

THE JUSTIFIABLE LIMITATIONS OF PATIENT AUTONOMY IN CONTEMPORARY SOUTH AFRICAN MEDICAL PRACTICE

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Abstract

The European Enlightenment secured man's freedom from doctrinal thought. Scientific progress and technological innovation flourished in the 18th Century, radically changing the lives of all. Man's mastery and transformation of his environment was matched by revolutionary political reform, resulting in the dissolution of empire and the transfer of power into the hands of the people. Social transformation saw the city-states of pre-modern man supplanted by a globalized community whose existence grew from time and space distantiation facilitated by the new technologies and the development of symbolic forms. These sweeping social, political and ideological changes of the 18th Century fostered the belief that man's transformative authority was indeed his to command. Man believed he had a right to self-governance and to autonomous decision-making. Kant described moral autonomy as the freedom men have to show rational accountability for their actions and he saw in men a dignity beyond all price because of this moral autonomy. Personal autonomy is seen as the expression of the free will of individuals and is justifiably constrained by the need to respect the interests and agency of others. The principle of autonomy, in the context of medical practice, was not clearly articulated until the early 20th century. Prior to this, the ethical practice of medicine relied upon the beneficent intentions of the practitioners. The limits to patient autonomy have been delineated largely by issues of social justice based upon the need to share scarce resources fairly among members of society. However, autonomy remains a dominant principle and is most clearly exemplified by the process of informed consent obtained prior to any medical intervention. This thesis provides a conceptual analysis of autonomy in the context of informed consent. Following this, several different clinical scenarios are examined for evidence of justifiable limitations to patient autonomy. Each scenario is examined

in the light of different moral theories including deontology, utilitarianism, communitarianism and principlist ethical reasoning. Kantian ethical reasoning is found to be resilient in rejecting any limitation to the autonomy principle whereas each of the other theories allow greater scope for morally-justified curtailment of individual autonomy. The thesis concludes with reflection on post-modern society in which the radicalization of what began with the European Enlightenment sees the transformation of pre-modern society into a global community in which epistemological certainty is no longer available. In this environment, the emerging emphasis on global responsibility requires ethical accountability, not only when individuals secure transactions between one another but also between individuals and unknown communities of men and women of current and future generations. The thesis concludes that patient autonomy is justifiably limited in South African medical practice because of issues related to social justice but that the impact of the new genetic technologies and post-modernity itself may in future set new limits to individual patient autonomy.

Abstrak

Die Europese Verligting het die mensdom bevry van verstarde, dogmatiese denke. Wetenskaplike en tegnologiese ontwikkelinge het tydens the 18de Eeu die lewens van almal radikaal verander. Die mens se bemeestering en transformasie van sy omgewing het gepaard gegaan met revolusionêre politieke hervormings wat gelei het tot die ontbinding van tradisionele politieke ryke en die oordrag van mag aan die mens. Sosiale transformasie het veroorsaak dat die politieke ordeninge van voor-moderne mense deur 'n globale gemeenskap vervang is wat ontstaan het as gevolg van onder meer die ontkoppeling van tyd en plek (Giddens), en wat deur nuwe tegnologiese ontwikkelings en die ontstaan van simboliese vorms moontlik gemaak is. Hierdie uitgebreide ontwikkelinge het die idee laat ontstaan dat niks vir die 18de Eeuse mens onmoontlik is nie. Die mens het geglo dat hy 'n reg het op self-bestuur en outonome besluite. Kant het die morele outonomie van die mens beskou as sy vryheid om verantwoordlikheid te neem vir sy eie rasioneel-begronde handeling en verder het hy 'n besondere waardigheid in die mens geïdentifiseer vanweë sy morele outonomie. Omdat 'n mens hierdie eienskap besit, beskik hy oor 'n hoër waardigheid as alle ander lewensvorme. Persoonlike outonomie is die uitoefening van die vrye wil van die individu en word om geregverdigde redes beperk deur die regte van ander mense. Die beginsel van outonomie met verwysing na mediese etiek het nie voor die begin van die 20ste eeu prominent geword nie. Voor hierdie tyd het mediese etiek staatgemaak op die goeie voorneme van die praktisyn. Die grense van individuele outonomie word nou bepaal deur die noodsaak van sosiale geregtigheid. Al is dit die geval, bly die beginsel van outonomie die belangrikste beginsel in die etiese debat en word meestal gesien as 'n deel van die proses van ingeligte toestemming. Hierdie tesis verskaf 'n omvattende ontleding van

outonomie met betrekking tot ingeligte toestemming. Daarna word verskillende kliniese gevalle beskryf en ontleed, en verskeie etiese teorieë gebruik om die wyse waarop pasiënt outonomie reverdigbaar ingekort behoort te word, te bespreek. Die teorie van Kant is in staat om enige inkorting van outonomie in alle gevalle te weerstaan. Elkeen van die ander teorieë verskaf redes waarom die outonomie van individuele pasiënte legitiem ingekort mag word. Hierdie werk sluit af met besinning oor die post-moderne gemeenskap wat 'n globale samelewing moet aanvaar sowel as die ontoereikende van enige kenteoretiese sekerheid. Die ontwikkelende verantwoordelikheid vir die totale mensdom in hierdie wêreld veroorsaak dat individue nie meer slegs moet besluit oor die morele verhouding met sy medemens nie, maar ook oor sy verhouding met mense van gemeenskappe wat geskei is in tyd en ruimte, insluitend sy verhouding met die mense van toekomstige generasies. Hierdie werk sluit af met die gevolgtrekking dat pasiënt outonomie regverdigbaar beperk word in die Suid Afrikaanse mediese praktyk deur die noodsaaklikheid van sosiale geregtigheid. Die verwagte impak van nuwe genetiese tegnologieë en die ontwikkeling van 'n post-moderne gemeenskap mag nuwe beperkings bring vir pasiënt outonomie.

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DEDICATION

I wish to dedicate this work to my wife Wendy, whose sense of forbearance must have been sorely tested in the many hours I spent in philosophical self-absorption!

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Chapter 1:

Introduction: Self-awareness, an Enlightenment notion

The idea that individual autonomy should be regarded as the dominant precept in bioethical deliberation developed during the latter half of the 20th Century. This idea supplanted a more traditional view that the practice of medicine should be based largely upon the beneficent intentions of doctors. Respect for the autonomously-expressed wishes of the individual was philosophically consistent with the Enlightenment ideal of individual sovereignty and the exposition of Human Rights, articulated since the 18th Century. Today, the choices made by individuals seeking medical care are often regarded as being paramount. Yet, in any society of women and men, autonomy cannot be seen as an unlimited right to pursue one's own self-interest. Individual autonomy is justifiably limited in various circumstances and the ethical basis for limiting autonomy may be derived from ethical theories rooted in modernity. In addition to the arguments based upon deontological and utilitarian theory, the contemporary awareness of environmental degradation and persistent global poverty amidst great wealth has resurrected a communitarian ethic which also resonates with African communitarian philosophy in the form of Ubuntu. An ethic of responsibility for both the current and future global community has thus developed and created its own limits to the autonomously-enacted will of the individual. This thesis seeks to describe some of the ethical argument that may be employed in describing the justifiable limitations applicable to patient autonomy in contemporary South African medical practice. The text begins with a description of how the Enlightenment established the idea that man was master of his own

destiny and how sweeping changes in his social and political environment fostered his belief in himself to the point that nothing seemed to lie beyond his control. The second chapter deals with the notion of self-governance or autonomy and then moves on to describe the paradigm biomedical example of autonomous action contained by the precept of informed consent. The fourth chapter outlines a number of different scenarios in which some limitation of autonomy may be justified in terms of Kantian, utilitarian, communitarian and principlist ethical theory. The final chapter considers the evidence in favour of justifiable restrictions to patient autonomy and also examines some of the more recent challenges presented by a "post-modern" society in which a globalised perspective induces accountability, not only for transactions taking place between individuals living in the same community, but also for those that may influence communities of men and women whose lives are lived at some distance (of both space and time) from our own.

To establish why the idea of self-governance became the dominant principle of bioethics during the 20th Century, it is necessary to examine some aspects of the European Enlightenment which served to foster man's belief in himself as an individual endowed with a limitless capacity for taking control of every aspect of his life and using it to further his own ends¹.

The events of the 18th Century, in particular, changed man's perceptions of life radically; the lives of European individuals were transformed in every dimension imaginable: man's capacity to understand his environment, his mastery of technology, the expansion of sovereignty through exploration of distant lands together with social and political reforms heralded hitherto unprecedented changes in the

¹ In the text of this document "man" is frequently used to refer to humankind of both genders. This is done without any intention to discriminate between male or female gender in any way and attributes no greater status to one gender over the other. It also implies no disrespect for either gender. Similar considerations are applicable to the terms "himself" and "herself" throughout this text.

lives of individuals. This transformation happened so rapidly that the life of an individual man could not escape an awareness of the changes taking place all around him.

These changes were imprinted on the psyche of modern man leaving him with a sense of mastery; "enlightenment" encompassed the sense that the Sun had broken through the gloom of the Middle Ages leaving man free, rational and (most importantly of all), seemingly omnipotent. Man's belief in himself became his defining creed and his own omnipotence always implied the necessity for individual freedom.

The European Enlightenment began with the refutation of doctrinal authority; in particular, Copernicus and Galileo established that the Earth was not the centre of the Universe but merely a "grain of dust amid countless others" (Barth 1976: 37). This discovery founded upon empirical observation and man's capacity for rationality set aside the authority of the Church and opened the door leading down the path of scientific discovery. The philosophy of this time has been described by Barth (1973: 39) in the following terms:

"(Man)... began to be conscious – and more forcibly than before – of a capacity for thinking which was responsible to no other authority than himself. This free thought he once more finds related to nature which was just as freely observed. Mathematics were once more discovered by him to be the bridge which carried him across in both directions, from concept to intuition, from intuition to concept. Logic, observation and mathematics were the three decisive elements of the absolute power now disclosed in science."

Barth (1973: 40) further observes that the pursuit of scientific endeavour became separated from the Universities in the 18th Century and became the endeavour of all:

“...the human capacity for acquiring knowledge, which had been so long neglected, now began to spread in every sphere like a stream running along dry beds, and produced a movement from whose influence no clear mind could withdraw.”

The scale of these events can be measured in the realization that every science can trace its roots back to the Eighteenth Century and each technology that followed in the wake of scientific enquiry radically changed the lives of all. The steam cylinder was invented in 1690, steam heat appeared 55 years later and the steam engine less than ten years after that. Galvani discovered electricity in 1780 and gas was used for lighting soon after this. Spinning machines were made in 1738; beet-sugar was produced in 1747; the mercury thermometer was discovered in 1714. Each of these inventions transformed the lives of individuals in startling ways. Barth (1973: 41) has encapsulated what this meant to the man of the 18th Century:

“If we are to understand the feeling of life which surged through the whole of Europe, we must not underestimate the significance of the hopeful excitement which was also stirred by these discoveries too; here too is manifested the existence of the absolute man, the man almost capable of anything”

Not only were transformative events shaping the everyday world of individuals at this time but simultaneously socio-political upheaval also saw the revolutionary transfer of political power into the hands of individuals. The structure of emperors and empires gave way to a new order brought about by the French and American Revolutions. Following the demise of hierarchical authority (under whose banner no single social class could lay any claim to dominance), power came to be devolved to social classes who were able to determine the law of the state. The first to seize power and declare their authority to be that

of the state were the princes. This has been described as the revolution from above that followed the dissolution of the empire. The princes exercised their absolute authority at the expense of the nobility and the middle classes – a situation exemplified by the rule of Louis IV and his offspring; this situation was destined to change because of economic and educational transformation.

Machine-based industry expanded steadily during the eighteenth century, gradually displacing the agrarian economies of the old order. This growth in industry was accompanied by a rapid growth in population that provided labor for the industrialized economies; at the same time, currency reforms took hold with the development of central banks to control the issue of paper money (Craig 1971: 5). Land, previously seen as the basis for social organization, was displaced by capital and because of this the old divisions of society began to crumble. A bourgeoisie middle-class whose existence was based upon the manipulation and accumulation of money emerged and grew; they exercised economic power and sought both political and social influence, espousing liberal ideas. Beneath the bourgeoisie were the lower classes who provided labour in the new society. Labour, seen as a commodity to be bought and sold in market transactions, not surprisingly spawned political instincts among the lower classes that were focused on finding political power and securing economic welfare by means of a socialism that held governments responsible for improving their lot (Craig 1971: 6).

Education, meanwhile, became more generally available because the industrial revolution allowed the mass production of cheap books and urbanization concentrated people in the cities. Among the educated classes, classicism was displaced by romanticism which also heralded greater freedom of expression (Craig 1971: 7). These two factors, economic and educational transformation, led to the revolution from below that saw political power being transferred from the governing

princes into the hands of representatives of the proletariat. The ideology of revolutionary change was encapsulated by the declaration of Universal Human and Civil rights ratified by the French National Assembly in August 1789, which had been preceded some 13 years earlier by a similar statement contained in the American Declaration of Independence. The equality of men and their "inalienable" rights to freedom, the possession of property and security are also reflected in American quest for "Life, liberty and the pursuit of happiness".

Governments were from now on seen as agents of the people whose task it was to protect the rights of individuals and whose existence would be regarded as legitimate only for as long as they continued to serve these ends and to act with the consent of the governed.

Thus the transition from empire via the absolute authority of the princes was seen to come to an "ultimate reality" which was the concept of the state consisting of the sum of the individuals forming a nation (Barth 1973: 50). The opinion of individuals within the ruling sector of society became inviolable. Barth (1973: 53) has argued that this political transition reflected Hobbes's philosophy (1660: chapter XXI) that man's nature is restrained by his reason and his desire to preserve himself. He adopts self-imposed restrictions on his liberty by ceding some of his rights to the State which in turn guarantees his safety by exercising power over all within the State (Hobbes 1660: chapter XXI). The authority of the State could be vested in the monarchy, the aristocracy or a democracy; the public law determined by the State defined both right and wrong and was binding upon every citizen's conscience, but it was the individual who remained sovereign over the state by choosing to cede certain rights while still retaining the right to remove any government that failed to act in accordance with his desire for safety and happiness.

The absolute authority of eighteenth century man was shown not only in his growing mastery of his environment through technological invention, but it emerged also in his burgeoning political power and growing intellectual stature fostered by the rapid spread of education. Barth extends this metaphor of man's mastery of his world into aspects of Eighteenth Century culture. He describes 18th Century man as imposing his notion of form upon all manner of objects around him. In doing so he gave expression to his belief in himself as one whose knowledge of what was "intrinsically right, fitting (and) worthy" was to be taken for granted (Barth 1976: 55). This self-belief resonated in his manipulation of nature into geometrical forms which he further adorned with architectural structures in pursuit of beauty - such as the Palace at Versailles. His architecture also sought to transpose natural materials into forms of his making and his cities imposed themselves upon the environment rather than being built in accommodation of the geography of the land. Barth (1997: 56) writes:

"What other age has dared to make architecture of its inmost heart to the extent that this one did? But this was an age which simply had to, for its inmost heart was precisely this idea of man as one taking hold of everything about him and subjecting it to his will"

His dress code too showed similar adherence to form, even at the expense of his own discomfort. Eighteenth Century man projected a sartorial image of himself far nobler than his natural physique would ever have allowed. His study of history too became critical and self-absorbed. He assumed the inviolability of his own standards, through the lens of which he judged all that had preceded him. The light of his convictions served to illuminate the darkness of the past and his "... sovereign will for form looked upon history, as it did upon nature, as just so much raw material." (Barth 1997: 59).

Education became a cornerstone of eighteenth century culture because man believed too that he had command over his ability to introduce young people to real life based upon educational theories derived from the principles of Socratic dialogue together with the teaching of skills. The emphasis on education was overwhelming and government schools came into being in order to support education for all as a right and a duty. Freedom of association also emerged during the eighteenth century. The idea that men could form a community based upon free choice and common purpose created an entirely new structure around which orders of men were created. The associations of the past based upon marriage, family life and the professional association of the guild were supplanted by a new community that was regarded as being the "true, real and living" community. Barth (1997: 66) writes:

"In spite of all the diversity of their forms it is impossible not to recognize the single unifying intention, spirit and conviction underlying all this building of free associations of feeling and aim: the conviction that it is possible to create a community." (The emphasis is mine)

Hence, man's absolute belief in himself found its expression in every walk of life. The world he inhabited was subject to his authority: he shaped its form, he controlled its environment and exercised his mastery in every sphere of life without exception, and nothing lay beyond his grasp.

Given this environment, it is not difficult to see why a belief in self-governance was to become the dominant and axiomatic principle of bioethics. The 18th century writings of Kant and the 19th century utilitarian liberalism of John Stuart Mill gave expression to the idea that man had a dignity and a value beyond all price and that the happiness of man was to be considered morally relevant. At the end of the 19th century, the ideas formulated by G.E. Moore (writing in Principia Ethica, published in 1903) and W. D. Ross (The Right and the Good,

published in 1930) added aspects of intuitionism to man's notion of morality which subsequently led to Beauchamp and Childress's (2001: 405) recently-formulated principles of bioethics based upon four prima facie principles that include the need to respect the autonomous will of the individual.

Although this self-belief may prove to have been illusory, the circumstances of modernity nevertheless swept away the old order so thoroughly that man may now be left with no option but to pursue his own ends based upon his belief in himself.

Giddens (1991: 3) has outlined the consequences of modernity as an increasingly radicalized transformation of society derived from time and space distantiation. The combined consequences of mechanical time-keeping, the spread of the written word and distant exploration with mapping of the globe fostered a process whereby individuals and their communities were dis-embedded from one another as purely local communities, giving rise instead to restructuring "across indefinite spans of time-space" (Giddens 1991: 21). Symbolic tokens (e.g. money) and expert systems created links between individuals in ways that had not previously been possible and the utilization of these symbolic tokens required the exercise of trust. Trust became a necessary social innovation because man, absent in time and space from others whose lives and actions influenced his own, had to rely upon the validity of the guarantees inherent in the symbolic forms that linked his life with unknown others. That trust was seen to exist in the context of human activity which was "... socially created, rather than given in the nature of things or by divine influence" (Giddens 1991: 34). Trust was inextricably linked to the notion of risk which was, in turn, seen to displace fortuna; it was

“...an alteration in the perception of determination and contingency, such that human moral imperatives, natural causes, and chance reign in place of religious cosmologies”. (Giddens 1991: 34)

Individual man therefore found himself responsible for his own decisions and their consequences in an extended social context, very different to the confined relationships of pre-modern traditional cultures.

The old order was also thoroughly dislodged not only by the pace and extent of social transformation that began in the 17th and 18th centuries but also in the continual process of reflexive change that was to follow in the wake of modernity. Traditional cultures had been slow to change and continuity was achieved by honoring the past and all its symbols which represented the experience of previous generations. The process of scientific method and the authority of rational enquiry brought with it an accumulation of knowledge that was held to be reflexively important to society as a way of controlling and improving the circumstances of all. This notion has been characterized by Giddens (1991: 39) as “deeply unsettling” because the expectation of greater knowledge leading to greater certainty went unfulfilled. He writes:

“For when the claims of reason replaced those of tradition, they appeared to offer a sense of certitude greater than that provided by pre-existing dogma. But this idea only appears persuasive so long as we do not see that the reflexivity of modernity actually subverts reason, at any rate where reason is understood as the gaining of certain knowledge. Modernity is constituted in and through reflexively applied knowledge, but the equation of knowledge with certitude has turned out to be misconstrued.” (Giddens 1991: 39)

This lack of certainty was a consequence of the limitations of reason itself. Giddens (1991: 39) cites Karl Popper who argued that all science rested upon shifting sand.

Giddens (1991: 39) writes:

“In science nothing is certain, and nothing can be proved, even if scientific endeavour provides us with the most dependable information about the world to which we can aspire”

He further adds:

“No knowledge under conditions of modernity is knowledge in the ‘old’ sense, where ‘to know’ is to be certain”. (Giddens 1991: 40)

Modern man, faced with the dissolution of pre-modern society entered the 18th Century invigorated by his apparent mastery of all around him; his world changed and continued to change as every element of pre-modernity was swept away. The society he once occupied became a global community, that which he once knew to be true was scrutinized in the light of reason and only practices authenticated by reason rather than tradition were held to be legitimate. These global and revolutionary changes in the circumstances of all communities were all derived from man’s rejection of doctrinal authority and his belief in the authority of individual rational enquiry. The scale of the change invoked by the advent of modernity allowed no retreat; man was confronted with choices that were of his own making and self-governance replaced the old social context and the vagaries of fortuna.

However, man’s control of society and nature was far from perfect; the dark side of modernity emerged during the following 300 years and included evidence of bureaucratic manipulation of individual creativity and autonomy, the creation of degrading and repetitive forms of labour, environmental degradation, the consolidated use of political

power leading to totalitarian rule, the creation and exercise of industrialized military power and the development of nuclear weaponry. More profoundly, however, modern man was confronted by his own limitations, especially in the scope and reach of reason itself. Giddens (1991: 48) observes:

“Enlightenment thought, and Western culture in general, emerged from a religious context which emphasized teleology and the achievement of God’s grace.”

He continues:

“It is no way surprising that the advocacy of unfettered reason only reshaped the ideas of the providential, rather than displacing it. One type of certainty (divine law) was replaced by another (the certainty of our senses, of empirical observation), and divine providence was replaced by providential progress.” (Giddens 1991: 48)

However, as Giddens continues to argue, the claims of reason were less than absolute:

“Yet the seeds of nihilism were there in Enlightenment thought from the beginning. If the sphere of reason is wholly unfettered, no knowledge can rest upon an unquestioned foundation, because even the most firmly held notions can only be regarded as valid ‘in principle’ or ‘until further notice’.” (Giddens 1991: 48)

The notion of the Sun breaking through the gloom of the Middle Ages was thus moved on in an unexpected way. The assurance and self-belief of the Enlightenment now reflexively gave way to a more searching examination and self-governance had to be pursued without self-assurance. Giddens writes:

“Modernity turns out to be enigmatic at its core, and there seems no way in which this enigma can be ‘overcome’. We are left with questions where once there appeared to be answers, and I shall argue subsequently that it is not only philosophers who realize this. A general awareness of the phenomenon filters into anxieties which press in on everyone”. (Giddens 1991: 49)

Despite this, self-governance and autonomy are Enlightenment ideals whose currency remains unchanged although the limitations to these ideals are emerging more clearly as modernity itself comes to terms with the consequences of the Enlightenment.

Thus, with man’s belief in his own agency being one of the central tenets of the Enlightenment, this thesis will now examine the concept of self-governance before moving on to a consideration of the justifiable limitations to patient autonomy in contemporary South African medical practice. The last chapter addresses the impact of ‘post-modernity’ on the concept of individual autonomy and the possibility that modernity itself has set limits to individual autonomy.

Chapter 2

A conceptual analysis of autonomy

The notion of autonomy

Autonomy is commonly understood as the process of self-governance by means of which man expresses himself; it is his capacity to choose who he is, how he behaves and what he wishes to do. Since the advent of modernity, self-awareness has led man to believe he has a right to make decisions that are his own; this belief in the primacy of individual autonomy has become constitutive of man's being and he now seeks freedom of choice in every aspect of his life: he chooses those with whom he wishes to associate, he chooses the career he wishes to pursue, he chooses the entertainment he seeks, he chooses the beliefs he elects to hold and he chooses the political rulers by whom he wishes to be governed. The exercise of autonomous choice has become the quintessential marker of man's political freedom and respecting the individual's right to freedom of choice is so far beyond question in contemporary western society that individual freedom of choice is usually taken for granted. In medicine, the concept of autonomy is enshrined by the process of informed consent which allows individual patients to choose between different therapeutic options; this freedom to choose is a process sometimes found to be in conflict with the beneficence-based views of medical practitioners who are, nevertheless, obliged to respect patient autonomy in almost all circumstances.

Being free to make choices cannot be an unconditional freedom for any man living a social life. The interests and needs of others have to be weighed against the autonomously-declared desires and actions of the individual. Society proscribes autonomous actions that may harm others and also limits the choices offered to individuals in order to share resources fairly among everyone. In medicine, the need to protect society

from dangerous physical and mental illnesses may lead to interventions exercised against individuals without their consent; one example of such circumstance arises from the need to contain deadly epidemic diseases by means of quarantine measures and public health vaccination policies. Such interventions may lead to perceived infringements of individual autonomy. Another example of how autonomy may be overruled is to be seen in the way attempted suicide is dealt with by most civil institutions.

Autonomy is thus a form of conditional freedom with apparent limits. Individual choice may be exercised in matters of specific material concern where the options exercised contain no inherent moral dilemma. A medical example might be that of a person called upon to decide whether or not to accept a particular course of chemotherapy to treat cancer. The moral content of such decision-making is to be found in the process by which such decisions are made (e.g. the process of obtaining informed consent) and issues of a just distribution of resources within society (e.g. should scarce medical resources be spent on treatment that has limited benefit?).

Individual choice exercised in choosing the principles according to which others are to be treated are moral choices. Autonomy may thus be exercised both in matters of moral choice as well as in matters of personal preference. These types of autonomous choice may be called moral or personal autonomous choices and will be considered separately.

The concept of moral autonomy

Morality evades simple definition beyond that offered by Socrates, namely a process of reflection on how we ought to live². Different ethical theories have provided more or less coherent answers to Socrates' challenge of defining how we ought to live but it was the Enlightenment that led to the

² Plato reports the dialogue between Socrates and Thrasymachus in which he poses the question: "Is the attempt to determine the way of man's life so small a matter in your eyes – to determine how life may be passed by each one of us to the greatest advantage?" The translation cited has been made by Benjamin Jowett and is available online at <http://classics.mit.edu//Plato/republic.html>.

idea of self-awareness and the possibility of individual choice. Since the Enlightenment, the significance of choosing between different options was no longer just a question of either complying or refraining from doing what was expected of you but became a choice of whether to pursue the good of man or not. The philosophical views of the absolute 18th Century man described in the preceding chapter were given expression in the writings of Immanuel Kant (1785: 7)³ who argued that a capacity for conscious choice set man aside from all animals and formed the basis of morality. Because of his capacity for reason, man was able to make choices with an understanding of the likely consequences and could therefore be held accountable for his actions. This has become a minimal conception of morality, shared by several different ethical theories; Rachels (2007: 14) writes that the conscientious moral agent makes the effort to seek guidance for his or her actions based upon the best reasons for pursuing a particular action in preference to others while giving “equal weight to the interests of each individual who will be affected by what one does” (Rachels 2007: 14)

Kant went further in seeking the principle(s) of morality by means of which man could discern what he ought to do. Kant held that morality could never be a matter of relative truth; instead, he argued that moral principles would need to be universally applicable, in the same way that the laws of nature were universally applicable (Kant 1785: 52). By his account therefore, morality is based upon a priori principle(s) that are universally true; man, applying reason to the application of these a priori moral principles, can derive maxims from which he can discern what he ought to do. Having done so, he can then choose whether or not to abide by these maxims. Morality, therefore, is a matter of reasoned choice leading to accountability because man is free to make his own decisions;

³ The translation of Kant's *Groundwork of the Metaphysics of Morals* cited is made by H.J. Patton and published by Routledge. In this translation, the pages have been numbered in various ways, including the numbering assigned to the second edition of Kant's work, which was published in his own lifetime. The page numbers referenced are those of the second edition.

he is self-governing (or autonomous) in respect of the moral choices with which he is faced.

Moral autonomy, as Kant describes it, is presented as unconditional freedom. Self-governance in all other respects of human existence is necessarily constrained by the social character of our lives and it seems paradoxical to claim complete moral freedom. Kant was able to make this claim because the moral principles he sought to define were metaphysical principles, devoid of all empirical particularity. He suggested that the a priori principle of all morality is grounded in the existence of a good will leading to actions that are universally applicable. Kant (1785: 52) argued that this is the moral law, derived from pure reason; furthermore, the dictates of this law are a "categorical imperative" to all rational human beings; these laws are "imperative" because they contain injunctions that ought to be obeyed and "categorical" because they are derived from the unconditional demands of pure reason; in this respect they differ from "hypothetical" imperatives, compliance with which will be necessary only in pursuit of some conditional outcome. To knowingly act on maxims that are inconsistent with the categorical imperative amounts to immorality. Moral man is therefore obliged to consider his actions in the light of the categorical imperative and is free to choose between maxims that endorse or reject this a priori principle (Kant 1785: 88)⁴. "Autos nomos" or self-governance is thus the property of man by means of which he can choose those maxims upon which his conduct will be based; it is the law he makes for himself, arising from his will. Kant concedes that this freedom to choose is only an idea from reason; it is, however, a necessary idea as a presupposition for any being who is conscious of a will (Kant 1785: 100).

Kant's argument that moral agency is an inalienable property of all rational men leads to the development of his notion of human dignity

⁴ See footnote 3 concerning the reference made to Kant's *Groundwork of the Metaphysics of Morals*, translated by H.J. Patton

(Kant 1785: 86). In his capacity for both reason and moral action grounded in autonomous choice, man is unique and therefore, in possession of a certain dignity that sets him apart from all other creatures; respect for human dignity is the basis upon which limits are set concerning the way in which men deal with one another. Kant argues that respect for moral agency and autonomy requires us to treat others in such a way that they would always be an end in themselves and never merely the means to some other end (Kant 1785: 65). From this principle, maxims may be derived that establish the necessary limitations on how other rational human beings may be treated. By Kantian reasoning, similar considerations do not apply to animals.

In summary, moral autonomy, as an Enlightenment concept, therefore concerns how we ought to live, given our awareness of ourselves as moral agents imbued with the freedom to choose between right and wrong. Moral autonomy is unconditional freedom of choice that sets rational man apart from all other animals and which, in itself, commands us to respect all other rational beings.

The exercise of autonomous choice in matters of personal preference may have moral content. How we ought to be informs the choices we make in different ways but broadly compels us to respect the interests and opinions of others. 'Respect for autonomy' as a prima facie principle of medical ethics is an injunction to respect the dignity of other human beings and serves to promote the freedom of others to choose what may happen to them. Personal autonomy, unlike moral autonomy, may be denied, infringed or violated by our own actions as well as by the acts of others. The next section is a conceptual analysis of personal autonomy.

The concept of personal autonomy

Self-governance in pursuit of one's desires and the attainment of individual human projects without the interference of others is the exercise of agency characterised as 'personal autonomy'. Self-governance

in respect of our personal lives has become a foundational freedom upon which the expression of our moral authority rests. This notion has been clearly articulated by Isaiah Berlin (1969: 131) when he wrote:

*I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be an instrument of my own, not other men's, acts of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes that affect me, as it were, from outside. I wish to be somebody, not nobody; a doer – deciding, not being decided for, self-directed and not acted upon by external nature or by other men as if I were a thing, or an animal, or a slave....I wish, above all, to be conscious of myself as a thinking, willing, active being, **bearing responsibility for my choices and able to explain them by references to my own ideas and purposes.***

To be autonomous requires a capacity for rational appreciation as well as the ability to put into effect any decisions that may be made. An absence of controlling influence is therefore necessary if the freedom to make an autonomous choice is to be realized. Both competency and liberty may vary with time and circumstance. Consequently, personal autonomy may be characterised as an ideal form of autonomy or may be measured by degrees in order to determine which decisions are substantially autonomous.

More detailed consideration will be given now to the determination of agency and freedom.

- **The issue of competency and agency**

Being competent implies an ability to carry out a task successfully. In the context of personal autonomy this requires an awareness that a choice

may be made; it also requires some process of rational justification in favour of a particular option and the intentional selection of a specific action.

a. Awareness

Awareness is the degree to which we are conscious of the environment in which we find ourselves. This will vary during the course of a normal human life and is also subject to the effects of disease. In addition, the extent to which a person may be aware of circumstances can be limited by the knowledge they possess, especially specialized knowledge which includes scientific medical knowledge.

The variation in biological awareness applies to babies, very young children as well as those who have any form of intellectual impairment, for example: those who suffer from mental retardation, people suffering from the consequences of cerebrovascular accidents and those whose lives end in a persistent vegetative state. Perceptual impairment is a matter of degree, being profound in some and limited in others. Consequently, awareness varies along with the capacity for making autonomous decisions (Beauchamp and Childress 2001: 58).

Knowledge about the consequences of the choices confronting an individual is also a necessary component of the awareness upon which autonomous decisions will be based. In the practice of medicine, the benefits and risks of medical treatment are not self-evident to most lay people. Hence, disclosure of information by those who provide medical care is an essential element in allowing autonomous choice.

b. Understanding

Knowing that a choice may be made necessitates deliberation over which choice might be best; the rational justification of choice requires reflection upon the circumstances at hand while weighing the options available in terms of their costs, benefits and consequences. A reasoned decision is

one that requires self-examination to determine the acceptability of an action to oneself and others.

Completely unreasoned decisions lead to arbitrary acts that are not an expression of the will of the individual and do not represent autonomous actions.

Although reason has primacy in determining which choices are autonomous, many decisions are based upon a mixture of reason and emotion. Self-governance, in the sense of deciding for oneself, does not require actions to be based upon reason alone in order for those actions to be authentically those of the agent (Christman 2003⁵); however, autonomous actions, brought to judgement, may be more easily justified if they are based upon reason than those based upon pure emotion.

Understanding, in so far as it may reflect rational deliberation, is a measure of the competency of the agent called upon to make a decision. Hence, children given the opportunity to decide upon medical treatment may decline necessary treatment out of fear. Such decisions are not competently made or autonomous because they are unreasoned choices in which fear supplants any process of weighing the benefits of treatment against its costs.

Understanding, as the capacity to make reasoned decisions, is thus set against a continuum that varies from pure rationality through mixed rational and emotional responses to predominantly emotional responses with completely arbitrary actions set at the other extreme. Full understanding may be an ideal infrequently realized but some measure of adequate understanding may be necessary if actions are to be judged as autonomous.

⁵ The article cited is a publication in the Stanford Encyclopaedia of Philosophy; the detailed web address is referenced in the bibliography

c. Intentional choice

The exercise of personal autonomy means making an intentional choice with awareness of the options and after deliberation about the desirability of a particular course of action. Some acts, however, take place without any particular thought; these acts are not deemed to be autonomous actions. Competent adults may, for example, consent to medical intervention without accepting responsibility for making their own decisions, choosing instead to rely on the advice of medical professionals. Interventions commissioned in this way, do not reflect the intentional choice of the patient and cannot be regarded as an expression of the autonomous will of the patient. Those who have diminished cognitive capacity may fail tests of competency at multiple stages including inadequate awareness, inadequate understanding and diminished capacity for making an intentional choice.

- **The issue of liberty**

Making an intentional choice with awareness and understanding does not mean that the choice made was exclusively based upon the free will of the individual. To be personally autonomous means making reasoned decisions voluntarily and without coercion.

a. Volition

Deliberate actions may reflect the will of the individual and nothing else or may be grounded in motivations arising only partly from the will of the individual. Volition may therefore vary and autonomous acts are most clearly defined as acts of self-governance when volition arises solely from the will of the individual.

Knowing what is of us and what is imposed upon us is a judgement not easily made. Higher and lower order desires have been invoked as one

means of determining volition. Dworkins (1988: 16) suggested that higher order desires are used to scrutinize more specific lower order desires that are directed towards particular ends. He writes:

“A person is autonomous if he identifies with his desires, goals, and values, and such identification is not influenced in ways which make the process of identification in some way alien to the individual”.

In other words, higher order desires are those with which the individual can identify and of which the individual can approve; lower order desires need to be consistent with higher order desires if actions arising from lower order desires are to be seen as an authentic expression of an autonomous will. Being certain that higher order desires are truly our own would entail the belief that these desires have not been shaped by circumstance.

b. Controlling influence

Volition may be conditioned by the influence of others in many ways; some find themselves compelled to carry out the wishes of others under duress. Such profound interference with the will of another person is clearly a violation of their right to self-governance and the individual will be aware that they are acting on behalf of others, rather than themselves.

More pervasive forms of influence are common in modern society; the most obvious example is advertising, through which a desire for material goods may be created. The mass media also conditions the psyche and expectations of all who are exposed to it: how we should dress, eat, behave towards one another, communicate with one another, what we should aspire to possess and what counts for success are all shaped and projected through stories and a structured view of life presented by the mass media. This view of life is normative; these expectations are assimilated into the psyche of modern man to the point where it may no longer be clear what volitions arise solely from the will of the individual.

Subliminal influence may deny man the capacity to discern his own desires separately from those that have been induced in him by the influence of others. Hence the desire to possess a pair of designer sunglasses or drink some particular branded cool-drink or the tendency to believe in a particular religious precept may express the volition of the individual subliminally influenced by the social milieu in which he finds himself. Acting on such volition may be an act of self-governance, yet not an entirely authentic action. Ideally, any infringement of authenticity may be regarded as a threat to self-governance and in the extreme, psychological compulsion may violate autonomy as profoundly as any other form of duress.

Man, as a social being, cannot escape communal influence and there is no clear dividing line between influence that perverts autonomy and that which is constitutive of a social existence. Volition is therefore expressed on a continuum from pure free will on the one hand to volition completely controlled by external forces on the other. In between these extremes is volition conditioned by social engagement.

Autonomy is incompatible with controlling influence and the distinction between conditioning influence and controlling influence is the judgement necessary to establish whether individual acts are substantially authentic and autonomous.

- **Ideal and substantial autonomy**

The preceding discussion describes the ideal requirements of autonomous action while indicating that ideal standards are seldom attained.

Conditioning-influence and varying degrees of competence, especially limited understanding, allow personal autonomy to be conceptualized as a continuum with ideal autonomy set at one extreme. Substantial autonomy is a standard that accepts some qualification of ideal autonomy caused by

circumstantial influences and variations in agency. These include the ability to understand complex concepts, such as the choices that may arise between different forms of medical therapy. Agency (reflected in awareness, understanding and rational choice) may also be restricted by age and illness. Beauchamp and Childress (2001: 71) point out the distinction between the *legal* competency required to sustain individual autonomy exercised in the administration of personal affairs and the competency necessary to make choices reflecting *personal autonomy* in other aspects of life. The law makes an all-embracing judgement regarding competency whereas an individual incompetent in civil administration may yet be able to understand and exercise a reasonable choice over other aspects of their lives, including decisions about medical care. Substantial autonomy may also exist among young people before they attain the age of legal consent and the cognitively-impaired may retain the ability to decide issues of medical care despite a legal declaration of incompetence.

The threshold level defining substantial competence is arbitrary. Without defining what that threshold should be, Beauchamp and Childress (2001: 73) suggest that the standard should be based upon certain levels of *incompetence*. These may range from an inability to state a preference, an inability to understand information or an inability to make a reasoned decision.

Conclusion

In conclusion, to be autonomous means having the freedom to give expression to one's own will through the imposition of actions and choices in ways that satisfy one's own volition. Moral autonomy is unconstrained by circumstances other than the rationality and good will of the individual whereas personal autonomy is justifiably restricted by our social contract.

In medical practice, the beneficence of the practitioner has always been assumed; the transformational impact of the European Enlightenment

stimulated an awareness of individual authority which led directly to the notion of self-governance. The authority and beneficence of the doctor was no longer the sole determinant of what was right and acceptable; instead the will of the individual, empowered by the disclosure of relevant information, became the most important moral and legal cornerstone of ethical practice in modern medicine.

The next chapter examines the expression of autonomy in medical practice by examining how informed consent gives expression to the self-governance of individuals. Informed consent is the paradigm example of autonomy in contemporary medical practice.

Chapter 3

Informed consent: the paradigm example of autonomy in bioethics

In bioethics, respect for patient autonomy has become the central tenet of clinical medicine during the last century and is exemplified by the practice of seeking informed consent for medical interventions that carry both a prospect of therapeutic benefit as well as the risk of potential harm. This respect for the right of individuals to make their own decisions in matters that concern them directly did not always exist; the first articulation of this right is found in the judgement rendered by Justice Benjamin Cardozo in the case of *Schloendorff v. Society of New York Hospital* in 1914. In this case, a surgeon removed a tumour without the consent of the patient who had agreed only to an examination under ether. Cardozo's judgment contained the following stipulation:

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.”

The need for informed consent was next clearly articulated in the mid-20th century as a reaction to the human experimentation that took place in Nazi concentration camps (The Nuremberg Code of 1947⁶). Beauchamp and Childress (2001: 77) have pointed out that in the last 50 years the grounds for seeking consent have shifted: the focus of informed consent

⁶ Details in Mitscherlich and Mielke, 1949

has moved away from the prevention of harm to the need for showing respect for the autonomy of individuals. The protection of autonomy rights of research subjects are now enshrined in the Declaration of Helsinki published by the World Medical Association.

The process of seeking informed consent contains elements that draw on each and every aspect described in the conceptual analysis of autonomy, together with additional contextual aspects. Beauchamp and Childress (2001: 80) have described three broad components that are constitutive of the consent process; these include threshold elements (issues of competency), information elements (disclosure of essential information) and consent elements (the process of authorization). Each of these elements will now be described in more detail by way of exemplifying the principle of autonomy in bioethical practice.

- **Threshold elements**

Competency and agency are required of the patient before the process of securing informed consent can commence. Discrimination between those who are and those who are not competent is important because it identifies those from whom informed consent ought to be elicited.

- a. Competency**

Both awareness and understanding are necessary criteria in the establishment of competency. In biomedical practice, variations in cognitive capacity are common and the preceding discussion about impaired agency and the establishment of threshold levels of incompetence all apply. Questions about competency also arise, however, when cognitively-normal patients make decisions that do not seem to be in their own best interest. One of the most frequently cited examples of this is that of Jehovah's witnesses who refuse blood transfusion even at the potential cost of their own lives. That patient's views differ from those

of attending clinicians should not, however, be sufficient reason to call their judgement and competency into question; medical information must be assimilated into the context of an individual's life because his or her material, psychological and social existence nuance disclosed information in a way that is unique for each and every individual human being. In this way the narrative unity of individual lives is unique and inseparable from the capacity for making autonomous choices, even when those choices appear to be irrational and hence incompetently made (MacIntyre 1985: 208).

b. Understanding

Beauchamp and Childress (2001: 88) have defined adequate understanding as the acquisition of pertinent knowledge leading to relevant beliefs. While legal standards of consent focus on aspects of disclosure, understanding the implications of a situation or proposed therapy is essential to the expression of the autonomous will of the individual.

The promotion of understanding is partly determined by the way in which information is sometimes, inadvertently, disclosed; for example, the disclosure of risk may be couched in terms that reflect the risk of dying or the probability of survival. Choosing to disclose the same risk in different terms may bias the understanding of patients in ways that militate against the autonomous choice of individual patients. Understanding may also be impaired by the use of technical language or the disclosure of an overwhelming amount of detailed information. Rational deliberation may not be possible under such circumstances.

Understanding needs to lead to rational beliefs if autonomous decisions consistent with informed consent are to be made. The caveat that some beliefs are grounded in a unique view of life (the Jehovah's witness example) must be considered before regarding the views of some as irrational.

c. Voluntariness

This aspect of informed consent may be seen to encompass the issue of both volition and controlling influence. Beauchamp and Childress (2001: 93) have defined voluntariness as the capacity of the agent to will an action without being under the control of another's influence. They draw a distinction between influences and controlling influences; in the former category are acts of love and education while the latter group contains threats, lies, emotional appeals and direct manipulation. These may be further categorized into coercive influences involving threats of harm or the use of force that "displaces a person's self-directedness"; persuasive influences arising from reasoned (but not emotional) argument should be distinguished from manipulative influences which is the process of swaying people into doing what the manipulator wants by means other than coercive or persuasive techniques. In medicine, informational manipulation is held to be the key form of manipulation and is incompatible with autonomous action.

Beauchamp and Childress (2001: 94) acknowledge the prevalence of influence in everyone's lives and caution against over-calling the influence of manipulative intervention, especially when it fails to imperil autonomous choice. The need to present reasoned arguments in favour of medically essential treatment is necessary and cannot be seen as manipulative treatment. They argue that even threatening coercion and direct manipulation may be necessary sometimes (e.g. in dealing with an unruly patient), although they express greater concern over manipulation arising from the promise of rewards. The rewards may take the form of free care or financial assistance of various kinds, all of which may be irresistible to impoverished subjects. Such people fall under the controlling influence of the person making the offer.

- **Information elements: disclosure and intentional non-disclosure**

Awareness and understanding as components of competent decision-making in the practice of medicine are usually dependent on the disclosure of information by medical practitioners. The way in which information is disclosed, how much is disclosed together with the obligation to ensure that the disclosed information is understood are all relevant to the process of informed consent and autonomous decision-making.

- a. Standards of disclosure**

In biomedical practice, complete understanding of all the circumstances pertaining to a particular diagnosis and specific forms of treatment is unlikely and usually impossible. Autonomous decision-making is, however, dependent upon access to sufficient information, including the opinions of the attending physician; Beauchamp and Childress (2001:81) suggest that the physician should incorporate information deemed to be medically relevant as well as a professional recommendation regarding intervention among the other facts disclosed to the patient.

The amount of information necessary may be judged according to several standards. A reasonable doctor standard of disclosure presupposes that what ought to be disclosed is best judged by the medical profession itself. The reasonable person standard is a hypothetical construct of what a reasonable person would wish to know about a given situation. Both these standards are impractical with the latter being indefinable while the professional standard of disclosure is non-existent as well. A subjective standard has also been suggested based upon the individual needs of specific patients; this too is poorly defined although, as Beauchamp and Childress (2001: 83) point out, is morally defensible because it gives recognition to the unique requirements of the individual.

Disclosure is therefore required, albeit the extent of that disclosure remains undefined. On occasions, however, physicians have deemed it necessary to withhold information from patients in their own best interests. This is an example of paternalistic behaviour.

b. Non-disclosure and medical research

The extent to which paternalistic behaviour may be justified in the provision of health care will be addressed in the subsequent chapter. Non-disclosure of information may be touted as necessary if such information, given to the patient, results in anxiety or irrational decisions. Such interference in the process of autonomous decision-making has been condemned by the American judiciary and is morally indefensible because it unjustifiably denies the dignity and agency of the individual.

Beauchamp and Childress (2001: 84) conclude that non-disclosure would only be morally defensible if the information provided was likely to render the patient incompetent.

Other examples of non-disclosure may be seen in the therapeutic use of placebo drugs and in the pursuit of research studies. In the case of placebo drugs, manipulation of the patient's understanding about how they are being treated is implicit to the use of such "therapeutic" agents. Justification for the use of placebo can only be sought in an appeal to paternalistic beneficence. This is, however, unlikely to justify the denial of patient's autonomy rights.

Non-disclosure in pursuit of medical research also cannot be morally defended where manipulation is pursued by the researchers. Beauchamp and Childress (2001: 88) argue an exception to this rule in the case of behavioural and physiological psychology research providing that participants in research programmes have knowledge of and agree to deception as part of the study.

Non-disclosure is thus morally largely indefensible.

- **Consent elements**

Giving consent requires the exercise of agency. The expression of agency may be mediated by the patient himself or by means of deferred or delegated authority. The manner in which consent is granted by way of expressing a preference for a particular option is defined both by the law as well as by the moral considerations arising from the preceding discussion concerning the exercise of autonomous choice.

- a. Authorization and legal standards**

The legal stipulations concerning informed consent incorporate tests of competency, elements of disclosure and finally witnessed documentation of assent. The law addresses competency in the context of age with children requiring the assent of a guardian; in other respects, those with cognitive impairment who are deemed incompetent in civil administration are seen as globally incompetent in the eyes of the law and need to rely on surrogate decision-makers.

Standards of disclosure have evolved by means of a series of court rulings and case law that established firstly the professional standard which has been supplanted by the reasonable person standard. As a result of these rulings, guidelines have been constructed suggesting that essential elements of disclosure should include information about the nature of a proposed procedure, the alternatives to the proposal as well as the risks and benefits of the procedure.

Assent is usually granted in writing although verbal agreement suffices for some interventions such as blood transfusion. In this process, the law places greater emphasis on issues of disclosure and the formalities of witnessed consent than on understanding and voluntariness, each of which are morally important to the process of informed consent. That which satisfies legal requirements may not amount to informed consent.

b. Authorization and moral requirements

The moral requirements of informed consent with respect to competency, understanding and volition following adequate disclosure end with the assent or refusal of treatment by the patient. The moral standard of consent differs from the legal standard by placing greater emphasis on understanding and voluntariness; it also allows greater freedom in the assessment of competency including the competency of minor children, whose capacity for autonomy may go unrecognized by the law.

c. Deferred and delegated autonomy

“Delegated” autonomy is invoked when choices must be made on behalf of someone who is incompetent. Delegated autonomy may be exercised by a surrogate decision-maker or may be dependent on an advance directive issued by the person concerned while they were still competent.

Surrogate decision makers may be a family member, a physician, a hospital administration or a court of law. Whoever is called upon to exercise surrogate authority may do so by invoking different criteria. Beauchamp and Childress (2001: 99) describe three standards of decision-making that surrogates may apply: the patient’s best interest, pure autonomy and substituted judgement. They describe the substituted judgment standard as one that requires the surrogate to “don the mental mantle of the incompetent” in order to arrive at a decision; to do this, it presupposes a deep understanding between the surrogate and the subject and also assumes that the subject was once competent. The pure autonomy standard is based upon the previously expressed opinions of the once competent will of the subject; this amounts to an informal type of advance directive, which may lead to dispute among care-givers. The best-interest standard requires the surrogate to determine the option with the highest net benefit by assigning weightings to the interests the patient was known to have in each option; this amounts to a quality-of-life evaluation. Beauchamp and Childress (2001: 103) express the opinion

that the process of surrogate decision making is now preferentially addressed through autonomously executed advance directives or by means of substituted judgement with the best-interest standard reserved for situations where neither of the two preceding options can be exercised. In reaching this conclusion they have prioritised in descending order those decision-making exercises that are most likely to give expression to the previously autonomous will of the individual.

Conclusion

Informed consent is the expression of individual choice. Its pre-eminence in all of medical practice is a very visible rejection of paternalism based upon the beneficence of the medical practitioner. What the individual wills for him or herself is held to be that to which the individual is entitled. Yet the sovereignty of the individual is limited not only by the limitations of his or her own agency but also by the claims of others in his or her community. Autonomy is restricted in order to sustain the justifiable interests of others. The next chapter considers the ways in which personal autonomy may be limited.

Chapter 4

The scope of autonomy

I have argued that self-awareness as an Enlightenment ideal fostered our sense of self-governance. The idea that rational man has unrestricted freedom to choose between right and wrong is the basis of his moral autonomy and cannot be infringed by others. Furthermore, as Berlin has argued, self-governance in respect of our personal lives is a foundational freedom upon which the expression of our moral authority rests.

However, there are many ways in which our personal autonomy may be restricted. Most obviously we may deprive others of their right to autonomous decision-making by directly interfering in their lives or by manipulating their desires; this may be an exercise conducted in pursuit of our own self-interest, for which there is generally no moral defence; it may be, however, that we judge our interventions to be in the best interests of others: either in the sense of promoting their welfare or preventing them from coming to harm. In the latter circumstance, the exercise of beneficence and non-maleficence may overrule personal autonomy although it would require justification before being considered morally acceptable; Hence, our social lives compel us to consider whether the exercise of our personal sovereignty may not adversely affect the legitimate interests of others within our community, for in pursuing our interests, we are also morally obliged to respect the will of others in the same way as we ourselves wish to be respected.

Furthermore, the benefits of a shared social existence need to be distributed fairly within a community, even if doing so frustrates the autonomously-formed aspirations of some individuals.

Finally, we also need to consider the primacy of our interests when set against the interests of the community as a whole.

I will consider each of these restrictions to the scope of personal autonomy in more detail with specific reference to biomedical aspects.

Refraining from harming others

In exercising our right to autonomous action we are clearly free to pursue our own interests and beliefs only in so far as the consequences of our acts may have an effect on ourselves and no-one else. When the expression of our agency has an influence on others, the possibility of either fostering or harming their interests exists. Whether we can justify either of these effects as a consequence of expressing our own autonomy requires deliberation.

a. The practice of avoiding harm: non-maleficence

To harm someone implies that their interests have been violated. In general, this may encompass the infliction of physical or psychological pain, physical harm, psychological duress, loss of liberty, loss of privacy, loss of reputation, loss of property or loss of life.

In bioethics, the major forms of harm are those of death, disability and pain. These setbacks to the interests of the individual concerned are at first glance harmful and a *prima facie obligation to prevent the imposition of this harm would be seemingly justified*.

This argument, however, cannot be sustained where the autonomously-expressed free will of the individual embraces a life-style that gives rise to the risk of injury and illness; an example is that of cigarette-smoking, now clearly linked to chronic lung disease as well as a heightened risk of both premature pulmonary and cardiovascular mortality. May a physician

(or the state) intervene in the lives of others in order to prevent harm and promote the interests of the individual against their wishes?

The answer to this question is especially pertinent to bioethics because there is an asymmetrical power relationship between physicians and their patients as well as a presumption that power will be exercised beneficently (implying that beneficence is its own justification). In practice, the licence to intervene in the lives of others based upon beneficence has sometimes been seen to lead to the harmful imposition of risk and injury.

Two separate questions are thus presented: is it permissible to overrule the autonomy of individuals in order to *prevent* them from coming to harm and secondly, is it permissible to pursue the welfare of others against their wishes, especially where this may also *result* in some degree of harm. The answer to both these questions must take account of the primacy of personal autonomy.

Beauchamp and Childress (2001: 115) have considered the possibility of harm accruing to the interests of individuals in specific circumstances where the intentions and acts of the physician are potentially set against the interests of the patient. The first example they cite is that of withholding or withdrawing life-sustaining treatment from critically-ill patients. On the surface of things, allowing someone to die without treatment would not seem to be in the interests of the person concerned. Providing or withholding treatment ordinarily requires informed consent, either of the person concerned or, in the case of an incompetent patient, the consent of surrogates to whom such responsibility had been delegated. However, physicians may decide that treatment of a dying person is futile in the face of a poor prognosis and commonly decide to withhold life-sustaining interventions. In doing so, neither withholding nor withdrawing treatment would be held blameworthy and of the two, withdrawing treatment may be more defensible simply because it is

usually associated with greater certainty concerning the diagnosis and prognosis of the underlying condition. This opinion (to withhold life-sustaining treatment) may be held against the wishes of the individual or their family articulated by means of advance directives or the opinions of surrogates. Overruling these views by withholding treatment, where ongoing treatment had been requested, would need to be justified - and often is - on the basis of scarce resources and an appeal to justice in the distribution of goods available for the provision of medical care in the community as a whole. But, aside from this justification, the autonomous wishes of the patient or his or her surrogates would need to be respected and even futile treatment may not be withheld without informed consent.

Given that the justification for withholding care against the autonomously-expressed wishes of the patient is legitimately made only on the grounds that there are inadequate resources to provide care, the question arises whether less resource-intensive interventions are justified even if more heroic and expensive measures are not. Beauchamp and Childress (2001: 126) are of the opinion that withholding routine care, including artificial nutrition, is no different to withholding extraordinary care. They argue that such distinctions are morally irrelevant, stating that where treatment is futile, any consideration about the type of treatment provided or withheld should be based solely upon whether the treatment is likely to be burdensome or beneficial, using quality of life criteria.

This argument is not persuasive given that the legitimate grounds for withholding care are solely based upon resource distribution. Hence the provision of simple routine care including artificial nutrition would be justified, if requested.

Beauchamp and Childress (2001: 136) go on to extend their line of discussion about optional or obligatory treatment based upon quality-of-life criteria. Treatment, they argue, is optional if the burdens outweigh the benefits of intervention. Not only the terminally ill, but anyone seeking

medical care may choose to reject treatment regarded as burdensome. Neonatal care, for example, may have the capacity to secure survival of very small newly-born children, but does so with the attendant risk of severe morbidity, especially neurological damage. Treatment may be justifiably withheld in these circumstances, based upon the avoidance of harm; nevertheless, value judgements about quality of life necessitate informed consent by the patient or surrogates.

The decision to withhold or withdraw treatment must thus be based upon the wishes of the patient and may be limited by those value-judgements of physicians to which the patient assents; the autonomous wishes of the patient may also be legitimately limited by the availability of resources, which will be discussed further when considering issues of justice.

The issue of inadvertent but unavoidable harm is no less constrained by the need for informed consent. Some interventions have double effects that are simultaneously beneficial and harmful. The classical example of such an intervention may be the preterm delivery of a child in order to save the life of a pregnant woman. Beauchamp and Childress (2001: 129) describe criteria that would justify this type of harm; these criteria include a preponderance of good over bad effects, that the good effect isn't realized by virtue of inducing harm and that the intentions of the physician should be good. *However, none of these criteria supplant or supersede the need for informed consent:* to risk harming the child in order to save the life of a pregnant woman still requires the consent of the mother who is also the surrogate decision-maker acting on behalf of her child. Justification of the harm that accrues on the basis of beneficence towards the pregnant woman does not vitiate the need for consent nor does it deny the need to respect the autonomy of those concerned or the surrogate expression of autonomy by those who may act on their behalf.

The primacy of autonomy is further reflected in considerations pertaining to physician-assisted suicide. The definition of killing offered by Beauchamp and Childress (2001: 140) is the death of a human being, brought about intentionally by the actions of another; such actions include acts of commission and omission. In terms of this definition, there is no moral distinction between killing and allowing to die. An intentionally-arranged death in the form of physician-assisted suicide is one such example of killing⁷. Beauchamp and Childress (2001: 144) reflect on the anomalous position in most societies where medical practitioners are required morally and legally to respect the autonomously-expressed desire of a patient to refuse life-sustaining treatment, while the autonomously-expressed will of the patient to end their own life enjoys neither legal nor moral respect. They hold that the request of a competent person freely requesting to die, based upon net personal benefit, should not be seen as a setback to his or her interests and to act in respect of such wishes involves no moral harm. Failing to act on such wishes may indeed lead to harm by denying the autonomy of the individual and possibly prolonging existence that is of no value to the person concerned. This anomalous position is defended by social concern about the possibility of slippery-slope escalation that may see the premature deaths of individuals being organized and justified for increasingly less acceptable reasons; the need to hold those engaged in physician-assisted suicide accountable would weigh heavily in the social acceptance of such measures and in most countries the autonomy of individuals is denied in favour of socially-determined policies that prohibit physician-assisted suicide despite moral justification. However, communitarian perspectives have their own moral standing and this infringement of individual autonomy may be justified by these considerations which will be discussed later.

⁷ Rachels (2003: 91) describes the case of Mathew Donnelly who was killed by his sibling in order to alleviate the severe and unremitting pain he was destined to endure for the last year of his life. Rachels outlines the moral argument justifying this type of mercy killing, referring to utilitarian theory.

In conclusion: *the prevention of harm* which others choose to inflict on themselves remains a matter of ensuring that such harm is intentional and rational in the way that informed consent would be sought for any other potentially beneficial or harmful intervention; once an autonomous decision is made, there are no moral grounds for infringing the autonomy of the individual other than social concerns, such as those alluded to in respect of physician-assisted suicide.

Inflicting harm on others during the provision of medical care, either deliberately or inadvertently is morally justified in some circumstances but always requires the consent of the patient or surrogates acting on their behalf. Where that consent is withheld, harm may be inflicted justifiably (and with traces of moral regret), only as a matter of justice where equitable distribution of social goods precludes specific interventions.

Autonomy of the individual is thus preserved and respected in all circumstances save those superseded by the needs of distributive justice or communitarian-based morality.

b. The practice of promoting the interests of others: beneficence

Beneficence is the positive promotion of the welfare of others. Non-maleficence is viewed as refraining from harming others whereas deeds that prevent and remove harm may be seen as good acts performed in favour of other people and are commonly grouped with other positive acts as examples of beneficence. Medicine, since antiquity, has been viewed as a beneficent profession and the presumption of beneficence persists as the dominant *prima facie* principle of medical care. Beneficence is also the underpinning philosophy of utilitarian theory that seeks the greatest balance of welfare or happiness among people as the single principle from which right or wrong may be adduced.

Adherence to the principle of beneficence may supersede the preferences of individuals; this is often justifiably the case where parents intervene in the lives of their children. To intentionally override a person's known preferences or actions with the goal of benefitting or avoiding harm to the person whose preferences or actions are overridden is both beneficent and an example of strong paternalism. To apply paternalistic, beneficent intervention in the life of an autonomous adult would violate that person's autonomy. Neither individuals nor state institutions can morally justify such infringements of autonomy; John Stuart Mill (1859 / 2006: 16) argued that the happiness of individuals depended substantially on their freedom from external authority⁸. He claimed that the entire extent of legitimate authority exercised by the state was confined to preventing individuals from harming one another and that the state had no licence to intervene in the lives of individuals in a paternalistic way. In 'On Liberty' he famously rejected any interference in the lives of individuals, even in the form of institutionalised beneficence when he wrote:

'The only purpose for which power can be rightfully exercised over any member of a civilized community against his will, is to prevent harm to others'. (Mill 1859 / 2006: 16)

Paternalism is, however, encountered in medical practice, being seen in the provision of public health measures as well as in the management of individual patients. In public health, many instances of protection that seem paternalistic (such as vaccination policies) may be justified on non-paternalistic grounds, specifically, the protection of third parties; here, communitarian values rather than beneficence trump individual autonomy. In the case of individual patients, paternalistic intervention is commonly seen in cases of attempted suicide. Social institutions such as the police, emergency services, religious organizations and citizens in general all seek to intervene in the prevention of suicide. Although

⁸ The compilation of works by John Stuart Mill cited is the Penguin Classics publication edited by Alan Ryan.

decriminalized it provides grounds for involuntary hospitalization in many countries, including South Africa. Yet the prevention of attempted suicide may frustrate the autonomous will of the individual. In their analysis of suicide, Beauchamp and Childress (2001: 189) refer to John Stuart Mill and conclude that based upon autonomy-rights, John Stuart Mill has not endorsed intervention, being prepared only to concede that a strategy of temporary intervention be found acceptable as a way of ensuring that the individual decision made was informed and truly autonomous. Despite the moral grounds for allowing suicide, the law continues to support involuntary hospitalization. This anomalous situation is rooted in communitarian adherence to symbolic acts that express concern for the welfare of individuals and the belief that most who attempt suicide are indeed, mentally ill. In this respect, as it has been the case throughout this discussion, autonomy is overruled not by beneficence itself but by communitarian perspectives.

Sharing social goods: the issue of justice

In the preceding discussion, autonomy has been overruled justifiably by the interests of others; in following our own desires we may suffer setbacks to our interests when the goods needed to execute our life-plans are denied because of opposing claims. In medicine, resource distribution has become of critical importance as the cost of technology escalates to the point where all the care that is available cannot be given to everyone who might benefit from it. Furthermore, access to medical care is increasingly regarded as a human right serviced by individual governments whose remit it is to provide the essential needs of the community. This dichotomy between the right to health care and limited resources is resolved broadly by the notion that the right of access to health care should be limited to a bare-minimum standard of care for all and that care over and beyond this limit should be available to those who

can afford it. Within this framework, a fair distribution of what is available must be elaborated because the autonomous wishes of some individuals will necessarily be denied by such a system.

a. Creating a fair distribution: theories of justice

Different views of justice have been derived from different moral theories; each of these theories of justice has implications for individual members of the society trying to secure their own welfare.

Utilitarian theory is usually invoked in the design of public health policy. Utilitarians adhere to one principle only: that of maximized welfare. In pursuit of this goal, no other considerations are pertinent and individual rights provide no obstacle to the exercise of distributive justice which is seen as a policy leading to maximum overall utility. In the context of this theory the autonomous will of the individual is revoked without any moral remorse should the overall calculus of interest find it necessary to do so.

Libertarians see justice achieved through the conservation of property and liberty rights. Just procedures are more important than the actual distribution of social goods (including health) and the pursuit of health is a matter of individual initiative conducted under fair circumstances. Libertarians make no appeal to fairness in the distribution of social goods and the autonomous will of the individual seeking social goods may be denied on the basis that health care is a matter of personal endeavor rather than a responsibility of government.

Egalitarians believe that everyone in a society should have an equal share of certain goods, including health care. John Rawls' theory of justice incorporates a 'fair opportunity' rule stating that no person should receive social benefits on the basis of undeserved advantageous properties and no person should be denied social benefits on the basis of undeserved

disadvantageous properties (Beauchamp 1991: 367⁹). The application of this rule to existing biological and social inequities justifies the distribution of any inequalities that do exist in favor of those who are least benefitted. In medical care, the fair opportunity principle has been invoked by Norman Daniels (2004: 75) as follows:

“Since maintaining normal functioning makes a limited but significant contribution to protecting the range of opportunities open to individuals, it is plausible to see the principle guaranteeing fair equality of opportunity as the appropriate principle to govern the distribution of health care, broadly construed to include primary and secondary preventive health as well as medical services.”

Beauchamp and Childress (2001: 234) also refer to fair opportunity in their discussion concerning the principle of justice:

“...social institutions affecting health care distribution should be arranged to allow each person to achieve a fair share of the normal range of opportunities in that society”

This implies that those suffering from disease or disability do not enjoy equal and fair opportunity in the pursuit of social goods; health care (inter alia) becomes a right sustained in the interest of building a fair and just distribution of social goods by allowing all members of a society fair opportunity of participation. This theory of justice protects the capacity of all members of a society to pursue and exercise their autonomous desire for medical care. It takes account of the burdens and benefits attributable to natural social and biological inequities (the lotteries of life) and seeks redress for those inequities in a way that is fair. While this theory also recognizes health care as a right, it does not deny the possibility that

⁹ Rawls' book *A Theory of Justice* was published by Harvard University Press in 1971. The citation provided here refers to extracts from this text, reprinted in Beauchamp's book *Philosophical Ethics* published in 1991.

limited resources can frustrate the will of the individual although the burden of dealing with such economic limitations in the provision of health care is seen to be fairly distributed.

Even if health care is recognized as a right and egalitarian precepts are used as the basis upon which health care is structured, the manner in which scarce resources are to be distributed remains at issue.

b. Distributing scarce resources: rationing

Macroeconomic decisions are made by governments in respect of social service delivery. These political decisions determine the extent of the funding available for the provision of health care. The way in which this budget is distributed is also a political decision that may project an emphasis on preventative or curative services. Regardless of how these macroeconomic decisions are made, insufficient resources will be available to service all the possibilities of modern technological medicine and some individuals will be denied access to treatment, including life-sustaining treatment. Rationing what is available may be achieved by restricting expensive treatment programs, by establishing attainable bare minimum standards of care and by choosing to restrict the availability of care to certain segments of the population, such as the aged.

Expensive programs such as transplantation services may not be affordable and such interventions may be legitimately rationed by societies who make such decisions democratically, even if they are viewed as being discriminatory. Establishing a bare minimum of care may be difficult: Beauchamp and Childress (2001: 257) have documented the difficulties encountered by the state of Oregon when implementing this approach. The use of cost-effectiveness and quality-adjusted life-years as indices against which different interventions could be ranked in order of priority resulted in discrimination against the young and elderly as well as arbitrary nonsensical rankings. Rationing on the basis of age is discriminatory but more defensibly so than discrimination based on

gender or race; the most powerful argument made in favor of such rationing is that of prudential rationalization of health costs; by this account, the amount of money spent on any single individual is deemed to be the same and most would choose to endorse the expenditure of this income to secure a normal lifespan ahead of expenditure designed to guarantee an extended lifespan. By this reasoning, the available health expenditure should be biased in favor of providing services to the young. Notwithstanding this type of reasoning and other views supporting discrimination based upon the "fair innings" concept, Beauchamp and Childress (2001: 262) reject the notion of age-discrimination and hold that age-based decisions would be viewed as unjust in many countries.

Rationing available care is therefore unavoidable and no clearly accepted way of doing so exists at present. What is clear is that available resources should be used most beneficially and only treatments known to be effective should be utilized; that whatever rationing takes place should be socially-endorsed and that morally, it is problematic to discriminate between individuals (such as the aged) based upon the social worth of their lives. Beauchamp and Childress (2001: 268) conclude that queuing, using a lottery or randomization may be the only fair ways of allocating scarce resources with the first-mentioned being the most acceptable.

In conclusion, the demands of justice are that each person be treated fairly, including having access to health care. The way in which the wealth of society is disbursed will determine its capacity for health care and individuals may find themselves denied access to care because of social conventions. Although the processes by which such decisions are reached are varied (and subject to their own justification), the fact of rationing is inescapable.

Rationing constitutes a broadly-justified limitation to the interests and autonomously-exercised free will of the individual.

Individual interests versus community values: communitarianism

The freedom to be oneself and the awareness of being oneself is the product of Enlightenment philosophy fostered in rejection of all externally-imposed forms of authority, especially the church and autocratic political systems. To be autonomous became more important than being part of a socially-coherent community to whose beliefs and expectations one could be bound. This commitment to the sovereignty of the individual has been confronted with insistent social realities that give rise to questions about the limits to which any individual may pursue their own self-interest ahead of the community in which they live; these social realities are those of environmental degradation associated with global warming, the population explosion that threatens the sustainability of resources and increasingly vast disparities in both wealth and power within communities. The individual is confronted by his or her dependence on the society in which he or she lives and is forced to consider his or her obligation to sustain that society, if for no other reason than to secure their own survival. This curtailment of the interests of the individual in favor of what might be best for society as a whole is a paradigm shift away from the supremacy of the autonomous being. Communitarian philosophy emphasizes the social roles, traditions and virtues necessary to play a role in the life of a community. The importance of man co-existing with man is further elucidated by theories of relational ethics and in the South African context the concept of Ubuntu articulates our inter-relatedness and responsibility for one another. Each of these philosophies presents a challenge to the autonomy of the individual and will be described individually.

a. Communitarian philosophy

Communitarianism has been articulated by several philosophers including Charles Taylor, Daniel Callahan and Alasdair MacIntyre. MacIntyre (1985: 121) draws on the structure of ancient Greek society to illustrate a view

of man in which he is a member of a community rather than an individual within that society. In ancient Greece, men lived in city-states (the polis) that assigned to each individual a clearly defined social role. Within these roles the issue of the good of man became a judgement measured against his or her success in attaining a designated social destiny. Virtues were required and actively taught in order to be successful in a particular role. The concept of the dignity of individual men did not exist among the ancient Greeks and the exercise of moral judgement became a question of virtuous conduct within designated social roles (together with adherence to the laws of the polis). Man was not required to choose that which was right: instead, what was required of him was defined by his social role and the only possibility he could exercise was that of failing to do the right thing by not fulfilling his designated social role. Within these communities, the concept of individual human rights did not exist and practices now unacceptable in any modern liberal-individualist philosophy were tolerated without question: in particular, the subjugation of slaves and women. Aristotle also held the view that the exercise of moral judgement required intelligence, education and a political structure within which to exercise social skills; those who lacked these attributes were excluded from participation in the moral community of the polis through no fault of their own (MacIntyre 1985: 158).

Despite these shortcomings evident in pre-modern society and faced with the consequences of modernity, several philosophers have advocated a return to communitarian ideals. MacIntyre (1985: 259), among others, has rejected the tenets of liberal individualism; his views draw a sharp distinction between the 'self' of modernity (radically free individuals who are answerable to themselves before all else) and the pre-modern 'self' who lacked self-consciousness and whose measure of the good life was bound to the social role he occupied and through which he reached his telos - a conception of man allowing little room for individual autonomy

with the interests of the community exercising precedence over individual aspirations (MacIntyre 1985: 259).

Daniel Callahan (2003: 289) has also targeted the role that autonomy plays in liberal societies arguing that being free to choose is not enough. He reasons that autonomy:

“...as a moral principle ought to encompass not simply our right to make our own choices whenever possible, but also lead us to take seriously the ethical implications of the different choices open to us, whether in our public or private lives. Serious ethics, the kind that causes trouble to comfortable lives, wants to know what counts as a good choice and what counts as a bad choice.”

Callahan (2003: 288) sees autonomy playing a dominant role in modern ethical reasoning, especially in the principlist approach endorsed by Beauchamp and Childress. He observes that this approach is inherently individualistic and emphasizes autonomy; he observes that even the other principles that may conflict with one another are themselves to some extent derivative aspects of autonomy and where conflict occurs, the important conflict is always a contest between autonomy and one of the other principles. Non-maleficence he believes may be seen as a historical variant of autonomy; beneficence is eschewed by modern liberals because it requires some conception of what may be good for someone else, thus impeding their right to autonomy. Callahan (2003: 288) observes that

“...only religious believers are willing to take beneficence seriously”.

Even justice, he suggests, involves allocating resources in an equitable manner so that others can function as autonomous persons (Callahan 2003: 288). Callahan's views suggest that there is little real moral opposition to the dominance of autonomy within principlist discourse with the communitarian challenge bringing a new perspective on autonomy

and doing the right thing; specifically, benefitting the community becomes a responsibility that challenges the individual's right to do as he will. Being self-aware is no longer enough; an awareness of the needs of others is required and the sensitivity to

"....understand the embedded quality of our lives....to take the measure of the culture of which we are a part" (Callahan 2003: 288)

The application of communitarian thought to the practice of medicine would place limitations on the autonomy of the individual both in the field of public medicine and in the care of individual patients. In public medicine, the aspects of justice used to secure a fair distribution of medical resources would be defended on the basis of fostering the life of the community. Rationing care would more easily accept restrictions on the care provided to the aged by acknowledging the narrative unity of individual lives; lives that are seen to have been lived in fulfilment of a given telos. Callahan (1990, cited in Beauchamp and Childress 2001: 261) has argued that while medical care should be provided to all, society should help the elderly by relieving their suffering rather than by seeking to extend their lives; this would be justifiable simply because once life's possibilities have been "on the whole achieved", death becomes a relatively acceptable event. This view resonates broadly with that of other communitarians: MacIntyre (1985:218) also deduces that judgements made about individuals need to incorporate some measure of the narrative unity inherent in their lives.

In the medical care of individual patients, the practices of antiquity were founded on beneficence and paternalism; in modernity, beneficence came to be seen as paternalistic, yet paradoxically, it retains some acceptance (although always set against individual autonomy). The autonomous agent now seeks control over his or her own care and in doing so, has changed the role of the physician. Some have suggested that the role of the physician is radically reduced to "...that of mere ancillary or servant to

the patient” (Charlesworth 1996: 6). Daniel Callahan (1988: 60) has added his perspective, saying the following:

“If we want to have good doctor-patient relationships, we can’t reduce that relationship exclusively to the language of rights, particularly the language of patient rights. A consequence is to jeopardise the doctor’s important role as a moral agent. At one extreme the doctor is turned into nothing but a plumber. The challenge is to recognise that when doctors and patients enter into a relationship they begin to create a community, or at least a profound relationship which the language of rights does not adequately describe. In one sense each has to help the other. The doctor has to educate the patient, help the patient understand what might serve his or her welfare. And the patient has to find a way to tell the physician what he or she is trying to live for. It ought to be a richer language than is captured in the language of autonomy and rights.”

Paradoxically, this rejection of radical patient autonomy also serves to underline autonomy as a central feature of the doctor-patient relationship by delineating the autonomy of both the patient and the physician.

In conclusion, communitarian philosophy restricts the scope of personal autonomy by making beneficent contributions to society a prerequisite for moral agency. In medicine, the focus shifts from respecting the wishes of the patient to determining which needs of individuals may be accommodated by society as well as what demands society may make of individuals.

b. Relational ethics and Ubuntu

Not only does a sense of community call us to account for decisions we make but our relations with other individuals do so too. The idea that human beings have intrinsic worth governing the way they may be deliberately treated by others is the familiar essence of all moral argument. Emmanuel Levinas has observed that we are called to moral accountability by our inter-relatedness with one another (Bergo 2008¹⁰). He argues that inter-relatedness is inescapably part of us; we are drawn to social interaction by the presence of others in a precognitive and affective way. Because of this, we are faced with recognising the primacy of human relations; this is a different conception of man to the self-aware and self-governing man who emerged from modernity. Levinas suggests we need to recognise the importance of being inter-related and to accept responsibility for our own actions and the respect we owe to others, regardless of whether the other reciprocates. This accountability to others is nurtured from early in our lives by our developmental dependence on parents and care-givers; being self-governing and accountable to others imposes limits on our autonomy which is shaped through social engagement.

The concept of relational ethics provides little specific substance to the limitations of personal autonomy but, like communitarian philosophy, it claims general restrictions to the autonomous freedom of the individual. It also resonates with the African concept of Ubuntu because the communitarian view of man is not uniquely a product of the Western intellectual tradition.

In South Africa, the concept of Ubuntu is used to define man in his social context. Ubuntu is a Zulu word with spiritual meaning, further exemplified

¹⁰ The account of Levinas' philosophy is based upon the description of his work published by Bergo in the Stanford Encyclopaedia of Philosophy and is available at the web address detailed in the bibliography.

by the Zulu maxim of *umuntu ngumuntu ngabantu* (Louw 1998¹¹). Translated, this means “a person is a person through other persons”. The South African Governmental White Paper on Welfare (also cited in Louw, 1998) defines Ubuntu as

“The principle of caring for each other’s wellbeing...and a spirit of mutual support...Each individual’s humanity is ideally expressed through his or her relationship with others and theirs in turn through a recognition of the individual’s humanity. Ubuntu means that people are people through other people. It also acknowledges both the rights and responsibilities of every citizen in promoting individual and societal wellbeing”

Louw (1998) has pointed out that the way in which Ubuntu respects the particularity of others says something of the way in which it views individuality. Individuality in the modern Western idiom is Cartesian in its conception of individual existence set against the rest of the community and society; in African culture, the individual can only define himself by virtue of his relationships with others. As Louw (1998) puts it:

“Thus understood, the word ‘individual’ signifies a plurality of personalities corresponding to the multiplicity of relationships in which the individual in question stands. Being an individual by definition means ‘being-with-others’. ‘With-others’...is not added on to a pre-existent and self-sufficient being; rather, both this being (the self) and the others find themselves in a whole wherein they are already related’. This is all somewhat boggling for the Cartesian mind, whose conception of individuality now has to move from solitary to solidarity, from independence to interdependence, from individuality vis-a-vis community to individuality a la community.”

¹¹ The paper cited was presented at the 20th World Congress of Philosophy in Boston. The proceedings, including this text are available in the Paideia archive, the web address of which is included in the bibliography.

This notion of solidarity with a community of people places restrictions on individual autonomy. In so far as Ubuntu is a philosophy of respect and compassion for others, it has a curious parallel with Western history because it also lends itself to oppressive political collectivism based upon solidarity; the desire for consensus inherent in Ubuntu “..can easily derail into an oppressive collectivism or communalism” (Louw 1998). The parallel with political oppression in pre-modern Western society is evident, albeit that the oppression of Western society took place in spite of a communitarian spirit and not because of it. Freedom of the individual in every respect is a construct of the European Enlightenment. Speaking of traditional African society, Sono (1994: xiii, xv cited in Louw 1998) has articulated the conformity commanded by Ubuntu as follows:

“Discursive rationality is overwhelmed by emotional identity, by the obsession to identify with and by the longing to conform to. To agree is more important than to disagree; conformity is cherished more than innovation. Tradition is venerated, continuity revered, change feared and differences shunned. Heresies [i.e. the innovative creations of intellectual African individuals, or refusal to participate in communalism] are not tolerated in such communities.”

These considerations pertaining to Ubuntu are a significant statement about a large segment the multicultural South African society: a society that contains elements of both Western liberalism and African communitarianism. The practice of medicine and the emphasis placed upon autonomy, especially in respect of informed consent in which an individual is required to make his or her own decision has little in common with the social conformity characteristic of the African Ubuntu tradition. What is legally and morally compelling to a Western physician may be less important and altogether less explicable to those raised in African tradition. To regard informed consent as a duty to be imposed upon an individual with little awareness of individual autonomy would amount to a

failure to understand the context of the patient. It is possible that individuals such as these may be manipulated into agreeing to interventions that are not in their interest or, at the other extreme, exposing them to paternalistic decisions. The competency of patients who judge issues from a communitarian perspective may also be called into question because the decisions reached by an individual may not appear to be consistent with their own best interest. Again, the context and narrative unity of an individual's life lived in a particular social tradition must be incorporated into any judgements reached about the consent or otherwise granted for medical intervention.

In conclusion, communitarianism at the very least limits the autonomous actions of individuals to those that are consistent with the welfare of society at large. In a more pervasive African form, it is a way of being that lacks self-awareness that subjugates the interests of the individual to those of society.

Conclusion

The preceding discussion shows the spectrum across which autonomy rights of the individual may be restricted. In the liberal individualist Western tradition, the restrictions to autonomy are largely those occasioned by the need to refrain from harming others and the necessary setbacks to the interests of individuals brought about by resource limitation.

Communitarian interests, as discussed in the preceding paragraph raise more profound questions that challenge the very assumption of individuality.

The practice of medicine has nevertheless migrated from a model of beneficence to one in which the autonomy-rights of the patient are manifestly dominant. Those elements that restrict the scope of

autonomous action challenge this a priori assumption of individual dominance. Yet in each circumstance justification is demanded before any aspect of autonomy may be discounted.

The South African community is unique in diverse ways: it firstly reflects the juxtaposition of Western and African traditions – which are in some respects incommensurable. Secondly, South Africa faces severe financial challenges in meeting the demand for social services, including health care. Both these factors impose upon any a priori assumption of individual hegemony. The next chapter examines some South African clinical scenarios in which autonomy is restricted.

Chapter 5

The justification for some infringements of autonomy in clinical medicine within the South African context

That personal autonomy can be, and is, justifiably infringed is evident from the preceding discussion. Yet autonomy remains a foundational concept in Western thinking since the Enlightenment and any limitation to the scope of autonomy merits careful consideration because not all infringements of autonomy will be justifiable. To allow infringements that cannot be justified would be to deny the dignity of fellow human beings.

In South African medical practice there are some circumstances where autonomy may be infringed that are generic to medical practice globally and other circumstances that are unique to South Africa. This discussion will focus on several of these situations, combining case history and descriptive information with ethical analysis aimed at determining how justifiable evident infringements of autonomy may be. The discussion will include aspects pertaining to the application of the South African Mental Health Act, case history and discussion related to the Choice of Termination of Pregnancy Act, some considerations pertaining to involuntary incarceration of people with infectious diseases, especially extremely drug resistant tuberculosis and finally some discussion about research ethics in African Countries.

Coercive treatment: the South African Mental Health Care Act

This first example of justifiably infringed autonomy concerns the radical loss of autonomy brought about through involuntary hospitalization.

The South African Mental Health Care Act is a multifaceted document describing the circumstances under which psychiatrists and other mental health practitioners may conduct clinical practice in South Africa. In common with other such international guidelines, it makes provision inter alia for involuntary hospitalization of mentally ill patients under prescribed conditions. Szasz (2003: 1449) has pointed out that, in general, the provisions of mental health law bring

“The avowed desires of patients and doctors (into) conflict more often in psychiatry than in any other branch of medicine”.

The prima facie obligation to respect patient autonomy is directly called into question by the provisions of this type of legislation.

a. Provisions of the South African Mental Health Care Act of 2002

The relevant aspects of the Act pertain to involuntary treatment. These provisions are contained in section 32 of the Act and are cited as follows:

“A mental health care user must be provided with care, treatment and rehabilitation services without his or her consent at a health establishment on an outpatient or inpatient basis if-

(a) an application in writing is made to the head of the health establishment concerned to obtain the necessary care, treatment and rehabilitation services and the application is granted;

(b) at the time of making the application, there is reasonable belief that the mental health care user has a mental illness of such a nature that

- (i) the user is likely to inflict serious harm to himself or herself or others; or*
- (ii) care, treatment and rehabilitation of the user is necessary for the protection of the financial interests or reputation of the user; and*
- (c) at the time of the application the mental health care user is incapable of making an informed decision on the need for the care, treatment and rehabilitation services and is unwilling to receive the care, treatment and rehabilitation required.”*

In section 33, the Act specifies who may apply to have the user committed for involuntary care:

“(1) (a) An application for involuntary care, treatment and rehabilitation services may only be made by the spouse, next of kin, partner, associate, parent or guardian of a mental health care user, but where the –

(i) user is below the age of 18 years on the date of the application, the application must be made by the parent or guardian of the user; or

(ii) spouse, next of kin, partner, associate, parent or guardian of the user is unwilling, incapable or is not available to make such application, the application may be made by a health care provider.

(b) The applicants referred to in paragraph (a) must have seen the mental health care user within seven days before making the application.

(2) Such application must be made in the prescribed manner, and must set out the relationship of the applicant to the mental health care user;”

On admission, assessment by two practitioners is required and if involuntary treatment is considered necessary, the user must be referred to a psychiatric hospital within 48 hours. Once admitted to a psychiatric

hospital, further formal assessment is required within 72 hours of admission. Treatment is continued for as long as it is deemed necessary or until the 'user' is considered to have regained their competency. In section 38 of the Act, this is set out as follows:

“Recovery of capacity of involuntary mental health care users to make informed decisions

38. (1) If the head of a health establishment is of the opinion from personal observation, information obtained or on receipt of representations by the user that an involuntary mental health care user is capable of making informed decisions, he or she must enquire from the user whether the user is willing to voluntarily continue with the care, treatment and rehabilitation services.

(2) If the involuntary mental health care user consents to further care, treatment and rehabilitation services, section 25 applies.

(3) If the involuntary mental health care user is unwilling to continue with care, treatment and rehabilitation services and the head of the health establishment is satisfied that the user no longer has a mental illness as referred to in section 32(b), the head of the health establishment concerned must immediately cause the user to be discharged according to accepted clinical practices.”

The Act does not define “informed decision” and considers mental illness to be “a positive diagnosis of a mental health related illness in terms of accepted diagnostic criteria made by a mental health care practitioner authorised to make such a diagnosis”. The Act therefore makes provision for involuntary care that by definition constitutes an infringement of individual autonomy rights.

A clinical case history will be used to illustrate the application of this Act and the ethical arguments pertaining to the application of this Act.

b. Case History

Ms P was admitted to a state hospital in the early hours of the morning, having been brought to hospital by the police, a trauma counsellor and the paramedics who had been asked to intervene by Ms P's estranged husband. Ms P had threatened to commit suicide and was found at home, surrounded by knives, in an aggressive state. Sedation given by the paramedics allowed her to be transferred to hospital where she was again sedated because of severely aggressive behaviour. Her next of kin (the estranged husband) could not be contacted and the medical officer on duty completed a "form 4" which allows involuntary hospitalization for the purposes of psychiatric assessment in terms of the South African Mental Health Care Act (SAMHCA).

Ms P was then admitted to a "safe room", which is a detention room within the hospital.

The following morning, Ms P was interviewed by another medical officer. Ms P was reluctant to talk to the doctor but divulged that she was suicidal because her husband had left her for another woman. She declared that she was no longer suicidal and wanted to go home. The medical officer recorded that Ms P's demeanour was calm and rational and there were no symptoms of psychotic illness. Because the referral to hospital had been initiated by Ms P's estranged husband to whom she had disclosed her suicidal intentions, the night before, the medical officer suggested to Ms P (who agreed) that it would be useful to discuss the problem with her estranged husband prior to discharge. At this point Ms P asked to smoke a cigarette, a request refused by the doctor. Ms P became agitated, hurling a chair against the door of the safe room, as the doctor left the room.

The medical officer subsequently phoned Ms P's estranged husband and obtained information that Ms P had previous admissions to a psychiatric institution where a diagnosis of borderline personality disorder had been made. He reported that Ms P was becoming increasingly violent and that she had assaulted him in various ways previously; because of these assaults, he had applied for a protection order against her. He had requested police assistance the night before because of repeated messages from her that she intended to commit suicide. With this information in hand the doctor concluded that Ms P had poor impulse control and was a danger to herself and others and would merit further assessment at a psychiatric institution. Consequently, a "form 5" was completed in terms of the SAMHCA and Ms P was sent to the institution in question the same day, without her consent.

Three days later, the same doctor was approached by a hitherto unidentified member of the public (Ms M) with a request for assistance. The story related to the medical officer was that Ms M (and her children) were being threatened and harassed by another woman (Ms P), who had recently been discharged from a psychiatric institution. On further questioning, it became evident that Ms M was the girlfriend of Ms P's estranged husband and that the harassment had consisted of her home being invaded by Ms P who verbally abused her and her children. Ms M was concerned for her own safety and that of her children. A legal protection order had been sought by Ms M, but not yet implemented.

The medical officer advised Ms M that if Ms P was harassing her and was thought to be mentally ill, then she could press legal charges against Ms P and could also fill out a "form 4" in terms of the South African Mental Health Act which would compel the police service to identify Ms P and request her attendance at the hospital for a further mental health assessment; failing voluntary compliance, the police would be obliged to detain Ms P against her will for the same purposes.

The "form 4" was duly completed by Ms M and Ms P was brought back to the state hospital by the police trauma counsellor. A consultant psychiatrist assessed her the same day and noted that Ms P was now living with her mother and had custody of her own children. The assessment further noted an absence of any psychotic or suicidal ideation and recorded Ms P's affirmation that she was able to control her own impulses and that there was no evidence of manipulative behaviour. The interview further documented Ms P's acceptance of responsibility for her own actions, including any antisocial actions. The consultant concluded that Ms P had a borderline personality disorder and mild depression with good insight; voluntary or involuntary admission was deemed unnecessary and follow-up organised through the services of both a psychologist and a psychiatrist.

c. Infringement of autonomy on psychiatric grounds: the moral issues

The actions of Ms P in this case are centred on her threat of suicide and on her alleged intrusive and sometimes violent behaviour towards others. The intervention sought in this case was the involuntary restraint and treatment of Ms P. The issues of violent anti-social behaviour brought about by mental illness and suicidality will be dealt with separately although the intervention sought in both circumstances amounts to a denial of Ms P's autonomy.

Anti-social behaviour

To deny someone their right to autonomous action in the face of anti-social behaviour is a self-evident and accepted limitation to the autonomy of any individual.

Deontological ethics

In terms of ethical theory, Kantians would demand respect for the dignity of rational human beings; every person would need to be seen as an end in themselves and not merely the means to some other end. Kantian ethics would not justify the actions of Ms P against others because any violence perpetrated against others would both harm their interests and make them subservient to the will of the perpetrator. An individual, perpetrating harm, would expose themselves to the process of the law, retributivism and punishment. However, Kantian theory would not seek to suppress individual autonomy, even in this circumstance; it would rather entail respecting the agency of the autonomous human being and then holding him responsible for his actions. The prevention of harm by preempting the expression of individual will is also denied in some of Kant's own examples of how the moral law is applied: the case of the inquiring murderer is an instant where any breach of principle (by lying to save the life of an innocent person) is denied, even when dire consequences were likely to follow¹². This example is seen as one which demonstrates the inflexibility of the Kantian view by showing how it contradicts common-sense morality. For Kant, however, autonomy was beyond infringement and the existence of morality depended upon the possibility of choosing to do the right thing

Despite the Kantian injunction to respect autonomy, the idea of autonomy itself requires the capacity for rational action. This was obviously pertinent to Ms P and is also pertinent to any person with disturbed cognitive capacity. Ms P had a diagnosed psychiatric disorder and her capacity for rational behaviour needed to be carefully weighed before considering her capable of autonomous action. The determination of competency has been addressed in chapters two and three; varying levels of incompetence are used to define whether someone is able to give

¹² The "Case of the Inquiring Murderer" was the subject of an interchange between Kant and one of his contemporaries who took issue with his insistence that absolute rules were the necessary basis of morality. This case is described and discussed in Rachels (2007: 124).

informed consent: understanding and rational deliberation are all attributes necessary to the process of informed consent. In Ms P's case, her initial presentation with severely violent agitation and suicidal intent would indicate that she was indeed incompetent at the time she was admitted. It is notable that the Act does not define what constitutes competency or an 'informed decision'; such judgements are thus left in the hands of the attending physicians with the need to test for competency clearly defined in section 32(c) as well as in section 38 of the Act. Those who are competent and therefore responsible for their actions are dealt with by the provisions of ordinary criminal and civil law and in Ms P's case, this was exactly the point upon which the consultant psychiatrist saw fit to discharge Ms P for further outpatient follow-up. The moral obligations of the practitioners called upon to carry out the stipulations of the Act require them therefore to concentrate on the issue of competency because the Act only mandates involuntary care on the basis of incompetence in the setting of mental illness. In this case, there is sufficient reason to argue that Ms P's involuntary detention was justified and that her autonomy was not infringed in the process because she was incapable of making an informed decision at the time of her admission. Her circumstances are representative of any person with mental illness detained against their wishes providing the stipulations of the Act are correctly applied.

Setting aside considerations that pertain to the act of her detention, further deliberation is necessary when defining whether Ms P's autonomy may have been justifiably or unjustifiably infringed by the circumstances of her detention. Self-governance consists of a spectrum of decisions about the way in which we choose to live our lives, not all of which are material to the welfare of others - or even of any life-sustaining significance to ourselves: the process of overruling Ms P's autonomy should have been limited to those aspects of her behaviour that constituted a danger either to herself or those around her. Competency

and autonomy vary over time and in respect of the task at hand. The law mandates intervention and sets limits to the intervention by establishing criteria for mandatory re-appraisal and further management, but it fails to define criteria according to which the remaining aspects of patient autonomy are to be recognised and protected. Having been detained against her will places the patient in the power of individuals who represent the state; their commitment to recognize the autonomy of the patient is a moral issue to be decided by each individual practitioner and includes the patient's right to communication, visitation, privacy and economic rights. In Ms P's case, the procedures laid down by law were followed and her freedom and full autonomy were rapidly restored; however, during her period of detention there is little information available regarding the way in which she was treated. This is of concern and any infringement of the patient's right to self-governance beyond that which is absolutely necessary would not be justified.

Utilitarian theory

The utilitarian evaluation of autonomy in the context of this case would be constructed around the aggregate interests of all involved, seeking above all else the greatest happiness for the greatest number of people. The gratification of individual desires would not be justifiable if the consequences of the actions performed by Ms P were detrimental to the interests of those around her. The intervention carried out by the medical authorities with the intention of preventing Ms P from harassing or harming those close to her would be justified by the net utility of the intervention. As described in chapter four, beneficence is the underpinning principle of utilitarian theory and is in itself sometimes argued to be a justifiable reason for overruling autonomy. Utilitarians would differ from Kantian ethicists in this circumstance because they would see a moral obligation of preventing harm to others that supersedes the autonomy rights of Ms P. Even if Ms P were fully

autonomous and competent, the obligation to prevent harm would have made intervention morally obligatory.

Communitarian philosophy

Communitarian philosophy would find anti-social conduct antithetical to the interests of society. The autonomy of the individual would not be of primary concern and what ought to be done about anti-social behaviour would be measured against the intentions of the agent making decisions. Those restricting Ms P's actions acted out of concern for the safety of those around them and their actions were justifiable for that reason. However, the obligation of those intervening may be seen to extend beyond that of preventing harm to others; understanding the narrative unity of Ms P's life would also be required because it would indicate the basis of her behaviour, rooted as it was in the loss she sustained when her partner left her. Having that appreciation in mind, virtue ethics would require that any intervention contemplated should also provide therapy aimed at alleviating Ms P's suffering, possibly by means of psychotherapy. The autonomous character of an action would be of less concern to virtue ethicists than the reasons for the action and they would support the role of professionals acting within the scope of their practice in the interests of the broader community and Ms P herself.

Principlist ethical reasoning

A principlist approach to the case in question would begin by considering the obligation to respect the autonomy of others as a prima facie obligation that could be over-ruled by other competing principles. Autonomy would ordinarily require us to allow Ms P to determine her own conduct and treatment in so far as it affected her and her alone. When the scope of autonomous action allowed others to be harmed, the principle of beneficence was exercised in protection of those who may be harmed even if that meant a setback to the interests and intentions of Ms P. 'Autonomous' action on the part of Ms P would, however, need to be

scrutinized given her background history of psychiatric illness and the preceding discussion about competency would necessitate a judgement about Ms P's autonomy. No conflict of prima facie principles would need to be invoked if Ms P was incompetent. In her case, it would appear that Ms P suffered from episodes of emotional stress in which she failed to control her impulses and became capable of violent behaviour. The prior diagnosis of borderline personality disorder made in her case indicated a susceptibility to affective instability, impulsivity and suicidality – all of which are characteristics of this condition, described in the DSM (The Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association). Ms P would be viewed as an individual with fluctuating competency and autonomy. Her episodes of anti-social behaviour during periods of affective instability would justify involuntary care without any infringement of autonomy.

In conclusion, the Act under which Ms P was admitted is inclined to a Kantian view of antisocial behaviour because it emphasizes the issue of competency as the criterion justifying involuntary treatment and because it stresses the immediate restoration of liberty and full autonomy to individuals who show evidence of being competent. In substance, therefore, although the Act allows individuals to be held against their will, there is no evidence that this amounts to an infringement of personal autonomy.

What is morally questionable is the notion that the autonomous interests of the individual being treated against his or her will are not fully protected by the informed consent of surrogates; nor is the scope of the restrictions applied to the autonomy of the individual clearly defined. These are significant omissions to an Act that allows psychiatric care to be provided in a way that no other branch of medicine may be practiced, either legally or morally. There is little protection for the interests of the individual and in expressing a related concern in the context of international models of psychiatric care, Szasz (2003: 1449) has pointed

out that both the American and English legal systems maintain a “fiction” that those responsible for committing a “loved one” have a caring relationship with the person committed. Szasz (2003: 1450), however, argues that the family is all too often “a source of the most insidious danger” to the incarcerated member of the family. He extends the same argument to the possibility of an individual being legally bound to accept treatment from a psychiatrist appointed by the state under circumstances where there is no reason to assume (as the law does) that the appointed doctor will necessarily maintain a therapeutic relationship of care in respect of the detained individual.

The autonomous interests of individuals may be unjustifiably infringed by the practice of psychiatric intervention but not through the act of involuntary detention. The infringements, if they occur, follow hospitalization and only an awareness of moral behaviour on the part of the attending physicians may prevent this from happening.

Suicidality

Where no harm to others is risked, the provisions of the Act allow individuals to be admitted against their will, for their own protection. All the preceding discussion about competency applies to the justifiability of involuntary admissions for this reason. In addition to these considerations, other ethical arguments may also pertain.

Deontological ethics

Suicidality would not be condoned by a Kantian ethicist. Kant writes in the Groundwork to the Metaphysic of Morals that the self-love through which an individual may decide that the continuation of life threatens more evil than it promises pleasure could never become a universal law of nature simply because such laws are aimed at stimulating the furtherance of life and not its destruction (Kant 1785: 53¹³). By this view, suicidality is in

¹³ See footnote 3 for details on the page cited

breach of the categorical imperative and therefore morally indefensible. The issue of autonomy is not superseded by this consideration and a Kantian ethicist would persist in judging the action of suicide to be wrong while still respecting the right of the individual to make an autonomous choice between right and wrong. By this reasoning, the application of the Act would be judged on the basis of whether or not the person admitted in terms of its provisions was competent or not.

Utilitarian theory

Utilitarianism would seek the greatest happiness for the greatest number of people by rejecting interference in the lives of individuals. The issue of attempted suicide usually entails the intervention of others seeking to prevent an individual from bringing harm to him or herself. John Stuart Mill (1859 / 2006: 16), believing that the happiness of individuals depended substantially on their freedom from external authority, claimed that the entire extent of legitimate authority exercised by the state against individuals was confined to preventing people from harming one another. The state had no licence to intervene in the lives of individuals in any sort of paternalistic way, even when they put their own lives at risk. The only qualification allowed to his principle was that temporary intervention to prevent suicide could be justified in order to establish that the deed was indeed the autonomously-made decision of a rational being. Under such circumstances, the scope of involuntary detention and treatment would only be justifiable for brief periods of time and with specific goals in mind. In Ms P's case, the initial commitment under the Act would have been justifiable but subsequent intervention would not be defensible, were it to be based upon suicidality alone. In general, utilitarians would therefore consider preventing someone from committing suicide an unjustified setback to their interests, not because it infringed autonomy but because it did not adhere to the single principle of utility, expressed as happiness founded upon freedom from external authority.

Principlist ethical reasoning

Principlists would also address the issue based upon competency. Beauchamp and Childress (2001: 188) have argued that beneficence justifies intervention to prevent suicide and consider intervention symbolically significant because it is an expression of communal concern over attempted suicide; they do nevertheless concede that in some circumstances suicide is justifiable and should be allowed to happen, even with the assistance of others; however, in Ms P's case, there were significant concerns about her impulsivity and competency that made intervention to prevent her from killing herself justifiable. In the absence of substantial autonomy, beneficent intervention would be clearly applicable; however, according to the principlist view, both suicide and intervention to prevent suicide may be justifiable in the case of competent people, although the latter would necessarily involve overruling the autonomy rights of the individual. To do so would be an acceptable infringement of a prima facie principle, even if the resultant action left traces of moral regret.

The principle of beneficence would also apply to therapy aimed at ameliorating the effects of poor impulse control and depression. This treatment usually requires the informed consent of the patient and in Ms P's case beneficence would not justify involuntary treatment because her fluctuating levels of competency would still allow the discussion of psycho-pharmacotherapy at a time when Ms P could make an autonomous choice; the medical practitioners confronted by her emergency admission, however, would have had an obligation of beneficence in pursuing counselling about psychotherapy and psycho-pharmacotherapy. In Ms P's case this happened with follow-up being organised by both a psychologist and a psychiatrist. Again, the Act is inconsistent with the general moral requirement that autonomous authorisation be sought from individuals or their surrogates before instituting treatment.

In summary, the Kantian view can never be invoked in defence of any breach of autonomous action; nor, can it be used to justify intervention in the prevention of suicide. The utilitarians would view attempted suicide as an action against which only temporary intervention could be justified, but not for reasons of respecting patient autonomy. Principlists, following the arguments advanced by Beauchamp and Childress (2001: 188), would find reasons of beneficence sufficient justification for overruling the prima facie principle of respect for patient autonomy.

These conclusions and the South African law should be seen in the context of broader international conventions. Tannsjö (2004: 430) has used the stipulations of the Convention on Human Rights and Biomedicine of 1996 as a basis for discussing the grounds that may be advanced for 'coercive treatment'. This Convention only supports coercive treatment of a patient with a mental disorder where that disorder will result in serious harm to the affected individual themselves. Harm accruing to others is regarded as insufficient justification for coercive intervention. Tannsjö (2004: 431) further reflects on the application of the Convention to patients with psychiatric illness; three possible ways of applying the Convention are considered: the first possibility is that coercive treatment should be provided based solely upon the needs of the patient; the second iteration restricts coercive treatment to conditions considered life-threatening in the absence of intervention. The third option justifies all forms of involuntary treatment on the basis of incompetency. Tannsjö (2004: 431) concludes that the incompetency model is the most defensible model and that mental illness in itself is no reason for coercive intervention, even in the face of suicidality. These arguments deny beneficence as a basis for coercive intervention; they also deny utility and in placing autonomy and competency at the center of judgements about what is acceptable, endorse a Kantian perspective. The South African Mental Health Care Act is consistent with this view and may be more

morally defensible than similar laws in other Western Countries (Sweden, Italy, Germany).

In dealing with the dangerously insane, Tannsjo (2004: 433) further argues that full legal responsibility should be endorsed with coercive treatment reserved for the incompetent. Tannsjo argues that psychiatrists should not be legally responsible for incarcerating those mentally-ill people for whom no cure exists and that there ought to be a clear distinction between punishment and treatment. These views differ from the stipulations set out by the SAMHCA and Tannsjo (2004: 434) acknowledges that the full responsibility model is very controversial; in the circumstances of the current case, Tannsjo's arguments are all morally directly applicable, especially with regard to their emphasis on competency.

In conclusion, the South African Law (the Mental Health Care Act) emphasizes and protects the function of personal autonomy and does not mandate any breach of Kantian principle either for the benefit of the individual or society. However, other moral theories provide no support for the idea that the autonomy of the individual psychiatric patient should primarily determine what ought to be done where the interests of the individual may be affected by his or her own actions or even where the interests of society are put at risk through the actions of individuals. Hence the morally justifiable limits to the personal autonomy of psychiatrically-ill people exceed the stipulations of the law which curtails the extent of social intervention against the individual. That this is so, in the South African context, reflects the dominance of Western intellectual values within the legislative framework of the country.

Maternal – Fetal conflict and the South African Choice on Termination of Pregnancy Act

Having seen how the law protects competent individuals from being treated against their will for psychiatric illness, the second example is one where the autonomy rights of individual women come into conflict with interests of their unborn children.

The decision to end a pregnancy may be made for a number of reasons. These include the possibility of harm accruing to the interests of the fetus, harm accruing to the interests of the pregnant woman or because it is her desire to end an early pregnancy. Setting aside incompetent pregnant women, the request to end a pregnancy is always a direct extension of the will of the pregnant woman and in such circumstances it is her autonomous will that may be tested against the rights and interests of the unborn child. The practice of abortion is regulated by the law although the moral question of whether the autonomy of the pregnant woman has justifiable limitations remains the subject of debate. The arguments supporting and limiting the autonomy of the pregnant woman will be presented in the discussion of an illustrative case report. The relevant provisions of the Act will be briefly reviewed prior to this.

a. Provisions of the Act

The Act entrenches the right of the pregnant woman to make autonomous decisions about her pregnancy with the option of ending the pregnancy being at her behest alone up to 12 weeks and thereafter for reasons pertaining to any adverse risk that could arise because of the pregnancy. This adverse risk, construed as either a risk to the pregnant woman herself or her child, would be sufficient grounds for termination of the pregnancy providing two other practitioners support the termination on the stipulated legal grounds. The relevant sections of the Act are the following:

“Recognising that the Constitution protects the right of persons to make decisions concerning reproduction and to security in and control over their bodies...” and,

“2. A pregnancy may be terminated -

(a) upon request of a woman during the first 12 weeks of the gestation period of her pregnancy;

(b) from the 13th up to and including the 20th week of the gestation period if a medical practitioner, after consultation with the pregnant woman, is of the opinion that-

(i) the continued pregnancy would pose a risk of injury to the woman's physical or mental health; or

(ii) there exists a substantial risk that the fetus would suffer from a severe physical or mental abnormality; or

(iii) the pregnancy resulted from rape or incest; or

(iv) the continued pregnancy would significantly affect the social or economic circumstances of the woman; or

(c) after the 20th week of the gestation period if a medical practitioner, after consultation with another medical practitioner or a registered midwife, is of the opinion that the continued pregnancy-

(i) would endanger the woman's life;

(ii) would result in a severe malformation of the fetus; or

(iii) would pose a risk of injury to the fetus.

Subject to the provisions of subsections (4) and (5), the termination of a pregnancy may only take place with the informed consent of the pregnant woman.

(2) Notwithstanding any other law or the common law, but subject to the provisions of subsections (4) and (5), no consent other than that of the pregnant woman shall be required for the termination of a pregnancy.

(3) In the case of a pregnant minor, a medical practitioner or a registered midwife, as the case may be, shall advise such minor to consult with her parents, guardian, family members or friends before the pregnancy is terminated: Provided that the termination of the pregnancy shall not be denied because such minor chooses not to consult them.

(4) Subject to the provisions of subsection (5), in the case where a woman is-

(a) severely mentally disabled to such an extent that she is completely incapable of understanding and appreciating the nature or consequences of a termination of her pregnancy; or

(b) in a state of continuous unconsciousness and there is no reasonable prospect that she will regain consciousness in time to request and to consent to the termination of her pregnancy in terms of section 2, her pregnancy may be terminated during the first 12 weeks of the gestation period, or from the 13th up to and including the 20th week of the gestation period on the grounds set out in section 2(1)(b)-

(i) upon the request of and with the consent of her natural guardian, spouse or legal guardian, as the case may be; or

(ii) if such persons cannot be found, upon the request and with the consent of her curator personae:

Provided that such pregnancy may not be terminated unless two medical practitioners or a medical practitioner and a registered midwife who has completed the prescribed training course consent thereto.

(5) Where two medical practitioners or a medical practitioner and a registered midwife who has completed the prescribed training course, are of the opinion that-

(a) during the period up to and including the 20th week of the gestation period of a pregnant woman referred to in subsection (4)(a) or (b) -

(i) the continued pregnancy would pose a risk of injury to the woman's physical or mental health; or

(ii) there exists a substantial risk that the fetus would suffer from a severe physical or mental abnormality; or

(b) after the 20th week of the gestation period of a pregnant woman referred to in subsection (4)(a) or (b), the continued pregnancy-

(i) would endanger the woman's life;

(ii) would result in a severe malformation of the fetus; or

*(iii) would pose a risk of injury to the fetus, they may consent to the termination of the pregnancy of such woman after consulting her natural guardian, spouse, legal guardian or curator personae, as the case may be:
Provided that the termination of the pregnancy shall not be denied if the*

natural guardian, spouse, legal guardian or curator personae, as the case may be, refuses to consent thereto.”

The articles of the Act stipulate no upper limit for the duration of pregnancy at which termination of the pregnancy may be legally procured. The articles of the Act also make no reference to the consequences of the procedure for the fetus: neither the possibility of livebirth or stillbirth are contemplated and there is no reference to the act of fetocide (killing the baby in utero by means of a lethal injection) prior to termination of the pregnancy.

b. Case History

Ms NH was admitted to the Groote Schuur Hospital Maternity Unit under the provisions of the Choice on Termination of Pregnancy Act of 1996 for the purposes of terminating her pregnancy.

Ms NH was a 21 year old woman who had previously given birth to two children, aged 4 and 6 years at the time of her admission. Neither of these children were cared for by her, the eldest being in the custody of his father and the younger living with Ms NH's mother.

Ms NH had a poor social history having lived on the street for more than a year before going to live with her aunt in Mannenberg. She had a further history of both alcohol abuse and admitted to using TIK (methamphetamine).

Ms NK was raped by an unknown assailant, as a result of which she developed suicidal depression leading to attempted suicide by means of a paracetamol overdose. She was initially looked after in the emergency unit at Jooste Hospital after which she was referred to the liaison psychiatry service at Groote Schuur Hospital. The evaluation carried out there suggested that Ms NH had persistent suicidal ideation and that the pregnancy that had been the result of the rape was partly responsible for her severe depression. The psychiatric opinion strongly suggested that

the ongoing pregnancy constituted a threat to her life and mental wellbeing and should be terminated immediately.

As a consequence of this decision, Ms NH was referred to the gynaecology department where two consultants agreed that the circumstances merited termination of the pregnancy.

In hospital, further evaluation revealed that the pregnancy was advanced beyond 20 weeks and that the estimated gestational age of the fetus was between 23 and 24 weeks. An induction of labour was commenced on the 30 of September 2008 and ended with the delivery of a freshly stillborn female child weighing 760 grams on the 10th of October. The induction of labour proved to be abnormally protracted and by the time the child was delivered the pregnancy had progressed beyond the 24th week of gestation.

Of note, the care of Ms NH during the induction of labour was provided by rotating teams of labour ward doctors, most of whom raised no ethical objection to the procedure in question. However, on the day before the delivery took place, both the doctors on duty decided that they disagreed with the procedure in question and expressed a desire not to be involved in the management of Ms NH. One of these two doctors was persuaded by the consultant on call that the resident staff had a duty of care to Ms NH who was some way into the process of ending the pregnancy; consequently Ms NH continued to receive care that night and delivered the next day.

Ms NH was discharged soon after delivery, for follow-up by the psychiatric unit and social workers.

c. The justifiable limits to personal autonomy in the setting of maternal – fetal conflict

This case presents several issues: the first of these is whether or not it is permissible to kill a preterm fetus by ending a pregnancy prematurely in

order to save the life of its mother; the second is whether the rights of the child who is to be born ever supersedes the rights of the pregnant woman to pursue her own autonomous interests.

Prior to reflecting on these issues, it is necessary to consider what "termination of pregnancy" might mean for the pregnant woman and the child-to-be-born. The terminology employed by the act governing medical intervention in pregnancy is not helpful, being defined in all but one respect, namely: what it means to carry out a 'termination of pregnancy'. Conceptual analysis of this phrase will show that the process of ending a pregnancy is a technical issue with a range of consequences, depending on the gestational age at which the pregnancy ends. These consequences range from the surgical removal of a very young conceptus showing few identifiable characteristics of being a human fetus, and no signs of life to the delivery of a child clearly discernable as an anatomically fully-developed human being, with or without signs of life.

To terminate a pregnancy, as such, implies no stipulation regarding the circumstances of a child's birth and fails to imply any particular outcome for the child after birth. Hence, an example may be made of a termination of pregnancy carried out for severe hypertension in pregnancy which is aimed at ending the pregnancy for the sake of the pregnant woman and may result in the delivery of preterm child who has the capacity to survive.

Terminating a pregnancy is not usually considered to be the same as killing a fetus. However, the consequence of carrying out a termination of pregnancy may lead to the death of a fetus or the death of a newborn child who is born alive but too premature to survive. As the preceding example illustrates, there is also a third possibility: terminating a pregnancy may result in the preterm delivery of a child that has grown sufficiently to have a statistical (and actual) chance of surviving premature birth. The possibility of neonatal survival becomes increasingly

likely the further the pregnancy has progressed at the time it is ended. Hence, terminating a pregnancy may result in the delivery of a child who survives but may also be seen as ending the life of a fetus or that of a newborn child.

In terms of the South African law, the purposes of the Act are defined in terms that aver termination of pregnancy as a form of contraception, stating in the preamble:

“Believing that termination of pregnancy is not a form of contraception or population control...”,

Instead, it chooses to argue that the parents have a ‘right’ to ‘fertility regulation’:

“Recognising that both women and men have the right to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice”

This implies that the number of children reared by a woman and her partner may be legitimately controlled, partly by invoking the provisions of the act in question. Hence the act legitimizes practices that may end in the death of a fetus or the death of a newborn child or the delivery of a child that survives, with or without the handicaps associated with preterm birth, and does so in the interests of fertility regulation. In this context any child surviving such a pregnancy would be, by definition, unwanted. The Act therefore renders legal those actions that may have harmful effects not only on the fetus but also on the child to be born. The arguments concerning the moral status of the fetus compared to the newborn child will not be examined here; suffice be it to say that killing a fetus is different to killing a newborn child and to find moral justification for terminating a pregnancy is less compelling the less likely it is that pregnancy termination will end in the death of a child (in other words: moral justification becomes increasingly difficult as the risk of preterm

delivery ending in neonatal survival increases the closer the pregnancy is to the limit of biological viability – which is usually described to be 24 weeks of gestational age).

Moral justification for ending a pregnancy is also more easily found where beneficence can be invoked as a necessary principle in supporting the life and welfare of the pregnant woman or her child. Hence, ending a pregnancy may be deemed necessary under circumstances where the pregnancy is desired but the termination of pregnancy is carried out in the interests of the pregnant woman's physical or mental health or where there is significant risk of the child suffering as a result of being born disabled. The death of the fetus or newborn child under these circumstances may be an unintended consequence of ending the pregnancy. This is the classical situation where the rule of double effect may be invoked. Beauchamp and Childress (2001:129) have described the criteria that would justify this type of harm (previously described in chapter four); briefly, these include a preponderance of good over bad effects and that the good effect isn't achieved solely by inducing harm; in addition, the intentions of the physician have to be good. Within these stipulations, the autonomously-expressed wishes of the pregnant woman would prevail and the action of ending the pregnancy would be morally justifiable on the basis of respecting maternal autonomy and beneficence towards the pregnant woman and child.

Pregnancy may, however, be ended where the pregnancy itself is undesired and the autonomous will of the pregnant woman is focussed on ending the pregnancy without her having to contemplate the possibility of rearing the child in question. Here, the harm that accrues to the interests of the fetus (or child to be) is not sustained by way of any unintended double effect: the death of the fetus or child is the consequence directly sought by interrupting the pregnancy. Such circumstances may prevail in cases of rape where the child itself is unwanted (as it is in this instance). With this conceptual analysis in mind, the moral question is focussed on

whether the pregnant woman's desire to end the pregnancy as a means of killing the fetus is justifiable. The case in question is complicated by the suicidality of the pregnant woman, which poses additional questions.

Deontological ethics

The moral status of the pregnant woman as a rational, sentient being would demand recognition of her views and a Kantian approach would lead us to examine her request to end the pregnancy in the light of needing to treat every person as an end in themselves and not merely as the means to some other end; in addition the maxim applied would need to be universalizable. To refuse the pregnant woman's request would assume that ends, other than those sought by her would be served by such a refusal. However, it would also be true that not all ends sought by others could be deemed to be desirable or universalizable; consequently there can be no endorsement of the ends of others where such purposes are unacceptable to society at large; furthermore, where the ends sought are dependent on the agency of others, they too would have the moral choice of either acceding or refusing such a request: Kantian ethics would deny neither the autonomy of the pregnant woman, nor that of those implicated in her care.

Aside from the question of respecting autonomy, from a Kantian viewpoint, the issue of taking a life cannot be endorsed because it would not be in the interest of another human being, but is an act pursued in favour of the ends of others. No circumstantial or consequential considerations would mitigate this rule, even when adverse consequences might be reasonably foreseeable.

Utilitarian theory

Utilitarians would view the situation differently. Act-utilitarians would consider the consequences of ending the pregnancy and would have no difficulty in concluding that it is substantially in the pregnant woman's

interest to end the pregnancy. The argument concerning the interests of the fetus would devolve to a consideration concerning the moral status of the fetus and the likelihood of the fetus suffering as a consequence of the pregnancy being ended. The fetus would be assigned a lesser moral status on the basis of an absence of reflective self-consciousness and an absence of any will regarding the future. Whereas utilitarians would never discount the significance of taking life, they would argue that it is a far less serious matter to take the life of a being lacking sentience than it is to end the life of an adult human being (Singer 2000: 156). Justification is required in order to kill and the consequences of killing this fetus would be justified by the pregnant woman's circumstances. Although rule-utilitarians may end up with a different view of killing in the sense that most people would be happier with the notion that no-one in society should be generally licensed to kill others without rigorous control, they would nevertheless have no difficulty in justifying this type of killing as one that society at large would endorse. Utilitarians, arguing from a consequentialist perspective, would also see no distinction between killing this fetus and terminating the pregnancy with the death of the neonate being a necessary consequence of extreme prematurity. They would therefore endorse, not only ending the pregnancy, but the practice of fetocide as well. The argument concerning suffering of the child would also be of concern to a utilitarian because the avoidable suffering of any being would require justification, if it is to be morally accepted. The extent of the suffering experienced by a fetus undergoing a lethal intracardiac injection in utero, the suffering endured by a preterm infant facing an inevitable death and the possibility of suffering endured by a preterm baby surviving into childhood with some of the many disabling complications of severe prematurity are all pertinent to the utilitarian point of view. Whereas the utilitarian would have no difficulty putting the interests of the pregnant woman ahead of those of the child, they would not wish the child to suffer any more than necessary. Allowing that some of the notions regarding suffering described above are scientifically poorly-

characterised, the utilitarians would probably choose the option least-likely to cause suffering to the fetus and the child. Hence, they would probably support the notion of fetocide before termination of pregnancy (this is, in fact, obstetric policy in the United Kingdom – that all pregnancies being ended after 22 weeks gestation, as therapeutic interventions for the benefit of the pregnant woman - or where lethal fetal anomalies are suspected, are preceded by lethal injection of intracardiac potassium chloride into the fetal myocardium¹⁴).

The utilitarian viewpoint would thus seek to maximise the preferences of the greatest number of people who have any relevant interest in the case in question as the sole moral principle determining what ought to happen. Autonomy of the individual would not be an issue and the circumstances of this case as well as the consequences of ending the pregnancy happen to support the request of the pregnant woman whose interests would therefore be inadvertently advanced by utilitarian arguments.

Communitarian philosophy

A virtue ethicist would not seek to find a viewpoint based solely on the consequences of ending the pregnancy nor on the application of any particular rule. In the context of virtue ethics, what ought to be done will be measured against the intentions of the agent making the decision. The judgements made follow no prescribed rule, instead allowing decisions to be based upon right reason and made in the context of the narrative unity of the lives of both the pregnant woman and those who need to intercede on her behalf; in their lives the exercise of virtue or vice would determine the likelihood of right action. The narrative unity of the pregnant woman's life will have been scripted without reference to pregnancy under circumstances such as these although there must also be some Sophoclean conflict inherent in her biological commitment to motherhood and her necessary rejection of all the manifestations of violence

¹⁴ This recommendation has been made by the Royal College of Obstetricians and Gynaecologists and is cited by the Nuffield Council on Bioethics (2006: 56).

perpetrated against her. A pregnancy as a result of rape would be seen to lie outside the ordinary narrative of her life and no-one could judge her any less favourably in her scripted social role in choosing to end a pregnancy such as this. Given her state of mind and the advice of the therapists caring for her, regardless of whether intervention would be clearly morally right, failure to intervene would be wrong. Virtue ethicists, in the mould of MacIntyre would also examine the intentions and actions of the medical team who assist in the process of procuring the termination of pregnancy. Here, the nature of the practice concerned needs examination. Where the practice of medicine is concerned with standards of excellence and conducted in the service of both internal and external goods, it leads to conduct based upon the relationships between those who subscribe to the practice and incorporates subordination to the judgement of others. It implies a concept of virtuous action within a particular social idiom, rather than leaving the decision of what ought to be done to the precept of the individual agent. Specifically, in this circumstance, it would require medicine to be practiced in the interests of the pregnant woman, her family and society, and with reference to both traditional and contemporary views of acceptable practice; in other words, the actions carried out serve the purposes of internal goods and are not (for example) predicated solely upon the question of financial remuneration for the practitioners concerned. In this case the actions, directed within the confines of professional practice, served the interests of the woman concerned and were consistent with good practice. In summary, the virtue ethicist provides little guidance on what ought to happen, leaving a far wider scope of actions permissible within the confines of a broadly-stated morality enshrined in the laws of the country.

Again, the issue of autonomy does not define what is morally permissible for the virtue ethicist who would accede to or refuse the autonomously-willed actions of the pregnant woman according to judgements that have no reference to the principle of autonomy.

Principlist ethical reasoning

Principlists would find themselves weighing up the competing principles of respect for the autonomy of the pregnant woman (together with beneficent concern over her suicidality) against the principle of non-maleficence towards the fetus. Beauchamp and Childress (2001: 397) describe a process of principle-based reasoning that incorporates both deductivist and inductivist approaches, brought into a "reflective equilibrium" by means of which conflicting judgements may be reconciled. Beauchamp and Childress (2001: 400) admit that such deliberation must depart from a starting point of considered judgements reflecting settled moral convictions or common morality; a common morality which, they argue, attracts greater social consensus than any theory of morality. These settled moral convictions of common morality are born of the intuition that we stand in a morally significant relationship to a number of our neighbours; relationships that create inalienable duties as well as actual or prima facie obligations. This theory, advanced originally by Ross (1939: 169) describes duties in several different categories including those arising from previous acts (duties of fidelity, reparation or gratitude); duties of justice arising from unfair distribution; duties of beneficence, non-maleficence and duties of self-improvement. These duties have been concertinaed into the four "principles" subsequently described by Beauchamp and Childress (2001: 402). The reflective equilibrium established by weighing competing prima facie principles will determine what ought to be done in a given situation. The principles overruled in this process do not lose their moral authority and in the process of being overruled they may leave traces of moral regret.

By this reasoning, a principlist may examine the situation of the case in point from the perspective of beneficence towards the suicidal pregnant woman; her request to end the pregnancy would coincide with what beneficence would require of those providing care. Non-maleficence towards the fetus would be a justifiably overridden prima facie principle.

Autonomy of the individual would not necessarily prevail in the deliberations of principlists and as the consequences of ending the pregnancy became more serious for the fetus (for example, if the fetus had attained viability and delivery would have carried a risk of neonatal survival), the principlists would argue instead that the principle of non-maleficence should prevail over the pregnant woman's right to have her autonomous wishes respected.

When the case in question is viewed in different social contexts, irreconcilable moral conflict may become evident. Whereas the pregnant woman sees the child and the pregnancy in the light of the assault perpetrated against her, those caring for her have no such context, seeing only a pregnant woman and her fetus. A paediatrician asked to care for a newborn child would not be able to discriminate between newborn children based upon the circumstances of their parents; they would not perceive one child as illegitimate when compared to another. The same conflict arises when an obstetrician is asked to end the life of one child while protecting the lives of all others of similar gestational age. Thus the moral conflict is inescapable and an acceptance of one course of action rather than another can only be made while acknowledging the loss of one principle or another. Consensus is attainable only to a limited extent and within the laws and traditions of social practice, some may choose to sacrifice one principle rather than another, although whatever course of action is chosen, inevitably, something will be lost. However, in considering the implications of the legislation pertaining to termination of pregnancy and the ethical arguments that may be adduced for and against abortion, it is apparent that the South African law is biased in favour of the autonomy of the pregnant woman; yet no moral law creates such a binding obligation to respect the wishes of the pregnant woman. The law fails to consider the implications of termination of pregnancy for the child to be born and in doing so fails to recognise the moral status of the fetus or the child to be born. In this circumstance, Kantian ethicists

would not endorse taking another (innocent) life, nor would they expect others to support the autonomous actions of those (including the pregnant woman) who chose to procure this abortion. Instead they would see such actions as morally wrong and to be dealt with through the law. Utilitarians would not disallow the actions of the pregnant woman although they would expect some limits to exist in terms of which the harm that may accrue from the procedure would be contained. Virtue ethicists would support the termination of pregnancy in this circumstance but only because it would be the right thing to do. Termination of pregnancy for lesser reasons would not necessarily be supported by virtue ethicists. Principlists would find in favour of the intervention only because of beneficence to the pregnant woman. The autonomy of the mother would be a prima facie interest that under other circumstances could be overruled by non-maleficence. Thus the legislation on the statute books has a liberal-individualist bias unsupported by moral argument with insufficient recognition given to the justifiable limitations on autonomy.

In the context of the preceding case that examined people facing detention for psychiatric reasons, this case demonstrates again that personal autonomy may not be justifiably limited in terms of the law, which also has a liberal-individualist bias on the abortion issue. However, morally, arguments for the limitation of autonomy rights may be made and the endorsement of this termination of pregnancy by utilitarian, communitarian and principlist theory were sustained in spite of the pregnant woman's personal autonomy and not because of it.

The management of extremely drug resistant tuberculosis

So far, having seen no South African exceptions to the legal requirement to respect the autonomy of the individual, the next case examines the issue of personal autonomy when set against the interests of the community.

The control of infectious diseases is an area of public health concern where the interests of the community may supersede those of the individual. Utilitarian arguments have been used to support measures that may infringe the rights of individuals in favour of benefitting the majority of the population. Even in the calculation of the greatest good, the harm incurred by some for the benefit of the majority has to be reconciled with the degree of harm caused. In common morality, limitless infringements of individual rights cannot be justified simply because the majority are likely to benefit.

In South Africa, the mortality rate from tuberculosis (TB) has been climbing steadily and reached 218 / 100 000 population during 2006 (World Health Organization 2008¹⁵). It is the leading cause of mortality in the country, second only to HIV-AIDS. This has happened despite the existence of effective treatment. More recently, drug-resistant forms of the TB bacillus have been identified and an extremely drug resistant form of TB (XDR-TB) has emerged. XDR-TB has been managed by isolating individuals identified as carriers of the XDR-TB bacillus. Being incarcerated against their will resulted in some people escaping from centres of detention; they were subsequently pursued and re-apprehended. This extreme measure has elicited moral and medical debate and faces the issue of how far the interests of the community can be advanced at the expense of the autonomous individual.

¹⁵ The figures quoted are derived from data published by the World Health Organization and cited also by the Health Systems Trust whose website is to be found at <http://www.hst.org.za/index.php>.

Some of this debate will be illustrated with a selection of press-releases discussing the incarceration of the XDR-TB patients and then the ethical arguments will be presented.

a. The nature of the problem presented by XDR-TB: scientific publications

In January of 2007, Singh et al, publishing in the Public Library of Science Medicine journal, described the XDR-TB epidemic in South Africa, urging that there was no time for complacency or denial (Singh 2007: 0019). In this publication, Singh et al describes the nature of the problem presented by XDR-TB and also documents the high risk of mortality associated with the disease:

“On September 1, 2006, the World Health Organisation (WHO) announced that a deadly new strain of extensively drug resistant tuberculosis (XDR-TB) had been detected in Tugela Ferry (Figure1), a rural town in the South African province of KwaZulu-Natal (KZN) [1], the epicentre of South Africa’s HIV/AIDS epidemic. Of the 544 patients studied in the area in 2005, 221 had multi-drug-resistant tuberculosis (MDR-TB), that is, Mycobacterium tuberculosis that is resistant to at least rifampicin and isoniazid. Of these 221 cases, 53 were identified as XDR-TB (see Table 1 and [2]), i.e., MDR-TB plus resistance to at least three of the six classes of second-line agents [3]. This reportedly represents almost one-sixth of all known XDR-TB cases reported worldwide [4]. Of the 53, 44 were tested for HIV and all were HIV infected.” (Singh 2007: 0019)

“The median survival from the time of sputum specimen collection was 16 days for 52 of the 53 infected individuals, including six health workers and those reportedly taking antiretrovirals [2]. Such a fatality rate for XDR-TB,

especially within such a relatively short period of time, is unprecedented anywhere in the world.” (Singh 2007: 0019)

Singh et al continue to outline the extent of the risk presented by the development of XDR-TB, citing recommendations made by the World Health Organization:

“In recognition of the global threat posed by these factors, on September 9, 2006, WHO urged a response to the outbreak akin to recent global efforts to control severe acute respiratory syndrome (SARS) and bird flu [14]. The South African government's initial lethargic reaction to the crisis [15,16] and uncertainty amongst South African health professionals concerning the ethical, social, and human rights implications of effectively tackling this outbreak [17,18] highlight the urgent need to address these issues lest doubt and inaction spawn a full-blown XDR-TB epidemic in South Africa and beyond.” (Singh 2007: 0020)

Singh et al also concede that the number identified cases fell far short of the number of cases likely to be present in the community:

“Diagnosed cases of XDR-TB likely represent a small proportion of the true extent of the problem. The number of persons harbouring latent infections is unknown (and likely unknowable at present). Official statistics also likely underestimate the true prevalence of XDR-TB, as the current national TB guidelines prescribe the conditions under which M. tuberculosis susceptibility testing should be done [13]. These guidelines recommend susceptibility testing for those patients who have previously been treated for TB or fail to respond to treatment after two months of TB treatment, at which point there is a high treatment interruption rate. In addition, specialised laboratory facilities are required for such testing. Routine

sputum culture and susceptibility testing of all patients suspected as having TB should form part of a multi-faceted approach to identifying and addressing TB drug resistance.” (Singh 2007: 0020)

This exposition of the problem presented by XDR-TB leaves little doubt about the potential severity of infection with extremely drug-resistant forms of the bacillus. Treatment of this condition necessitates between 18 and 24 months of pharmacotherapy with anti-tuberculous drugs that have significant toxicity. The South African Medical Research Council put out a press release in 2007¹⁶, setting out its viewpoint regarding the epidemic and the measures necessary to contain the spread of the infection, especially the public health measures:

“Aside from the clinical challenges, management of XDR-TB poses a significant challenge to public health practice, especially within the context of HIV, given the effective transmission of XDR-TB to HIV-positive individuals and the consequent extraordinary high mortality reported. Classical public health interventions for infectious diseases aim to contain infection, often through quarantine or detention of affected individuals. However, protection of public health always comes at a cost to individual rights, particularly those around freedom and privacy, creating an inherent contradiction in the control of infectious diseases such as XDR-TB.

In liberal democracies, the power vested in public health legislation is generally accepted, ie. the state intervening and limiting individual rights when the unlimited exercise of such rights may result in harm to the greater community, given the ethical and legal obligations of the state to ensure that communities are protected against the consequences of an infectious

¹⁶ This document does not contain details concerning authorship of the opinion expressed although queries are directed to Dr Karin Weyer. The press release was made on the 30th January 2007 and is available at www.doh.gov.za/docs/pr/2007/pr0130.

disease. It is accepted that fundamental individual rights may legally be limited by a law of general application that complies with the necessary Constitutional safeguards, and public health legislation usually contains substantive provisions that override individual rights in order to prevent serious risk to public health. Nevertheless, contemporary biomedical ethics put strong emphasis on the rights of the individual and on the principles of autonomy and self-determination, stressing that any limitation must be reasonable and justifiable in an open and democratic society, based on human dignity, equality and freedom, and using the least restrictive measures available to accomplish public health goals.”

This publication goes on to express the view that some of the legislation invoked by health authorities in controlling XDR-TB may be unconstitutional and remains to be tested for validity. That this has not yet happened is surprising, considering the subsequent events in the country.

b. The history of events in South Africa since the identification of XDR-TB

In South Africa, patients identified with XDR-TB have been incarcerated against their will for in-patient hospital treatment. This has been reported in numerous press articles including the following release in the New York Times, published on the 25 March 2008 and written by Celia Dugger (2008: March 25)

PORT ELIZABETH, South Africa — The Jose Pearson TB Hospital here is like a prison for the sick. It is encircled by three fences topped with coils of razor wire to keep patients infected with lethal strains of tuberculosis from escaping. But at Christmas time and again around Easter, dozens of them cut holes in the fences, slipped through electrified wires or pushed through

the gates in a desperate bid to spend the holidays with their families. Patients have been tracked down and forced to return; the hospital has quadrupled the number of guards. Many patients fear they will get out of here only in a coffin.

“We’re being held here like prisoners, but we didn’t commit a crime,” Siyasanga Lukas, 20, who has been here since 2006, said before escaping last week. “I’ve seen people die and die and die. The only discharge you get from this place is to the mortuary.”

Struggling to contain a dangerous epidemic of extensively drug-resistant tuberculosis, known as XDR-TB, the South African government’s policy is to hospitalize those unlucky enough to have the disease until they are no longer infectious. Hospitals in two of the three provinces with the most cases — here in the Eastern Cape, as well as in the Western Cape — have sought court orders to compel the return of runaways.

The public health threat is grave. The disease spreads through the air when patients cough and sneeze. It is resistant to the most effective drugs. And in South Africa, where these resistant strains of tuberculosis have reached every province and prey on those whose immune systems are weakened by AIDS, it will kill many, if not most, of those who contract it.

As extensively drug-resistant TB rapidly emerges as a global threat to public health — one found in 45 countries — South Africa is grappling with a sticky ethical problem: how to balance the liberty of individual patients against the need to protect society.

It is a quandary that has recurred over the past century, not least in New York City, where uncooperative TB patients were confined to North Brother Island in the East River in the early 1900s and to Rikers Island in the 1950s.

In the early 1990s, when New York faced its own outbreak of drug-resistant TB, the city treated people as outpatients and locked them up in hospitals only as a last resort.

Most other countries are now treating drug-resistant TB on a voluntary basis, public health experts say. But health officials here contend that the best way to protect society is to isolate patients in TB hospitals. Infected people cannot be relied on to avoid public places, they say. And treating people in their homes has serious risks: Patients from rural areas often live in windowless shacks where families sleep jammed in a single room — ideal conditions for spreading the disease.

“XDR is like biological warfare,” said Dr. Bongani Lujabe, the chief medical officer at Jose Pearson hospital. “If you let it loose, you decimate a population, especially in poor communities with a high prevalence of H.I.V./AIDS.”

But other public health experts say overcrowded, poorly ventilated hospitals have themselves been a driving force in spreading the disease in South Africa. The public would be safer if patients were treated at home, they say, with regular monitoring by health workers and contagion-control measures for the family. Locking up the sick until death will also discourage those with undiagnosed cases from coming forward, most likely driving the epidemic underground.

“It’s much better to know where the patients are and treat them where they’re happy,” said Dr. Tony Moll, chief medical officer at the Church of Scotland Hospital in Tugela Ferry. It is running a pilot project to care for patients at home.

Some 563 people were confirmed with extensively drug-resistant TB last year in South Africa and started on treatment, compared with only 20 cases in the United States from 2000 through 2006. A third of those patients in South Africa died in 2007; more than 300 remained in hospitals.

Further complicating matters, South Africa’s provinces have taken different approaches to deciding how long to hospitalize people with XDR-TB. In KwaZulu-Natal, the other province with the most cases, the main hospital is discharging patients after six months of treatment, even if they remain infectious, to make room for new patients who have a better chance of being cured. The province is rapidly adding beds, part of a national expansion of hospital capacity for XDR-TB.

“We know we’re putting out patients who are a risk to the public, but we don’t have an alternative,” said Dr. Iqbal Master, chief medical officer of the King George V Hospital in Durban.”

This article clearly defines the nature of the problem and the ethical issue surrounding public health measures. The question posed is whether it is ever justifiable to restrict the autonomy and freedom of the individual in order to serve the interests of the community by protecting it from the risk of communicable disease.

Beresford (2006: September 8) writing in the Mail and Guardian newspaper in September 2006 defended the policy of isolating XDR-TB carriers as follows:

“The only way to prevent the spread of XDR TB is to isolate its carriers. Mary Edginton of the Wits medical school said urgent attention should be paid to public health laws that allow for the quarantining of people with diseases posing a public health risk, such as TB.

In the United States, doctors use similar laws to incarcerate and forcibly treat TB patients when it is considered to be in the public interest. South Africa has similar legislation, but it does not seem to have been enforced for many years, perhaps due to concerns that it is in conflict with the Constitution.

However, some experts say that this is merely a perceived obstacle as the Constitution also guarantees communal rights, including protection from infection and the right to a safe environment.

Karin Weyer of the Medical Research Council (MRC) has called for test cases to be taken to the Constitutional Court to establish the legal requirements for quarantine and compulsory treatment.

In an MRC policy brief published this year, before the XDR outbreak was announced, Weyer called for the enforced hospitalisation of high-risk MDR TB patients on the grounds that the risks to society outweigh individual rights. But she does not support forcible treatment of MDR TB patients, given the dangers and side effects associated with the drugs.

Edginton said quarantining was critical to curb the disease when some people would not or could not take the full course of drugs.

Even tougher issues are what to do with suspected MDR cases during the six weeks it can take for a laboratory to confirm the disease, and how to deal with MDR TB patients whom the treatment has failed to cure. Incarcerating the latter until they die which could be years would be ethically questionable and impractical.”

The question needing to be answered is whether involuntary hospitalization and loss of freedom and autonomy can be ethically defended.

c. The justifiable limits to personal autonomy when faced with infectious diseases

In dealing with public health issues, the ethical justification for coercive action is founded upon utilitarian theory.

Utilitarian theory

The notion that the greatest welfare of the greatest number should be the sole arbiter of what is morally acceptable has led to public health policies such as vaccination initiatives. These interventions are effective in reducing the burden of disease and have a very low statistical risk of causing harm to individuals undergoing vaccination. A similar rationale could be applied to XDR-TB, arguing that intervention is necessary to prevent harm to others and that a few will need to suffer in order to secure the safety and health of the vast majority of the population. Legitimate state-sponsored intervention, interfering directly in the lives of individuals, is mandated even by John Stuart Mill because it will prevent harm to others. By utilitarian standards, the consequences of intervention are the sole arbiter of what is acceptable; neither the nature of the intervention nor the rights of individuals are of any consequence in the utilitarian argument. Yet there is clearly a big difference between the two situations described: the vaccination policy that carries little risk and great benefit versus incarceration of XDR-TB patients for lengthy periods of time with no scientific evidence that such measures will have any impact on the prevalence of XDR-TB infection among the community. The scale of the harm caused to individuals drawn into coercive treatment and the scale of benefit accruing from the intervention are very different to the example cited concerning vaccination. It seems implausible to think that the same arguments should be applied to both situations. If the scale

of the intervention and the benefit accruing were irrelevant, a thought-experiment may be conducted in which a suggestion could be made that because HIV-AIDS is such a serious cause of morality and disease in Southern Africa, that every identified positive male should be subjected to penile amputation in the interests of curbing the epidemic. The harm accruing from such a bizarre policy is arguably less than that of incarcerating an innocent individual for periods of up to 2 years. Reduced to the absurd, the utilitarian argument clearly has limitations founded on common morality and the notion that individuals have rights. The interests of the majority cannot be exercised at the expense of individual rights. This point has also been made by Rachels (2007: 104) in his description of the "peeping Tom" whose inclination it was to take photographs of an unsuspecting woman who was changing her clothing and then circulating the pictures to his colleagues on the police force¹⁷. The notion that no harm had been done (because the great majority derived pleasure from this exercise) could not be sustained when the right to individual privacy was considered.

Deontological ethics

The Kantian view of the XDR-TB dilemma would be founded upon the need to respect the dignity of individuals. A Kantian ethicist would argue that the autonomy of individuals is limited only by the need to respect others. The risk of harming another being would only become morally significant if the action causing harm were consciously and deliberately executed. The occurrence of disease and the harm that one individual brings to another because of infectious disease cannot necessarily be an issue of moral blameworthiness. Those who have no awareness and no knowledge of the diseases they have cannot be held accountable for any harm they inadvertently bring to others. These considerations do not apply to individuals who knowingly put the life and welfare of others at

¹⁷ This case, cited by Rachels (2007: 104), is taken from the records of the U.S. Court of Appeals and can be accessed as *York v. Story*, 1963.

risk by virtue of their behaviour. Hence, an HIV-positive man who knowingly exposes his partner to the risk of disease without his or her consent does so in a morally-blameworthy fashion. Kantians would condemn such actions and yet see no reason to intercept those actions causing a risk to others; instead they would hold the agent responsible for his or her actions and allow him or her to face the consequences: both legal and moral.

A Kantian therefore would see little scope for restricting the autonomy of the individual in these circumstances although they would condemn actions that deliberately expose others to an increased risk of disease. By this account individuals would have responsibility for taking their own medication and seeking advice about treatment which may even incorporate voluntary quarantine.

Involuntary incarceration, by Kantian standards would be an exercise in which the individual would experience considerable setbacks to his or her interests. The categorical imperative indicates that everyone should be treated as an end in themselves and not merely as the means to some other end. The question then becomes one of whether involuntary quarantine for up to two years is “merely the means to some other end” and against the autonomous interests of the individual. By the newspaper accounts of the actions of those held against their will, the incarceration they suffered was not seen by them as being in their own best interests. Kantian ethics would therefore condemn such incarceration as morally indefensible.

Kantian ethics therefore defends autonomy of the individual, above all else. There is, nevertheless, an expectation that the individual should exercise their own moral agency in doing the right thing by way of seeking treatment and limiting the risk that may accrue to others. Although no Kantian would think it a morally-defensible, generalizable principle that any individual should wilfully expose others to a risk of

infectious disease, they would also regard any socially-imposed restrictions as an indefensible infringement of individual autonomy. In these arguments the Enlightenment notion of self-awareness and self-governance predominate.

Communitarian philosophy

The communitarian perspective would have no difficulty arguing the restriction of personal autonomy in favour of communal interests. In its South African iteration, Ubuntu would require respect and compassion for others as well as solidarity with the majority social view. When communitarian standards are invoked, medical decisions made by individuals may not seem to be in their own best interests because they may express the will of the community rather than that of the individual. However, what is practiced in South Africa may be philosophically consistent with a communitarian view without being the view of the community. Certainly those who sought their own freedom by escaping from custody had no feeling of solidarity with any communal compulsion regarding their management; although the exercise of legal authority is the mechanism by which public health interventions are achieved, both the laws enacted and those who invoke them do not necessarily derive from or, subscribe to, any particular ethical code.

Principlist ethical reasoning

From a principlist perspective, competing principles of preventing and removing harm to others (beneficence and non-maleficence) would be weighed against the need to respect the individual autonomy of those identified to be carriers of XDR-TB. Principlists faced with competing principles such as these would resort to specification by which the applicable moral norms would be further elaborated with particular reference to the question at issue. In this case, non-moral aspects of the managing XDR-TB would be relevant; any infringement of patient autonomy would need medical justification before being morally

acceptable. In this context the need for quarantine and the efficacy of such measures as a way of preventing the spread of XDR-TB would need to be established. This type of information is referred to by the South African MRC statement when they allude to conditions for enforced hospitalization. This, they argue, must take place within the stipulations of the Siracusa Principles (United Nations: 1985) which include, inter alia, the criterion that whatever restrictions are imposed upon the freedom of individuals should be:

“.....based on scientific evidence and not drafted or imposed arbitrarily, ie. in an unreasonable or otherwise discriminatory manner”.

On the issue of scientific evidence, value judgements need to be made. These are imprecise because the nature of medical scientific enquiry is that of gathering epidemiological evidence as a basis for inductive reasoning about the efficacy of interventions; as such, evidence is always a matter of probability and therefore subject to revision as a result of accumulating evidence. Evidence that locking-up XDR-TB patients will be an effective intervention in preventing the spread of the disease does not exist. Singh et al in their article (which actually advocates quarantine) quotes the World Health Organizations recommendations regarding multi-drug resistant TB: they write:

“WHO recommends that persons with MDR-TB voluntarily refrain from mixing with the general public and from those susceptible to infection, while they are infectious and in ambulatory care [30]. The document is silent on what steps to take should such voluntary measures fail.” (Singh 2007: 0021)

In the absence of good evidence that overriding patient autonomy is a necessary and effective way of preventing harm to others, principlists would not endorse coercive treatment to the point that individuals may be asked to surrender their liberty. To the extent that anti-tuberculous

therapy may be effective treatment of a communicable infectious disease, and in view of the non-maleficence principle, lesser forms of coercion would probably be justified by a principlist approach that overrules the prima facie respect for autonomy and informed consent. Hence, in the same way that vaccination is justified for the prevention of communicable disease, involuntary treatment of individuals infected with XDR-TB would be acceptable, even if such therapy was associated with a risk of adverse effects due to the toxicity of the anti-tuberculous medication. The justification for such a stance would be the evidence of drug-efficacy (which does exist), the need to protect the un-infected but exposed members of society from communicable disease and in the case of the affected individual, paternalistic concern for their health welfare. This reasoning would, however, only be invoked where informed consent could not be elicited from the individual.

The prevalence of tuberculosis among poor communities also raises issues of social justice when considering whether involuntary quarantine can be defended. Those who contract tuberculosis are often the poorest members of the community and the most susceptible to being further disadvantaged by having their liberty curtailed. Singh (2007: 0020) writes the following:

“In the modern era, tuberculosis is recognised as a disease that preys upon social disadvantage [23, 24]. Thus, the inadvertent deterrent impact that health and social welfare policies are having on the hospitalisation of such patients needs to be explored. Faced with the prospect of being deprived of their gainful employment and / or having their welfare benefits suspended for the duration of hospitalisation — which in the case of MDR-TB or XDR-TB could last 18 – 24 months — many MDR-TB patients opt not to stay in hospitals, where their treatment adherence and resistance profile could be closely monitored by health personnel.”

This insight is echoed by others: Solomon (2007) writing on the subject of forced confinement, cites Lisa Schwartz, a McMaster University healthcare ethicist and professor of epidemiology. She writes:

"Historically, the people most likely to be quarantined and have their civil liberties taken away are the poor, the marginalized, the less well-off, who don't understand the circumstances and have the most to lose by being quarantined."

Not only are the individuals most likely to contract XDR-TB those with the lowest personal stakes in the social lottery, but they may also have been exposed to the risk of infection as a result of poor social and medical services. Singh (2007: 0020) notes:

"The factors that facilitate the spread of tuberculosis are well known and abundantly present in sub-Saharan Africa. Alongside inadequate health care system response, poverty and global inequity contribute to the worsening of the global TB situation [19, 20]. According to South Africa's Medical Research Council, about half of adults in South Africa with active TB are cured each year, compared with 80 % in countries with better resources. Moreover, nationally, about 15 % of patients default on the first-line six-month treatment, while almost a third of patients default on second line treatment [21]. This highlights the urgent need for the health system (which includes health-care workers) to reinforce the DOTS (directly observed treatment, short-course) and DOTS-plus strategy, to revise current adherence counselling and public information strategies, and to actively promote avoidance of a 'victim blaming approach'. The emergence of MDR-TB and XDR-TB is an indicator of the poor implementation of South Africa's TB Control Programme."

The requirements of social justice may be met in different ways; libertarians see justice achieved through the conservation of property and liberty rights while egalitarians believe that everyone in society should have an equal share of certain goods, including health care. John Rawls (Beauchamp 1991: 367¹⁸) has argued that justice is the “first virtue of social institutions”. From the original position, he derives his two principles of justice, namely that each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others and secondly that social and economic inequalities are to be arranged so that they are reasonably expected to be to everyone’s advantage and attached to positions and offices open to all. By this account, injustice consists of inequalities that are not to the benefit of all. No-one, asked to adopt the original position behind the veil of ignorance, would choose to be exposed to the possibility of indefinite quarantine should they happen to contract tuberculosis. No-one operating from behind a veil of ignorance would choose to organize state health facilities in such a way as to render access to effective anti-tuberculous treatment impossible. Yet, those who face involuntary quarantine due to XDR-TB face a loss of liberty (and autonomy) partly on the basis of an unjust social structure that has failed to arrange the inequalities in social services to the advantage of those who benefitted least from the social lottery. This situation does not mandate any further loss of individual liberty but compounds the social injustice inherent in South African society.

In summary, the classical defence of coercive public measures using utilitarian arguments fails on the grounds that the extent of the intervention sought against individuals has no precedent and exposes the limitations of utilitarian theory where extreme positions, contrary to common morality, arise because of its failure to recognise individual

¹⁸ Rawls’ book *A Theory of Justice* was published by Harvard University Press in 1971. The citation provided here refers to extracts from this text, reprinted in Beauchamp’s book *Philosophical Ethics* published in 1991.

rights. Kantian ethics also fails to justify involuntary quarantine, instead making individuals morally responsible for seeking their own treatment and in the process refraining from bringing harm to others knowingly. The communitarian arguments would support the quarantine of infected individuals if that view was held to be representative of communal opinion; however, there seems little evidence of that and the acceptance of being a member of society encompasses an acceptance of both the benefits and burdens of that community. Finally, the principlists would find no defence for involuntary quarantine in the absence of convincing scientific evidence although lesser interventions of greater scientific validity would be endorsed.

A compromise to the ethical dilemma presented by XDR-TB may lie in tolerating some infringement of autonomy founded upon coercive treatment of individuals who refuse voluntary intervention; however, there seems to be little moral justification for involuntary quarantine. This conclusion is not the same as that arrived at by Singh et al who appeal to judicial mechanisms as a means of enforcing involuntary isolation. To do so, they cite a case on HIV-infected man who indulged in “irresponsible and risky” behaviour in Sweden. Following his detention in hospital, the man complained to the European Court on Human Rights; Singh (2007: 0022) writes:

“The court ruled that the institution of detention for infectious disease must be appropriate to the nature of the disease. Where these conditions are satisfied, deprivation of liberty is justified, both on grounds of public policy and in order to provide medical treatment to the affected party. In ruling in favour of the applicant the court found that the compulsory isolation of the applicant by Swedish authorities ought to have been considered only as a last resort in order to prevent him from spreading HIV after less severe

measures had been considered and found to be insufficient to safeguard the public interest.”

They follow this with a value judgement about XDR-TB:

“We believe that the forced isolation and confinement of individuals infected with XDRTB and selected MDR-TB may be an appropriate and proportionate response in defined situations, given the extreme risk posed by both strains and the fact that less severe measures may be insufficient to safeguard public interest”. (Singh 2007: 0022)

The example cited by Singh et al is a curious choice because it illustrates how the institution and application of rigorous public health legislation could lead to un-workable ends. By that standard, many in South Africa would run the risk of involuntary detention for any number of disorders that could be counted as harmful to others. Hence, many HIV infected but sexually active men and women could be detained; those who smoked in public places could be detained; those whose consumption of alcohol increased the probability of anti-social behaviour could be detained against their will: that this is not so rests upon the value judgements of those who are in a position to choose whether or not to invoke the powers of existing laws.

Despite these arguments, there are other situations where infectious diseases may induce involuntary hospitalization for in-patient care. These situations are often those of severe risk to the individual concerned as well as members of the public. An example would be quarantine of individuals with viral haemorrhagic fever. In these circumstances the risk is immediate and overwhelming and the duration of isolation a matter of weeks rather than months. Legislation to deal with such emergencies needs to be on the statute books and it is a matter of both medical and moral judgement whether the provisions of such laws are invoked.

Coker (2001: 221), examining the English and American response to XDR-TB concludes his assessment with the following remarks:

“There will always be a need to balance the rights of individuals and the need to protect the public health, and there will always be demands for the restriction of individuals’ liberty. But we should, I would argue, be cautious when we adopt these measures and consider the following points: First, that in the case of detention and the control of tuberculosis there is little evidence to show that this policy benefits the public health. Second, that there is a risk that fundamental human rights may be overridden unnecessarily. And third, that coercive practices may act as a smoke screen for improved, but more complex or more costly, public health responses to the root causes of tuberculosis control failures.”

He continues:

“Gostin has described a framework that reflects the Siracusa Principles mentioned earlier that tailors them for analysis of public health tools. He argues convincingly that, before coercion is justifiable, the risk posed should be demonstrable, the proposed interventions should be demonstrably effective, and the approach should be cost-effective. In addition, he argues that any sanctions should be the least restrictive necessary to achieve the purpose and that the policy should be fair and non discriminatory. If we scrutinize the policies of detention in New York City and England using these human rights principles, I would argue they are not just.” (Coker 2001: 221)

I would argue the same is true in South Africa. However, the law here (and elsewhere) makes provision for involuntary detention to protect the community. That stance is both legally and morally defensible but in the application of that law, morally unacceptable infringements of patient

autonomy have taken place. This case, unlike the preceding two discussions, carries both legal and moral grounds for restricting individual autonomy based upon the threat of communicable disease in the community, the only exception to this argument being the Kantian view.

Limitations of autonomy in South African medical research

The next example concerns the extent to which autonomy rights are respected when the welfare of the community may be enhanced by acquiring new knowledge through medical experimentation. This is an area of social life largely beyond direct legislative control and usually regulated by institutional review boards and professional codes of ethics, including the Helsinki Declaration (World Health Organization: 1996). In the examples cited so far, autonomy has only been legally breached when large-scale harm has threatened the community although moral arguments would sustain greater limitations to personal autonomy.

Ethically acceptable medical research depends upon the informed consent of those who participate in experiments aimed at establishing the scientific validity of hypotheses. Informed consent for any medical intervention is an expression of patient autonomy and a necessary component of self-governance. In the case of medical research the function of consent was initially focussed on preventing harm to those exposed to medical experimentation and was only formally spelt out after the Nazi war crimes became evident in the aftermath of the Second World War. Beauchamp and Childress (2001: 77) have expressed the view that the focus has now shifted from protecting the participants from harm to that of showing respect for their autonomy. However, the nature of the transaction that takes place when informed consent is elicited differs considerably between the situation of medical research and the practice of clinical medicine. In the latter circumstance, the attending clinician has a duty of beneficence to the patient and the patient is encouraged to understand his or her circumstances in the light of all the available options before electing a course of management that would be of greatest benefit. Medical research is predicated on entirely different objectives; here the attending clinician is intent upon establishing or refuting a hypothesis and, in part, the patient who is recruited to the clinical trial

represents a means to that end. Although research is conducted into therapeutic avenues that are assumed to have beneficial properties, the presumption of beneficial effects is always in question prior to the study. Some studies also incorporate the possibility of adverse outcomes. Hence the participating research subjects are not faced with the best of the available choices but simply a choice of whether or not to participate in a programme of treatment that is usually narrowly defined into one of two treatment options; of these treatment options, at the very least, the experimental treatment will be of unknown efficacy. The research subject therefore is faced by a clinician who does not have the sole objective of beneficence to the patient and who will then elicit consent to participate in clinical research, which does not have to do with selecting the best available option for treatment.

To justify medical research by arguing that it only may take place with the informed consent of the patient is dissimulation because the notion of informed consent differs between research and clinical environments. The procedural aspects of consent are similar but the scope and intentions of the consent obtained are different. If the autonomy of research subjects is to be fully respected, clinical research may become very difficult, if not impossible. The following hypothetical scenario illustrates how difficult it may become: consider the situation of a clinician who has a new drug to treat hypertension in pregnancy. This clinician wants to test the efficacy of the drug in a randomised controlled trial with an experimental arm consisting of the new drug and a control group being treated with a well-established drug of known efficacy. This clinician may then approach one of the pregnant patients attending the hospital because of hypertension in pregnancy and may ask her to participate in the study. If the question were to be phrased as:

“I have a new drug for treating hypertension in pregnancy that I would like to compare with existing treatment because it may be a better drug than those we use at the moment and you would be a suitable person to

try out the new drug, providing you are happy to do so. This study has been approved by our Research Ethics Committee and I can give you some more information about how the drug works which we will explain to you and will also provide you with a written copy”

A reasonable number of people are likely to consent to the experiment providing their questions have been satisfactorily answered. However, should the question be phrased differently, the response may be very different:

“I have a new drug for treating hypertension in pregnancy that I would like to compare with existing treatment. We suspect that this new drug may be a better drug than those we use at the moment but we really don’t know that this is the case. It may also have unexpected side-effects. Should you decide to help with this study you would have a 50% chance of getting the new drug which we are not sure is effective or you will receive the standard drug which we always use and know to be effective. Should you decide not to participate in this study, you would also have a choice of other anti-hypertensive drugs that are not included in the study, some of which are also known to be highly effective. This study has been approved by our Research Ethics Committee who think that finding out whether this new drug is safe and effective is a valid scientific question and they are happy that benefit of knowing about how effective this drug is outweighs any risk that may be involved in doing the study. I can give you some more information about how the drug works which we will explain to you and will also provide you with a written copy”

Given the latter form of counselling, most reasonable people would refuse to participate in the clinical trial of this nature unless they had additional convictions about the need to foster scientific knowledge and were prepared to sacrifice some their own interests in pursuit of this objective.

Obtaining informed consent as a precondition for medical research is a therefore a process that does not necessarily satisfy the objective of

allowing individuals to exercise full autonomy. But full autonomous decision-making is an ideal rarely, if at all, attainable and substantial autonomy may be all that can be achieved. In conceding that some infringement of ideal autonomy is likely, how far does this concession extend before "informed consent" is a smoke screen for unethical practice? Manipulation of research subjects may certainly occur through incomplete disclosure and deception, various forms of coercion and covertly by virtue of the use of the language of informed consent which disguises the true intentions of the researchers from their study subjects. The question to be addressed is whether Beauchamp and Childress (2001: 77) may have misconstrued the purpose of informed consent for medical research because it does not allow the expression of full autonomy for the individual; is it merely permission of sorts that at best serves to protect the patient through the principle of non-maleficence? Is medical research, in fact, a justifiable infringement of patient autonomy?

A case history will be presented followed by analysis of the preceding question

a. Case history

Benatar (2002: 1131) has described the situation of a black South African woman in the Journal of Social Science and Medicine:

"Ntombi is in her middle twenties. She has received little if any formal education and spends a large part of her day collecting fuel and water, and preparing food for the daily survival of her family. Like many rural Africans she has no access to electricity or piped water. During her short life she has witnessed, and been the victim of, more suffering and misery than any of us could imagine or bear. She has lost many of her close family parents, siblings and children to violence, poverty, and disease. Despite her misfortunes and multiple deprivations she copes with her lot with

courageous acceptance, and continues to make contributions to her family and her society. Ntombi lives on an annual sum of money approximately equivalent to the amount that a person from the modern western world lives on for less than a day. She is aware of the disparities in wealth between the people within her country. She may also possibly be aware from the television set in a local store of the lifestyles of people in other parts of the world. Those whom she sees as living comfortable lives are mostly white, while those who live like her are mostly black. The differences she sees in the other ways of life are awe inspiring, incomprehensible and unimaginable for her. Ntombi is pregnant with her third child and is receiving care from a local midwife. During her pregnancy a team of health care workers that includes people from her own country and others who are visiting from abroad approaches her. She is told that there is a significant possibility that she is infected with the human immunodeficiency virus and that her child may acquire this infection during childbirth or breast-feeding. She is asked if she would be willing to be tested for HIV infection and, if positive, to participate in a trial of a drug which may reduce the chances of transmission of infection to her child. She is also told that she should not breast feed her child if she tests positive in order to reduce the risk of transmission. She is both bewildered and afraid. She does not feel ill. Who are these people? What is their real intention? Why are health care facilities so inadequate in her village? Why is such a large team of people with access to seemingly vast resources coming to study her? Is it for her benefit or for theirs? How will her life change if she discovers she is HIV-positive? What will happen to her if she refuses to participate? If she accepts what will happen to her and her baby when the study is completed? Will she or her baby really be better off as a result of this study? What effect will failure to breast-feed have on

her baby? What will her spouse say about her participation in the trial? Whom can she ask for answers to these questions? Can she rely on all the explanations given by the researchers? Should she consult the leaders she respects within her community? Should the community play a role in deciding whether its members should participate in the trial, or should she decide for herself? If she is encouraged by the research team to decide for herself how may this affect her relationship with the community?"

This case history illustrates many of the difficulties inherent in consent for research and especially consent for research in multicultural developing-countries where the inequities in power between researchers and their clients are compounded by differences in social context.

b. The justifiable limits to personal autonomy in the setting of medical research

Analysis of the preceding case shows firstly that the educational and social milieu from which Ntombi came had deprived her of any idea of how western medicine is practiced and how scientific knowledge may be acquired. Her needs in arriving at an understanding of the proposal put to her was much greater than that of any educated person who enters a scientific study already able to justify the practice of scientific research. Ntombi was provided with no explanation for the proposal put to her other than it might prove to be beneficial to her child. Furthermore, those who approached her seeking consent for the study were not those she had trusted and confided in previously; instead they were a group of strangers and people from abroad, whose presence and involvement in her care must have been especially puzzling because she had no appreciation of what they were trying to achieve. These strangers then proceeded to suggest to Ntombi that she may have had HIV infection – a condition of which all South Africans will have had first-hand knowledge although many uneducated pregnant women may have had little idea that they

could pass the infection to their children during childbirth or through breastfeeding. This news was imparted to Ntombi without her having yet being tested and in a way that she was forced to consider the possibility of her unborn child being harmed by an infection which she did not know she had - because she was feeling completely well. Having been thus intimidated by the threat of inadvertently harming her baby, she was asked whether she wished to be tested and to participate in the study. This process effectively sought screening and treatment of Ntombi, not for her own sake, but in order to accomplish the ends of the study; furthermore, linking treatment to participation in the study meant that Ntombi was left with few choices if she were to protect her child from this hitherto, unforeseen harm. No alternative option of screening and treatment was offered to Ntombi and she was also not informed whether the trial drug was known to be effective, whether she would definitely get the drug or whether there were other ways of preventing infection. Ntombi was then also admonished about the risks of breastfeeding; this would have been antithetical advice given to a poor South African living in rural circumstances where the costs and implications of formula milk feeding would make such an intervention unlikely and unaffordable. Not only would this be impractical but it would also be completely at odds with the customary practices of her community. With this in mind, further pressure will have mounted on Ntombi to do what she could to help her child who now seemed to be at risk of unexpected illness. Ntombi, however, also found herself cut-off from her community where the decisions made were communal endorsements. Deviating from communal practice was not a common occurrence and here she was expected to make an important decision without having the wisdom of her elders available to her.

Ntombi was thus, disempowered in many different ways: at a threshold level, her competency to give consent went untested but may have been called into question had she elected to refuse the study on the basis of

communal pressure. Her understanding of the process of research as well as her understanding of the specific research question was inadequate because she lacked information. The disclosure of information was far short of what was required to allow Ntombi to make a rational decision about the study. Finally the process of voluntary decision-making was manipulated through coercion because her treatment and that of her child was made contingent on her participation in the study with no other alternative being offered. She was also not given the option of consulting her own social structures, whose views on the proposed study may have affected her subsequent relationships within the community.

Yet, in other circumstances, with other research subjects who may have been better educated, the request put to Ntombi may have been sufficient to allow an informed decision. Certainly, the request put to Ntombi may have fulfilled the legal requirements of informed consent. The moral question, however, remains: is informed consent, as an expression of patient autonomy and as it is practiced for the purposes of medical research, justified?

Deontological ethics

The notion of informed consent is based upon the need to respect the dignity of individual human beings by according them certain rights including the right of self-governance. It is a deontological notion defended by Kantian ethics. A Kantian ethicist would not agree with any person being used as a means to an end but would insist that any agent is also seen as an end in themselves. To be morally acceptable, the maxim according to which others are to be treated would also need to be universalizable. Where individuals are asked to participate in research projects, there would be an expectation that they should be able to benefit from their involvement while being given every opportunity to decide for themselves whether they wish to be involved. The requirements of informed consent would be sought and a Kantian ethicist

would not accept any form of manipulation or deceit; telling the truth and respecting the dignity of others would require full disclosure without coercion. In this case, Ntombi suffered on both these counts and a Kantian ethicist could not endorse any process in which the participants did not understand the experimental nature and purpose of a clinical study. Kantian ethicists would have difficulty defining or accepting substantial autonomy as a concept of less than ideal autonomous decision-making.

Utilitarian theory

A utilitarian approach to eliciting consent for research ethics would focus on the consequences of the process; where the benefits of ascertaining whether something is of great benefit to the majority of people is concerned, utilitarians would focus on the common good rather than the possibility of individual disadvantage, providing that any harm accruing to individuals was not overwhelming. Rule-utilitarians would create rules that served the greatest interest of the majority and some of these rules would necessarily protect individuals from exploitation of many different kinds. Rule-utilitarian reasoning applied to the situation of Ntombi would consider the beneficial consequences of medical research and would, in principle, support clinical trials; furthermore, rule-utilitarians may choose to accept that research conducted in circumstances where the researchers are held accountable for their actions (to research ethics committees and the scientific community at large) are likely to be adequately designed to ensure that no person is exploited or exposed to undue risk as a consequence of the study. Rule-utilitarians may accept that the process of obtaining fully informed consent is an onerous, if not impossible task and would raise no objections to the idea that only substantial agreement be sought for participation in a clinical trial. They would especially endorse this view if the process of obtaining consent became an impediment to effective research endeavour and prevented the conduct of clinical studies that were beneficial to the majority of people.

Communitarian philosophy

Communitarian philosophy, built upon the role of the individual in society would expect beneficent contributions to be made by individuals in support of their community. In this light, a readiness to participate in the training of medical personnel and assistance with the pursuit of medical knowledge through clinical research would be a required of everyone within the society. The rights of individuals would be secondary to the interests of the community. Within this theory, the issue of the virtues necessary to fulfil a social role are pertinent, not only in respect of the subjects of clinical research but also those of the researcher: the motivation for action is considered more morally important than the action itself. In this connection, the motivation for carrying out research may vary: some will carry out research because they believe in benefitting mankind; others will see research as an opportunity for establishing and furthering their own reputation and some may see research as an opportunity to earn money, the profit motive being further augmented by multi-national drug companies who are in the business of selling their products. The practice of medicine and the endeavour of conducting medical research have the characteristics of a complex, co-operative socially-established human activity. MacIntyre (1985: 227) has spelled out the importance of practices within society, arguing that those concerned with standards of excellence and conducted in the service of both internal and external goods may function for the wellbeing of the community as a whole. In this process, standards of excellence within a practice are established by the history and tradition of that practice. In the context of medicine, with some exceptions, physicians practice within the tradition they inherit, being subject to the standards of excellence of those that preceded them and generally serving their patients beneficently. Some, however, eschew these traditions and see medicine as a means of building personal wealth as a primary aim. The motivation of those who engage in research is less evident and it is likely that many

seek personal fame or even financial reward from contract research; the distinction between clinical practice and research may arise because medical research is less closely tied to a tradition of beneficence than clinical practice. In Ntombi's case the motivation for the research is obscure and to accept that this was an ethical study, by communitarian standards, would have required greater knowledge about the researchers. Whatever their persuasion, it is clear that the communitarians would be less concerned with issues of autonomy than issues of motivation. Communitarian philosophy in the African sense of Ubuntu would require solidarity with communal views: a concern illustrated by Ntombi who felt isolated from her community, being unable to ascertain their opinion nor know how they would react to any decision she might make on her own. The very concept of autonomous decision-making through the process of informed consent is contradictory to the idea of Ubuntu. That the researchers who sought her consent were insensitive to her predicament reflects a form of cultural imperialism through which the moral presumptions of Western society assume universal applicability. In summary, a communitarian approach would endorse less rigorous attention to individual personal autonomy providing the motivation of those engaged in the research were focussed on communal rather than personal benefit; the aspect of Ubuntu adds further emphasis on respecting communal views rather than individual perspectives. In this particular case, the consent sought was inappropriately pursued without understanding the social context of Ntombi and was consequently morally indefensible.

Principlist ethical reasoning

A principlist examining the situation described would explore the question of informed consent as it has already been described. The absence of adequate disclosure of information would be the first problem identified: a subjective standard would require that a greater amount of information be imparted to Ntombi than others who had a better intuitive grasp of

medical research; the failure to foster understanding of the issues also prevented informed consent from being obtained and finally the issue that voluntariness was negated by various attempts at coercive influence also prevented informed consent from being obtained. In the latter regard, Beauchamp and Childress (2001: 95) caution against overcalling manipulative influence by drawing attention to the prevalence of influence in everyone's lives. However, manipulation in pursuit of beneficent intervention is different to manipulation where the ends of others are being served. A principlist would examine Ntombi's case and conclude that informed consent had not been obtained while still allowing more latitude at every level than would be acceptable to a Kantian ethicist.

In summary, Ntombi's case represents an example of research consent that cannot be regarded as morally acceptable by any argument.

However, research is held to be morally defensible once the consent of the research subjects has been secured. This, ipso facto, encapsulates respect for the dignity and autonomy of the individual. The close examination of research practices, arguably, reveals that consent for research is a legal device with the protection of individuals secured by research ethics committees who scrutinize research proposals before they are implemented. If this statement is true, then society endorses some sacrifice of self-interest on the part of the research subject in order to gain knowledge that may be of benefit to many. As such, the autonomy of the individual is not held to be of overriding importance but justifiably infringed, to some degree.

Hence, in examining the arguments for the general moral acceptability of informed consent obtained prior to medical research, it is clear that with the exception of Kantian ethics, the autonomy of the research subject carries less weight than other moral considerations related to the overall benefit of scientific research.

Chapter 6

Conclusions

This thesis began with a consideration of how it came to be that individual autonomy occupies the central role in contemporary medical ethical discourse. In the social milieu of pre-modern man, there was no precept of individual consciousness distinct from the social role played by man. The practice of medicine was structured on the goodwill of the physician whose role it was to exercise the virtue of beneficence and justice in the ministry of the sick. The Hippocratic oath refers repeatedly to these precepts in phrases such as "I will apply treatment for the benefit of the sick according to my ability and judgement; I will keep them from harm and injustice". The precept of beneficent authority associated with physicians had currency well into the 20th Century, long after the advent of modernity changed what it meant to be a person living among a community of other people. Modernity shifted the moral focus from being virtuous in service of the community to individual accountability. The world was considered what the individual perceived it to be and morality was a matter of individual choice. The tradition of medical care, however, persisted and faith in the good intentions of the healer remained unquestioned until the advent of the Second World War. In the aftermath of the Nuremberg Tribunal, the abuse of human subjects for experimental purposes by Nazi war criminals was recognized and the need to protect individuals from harmful experimentation led to the promulgation of the Nuremberg Code which established the need for voluntary consent as a pre-requisite to legitimate research. What applied to research influenced medical practice which subsequently had to account for what an individual might choose to accept as treatment. The autonomous choice of the individual became an issue alongside the other more familiar ethical principle of physician-beneficence.

The third important change in medical ethics (along with physician beneficence and individual autonomy) had to do with the expansion of technological medicine after the Second World War. This resulted in escalating costs of medical care matched to an increasing demand for services from an expanding population. Governments and communities were faced with the realization that not everything that might be done for everyone could be done for everyone. Consequently, rationing and issues of a socially-just distribution of resources were added to the medical ethical agenda.

In the wake of the Second World War, beneficence remained the dominant principle with social justice being seen as a necessary constraint to patient autonomy. Informed consent itself, as an expression of autonomy rights, did not enjoy detailed examination until the 1970's (Beauchamp and Childress 2001: 77). When this happened, the aspect of disclosure of information concerning an intervention (something a beneficent clinician would do) surrendered primacy to the concept that the most important aspect of informed consent was to ensure that the agent understood and voluntarily consented to the intervention, as an expression of autonomous authorization. The ethical priority of the 1970's and 1980's had to do with treating individual patients in such a way that their autonomy was respected before all else. The beneficent physician was still expected to behave beneficently but autonomy had to be asserted and both beneficence and autonomy were governed to some extent by finite resources that had to be seen to be justly distributed. Thus autonomy superseded beneficence during the 1970's while social justice remained a moderating influence on both. This view of medical ethics, based primarily on the freedom of the individual was consistent with Enlightenment philosophy and the tenets of modernity.

Yet, despite being individually free, in the last century humankind found itself living with a legacy of unresolved global poverty amidst great

wealth, environmental degradation capable of threatening life and persistent moral uncertainty.

Liberal individualism which allowed unrestrained expression of self-interest was blamed by some and communitarian views re-surfaced in the late 20th century. These views now challenge the idea that man can indeed live as he chooses to do without reference to his community, his environment or the interests of future generations.

In medicine, individual autonomy remains the central ethical precept although it may now be set against a turning tide of moral philosophy which focuses on a growing sense of community-responsibility, the need to share fairly and show solidarity with others. Questions brought about by rapid changes in new technology, especially genetic technology, have also raised ethical questions that can only be answered with reference to ideas that take no account of individual autonomy as the cornerstone of bioethics. More will be said about genetic technology presently. This thesis set out to examine the role of autonomy as an ethical principle in South African medical practice. It does so by describing its role in determining what ought to be done and by exploring the justifiable limits to its application.

The thesis began with a conceptual analysis of autonomy. Moral autonomy as a form of inescapable individual accountability was distinguished from personal autonomy. Personal autonomy was described as an attribute of man, legitimately limited in various ways including the need to refrain from harming others as well as accepting and sacrificing personal needs in order to serve the interests of others. In doing this, social justice became a focus and our nascent understanding of responsibility for the welfare of our community was fostered. In the practice of medicine, each of these has played a role in shaping the morally-acceptable limitations to individual autonomy.

Several clinical scenarios were examined in the light of the prevailing moral theories to establish whether autonomy remains the dominant concern of ethical deliberation or whether there are existing or changing perceptions about the limits of self-governance in medical practice. The moral theories applied included deontological ethics, exemplified by Kantian theory: this philosophy is a direct expression of Enlightenment philosophy with its emphasis on freedom of the individual and underpins the notion of civil rights and the liberal-individualist society. Utilitarian theory was born of the rejection of divine moral authority as well as rule-based and abstract morality; utilitarianism solely sought happiness and the alleviation of suffering. It too, was a creation of modernity and a tool of social reform (Rachels 2007: 91). The application of utilitarian theory, however, was based upon the quantum of greatest good which sometimes led to the sacrifice of individual interests. Communitarian philosophy was the third theory applied to the ethical problems presented. This theory may be viewed as a reconnection with pre-modern traditions in which morality was a function based upon social obligation; it is a philosophy of growing significance given the plethora of social issues facing modern man. Finally, the cases presented were examined in the light of a principlist approach through which prima facie principles intermediate between moral principles and rules are applied to moral issues in order to evaluate the conflicting claims of individuals facing moral dilemmas. These principles are derived and modified by both deductive and inductive reasoning, appealing to a range of moral theories and relying on casuistry for specification. This approach is prevalent in bioethical reasoning and although describing only prima facie principles, individual autonomy remains arguably the most significant of the principles to be applied.

Kantian ethics, in each and every case described, stood resolutely against any infringement of individual autonomy. The case of the psychiatrically-ill woman did not merit any infringement of her autonomy for as long as she was able to make rational decisions. The woman seeking abortion

retained her right to make whatever decision she chose to make not because a Kantian would want anyone to choose to harm another being but because others needed to respect the autonomous agency of the woman and to allow her the opportunity of choosing to do the right thing or to pursue some less defensible course for which she would be held both morally and legally accountable. The XDR-TB patients would not be held morally blameworthy for the harm they may unconsciously bring to others and incarceration of people infected with XDR-TB would be judged as using certain individuals as a means to further the ends of others. XDR-TB patients would remain morally responsible for their own treatment but their autonomy and freedom to choose (treatment or voluntary quarantine) remain absolute. Finally, the issue of research and informed consent for research would allow no manipulation of individuals or their use to achieve the ends of others. Research subjects would need to willingly and freely accept the terms under which studies were conducted and no lesser consent would satisfy a Kantian ethicist. Kantians, therefore, would rigidly support individual autonomy as a central tenet of respect for the dignity of individual human beings.

Utilitarian theory, applied to the first case of psychiatric detention formulated answers that allowed autonomy to be restricted in the case of antisocial behaviour with temporary restriction of autonomy in cases of attempted suicide. The abortion question would be resolved in favour of the pregnant woman, not because it happened to be her autonomously expressed wish but because the greatest balance of happiness happened to coincide with the pregnant woman's wishes and under different circumstances the same moral reasoning may have resulted in a different outcome. In this regard, utilitarian theory is distinguished from deontological theory which would always defend a matter of principle without any regard for circumstances or consequences. The XDR-TB case would find no issue with infringing individual autonomy in the interests of the majority and the same would apply to the benefits of medical

research that may only be practicable if the standard of consent is set at a reasonable level and if there is a general expectation that research is necessary to sustain society in the face of new medical technology and challenges. Utilitarian theory therefore, as expected, provides a moral basis for discerning what may be acceptable in a number of situations without any categorical assertion of autonomy rights.

Communitarian philosophy applied to each of these situations would support intervention in the case of the psychiatrically-ill woman as an intervention carried out by others in terms of accepted social practices aimed at protecting the community and fostering the interests of the individual, not as a paternalistic exercise, but in the context of exercising virtue in support of others. The will of the individual would be secondary to communal concern. In the abortion case, the question was examined from the perspective of the pregnant woman whose life history could not have been scripted to include an unwanted pregnancy due to rape and the intentions and virtues of the medical team providing care were seen to be conducted in a manner consistent with accepted practice and with good motivation. Hence the will of the pregnant woman was supported, because it was consistent with communal understanding of who she was and what the community would be prepared to offer her. The XDR-TB case would have raised no objections to management that was deemed to be in the interests of the community and the same considerations are applicable to the question of research. However, in both cases what the community endorsed was unknown and may have been at odds with what was being done. Hence a communitarian approach in the South African context would endorse views that led to a morally-acceptable infringement of personal autonomy although the views of the community seem to have no impact on South African society.

The principlist approach retains a deontological approach but seeks justification for overruling conflicting principles in order to arrive at a solution. Hence, principlists avoided addressing the issue of autonomy in

the psychiatric case by questioning the patient's competence. With regard to suicide they would defend a policy of beneficent intervention, overruling the autonomy of the pregnant woman, partly in support of the social symbolism arising from being seen to help others. The abortion case-history shows how principlists could endorse conflicting responses to the autonomy of the pregnant woman and how non-maleficence to the fetus may justify overriding maternal autonomy. In both the remaining scenarios, treating XDR-TB and eliciting research consent, the latitude derived from using prima facie principles means that in every case to some degree individual autonomy may be overridden. Informed consent in the case of principlist reasoning is based upon substantial autonomy and XDR-TB patients may be reasonably expected to accept treatment against their will for the benefit of others and to fulfil the requirements of non-maleficence.

In summary, each of the theories presented stands in contradistinction to deontological theory that recognizes no limitation to autonomy because it sees the capacity for moral action arising only from the free will of individual human beings. Each of the other theories focuses to some extent on the individual in society and the possibility of right action in a social context. Each of the other theories is able to justify some restriction to individual autonomy by virtue of the interests of others.

Liberal individualism, the prevalent Western philosophy is evident also in contemporary South African law; in the cases presented, it is clear that both the Mental Health Act and the abortion legislation prioritize the autonomy and freedom of the individual. The South African law is more consistent with a deontological view than communitarian perspectives. But issues of social importance are increasingly being brought into question by global socio-economic inequality and environmental degradation which puts the survival of the species at risk. The notion of conserving resources to support future generations is currently seen as providing a limit to what man may now exploit simply because he can.

Clearly, there are justifiable limits to individual autonomy conditioned by the need to respect the legitimate interests of others. In medicine, the cost of technological medicine has already challenged society over issues of social justice and rationing of scarce resources is an inescapable priority in all countries of the World. These limitations have to do with the division of resources between members of an existing community. The limitations placed upon the individual choices we seek to make may be further limited by our responsibility to future communities of men and women.

New technology has brought new questions about who we are and what we may become. This is especially evident in the new genetic technologies. Genetic technology has allowed us to identify those at risk of diseases long before they have any manifestations of disease; they have also expanded the possibilities of therapeutic intervention in existing diseases and have made possible future manipulation of human characteristics through genetic engineering involving germ cell DNA. The possibility of manipulating and potentially improving the human genome brings into focus the benefits and risks of such interventions that may be borne by future generations; hence, the responsibility we now face is no longer just one of self-governance but the need to have a broader conception of the good of man and to bear responsibility for the survival of our species. In this way, the power of the new genetic technologies also challenges our conception of ourselves as a species. Dyer (1997: 172), writing about the ethics of human genetic intervention notes the following:

“One of the things that can be said about modern medical ethics is that it is focused on the individual. The centrality of autonomy in bioethics is a reflection of the importance modern (Western) civilization has placed on the individual. One of the things we might anticipate changing is that individualism. We might become, for example, more concerned with the

health of the population (public health) than the health of the individual. This change could be economic and probably will be economic. For example, genetic alteration might be given strong economic incentive if the cost of treating a genetic anomaly (let us imagine addictive propensities) outweighed the cost to society of altering such traits genetically."

This prediction is already true of resource-intensive Western medicine and will probably become equally true of genetic technology, once it is fully incorporated into clinical medicine. Dyer (1997: 171) further structures his argument on the development of a post-modern world which he describes as meaning different things to different people. To some it is a

"..liberation from restraints of tradition, an opportunity to start over, a shattering of old conventions, of form, of language, and of epistemology, particularly the epistemology of objectivist science".

For others however, it represents

"..a more humanistic reconnection with the traditions of the past, a linkage with human forms and styles that prevailed before the more sterile mechanisms of the modern era". (Dyer 1997: 171)

To which Giddens (1991: 52) would reply that post-modernity is the radicalization of changes that began with the European Enlightenment. The confidence in our own powers that emerged during the Enlightenment (Barth's 'absolute' man of the 18th Century) changed as his world around him was changed by him. The consequences of modernity have been profound in every respect, none more so than the "presumption of wholesale reflexivity" (Giddens 1991: 39) and our loss of certainty about what it is we know. These realizations may be sufficient reason to reconsider the certainty with which we exercise our own autonomous will. However, the other consequence of modernity with more far-reaching implications for the autonomy of individuals is that of time and space

distantiation which has led to the creation of a global community. The Enlightenment ideal that we are morally accountable to one another for who we are and how we behave retains its authority. But this alone cannot provide answers for a complex modern world in which the lives of individuals are set in a global community and increasingly inter-dependent. In asserting our right to self-governance, the justifiable limits to our autonomy extend beyond those that may cause direct harm to others. What we choose should be consistent with the welfare of the broader community, the planet and future generations.

In conclusion, South African medicine does not yet seem to be at the cross-roads represented by the transition from modernity into 'post-modernity' although the ethical challenges of new technology will doubtless slowly intrude upon the ordinary clinical practice of medicine. The moral challenges confronting the South African community still consist in meeting the challenge presented by the claims of absolute individual authority confronted by the need to accept the demands of social justice and the legitimate role of communitarian opinion. In this process individual autonomy is necessarily and justifiably limited.

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