughly human processes of sense making, knowledge creation and decision making in the provision of information will bring about an awareness of human fallibility, but also of the interdependence of human beings and the recognition of the need to therefore forsake the moral security of conventions, rules and appearances in favour of an almost limitless responsibility towards the "other" in which no reward or reciprocity is expected and relationships are not regarded as contractual, since contractuality is considered to neutralise morality (Bauman 1993:58, 78-79,

80).¹⁷¹ Moreover, the administering of a broadened understanding of information therapy will induce an awareness of accountability to one another and the accompanying obligation to act accordingly, since moral responsibility implies the integration of perceived needs and the power to respond to these needs. In administering a broadened understanding of information therapy, acting responsibly may therefore amount to the disregard of rules and conventions in order to be accountable to and appropriately respond to the needs of the other (Jonas 1984:92-94).

In a health care setup in which codes and conventions have become the rule rather than the exception, an approach to the complexity of illness according to a broadened understanding of information therapy and along the principles of an ethics of responsibility will indeed provide an adequate approach to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making and enable a scenario in which patients and health care professionals can operate as real partners, have shared goals and will make shared decisions on the best management of health care problems.

It has been noted in 6.7 that since suffering is intimately connected to the way in which illness is perceived by a patient, it is evident that the alleviation thereof will require attention to the meanings patients attach to illness. It was also argued that due to the fact that suffering is not identical to clinical distress and illness is not identical to the disease state, suffering is therefore also not necessarily alleviated when attention is only paid to illness as a disease state. In this regard, the administering of a broadened understanding of information therapy will also provide an adequate approach to the practical reality of suffering in the world. It will transfer suffering as an inescapable and mysterious entity from the private world of the individual to an intersubjective domain where it can be jointly assessed, addressed and borne. As such, it will relieve a patient from having to suffer in silence and introduce an approach to illness on the one hand attuned to the contingencies of life, but on the other also to the therapeutic value of shared burdens.

¹⁷¹ Bauman's use of the concept of the "other" is inspired by the work of Emmanuel Levinas.

FINAL CONCLUSION, CHALLENGES AND FUTURE PROSPECTS

It was stated as the desired outcome of the study to determine an adequate approach to the individualisation of the provision of information in health care and consequently also to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making to serve as the foundation for a therapeutic alliance in health care and for the eventual training and integration into the health care system of people practicing in this capacity.

The critical evaluation of evidence-based patient choice as partnership model in clinical decision making undertaken in Part I of the study revealed that due to a wide variety of reasons, none of the key skills of evidence-based patient choice can be regarded as completely adequate for the individualisation of the provision of information in health care and consequently for the honouring of the principle of respect for autonomy in clinical decision making and that huge gaps still exist between the ideal and current practices of evidence-based patient choice. Moreover, this analysis revealed the challenges posed to the practice of evidence-based patient choice, namely the remaining of the separate worlds of doctor and patient, the constitution of meaning in illness and of the dangers of abstractions and informational manipulation in health care. The identification of the challenges remained closely tied to the informed consent elements of competence, disclosure, understanding and voluntariness and as such provided a firm bases for the recommendations made in the second half of the study.

Against this background, it was concluded that whereas the concept of partnership in clinical decision making arose within the context of the development of the concept of respect for patient autonomy, any endeavour at determining and developing an adequate approach to partnership in clinical decision making should therefore also be undertaken within this context. A thorough and adequate understanding and application of the ethical principle of respect for patient autonomy as represented in the informed consent elements of competence, disclosure, understanding and voluntariness is therefore essential in the development of any new concept of patient-centred care. It was furthermore also concluded that in view of the fact that the practice of evidence-based patient choice remains deprived of a proper embeddedness in the context of the ethical principle of respect for patient autonomy, an undertaking of the transformation of

evidence-based patient choice to a therapeutic alliance will have to pay close attention to this cornerstone of partnerships in clinical decision making.

In addition, it was concluded that the determination of an adequate approach to the individualisation of the provision of information in health care and consequently also to the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making would require a specific focus on the matter of the individualisation of the provision of information and that in this regard an embeddedness in the human processes through which information is transformed is indispensable and not negotiable. It was furthermore noted that it can be regarded as fortunate in such an endeavour that the medical profession has already entered a phase in its development that allows room for third party mediation, since the concept is of pivotal importance in this study. With specific reference to the key skills of evidence-based patient choice, it was moreover concluded that although these skills are aimed at enhancing patient autonomy, a mere recognition of this ethical principle simply remains inadequate. It was noted that the notion of "evidence-based patient choice" refers to the moral requirement that patients' treatment choices be based on adequate evidence that a certain line of treatment will be the most efficacious in the particular situation of the relevant patient and that the issue therefore is not simply that of a desirable choice in general, but a choice that is individualised for a particular patient in his/her particular circumstances. However, it was argued that whereas these key skills are intended to contribute to the individualisation of the provision of information, they predominantly are of an objective and technical nature and as such therefore all remain deprived of a proper embeddedness in the human processes of sense making, knowledge creating and decision making without which it according to information science remains impossible to tap into the real value of information resources and technologies. Thus, in recognition of the fact that the individualisation of information requires the provision thereof in a manner that will facilitate patients' ability to make decisions about their health care and consequently also their autonomy in a sincere and credible way, it was argued that a new approach to this challenging aspect of medical practice is needed. As anticipated in the second and third chapters, it was argued that such an approach will have to do justice to the fact that the concept of partnership in clinical decision making emerged in the context of the ethical principle of respect for patient autonomy and therefore has to be embedded in and developed within this particular context. Moreover, it will be required to address the matter of the individualisation of the provision of information in full recognition of the complexities attached to the contemporary understanding of the concept of personal identity and to the application of the ethical principle of respect for autonomy in medical practice. Whereas the contribution of the key skills of

evidence-based patient choice to the provision of information in clinical decision making cannot be denied, it has to be recognised in any endeavour of this nature that it remains impossible to tap into the real value of information resources and technologies without a clear understanding and implementation of the human processes through which information is transformed into insight, knowledge and action. Whereas evidence-based patient choice is regarded as pointing the way to a potential future scenario of health care in which patients and professionals will operate as real partners, have shared goals and will make shared decisions on the best management of health care problems, it has been argued in the final chapter that this goal is only to be achieved through the utilisation of the therapeutic value of information.

Part II of the study was in its entirety devoted to recommendations for the transformation of evidence-based patient choice to a therapeutic alliance in health care. These recommendations were inspired by a single concept that has indeed already been raised as a possibility by some scholars, but has now for the first time been conceptually substantiated in an academic study. This concept is that of the provision of information outside a consultation through the introduction of information therapists into the health care team and was substantiated by the recommendations to review and further develop the philosophical foundations of evidence-based patient choice and to consider continental philosophical perspectives on the challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and of the dangers of abstractions and informational manipulation in health care. The discussion of these recommendations not only emphasised the complexity of the contemporary understanding of the concept of personal identity, but also of the complexities attached to the application of the ethical principle of respect for patient autonomy in medical practice.

Against this background, it was concluded that a combination of the perspectives of Locke and Kierkegaard add a completely new dimension to the debate regarding evidence-based patient choice as partnership model in clinical decision making, as well as to the evidence-based patient choice challenges of the separate worlds of doctor and patient, the constitution of meaning in illness and the dangers of abstractions and informational manipulation in health care. It was argued that this dimension is represented in the complexity of the contemporary understanding of personal identity and is to be regarded as of pivotal importance in the provision of a conceptual foundation for the transformation of evidence-based patient choice to a therapeutic alliance in health care. Whereas individualisation is recognised as the great challenge of evidence-based medicine and evidence-based patient choice is defined as "the use of evidence based information as a way of enhancing people's choices when those people are patients", this new dimension forcefully brings home the message of the complete inadequacy of any approach

that aims to individualise health care, but fails to acknowledge the dichotomy between self and person and the resulting essence of an intersubjective and mutual understanding of all the patient has to disclose about the self in clinical decision making.

It was furthermore argued that this new dimension to the debate regarding evidence-based patient choice as partnership model in clinical decision making also demands a recognition of the fact that the body has various ways of communicating its messages. To these belong visible lesions of all kinds, physical examinations that suggest pathological states and measurements of substances in the blood that may signal disease. However, while the body through various avenues relate what might be wrong with it, the person inhabiting it feels out of the ordinary and needs to be taken seriously as well. If autobiographies tell truths about their writers of which they are unaware, then patients' narratives tell truths about themselves of which they are also unaware. Acknowledging that autobiographical narratives cannot solely be read as either factual truth or simple facts but, as an intersubjective mode, lies outside a logical or juridical model of truth and falsehood, it has to be concluded that also doctors need to realise that they are not only collecting and verifying facts, but are also creatively reaching for a mutual interpretation of all that the patient might disclose about the self. Moreover, these perspectives raise the important issue of the separate worlds of patients and health care professionals in health care and the resulting need for mediation in health care. The in principle inaccessibility of the world of the other revealed by Locke, coupled to the ambivalence of and the difficulties attached to the constitution of a common communicative environment indeed create a major obstacle in health care in general and in the individualisation of the provision of information in particular. Considered together with the challenges attached to the complexity of the contemporary understanding of the concept of personal identity, the difficulties related to the in principle inaccessibility of the worlds of the other not only demand a new approach to the bridging of these divides, but also a new agent to serve as mediator between these separate worlds. In these circumstances it can be regarded as fortunate that the end of the twentieth century also brought a third phase in the development of the medical profession with the introduction of the concept of third party mediation in which mediation refers to a resolution in which a third party mediates in the relationship between the producer and the consumer and defines both the needs and the manner in which the needs are to be met.

These arguments led to the conclusion that whereas the goal of medicine is primarily the relief of a perceived lived body disruption and the restoration to a former state of perceived well-being, this action may include, but is not limited to the cure of organic dysfunction. In order to address a patient's experience of disorder, attention should not only be paid to the physical

manifestation of a disease state, but especially in the case of chronic illness, also to the changing relations between body, self and world. Such recognition holds the key to the mitigation of some of the dehumanising aspects of medical care. Treating a patient thus amounts to action that should not be objectified, but personalised. In this regard it was argued that many of the problems with modern clinical medicine result from the need to individualise the available knowledge and to make it applicable to the individual patient. The patient has to participate as an autonomous subject in this process, but the autonomy of the patient is based on informed consent and the patient thus participates in a communicatory act with the health care professional.

With regard to the aim of the study, namely to determine an adequate approach to establishing and maintaining patient autonomy in the involvement of patients in clinical decision making, it was in addition concluded that in postmodern ethical theory, a universal and simultaneously fundamental foundation of ethics is regarded as no longer possible or desirable. In addition, the purely rational foundation of ethics must even be doubted, since according to newer concepts of ethics, all people have some ethics and according to postmodern cultures, moral authority primarily derives from the actual consent of those concerned. Also, the modern theory of science is more influenced by the discursive consent model than by the traditional congruence concepts of truth. As a universal model for non-dominated communicatory action, it can be concluded that discourse ethics represents a much needed sharing of power which allows an expert to change his mind without losing authenticity and represents a case based dialogue implicitly or explicitly applying ethics which does not affect the validity of personal ethics or medical expertise. While also corresponding to the temporality and individuality of medical practice, discourse ethics admittedly depends on a set of conventions such as equality and reciprocity and on rules to be followed, such as argumentation and listening. It is thus both a rule based procedure and a case based ethics and as such represents a pragmatic approach of learning by doing how to bring general principles and values about in practice. This has the important implication that the discursive dialogue therefore has to be learnt and taught, but also has the potential of changing the minds of and educating the participants therein. It moreover, as an egalitarian interaction which is not primarily based on hierarchy, has the implication that the doctor/patient relationship ought to be a participatory and personal relationship, forming the basis of a therapeutic alliance in health care.

While thus reflecting both the relevance and complexity of the application of the ethical principle of respect for autonomy in the context of the individualisation of the provision of information and thereby also in that of the establishment and maintenance of patient autonomy

in the involvement of patients in clinical decision making, it was concluded that these perspectives pave the way for a discussion of a postmodern approach to these matters in the final chapter.

In response of these findings, the study in the final chapter concluded that a broadened understanding of the concept of information therapy can be regarded as an adequate approach to the complexity of the individualisation of the provision of information in health care and therefore also to the establishment and maintenance patient autonomy in the involvement of patients in clinical decision making. In explicating this broadened understanding and with regard to the evidence-based patient choice insistence on unprecedented access to information as one of, if not the most important influence in the attainment of it's goals, the study argued that, from an information science perspective, it is regarded as impossible to tap into the real value of information resources and technologies without a clear understanding of the human processes involved in the transformation of information and that therefore the mere recognition of the central importance of information and the provision thereof through predominantly technical means is inadequate. Instead, the study argued that the provision of information in health care needs to be individualised by embedding it in the human processes through which information is transformed into insight, knowledge and action. It was concluded that the broadening of the generic concept of information therapy acknowledges and accommodates the autonomy related complexities of the contemporary understanding of personal identity and of the application of the principle of respect for autonomy in everyday medical practice by involving and accommodating individuals with their unique make-up in every aspect of the establishment and maintenance of patient autonomy in the involvement of patients in clinical decision making.

Applied to the complexities attached to the contemporary understanding of the concept of personal identity, it was argued that a broadened understanding of the concept of information therapy with its recognition of the fact that information, insight and knowledge are created in the hearts and minds of individuals through a dynamic and disorderly social process that unfolds in layers of cognitive, affective and situational contingencies, provides an adequate approach to the aforementioned complexities attached to the dichotomy between person and self. Similarly, it was concluded that a broadened understanding of the concept of information therapy will acknowledge and accommodate the complexity of the application of the principle of respect for autonomy in medical practice through its recognition of the fact that in postmodern cultures, moral authority primarily derives from the actual consent of those concerned and that the doctor/patient relationship therefore has to be a participatory and personal relationship that could constitute the basis of a therapeutic alliance between the respective parties. In conclusion of the

argument in favour of information therapy as an adequate approach to the establishment and maintenance of patient autonomy, it was argued that the broadening of the generic concept of information therapy also reveals why it is regarded in information science as impossible to tap into the real value of information resources and technologies without a clear understanding of the human processes involved in the transformation of information into insight, knowledge and action. With reference to the key skills of evidence-based patient choice and the observation that it is impossible to tap into the real value of information resources and technologies without a clear understanding of the processes of the transformation of information, it was also noted that it is remarkable that none of these key skills can according to these processes be employed in isolation, or independent of the overall human frame of reference according to which the experiencing of a need for information leads to the looking for and the eventual use thereof.

In addition, the study argued that whereas a broadened understanding of the generic concept of information therapy indeed thoroughly individualises the concept, as such makes a substantial contribution in addressing the individualisation of the provision of information in health care and consequently also provides an adequate approach to establishing and maintaining patient autonomy in the involvement of patients in clinical decision making, the administering thereof however requires an agent of particular description. It was noted that the human processes through which information is transformed into insight, knowledge and action are intersubjective and demand the interventions of an agent to facilitate the effective functioning thereof. In this regard, the study concluded that the profile of an ethics consultant functioning in postmodern fashion can be regarded as fitting for the description of an information therapist as agent for the administering of information therapy amid the complexities attached to the contemporary understanding of the concept of personal identity and the application of the principle of respect for autonomy in medical practice. Moreover, and in addition to the complexities attached to the contemporary understanding of personal identity and the practical application of the ethical principle of respect for autonomy, it was argued that the administering of information therapy will be of benefit to both patients and health care professionals. Of particular importance in this regard, was the conclusion that the notions of an information therapist and ethics consultant need to be combined in the description of this new agent in the provision of information in the context of clinical decision making. It was argued that the information therapist is the person that mediates relevant and significant information between the medical professional and the patient, but should also be able to act as an ethics consultant, since the mediation of information fundamentally represents an ethical act. For this reason it was argued that the conveyance of true information requires the commitment of the entire person and the establishment of a relationship

of truthfulness that demands time and patience which further emphasise the need to attune information therapy and ethics consultation with one another.

Whereas the administering of a broadened understanding of information therapy to the complexities attached to the contemporary understanding of personal identity and the practical application of the ethical principle of respect for autonomy in medical practice will imply the provision of information outside the clinical consultation, the study argued that it will also pave the way for a reconciliation of the opposing perspectives of patients and health care professionals in a therapeutic alliance and for the establishment of an ethics of responsibility in health care. In this regard, it was argued that the human processes through which information is transformed into insight, understanding and action are closely related to other human activities such as intentionality and therefore extends and renders explicit the mysterious human processes through which the lifeworld is constituted.

As a final conclusion, it was argued that with regard to the individual patient, the mediation of the radically individualised human processes of sense making, knowledge creation and decision making will indeed instil the Kierkegaardian inspired recognition of the need to, through the concept of contemporaneity, take responsibility for past and future actions in the present as an adequate approach to the complexities attached to the dichotomy of person and self in personal identity. Such an approach to illness will allow patients personal equilibrium in dealing with their illness and the accompanying ability to deal with the matters at hand. Moreover, it was argued that similarly, in the broader health care context, the administering of the thoroughly human processes of sense making, knowledge creation and decision making in the provision of information will bring about awareness of human fallibility, but also of the interdependence of human beings. It was argued that in this regard, information therapy will also facilitate recognition of the need to forsake the moral security of conventions, rules and appearances in favour of an almost limitless responsibility towards the "other" in which no reward or reciprocity is expected and relationships are not regarded as contractual, since contractuality is considered to neutralise morality. Moreover, it was argued, that the administering of a broadened understanding of information therapy will induce an awareness of accountability to one another and the accompanying obligation to act accordingly, since moral responsibility implies the integration of perceived needs and the power to respond to these needs. In administering a broadened understanding of information therapy, acting responsibly may therefore amount to the disregard of rules and conventions in order to be accountable to and appropriately respond to the needs of the other. In a health care setup in which codes and conventions have indeed become the rule rather than the exception, an approach to the

complexity of illness according to a broadened understanding of information therapy and along the principles of an ethics of responsibility will therefore provide an adequate approach to establishing and maintaining patient autonomy in the involvement of patients in clinical decision making and enable a scenario in which patients and health care professionals can operate as real partners, have shared goals and will make shared decisions on the best management of health care problems. Moreover, it will provide an adequate approach to the practical reality of suffering in the world and will transfer suffering as an inescapable and mysterious entity from the private world of the individual to an intersubjective domain where it can be jointly assessed, addressed and borne.

The implementation of these recommendations however poses some severe challenges. Already research on the barriers related to clinical consultations conducted according to evidence-based patient choice guidelines indicate that a lack of medical evidence per se and of properly individualised medical information remain a major stumbling block. Furthermore, the attitudes of health care professionals, the limited time in clinical practices to keep up with the latest information, an adequate introduction of the latter into consultations, economic and resource constraints and a lack of technical resources and training in this regard are also regarded as severe challenges (Ford et al. 2002:179-187). Whereas the approach argued for in this study goes well beyond the parameters of the evidence-based patient choice partnership model, it is to be expected to encounter some formidable challenges.

With regard to the training of information therapists, the composition of an appropriate curriculum will pose a first and daunting challenge. In order to comply with the guidelines of the Health Professions Council of South Africa, it is suggested that information therapists should be qualified health care professionals with an additional background in philosophy, bioethics, information science and health informatics. Once an appropriate curriculum has been established, a next important challenge will be the registration of information therapists in order to ensure remuneration for services rendered. The official recognition of a new member in the health care team and of a new link in the information chain between patients and health care professionals and the eventual integration into the health care system of agents practising in this capacity, will pose a final and extremely formidable challenge. In this regard it is envisaged that fears regarding unbridled and inappropriate consumer demand for health care and the overstretching of agreed upon resources, together with the fact that clinical practice proved to be very resistant to change (Holmes-Rovner et al. 2002:271-276) will result in an arduous journey in the setting up moral reflective spaces in institutional life where sound and shared processes of ethical deliberations and negotiation can take place (Walker 1999:355).

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