

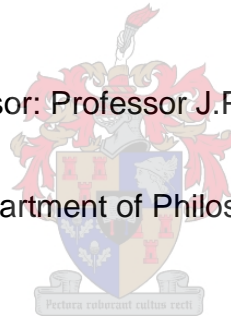
Patients' rights in South Africa's public health system:
Moral-critical perspectives

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Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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SUMMARY

The aim of this dissertation is to critically investigate the nature, status and efficacy of the application of patients' rights in the South African context, with particular reference to the situation of healthcare in the public sector (particularly public hospitals in urban settings). The study focuses initially on the ethical and moral grounding of human rights. Justice theories or theoretical perspectives are themselves abstract; however, they serve as a useful philosophical background that shape worldwide thought on the concept of "human rights". These philosophies lend a high degree of credibility to the notion of human dignity and therefore provide great wisdom in dealing with complex medico-ethical issues, such as patients' rights.

From human rights to patients' rights, the notion of rights is mapped out by following the historical development of the human rights culture internationally, regionally and locally. Against this backdrop, an exposé of South Africa's record in dealing with socio-economic rights is given by presenting Constitutional Court cases in the country dealing with socio-economic rights. The issue of economic, social and cultural rights cannot be dealt with without engaging in a discussion of the very idea of human rights.

Perspectives on patients' rights – the moral principles of autonomy, respect, informed consent and confidentiality and privacy, which form the core of patient's rights – are discussed in detail, focusing on their application to clinical settings.

It is necessary to assess whether there is a correlation between theory (international, regional and local human rights instruments, including the Constitution of the Republic of South Africa and the National Patients' Rights Charter of 1999 (PRC) and practice (the realities at the patient's bedside). The only way in which one can assess the realisation and enforcement of patient's rights is to go to a public hospital and ascertain from patients (out-patients and in-patients) as well as staff (all categories, including hospital management) what their opinions are about the realisation or non-realisation of patients' rights at that particular hospital. A case study (an ethics audit) of the Chris Hani Baragwanath Hospital (CHBH) is presented in this dissertation. Firstly, the researcher analyses the case study and identifies evidence of infringements and violations of patients' rights; secondly, key problems hindering the realisation of patient's rights at CHBH are identified and discussed. Case

studies and research projects subsequent to the CHBH case study that focus on the implementation of the PRC and respect for patients' rights are also given serious consideration in this dissertation.

Based on the findings from the ethics audit, case studies, and empirical studies including media reports, a reassessment of patient's rights in the South African context is considered. Wide-ranging recommendations are made to various stakeholders, such as the national Department of Health, Provincial Health Departments, professional associations and regulatory bodies, community-based organisations and non-governmental organisations. The study proposes a consultative process based on mutual respect, a non-confrontational attitude and trust between healthcare authorities and/or providers and the receivers of care (in-patients and out-patients), with the aim of initiating robust discussions about patients' rights in South Africa's public hospitals, which, it is hoped, will culminate in a resilient patient care policy and/or a revised patients' rights charter (if needed) for South Africa.

OPSOMMING

Die doel van hierdie proefskrif is 'n kritiese ondersoek na die aard, stand en doelmatigheid van die toepassing van pasiënte se regte in Suid-Afrikaanse konteks, met besondere verwysing na die toestand van gesondheidsorg in die openbare sektor (veral staatshospitale in stedelike gebiede). Die proefskrif fokus eerstens op die etiese en morele gronde van menseregte. Regsteorieë of teoretiese perspektiewe is uit die aard van die saak abstrak, maar dien as 'n waardevolle filosofiese agtergrond wat denke wêreldwyd rig oor die begrip van "menseregte". Hierdie filosofieë verleen 'n hoë mate van geloofwaardigheid aan die idee van menslike waardigheid en verskaf dus beduidende wysheid wanneer komplekse medies-etiese kwessies soos pasiënte se regte ter sprake is.

Vanaf menseregte tot pasiënte se regte, word die idee van regte in kaart gebring deur die historiese ontwikkeling van die menseregtekultuur op internasionale en op streek- en plaaslike vlak te volg. Gesien teen hierdie agtergrond, word 'n beskrywing gegee van Suid-Afrika se rekord in die hantering van sosio-ekonomiese regte, deur hofsake in die Konstitusionele Hof van die land in die hantering van sosio-ekonomiese regte te bespreek. Die hantering van die kwessie van ekonomiese, sosiale en kulturele regte kan nie vermag word sonder 'n bespreking van die spesifieke idee van menseregte nie.

Perspektiewe op pasiënte se regte – die morele beginsels van outonomie, respek, ingeligte toestemmings, vertroulikheid en privaatheid, wat die kern van pasiënte regte is, word in besonderhede bespreek, met die fokus op kliniese instellings.

Dit is nodig om verder te bepaal of daar 'n korrelasie is tussen die teorie (internasional, streeks en plaaslike mensregte-instrumente, insluitend die Grondwet van die Republiek van Suid Afrika en die National Patients' Rights Charter van 1999) en die praktyk (die werklikheid by die pasiënt se bed). Die enigste manier om die verwesenliking en toepassing van pasiënteregte te evalueer is om 'n publieke hospitaal te besoek om te bepaal direk van pasiënte (binne- en buitepasiënte) en personeel (alle kategorieë, insluitend hospitaal bestuur) wat hul opinies is met betrekking tot die verwesenliking en nie verwesenliking van pasiëntese regte by 'n spesifieke hospitaal.

'n Gevallestudie ('n etiekoudit) van die Chris Hani Baragwanath Hospitaal (CHBH) word in hierdie verhandling weergegee. Die navorser analiseer eerstens die gevallestudie en lê getuienis voor van die skending van pasiënte se regte en tweedens word kernprobleme wat die handhawing van pasiënte se regte by CHBH verhinder, geïdentifiseer en bespreek. Verdere gevallestudies en navorsingsprojekte oor die CHBH en wat gefokus het op die implementering van die PRC ten opsigte van pasiënte se regte, word ook ernstig oorweeg in hierdie verhandeling.

Gebasseer op die bevindinge van die etiekoudit, gevallestudies, en praktiese studies insluitende media verslae, word 'n heroorweging van pasiënte se regte in die Suid-Afrikaanse konteks gedoen. Omvattende aanbevelings aan verskeie rolspelers soos die Nasionale Departement van Gesondheid, Provinsiale Departemente van Gesondheid, assosiasies en professionele organisasies (regulatoriese liggame), gemeenskapsgebaseerde organisasies en nie-regeringsorganisasies word gemaak. Gebasseer op die voorafgaande besprekings, stel die studie voor dat 'n proses van konsultasie gevolg word wat gebasseer is op wedersydse respek, gebrek aan konfrontasie en vertroue tussen die gesondheidsorg owerhede en/of verskaffers en ontvangers van sorg (binne- en buitepasiënte), met die doel om ernstige gesprekvoering te inisieer rakende pasiënte se regte in Suid-Afrika se publieke hospitale, wat, so word gehoop, sal lei tot 'n buigbare pasiëntesorgbeleid en/of 'n kompak (hersien indien nodig) vir pasiënteregte in Suid-Afrika.

Dedication

This dissertation is dedicated with love to:

My husband Azwitevhelwi Prinsloo Nevhutalu, for supporting me incessantly throughout my academic career (basic, two masters' and a PhD degree).

My children Wanani (Wani), Luna Munei and sons-in-law, Kgotlelelo (Lelo) Sere Rantloane and Sfiso Melusi Sibanyoni.

My grandchildren, Rebone Dzuvha, Anza Kagiso and 'the ones to come'.

My late parents, Jan Mcheleza Wilson and Yandeya Flora Mabunda and my father-in-law Mikosi Jonathan Nevhutalu and mother-in-law Asnath Mafhungo Luna Köhler-Nevhutalu.

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- Ms Barbara Bradley for editing the dissertation.
- My family; you give me all the reasons to want to do more.

List of Acronyms

AHA	American Hospital Association
AIDS	Acquired Immune Deficiency Syndrome
AMA	American Medical Association
AU	African Union
BCE	Britannica Concise Encyclopaedia
BMA	British Medical Association
BPC	Black Peoples' Convention
CEO	Chief Executive Officer
CHBH	Chris Hani Baragwanath Hospital
CHP	Centre for Health Policy (University of the Witwatersrand - WITS)
CSOs	Civil Society Organisations
DENOSA	Democratic Nursing Organisation of South Africa
ER	Emergency Room
HAART	Highly Active Antiretroviral Therapy
HCP	Health Care Professional
HCT	HIV Counselling and Testing
HHRP	Health and Human Rights Programme (UCT)
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
HST	Health Systems Trust
HSRC	Human Sciences Research Council
HRW	Human Rights Watch
ICESCR	International Covenant on Economic, Social and Cultural Rights

MEC	Member of Executive Council
MIT	Massachusetts Institute of Technology
NAB	National Advisory Board
NCC	National Cancer Committee
NDoH	National Department of Health
NGOs	Non-Governmental Organisations
NHI	National Health Insurance
NHLS	National Health Laboratory Services
NHS	National Health System (UK)
NJSA	New Jersey Statutes Annotated
NSA	Non-State Agencies
NSDA	Negotiated Service Delivery Agreement
OHCHR	Office of the United Nations High Commissioner for Human Rights
OSC	Office of Standards Compliance
OSD	Occupation Specific Dispensation
PRC	Patients' Rights Charter
SAMA	South African Medical Association
SAMDC	South African Medical and Dental Council
SANC	South African Nursing Council
SANHANES	South African National Health and Nutrition Examination Survey
SASO	South African Students' Organisation
SOE	State of Emergency
STI	Sexually Transmitted Infections
TRC	Truth and Reconciliation Commission (of South Africa)
UCT	University of Cape Town
UDHR	Universal Declaration of Human Rights
WITS	University of the Witwatersrand

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General introduction and problem statement

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood (*Universal Declaration of Human Rights, Art 1*).

Patients, like individuals in other social roles, allow themselves to fit into a structure in which they trust that their basic rights will be protected (Tauber, 2005: 157). When a sick person comes into contact with a health professional, one assumes a special role, a “patient role” or a “sick role”. Undeniably, being a patient changes the basic sense of being. This is understandable, given the fact that above all other interests, once patients get to a healthcare facility or hospital, they want to get better (ibid). Because patients want to smooth the process of healing, they customarily readily accept their dependent status.

According to Neary (2000), traditionally, in medical care the patient puts unwarranted trust in the doctor, believing that he will (always) do his best. McLean (as cited in Neary, 2002: 119) describes the “traditional” view of medicine in which the patient makes only one decision as follows:

... to place herself in a given doctor’s care, thereby delegating all subsequent authority to the doctor ... their expertise justified the doctor making decisions on the patient’s behalf (ibid).

Maybe the patient’s trust in the doctor is to be expected, given the promise of both the Declaration of Geneva (1948, as amended in 1968 and 1983) and the International Code of Medical Ethics (1949, also amended in 1968 and 1983), emphasising the obligation to respect and preserve human life. Only in the last 50 years has there been talk of patients’ rights, hence Neary (2002) puts it as follows:

When you are ill, realising your lack of knowledge you consent to another – the medical professional – making decisions on your behalf. In that relationship you appear to have given up the right to self-determination and thereby voluntarily forfeit any claim to an entitlement to rights within the medical situation. If this was the case in the past there are many now who would argue that it is not a case that can be sustained any longer (Neary, 2002: 121-122).

The idea of patients' rights has been liberally espoused in the medical ethical literature since the end of the Second World War, which is understandable in view of the gross violations of human rights in some medical "research" practices of the Nazi German doctors. During the same period as the Nazi experiments, the Australian army deliberately infected Australian troops and Italian and German internees with malaria and dengue fever as part of a drug trial (Kenyon 1999: 1233). At the same time, US servicemen were coerced into participating in tests that exposed them to mustard gas or other toxic agents in gas chambers, despite researchers' awareness that exposure to mustard gas caused long-term health problems (British Medical Association) (BMA) 2001: 211).

The BMA (2001: 211-212) also highlights cases of non-treatment of patients; for example, in the Tuskegee Syphilis Study between 1932 and 1972 400 Afro-American men in Alabama in the USA suffering from syphilis were left untreated or given a placebo despite the availability of penicillin from the early 1940s as effective treatment for syphilis.

More recent international examples can be found during the preparations made for the Gulf War. In December 1990 the requirement for informed consent for experimental drugs or vaccines was removed for US servicemen facing possible combat situations. This was to facilitate experimental preventative measures against potential chemical or biological warfare. Doctors provided experimental products without explanation because informed consent was seen as impractical (Howe & Martin, 1991: 21-29).

In developing countries where medicine may only be available through pharmaceutical trials, participation in research may mean the difference between death and survival.

However, once the research trial has been completed and the data obtained, participants may be left without any form of medical treatment (BMA 2001: 211).

Atrocities committed against opponents and/or political activists by the apartheid government placed South Africa under scrutiny in the international human rights landscape. One of the most notorious cases involving unprofessional and negligent care of a detainee by district surgeons was the death of Stephen Bantu Biko on 12 September 1977. Biko was one of the country's well-known anti-apartheid activists and one of the main proponents of the philosophy of Black Consciousness. He founded the South African Students' Organisation (SASO) in 1969, as well as the Black Peoples' Convention (BPC) in 1972. Biko's death was due to errant disrespect for fundamental human rights and patients' rights as a special kind of rights emanating from a professional relationship between a health professional and a patient.

Dr Wendy Orr, a district surgeon in Port Elizabeth (1999), summarised the contents of "top secret" report completed by a district surgeon who visited Steve Biko while he was in detention. In this report, Steve Biko is quoted as saying:

I ask for water to wash myself with and also soap, a washing cloth and a comb. I want to be allowed to buy food. I live on bread only here. Is it compulsory for me to be naked? I am naked since I came here (BMA, 2001: xvi).

On 7 September 1977 Biko sustained a head injury during interrogation by the police. The doctors who examined him (lying naked on a mat and manacled to a metal grille) initially disregarded overt signs of neurological injury. A few days later, on 12 September 1977, alone and still naked, lying on the floor of a cell in the Pretoria Central Prison, Biko died from brain damage. This was a gross violation of a patient's rights (Truth and Reconciliation Report, 1998).

Biko's death continues to have serious consequences for the medical profession (Baxter 1985: 137).

Baxter laments that the conduct of doctors who attended the victim when he was in extreme distress was questionable on the basis of the evidence at the inquest, and the absence of any disciplinary action by professional regulatory bodies or by their peers (ibid).

According to the Truth and Reconciliation Commission (TRC) Report (1998), *Institutional hearing: The health sector*, the most obvious offence was the district surgeons' failure to carry out their duties within internationally accepted guidelines of medical ethics and human rights (Truth and Reconciliation Report , 1998 : 113).The TRC highlighted that the doctors failed to:

- a. maintain patient-doctor confidentiality;
- b. treat their patient with dignity and respect;
- c. examine the patient thoroughly;
- d. record and report injuries accurately;
- e. diagnose illnesses and prescribe appropriate medication;
- f. register complaints (particularly pertaining to assault and torture).

The findings of the TRC (1998) on the health sector highlighted these as serious ethical misdemeanours, which are an indictment on the part of the doctors who took care of Biko, as well as an affront to his rights as a patient.

Atrocities committed by the apartheid security police on detainees when the state declared a limited state of emergency (SOE) in July 1985 were equally appalling. For example, the magisterial district of Port Elizabeth, where Dr Orr worked, was one of the areas where the SOE had been declared. Within hours dozens of political leaders, student activists and trade union leaders had been detained, and this is what Dr Orr had to say:

From the first day that I started working with SOE detainees, I was overwhelmed by the number who showed me fresh injuries at their admission examinations – *bruises, lacerations, sjambok marks, abrasions, ruptured eardrums, swollen joints, limbs, etc.* (BMA, 2001: xiv).

The injuries to detainees as described by Dr Orr above clearly depict the gross human rights abuses in South Africa during the apartheid system of government. According to Dr Orr, both the then South African Medical and Dental Council (SAMDC) and the Medical Association of South Africa (now the South African Medical Association [SAMA]) had the task of ensuring that professionals were able to provide ethical and appropriate health care, regardless of the policies of the government in power (BMA, 2001: xvi). If the policies of the apartheid regime made it impossible for that to happen, Dr Orr argues that those bodies (SAMDC and SAMA) should have spoken out against those policies but they did not, and in this way, they failed in their duty (*ibid*).

Healthcare professionals (HCPs including doctors, nurses and allied health professionals) are privileged and burdened with the opportunity to uphold and protect the rights of people in their care. The nursing pledge, ethical guidelines, oaths and declarations emphasise ethics and morals in the daily practice and actions of all health professionals. It is crucial that doctors, nurses and all other HCPs remind themselves of the basic human rights, the rights that Steve Biko was denied – *the right to dignity, the right to life*.

In the past fifty years – and in particular during the last two decades – there has been a sudden profusion of resolutions, consensus documents and recommendations by scientific, professional and governmental organisations covering many human rights issues ... we are now facing the formidable challenge of ensuring that they are observed. Their respect requires vast changes in the attitudes of health workers, researchers, patients and communities; it requires a different undergraduate and postgraduate education of the health professions.

(Professor Sartorius, President of the World Psychiatric Association, 1998, as cited by the BMA, 2001: 503).

From the quotation above, it seems evident that in order to respect human rights in general and in particular patients' rights, health workers might have to undergo enormous attitudinal changes.

In its guidelines for good professional practice in the healthcare professions, the Health Professions Council of South Africa (HPCSA) describes the spirit of the professional guidelines as follows:

... practice as a health care professional is based upon relationships of mutual trust between patients and health practitioners ... to be a good health care practitioner, requires a life-long commitment to sound professional and ethical practices and an overriding dedication to the interests of one's fellow human beings and society ... (HPCSA, Booklet 11, 2007: i)

It is evident that there are high expectations of both professional and ethical conduct for HCPs in South Africa. Whether or not HCPs in South Africa's public hospitals live up to the expected standards is an issue that can only be seen and/or assessed by means of empirical studies (evidence-based).

At this stage of the dissertation, it is not wise to make further comments about the values (aspirational) set out by the HPCSA guidelines; the issue is deferred until the ethics audit of the Chris Hani Baragwanath Hospital (CHBH) and other surveys on the patients' rights charter and grey literature reports are presented and discussed in subsequent chapters.

Today, however, the tables seem to have been turned. To heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights, South Africa has adopted the Constitution of the Republic of South Africa (hereafter the Constitution) (Act 108 of 1996) with a Bill of Rights (the Bill). The Bill is a legal document in which the fundamental values and needs of the nation are embedded, and it specifies certain actions expected of the government. The Bill ensures that any violation of these basic rights by government is subject to sanctions (through the courts). Section 7 (1) states:

This Bill of Rights is a cornerstone of democracy in South Africa. It enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom (Constitution of South Africa, Act 108 of 1996).

The Bill includes a wide-ranging variety of rights, comprising, among others, the right to human dignity and the right to have access to health care. These rights are expressed as follows: “Everyone has inherent dignity and the right to have their dignity respected and protected” (Section 10).

Section 27 (1) of the Bill also states that: everyone has the right to access healthcare services, including reproductive health care. As section 28 of the Constitution states, the duty to interpret and enforce the rights is entrusted to the courts with powers to grant appropriate relief (Constitution Section 28). In other words, the Constitutional Court is the final arbiter for human rights in South Africa. In this way, the courts also have powers to declare any law or conduct that is inconsistent with the Constitution invalid to the extent of its inconsistency (Mbazira, 2006: 43).

It is in the context of the right to health care that patients’ rights (discussed in detail in Chapter 3) as special rights that arise from a professional relationship between patient and HCP are put into perspective in this dissertation.

In this study the nature, status and efficacy of the idea of patients’ rights in the South African context, with particular reference to the situation of health care in the public sector, particularly public hospitals in urban settings, will be investigated critically.

This dissertation endeavours to investigate a twofold problem. Firstly, the question is whether there is any correlation between theory and practice as far as the recognition and enforcement of patients’ rights in South Africa are concerned. For this purpose, a case study (an ethics audit) of the CHBH, the largest hospital on the African continent, will be analysed critically to establish whether or not patients are able to realise their rights in

public hospitals or not. The CHBH ethics audit (Landman, Mouton & Nevhutalu, 2001); conducted by the Ethics Institute of South Africa (EthicsSA) serves as the bedrock for this study. While the CHBH ethics audit is 14 years old, its importance cannot be underestimated, since it is the first ethics audit of a hospital in South Africa to assess business and professional (ethics) practices. The results of the audit received wide-ranging media coverage and acceptance by health authorities. The only other ethics audit of a hospital since the CHBH audit was conducted at Universitas Hospital (Landman, Mouton & Nevhutalu, 2002), also by EthicsSA, and with findings similar to those of the CHBH. This audit enjoyed the same publicity and acceptance as the CHBH ethics audit.

Media reports about hospital conditions, patient care and treatment depict findings that one can call 'carbon copies' of the CHBH ethics audit. These conditions seem to have deteriorated to unimaginable and unbelievable levels. (Recent surveys on patients' rights as well as grey literature reports will be discussed in detail in chapter 5.) The audit's contributions to discussions on patients' rights in the South African public health hospitals are invaluable. It is also equally invaluable to reflect on whether there are any enforcement mechanisms to ensure that patients get redress for their rights that have been violated.

Secondly, the case study reveals a gap between theory and practice. A second research question would thus be: what are the conditions under which it becomes feasible not only to talk or write – even in charters about patients' rights in the context of a developing country such as South Africa – but also to enforce those rights? Or, to turn to the initial formulation of the problem: What does or can it mean to espouse the idea of patients' rights in South Africa, given the real constraints on understanding the language of rights among patients and to a certain extent, healthcare providers, shortages of resources (human and material), skills and legal clout that permeate South Africa's body politic?

These questions and others arising from the study are answered in the sections that follow. An in-depth analysis of the findings of the CHBH ethics audit (Audit), is done in the hope of identifying the gaps that might exist between theory and practice as far as patients' rights

are concerned, i.e. what the Constitution states in the Bill of Rights, as well as the National Patients' Rights Charter (November 1999), and what happens at the bedside.

Moral theories are used as the point of departure and reference throughout the dissertation, while assessing the correlation between theory and practice and the realisation and enforcement of patients' rights in South Africa's public health institutions.

In Chapter 1, a brief account of the idea of human rights in the light of justice theories, namely those of Immanuel Kant, John Stuart Mill and John Rawls, which are considered the ethical and moral grounding of human rights, is provided. These philosophical origins of rights are critical when one adopts a rights-based approach to a project such as this study.

In Chapter 2, the origins and nature of the idea or notion of rights is traced. The human rights approach, international treaties that enshrine and safeguard human rights, including human rights instruments, South African constitutional court cases on socio-economic rights as well as the record of the Constitutional Court, and the emergence of patients' rights (internationally and in South Africa) are discussed.

Chapter 3, investigates perspectives on patient's rights – autonomy, respect, informed consent, confidentiality and privacy which are the ethical principles at the core of patients' rights.

In Chapter 4 the CHBH ethics audit is presented as a case study that is analysed critically. The key findings are identified to assess whether or not patients' rights are recognised and enforced at the CHBH. A generalisation of the findings by the ethics audit will be made, based on the fact that CHBH is the largest public hospital in South Africa. It is hoped that the findings at the CHBH will assist in answering the first part of the problem statement, which endeavours to investigate whether there is any correlation between theory and practice concerning the recognition and enforcement of patients' rights in South Africa's public health institutions.

In Chapter 5 surveys conducted subsequent to the CHBH ethics audit (2001) are presented. Firstly, a survey commissioned by the Health Systems Trust (HST) to look at the operationalising of health as a human right with specific focus on monitoring tools to support implementation of the patients' rights charter in the health sector, conducted by London, *et al.*; in 2006, is discussed. This is followed by discussion of a research report that was submitted in partial fulfilment of the requirements for the degree of Master of Public Health on *Providers' responses to the patients' rights charter in South Africa: A case study in policy implementation* (2009). Also in this chapter, various reports in grey literature reporting on a daily basis about patient negligence, violation of patients' rights, lack of essential medicines and nonfunctional hospital equipment, etc., are presented. The aim is to strengthen the fact that the findings of the CHBH ethics audit of 2001 are still relevant and that it is justified to use the ethics audit as a case study today when one argues for patients' rights in South Africa's public health institutions.

In Chapter 6, the actual problems preventing the realisation of rights in the South African healthcare system, based on the ethics audit conducted at the CHBH, subsequent surveys and reports from grey literature are identified and critically analysed. In this chapter attention is paid to the practical realities in a public hospital and assess the 'real' challenges facing the hospital that hinder the realisation of the ideals set out in the Bill of Rights and the PRC (1999).

In Chapter 7, the notion of patient's rights is revisited, the implications of the findings in the case study on the realisation of patients' rights at the CHBH is discussed and the findings are generalised to South Africa's public hospitals. The idea of patients' rights is reconsidered given the trends in patients' rights violations (identified from the case study, subsequent surveys and grey literature reports) as a way of proposing what an amicable solution to problems with South Africa's patients' rights would be. In light of the problems identified in Chapter 6, Chapter 7 reassesses patients' rights as presented in the 1999 PRC.

In Chapter 8 conclusions and recommendations are made on how South Africa can ensure the realisation and enforcement, firstly of socio-economic rights in general and, secondly, patients' rights in particular. The aim is to make strong proposals for a patients' rights charter that is both robust and resilient. These recommendations both encompass and expand on recommendations made by various experts, such as Landman, *et al.*, (2001), London, *et. al.*, (2006), Raphaely (2009) and Human Rights Watch (2011), in their studies on the implementation of the patients' rights charter in the public healthcare system in South Africa.

Chapter 1

Ethical and moral theoretical grounding of human rights

1.1 Introduction

The birth of human rights cannot be claimed by one solitary civilisation. No particular society or person can claim authorship. While the groundings of human rights are difficult to identify in moral philosophy, as Freeman (1994: 514) notes, “they can be derived from equal concern and respect for human persons”. Abtahi (2007: 56) claims they are rooted in the “superior principles called natural law which, dependent on the civilisations where they took shape, may be based on God, providence, conscience, morality, reason and so forth”. Whether they are termed Natural Rights, The Rights of Man, or Human Rights (the latter designation used since World War II) makes little difference (BCE, 2010). Whatever the names or circumstances, the idea that “humans share a particular dignity far pre-dates the current legalistic and politicised human rights present in contemporary times” (Sano, 2000).

Philosophically speaking, the idea of human dignity should place human rights primarily in the field of moral philosophy (with admittedly an overlap into political philosophy). Shestack (1998: 201) supports this, writing: "Human rights are a set of moral principles, and their justification lies in the province of moral philosophy."

However, the evolution of what we now term 'human rights' did not quite follow this pattern. Rather, in its texture, notions of the 'moral' exist; however, it is in the province of law nowadays that the concept of human rights is particularly prominent. Recognising the role of law in the debate does not mean that ethics and moral philosophy are removed from the

conversation. Since the idea of human rights is not fixed, we should recognise that there are periods in history when the legal aspects of human rights, for example in treaties, charters, declarations, and the growth of the field of human rights law, appear to obscure its moral grounding. Because the notion of human rights is dynamic, it would be a mistake to make the claim that moral philosophy has nothing to say or offer concerning human rights. Gert (2012) explains, "the term morality can be used either descriptively to refer to some codes of conduct put forward by a society or some other group, such as a religion or accepted by an individual for her own behaviour. If used normatively, morality can refer to a code of conduct that, given specified conditions, would be followed by all rational persons". As Van Niekerk (2011: 19) states, "... [this implies that] moral theories represent conceptual frameworks in terms of which action guides or standards for action are formulated and when confronted with moral problems or dilemmas; one always rightfully draws from moral or ethical theories."

In order to visualise how some ideas included in what we now term Human Rights might have relevance to moral theories, an overview of the philosophical movement towards the idea that human individuals have rights is presented in this chapter. In doing so, some of the circumstances, times and places, thoughts, theories, and people who influenced contemporary human rights will become evident. This selection of thinkers and ideas does not reflect all of the possibilities and others may disagree with these choices.

1.2 Religion and Human Rights

In human cultural development prior to philosophy and science, there was myth and magic, and from these arose religions and belief systems. Religious views and beliefs are prominent in human development and may mediate outcomes and events. Indeed, the story is told that Cyrus the Great, the first king of ancient Persia who conquered the city of Babylon in 539 BCE, produced the world's first charter of human rights (UHRW, 2013). He did so, according to Abtahi (2007:58), because he was influenced by the thinker-prophet Zoroaster. Zoroaster profoundly shifted parts of the predominant ancient Indo-Iranian religions in the then Persian empire. For example, "[He] abandoned the blood-sacrifice for an ethical offering of the self"

(Boyce, 1970: 34 n72). Freeing slaves, establishing racial equality and allowing religious freedom were some of the human rights articulated in what is now known as the Cyrus Cylinder, written in the Akkadian language in cuneiform script (Cave, 2013). The United Nations regards this as the first written record articulating human rights.

In traditional religions, the term 'human rights' *per se* is not found. However, theology, because it holds that there is a Supreme Being whose laws and commandments are higher than the individual or the state, offers a basis for human rights theory. Judeo-Christian religions hold that humans are created in the image of God, thus we are sacred, of great value to our Creator. In other religions with a deistic base, such as Islam and the Hindu Bhagavad-Gita, humans are set apart as having special dignity (Shestack, 1998).

Since humans are created in the image of God it is possible that some religions could provide a theory of human rights emanating from the human as a being of dignity, value and worth. Religion may also serve the positive purpose of shifting views about the ill-treatment of other people, as well as promoting the ideals of compassion and justice and in such ways support theories of human rights (ibid). Conversely, religions can thwart human rights by instilling in their followers that their religion is the only source of 'truth' and that all others are false, thus closing the discussion. However, without the acceptance of a 'visual' link to the Divine, religions have a limited option in creating a theoretical link to human rights. This is not to say that religions cannot and do not influence the minds of individuals to treat others with dignity, as in the example of Cyrus the Great.

1.3 Natural Law and Human Rights

From mythology comes the story of Antigone who defied the ruler Creon's command not to bury her brother because she claimed she was obeying an absolute order, higher than the ruler's command (Morford, Lenardon and Sham, 2010). This classic tale identifies the idea that there is a law or rule above positive law, which has been present for eons.

The early development of this thought may be identified in the writings of Sophocles and Aristotle, as Shestack (1998: 205) writes: "Natural law, so the Stoics believed, exemplified

the elementary doctrines of justice which were right reason, i.e., that done in accordance with nature [are] unalterable, and eternal." Mitis (2003: 39) tells us that this notion was prominent during the Greek Hellenistic and Roman ages.

In medieval times, the Christian theologian and philosopher St. Thomas Aquinas (1225-1274) wrote many still-influential texts. Concerning natural law, he asserted the absolute rights of individuals as part of the eternal law of God. Dimock (2007) explains this way of thinking: "God is the legislator of eternal law. The natural law is a subset of eternal law. Natural law binds only rational creatures. This is because rational creatures have free will and reason thus they are capable of participating more fully in the law."

Because God gave us 'natural reason', we are able to know right from wrong. Free will, also given to us by God, provides us with the ability to choose that which is right and when we do so we "participate more fully in eternal law", which becomes part of our being as "opposed to a measure imposed upon us from an external source" (Shestack, 1998: 207). While the ideas of natural law and natural rights were argued by Aquinas, certain extensions of thought were lacking in the social milieu; during that period, servitude and serfdom were societal norms (ibid).

In the later medieval and early modern periods, the social, political, and economic structure of society began to change as the owners of serfs and slaves, as well as the Church, faced new fractious questions. One of the influential thinkers during that time was Hugo Grotius (1583-1645). He was a "towering figure in philosophy, political theory, law, and associated fields" (Miller, 2011). A vastly productive writer and deep scholar on many topics, Grotius detached "natural law from religion" and is considered "a father of modern international law" (Shestack, 1998: 206). In philosophy, he is best known for his contributions to the natural law theories of normativity and international law (Kristeller, 1961:236).

Natural law, according to Grotius, should be secular and rationalistic. Grotius believed that individuals by their nature have a "natural social tendency to live in peace and harmony with others. All things, i.e. actions that were in keeping with social harmony were right.

Conversely, whatever opposed or disturbed social harmony was wrong and unjust” writes Shestack (1998: 207).

1.4 Early Social Contract Theories:

Europe in the 17th and 18th centuries underwent political, economic and social turmoil. The socio-economic advantages to the wealthy of what we now call serfdom and feudalism crumbled; peasants rose against their masters. The divine right of kings to govern their citizens was questioned and inquiries were raised concerning how states could be best managed without divine authority.

1.4.1 Thomas Hobbes (1588-1679)

Thomas Hobbes was one of the earliest proponents of the social contract theory. In his work, *Leviathan* (1651), he argues that peace can be furthered in society (thus promoting the well-being of its citizens) by means of the institution of a covenant as absolute sovereign (Hampton, 1992: 543). There is a "binding of people to covenants..." claimed Hobbes (1651, 81: chap xiv, 7). Covenants bind; that is why they are "artificial chains" (ibid: 138: chap. xxi, 5).

Humans are fundamentally selfish, Hobbes believed, so that is why they are in perpetual conflict with their neighbours. Hobbes argued that society came into existence as a way of protecting men from the repercussions of their own nature. Society should be governed by a sovereign and although this would entail curbing some individual rights, in return, society would receive protection. Without government, men would revert to 'the state of nature' ... for example, "men having all rights to all things and being enemies to other men". Hobbes describes this, writing:

In such condition, there is no place for industry; because the fruit thereof is uncertain: and consequently no culture of the earth; no navigation, nor use of the commodities that may be imported by sea; no commodious building; no instruments of moving, and removing,

such things as require much force; no knowledge of the face of the earth; no account of time; no arts; no letters; no society; and which is worst of all, continual fear, and danger of violent death; and the life of man, solitary, poor, nasty, brutish, and short (Hobbes 1691, XIII).

1.4.2 John Locke (1632-1704)

The Englishman John Locke was a libertarian who also developed a social contract theory. Locke differed in his view from that of Hobbes, arguing that the government is obliged to respect individual rights. In his work, *The two treatises of government (1689)*, he defends his claim that men are by nature free and equal, as opposed to the divine right of kings (the claim that God instilled the divine in monarchs and thus, because all people are bound to follow God's command, they are obliged to consent to the divine right of kings).

Locke argued that individuals have rights, such as the right to life, liberty and property. He writes in Chapter 2 of *The state of nature (1690)*: "All mankind... being all equal and independent, no one ought to harm another in his life, health, liberty or possessions."

Locke claims that individual rights are not dependent upon the laws of any given society. Based on his premise that men are naturally free and equal, a social contract concerns "the qualified discharge of certain rights to the government for the function of societal stability, liberty, and property" (Tackiness, 1999: 56-59).

Government can thus only exist through the will of the people, argues Locke. He defends the right to revolution in instances when despotic governments "fail to promote the public good and protect the rights of the people" (ibid: 57). Unlike Hobbes' absolute government, Locke's conception of the state is based on 1) the principle of majority rule; and, 2) the separation of powers.

In his 1689 work, *A letter concerning toleration* (Locke published two more works on this subject in 1690 and 1692), he did not condone coercion when choosing one's religion (at the time coercion was used to force people to adhere to whichever religion the ruler believed to be 'true'). He asserted that governments have no right to control the beliefs of

their citizens. In fact, he opposed the idea that churches should have any coercive power over their members. To coerce individuals into following a particular religion, has nothing to do with their true beliefs, because individuals can obey orders but that does not change their personal beliefs. In addition, Locke argued that if governments coerced religious homogeneity, social disorder would ensue.

In Chapter 2 of Locke's *Second treatise of government* (1689) he asserts that men in the state of nature are free and equal, and at liberty to do as they wish, confined only "within the bounds of the law of nature"(Locke, 1689). The 'law of nature', for Locke, signifies an obligation on the part of citizens to act for their own self-preservation. In addition, when an individual's own life "comes not in competition", the person ought, "as much as he can, to preserve the rest of mankind" and not interfere in their rights to life, liberty, or property (ibid). Locke's liberalism is identified throughout his works; for example, he argued, "a citizen's obligation to obey the law can be grounded only in that citizen's personal consent to the authority of the law" (Simmons, 1992: 919).

We can see that Hobbes and Locke had different perspectives concerning the social contract. Freedom, equality and the prominence of individual rights for Hobbes left humans (in the state of nature) without any tangible limits. Without reciprocal duties or obligations to others, this 'state of nature' was perpetually in a state of war (Hampton 1997:38). Locke, on the other hand, believed "we have a duty to respect the rights of others, even in the state of nature. The source of this duty, he says, is natural law (Locke 1689).

1.4.3 Jean-Jacques Rousseau (1712-1778)

Man is born free, and yet we see him everywhere in chains. Those who believe themselves the masters of others cease not to be even greater slaves than the people they govern (Rousseau, 1762: 5).

So begins the first chapter of Rousseau's work, *The Social Contract* (1762). For Rousseau, the natural state of man was that of a noble savage who led a life of sublime happiness;

simple and contented, man was essentially fearless and innately good. This idyllic natural state of man did not counter social interaction, and it was only primitive instinct and perhaps a sense of kindness that impelled him to seek the company of others. Rousseau believed the idea of 'owning something' (personal property) served to erode man's natural state (ibid.).

In his work, *Discourse on the Origin and Basis of Inequality among Men* (1754), Rousseau writes:

The first man who, having fenced in a piece of land, said "This is mine", and found people naïve enough to believe him, that man was the true founder of civil society. From how many crimes, wars, and murders, from how many horrors and misfortunes might not any one have saved mankind, by pulling up the stakes, or filling up the ditch, and crying to his fellows: Beware of listening to this impostor; you are undone if you once forget that the fruits of the earth belong to us all, and the earth itself to nobody.

Differing from Locke, Rousseau argued that as soon as the idea of owning property became individualised, conditions of inequality among men became inevitable. For example, if a person owns land then others are needed to develop it. In this way and over time, some individuals become owners and others become workers. Thus, the rise of social classes becomes inevitable. Owners of course need their property protected from those who through theft might try to take it. Owners would then turn to the government for laws that govern the legal position of their ownership, as well as laws concerning the protection of what is legally their own. Through this process, class inequality, i.e. difference between owners and workers, becomes established. Rousseau considers this the "naturalised social contract" (ibid).

As Rousseau conceives the social contract, individuals are obligated to accept a collective "general will". Because it is collective, "general will" symbolises the common good. The common good is both created and sustained by each member of society's work and

agreement. To be actualised, there will inevitably be some denial of an individual's particular wants or desires, sacrificed for the common good.

By looking at the social contract in this way, Rousseau presents a way by which society may be organised in collective defence of liberty and order. In addition, as pointed out by Shestack (1998:207), the "social contract establishes a community with potential for doing justice, thereby giving the citizens the morality that had been wanting in the state of nature".

Hobbes' position on humans 'in the state of nature' was dismal. Rousseau looked upon the human condition in this state as quite harmonious, idyllic. In contrast, Locke could think of circumstances in which members of society could reject a particular type of government, i.e. one denying liberty, return to the state of nature, and replace the government with a more civilly-minded one.

1.5 From Natural Law Theory to a Theory of Natural Rights

John Locke and his predecessor, Hugo Grotius, are often recognised as major contributors to the modern concept of natural rights. In a historical perspective, the doctrine of natural rights appears to have risen within, or at least in agreement with some of the tenets found in natural law. As topics, natural law and natural rights have received a great amount of attention by scholars throughout Western history. This sub-section does not purport to do justice to the large number of positions taken concerning natural rights and natural law. As some of the sequential historical developments in natural law and natural rights theory have been previously overviewed,¹ in this section the researcher will provide a general discussion of some key issues that are present in some of the many theories of natural law and natural rights.

When ordinary people today hear the word 'law', they often assume that it necessarily refers to a legal system in place which defines both the positive and negative boundaries of

¹ (1) Thomas Aquinas, *The Natural Law Theory*, Treatise of Law in the *Summa Theologiae*,
(2) Karl Marx, *Marxism and Natural Law*.

human behaviour. When the term 'natural' is added to 'law', confusion may arise as it is clear that there are no naturally occurring legal systems. What we now term 'natural law' may have had its origins in antiquity as ideas existed that there is a natural order of things, a natural *force* or law, if you will, to which the earth and its inhabitants conform. One way natural law is viewed is that it is based on the nature of the cosmos and from there comes the grounding of the moral and legal order (Blackburn, 1996: 256). For example, around the end of the second century during the time of the thinker Panaetius of Rhodes, the state revisited the idea that:

All men are fundamentally equal, whatever their differences of ability, wealth, and social position, in having rationality in common with the universal reason of God, This providential God prescribes a universal law of nature to men, knowledge which they possess innately. The positive law of state emerges from custom, in which the law of nature is obscurely embedded. Brought to consciousness it can be seen as a criterion for the adequacy and authority of positive law (Quinton, 1997: 288-289).

It was, however, the medieval theologian and philosopher St. Thomas Aquinas (1225-1274) whose works were particularly influential in this regard. They continue to motivate conversations concerning natural law today. Aquinas lived and wrote during the time when the Roman Catholic Church was the only Christian religion in Europe and it controlled and dictated much of the political, social and economic life of the people. Aquinas believed the very souls of all people were at stake and vigorously defended his faith through his writings using a question-answer form of discussion and debate (Thompson, 1988:200-201).

According to Murphy (2011), Aquinas' work has two major features which structure his examination of the natural law. They are taken from the Prima Secundae (at Question 94) of his work *Summa Theologiae*, Aquinas writes:

... The first is that, when we focus on God's role as the giver of the natural law, the natural law is just one aspect of divine providence; and so the theory of natural law is from that perspective just one part among others of the theory of divine providence. The second is that, when we focus on the human's role as recipient of the natural law, the

natural law constitutes the principles of practical rationality, those principles by which human action is to be judged as reasonable or unreasonable; and so the theory of natural law is from that perspective the preeminent part of the theory of practical rationality (Aquinas as quoted in Murphy, 2011).

In his work *Summa Theologiae* (1273) Aquinas provides a description of the natural law within us. According to Dimock (2007), “Formally defined, the Natural Law is humans' participation in the Eternal Law, through reason and will. Humans actively participate in the eternal law of God (the governance of the world) by using reason in conformity with the Natural Law to discern what is good and evil”. We see that Aquinas believed that we are rational creatures subject to and sharing in Divine Providence. As such, we are ruled and measured by God's eternal law. Our participation in the eternal law enables our understanding of the natural law. As such, we are inclined to act judiciously for ourselves and others (i.e. we know what is good and what is evil as a function of natural law). Aquinas writes, “... it is therefore evident that the natural law is nothing else than the rational creature's participation of the eternal law” (Aquinas, 1273).

Alternately, natural law may refer to an attempt to join the moral and legal order through rational and critical accounts of human behaviour from which rules of ethical and moral behaviour may derive (Blackburn, 1996: 256). The term ‘natural law’ used in contemporary times, generally refers to rational and critical accounts of human behaviour from which rules of ethical and moral behaviour may follow. For example, how we might best exercise our liberties could derive from reflecting on accounts of human behaviour. According to George (2008: 172),

Natural law theories, then, propose to identify principles of right action – moral principles specifying the first and most general principle of morality, namely, that one should choose and act in ways that are compatible with a will towards integral human fulfilment (George, 2008: 172).

The terms ‘natural right’ and ‘natural law’ are not quite the same although they are often used interchangeably. Both terms are based on supposed human nature and the world in

which we live (Barnett, 1997:655-681). In making a case for distinguishing between the two terms, Barnett argues that “natural law *ethics* is the appropriate term (although such principles are sometimes referred to simply as natural law)” (Barnett, 1997: 680). His basis for this claim stems from the identification of subtleties found in natural rights and natural law arguments. He writes, “natural-law ethics instructs us on how to exercise the liberty that is defined and protected by natural rights” (Barnett, 1997: 669). In this way of thinking, natural law (or as he terms it), natural law ethics may be viewed as action-guiding. That is, it speaks to good and bad human behaviour and virtues and vices (ibid).

A less-nuanced approach concerning natural law is given by Paust (2013). He tells us natural law theories are composed of “two different ways of viewing two different things” (Paust, 2013: 241). He makes a sharp distinction between the two perspectives. One way we can consider natural law is by looking at moral actions, or what is considered right or wrong. Another way of viewing natural law concerns legality, or what actions are deemed by any given government to be legal or illegal (Paust, 2013).

As an example of a natural law theory based on moral actions, we can consider the following scenario: When a patient is scheduled for an operation on her infected appendix, the surgeon has an ethical duty to obtain informed consent from her. The informed consent process, amongst other requirements, involves explaining to patients the possible risks and benefits involved in any proposed treatment or procedure such as surgery. This ethical duty is based on the notion that all humans are of intrinsic value and worth. Informing patients and receiving their consent to carry on or not with a proposed treatment or procedure is one way of demonstrating the principle of respect for persons. It would be wrong, ethically unacceptable that is, for a doctor not to follow the process of informed consent.

When natural law is viewed from Paust’s (2013) second perspective, that is an action considered by any given government as legal or illegal, the same scenario can be used substituting the word ‘legal’ for ‘ethical’. This particular legal obligation has been posited; it is a law that the government has enacted.² To not engage a patient in the informed consent

²National Health Act 61 of 2003, section 7(1)(e).

process would be breaking the law, because the law says the informed consent process must be provided for.³ Here it is noted that in this scenario whilst the perspectives are different (moral and legal) the duties of the surgeon to her patient remain the same. This is not, however, always the case. A legalistic view that says that 'X action is legal so it is acceptable' fails to understand that laws try to establish *minimal* guidelines concerning the behaviour of citizens. Laws tell us that there is punishment for certain acts that we do or fail to do, but they do not tell us what we should or ought to do. The term 'natural law' as used in secular societies now, places emphasis on rational human behaviour from which we derive the guidelines for ethical and moral conduct.

On natural rights, George (2008: 172) writes, "People possess [rights] simply by virtue of their humanity which, as a matter of justice, others are bound to respect and governments are bound to protect. At least from a historical viewpoint, we may say that theories of natural law and natural rights are entwined although natural rights theorists argue over just which human characteristics give more credence over others when being considered as a natural right. Such positive characteristics may include for example, "free-will, rationality, autonomy, and the ability to regulate one's life in accordance with one's chosen conception of the good life" (Wenar, 2011). Natural rights refer to our personal moral space and our liberty. As such, natural rights are shaped by the "principles of justice or the problem of distinguishing right from wrong behaviour" (Barnett, 1997: 680). Justice, its concept and principles, serves as one of the linchpins in theories of natural law and natural rights (ibid).

Natural rights are closely associated with and contribute to what we consider as modern human rights. In this way of thinking, everyone is born with an equality of certain rights, regardless of their nationality. Since these rights come from human nature or from God, natural rights cannot be justly taken away without consent. Natural rights theories, because they appeal to a higher authority, imply that the preservation and protection of an individual's freedom, security, and equity (elements of the idea of human rights) are prioritised. In understanding some of the tenets included in the relationships shared in

³This is also an example of positive law. Positive law maintains that no action is intrinsically right or wrong unless it has been set out in government legislation.

natural law, natural rights and human rights, we can better visualise how patient's rights are enhanced.⁴ As modern human rights further develop, it follows that certain refinements occur. Suffice to say here that beyond the basic human rights (such as life, liberty and property) afforded to all individuals, the idea of having a sub-set of human rights for patients is particularly important. The provision of access to healthcare for the sick may be viewed as a positive patient right as it places X in a position of acting for the good of the sick and vulnerable. The provision of healthcare services is sometimes a matter of life or death. By virtue of their humanity and their rights to life, liberty and property, the ethical obligation we have to care for society's most vulnerable persons may be traced back to themes found in natural law and natural rights. Moreover, within these entwined concepts, there remain certain 'old' themes which were retained in modern human rights development. As Quinton (1997) writes:

The priority of morality to politics (and not, as with Plato and Aristotle, their near identity) has been a recurrent (and for long periods of time, dominant) ingredient of Western political thought ever since the time of Cicero, wherever legal systems of Roman origin have prevailed and wherever the church has been unified and therefore powerful enough to limit the activities of the state, it is alive today in the notion of rights of man or 'human rights' (Quinton, 1997: 288).

From the late sixteenth century, continuing through to the eighteenth century, dramatic revolutions in, for example science, technology and thinking changed the course of Western history. This period was termed 'the Age of Enlightenment'. The rise of new sciences set in motion questions on "Proving and dispelling presuppositions concerning the earth and the human order"(Bristow, 2011). During the Age of Enlightenment, many thinkers of the time were engaged in philosophical, economic, and political debates. These topics ranged from, for example, dispelling the notion of the divine right of kings, to the idea that science was a 'cure' to many political and social ills. This era was characterised by the expectation "that philosophy (in this broad sense) would dramatically improve human life" (ibid). During this age of humanism and political change, the considerations of John Locke gained

⁴The researcher provides specific discussions on the notion and relationship of human and patient's rights in forthcoming chapters.

prominence. Because Locke argued for individual rights and the limitation of government, he is considered as one of the fathers of "liberalism"⁵ (Shestack, 1998). Locke argued that as individuals give their consent to the government to lead them (i.e. by voting them into office), so governmental authority is derived from the people rather than from the government.

1.6 Consequentialism and Utilitarianism

1.6.1 Consequentialism

LaFollette (1997) tells us that:

If the actions of someone clearly and substantially affect others (either benefitting or harming them), then even if we do not yet know whether the actions are right or wrong, we can all agree that they should be evaluated morally." (LaFollette, 1997: 4).

Consequentialism is a moral theory that argues that the right or wrong of an action depends only on its consequences. If, amongst the alternatives available to us, we choose the one that has better consequences than all the others, then that is the morally right choice.

Elizabeth Anscombe (1919-2001) coined the term "consequentialism". In her 1958 article, "Modern Moral Philosophy" published in the journal *Philosophy*, Anscombe wrote:

The denial of any distinction between foreseen and intended consequences, as far as responsibility is concerned, was not made by Sidgwick in developing any one 'method of ethics'; he made this important move on behalf of everybody and just on its own account; and I think it plausible to suggest that this move on the part of Sidgwick explains the difference between old-fashioned utilitarianism and the consequentialism, as I name it, which marks him and every English academic moral philosopher since him (Anscombe, 1958: 10).

⁵ 'Liberalism' is a term used in political philosophy which has at its core the principle of liberty. In contemporary literature, there is a wide-range of views on liberalism. This is because different thinkers argue particular aspects of their personal understanding of liberty. Differences in perspectives often involve a thinker's interpretation on the issues found in individual liberties and social equality. Generally, liberals tend to support ideas such as civil rights, freedom of the press, equal opportunity and freedom of speech.

Consequentialists argue that morality should guide our behaviour by ensuring that we achieve the best outcome. Consequentialists argue that the greater the amount of good consequences produced, the better the act. As a moral theory, consequentialism claims that the right act in any circumstances is the one that produces the best overall result (value), as determined from an impersonal perspective that gives equal weight to the interests of each affected party (Beauchamp and Childress, 2001: 341). Consequentialist decision-making involves reasoning, considering the options available and making a decision, a decision that we hope will bring the best overall outcome. We often make consequentialist-type decisions, but they are not consequentialism, they are purely prudential (LaFollette, 2007: 23) decisions are common in our daily lives. For example, in need of vegetables, I could drive 50 kilometres to where there is a vegetable sale, or I could shop locally where there is no sale. My decision could be based on, for example, the differences in vegetable price, consideration of my carbon footprint, or the amount of time it would take to travel back and forth. There are a variety of reasons that could be offered supporting my choice. Some individuals may reason the circumstances differently from mine and our final decision may be poles apart. But prudential reasoning, as in consequentialism, asks us to weigh the circumstances and arrive at an ethical conclusion. Making the right choice in consequentialism is achieved through reasoning and it obligates us to hold all the possible choices to the ideal – the best moral consequence (LaFollette, 1997:9). As Amartya Sen notes:

Consequentialist reasoning may be fruitfully used even when consequentialism as such is not accepted. To ignore consequences is to leave the ethical story half-told (Amartya Sen (1987: 75)

The quotation seems to reveal Sen's fascination with consequentialism. From Sen's thinking on consequences, one gets the sense that consequences have an 'ethical' thread in them. At a symposium on Sen's philosophy, Scanlon had this to say:

... consequentialism starts with some notion of value and explains notions such as right, wrong, rights, duty and obligation in terms of the production of the best states of affairs as measured by this standard (Scanlon 2001: 39)

Sen's viewpoint on the importance of taking consequences seriously; however, is not uncontested. It is, nonetheless not the aim of this dissertation to discuss such disagreements but to relate his notion of 'consequences' and 'ethical principles' to patients' rights as the subject of this study. The assumption that can be made is that consequences matter and cannot be put aside or be ignored. In the healthcare environment, clinical treatment and care vary from minor medical treatment and nursing care to the most invasive procedures and surgery. HCPs, more especially doctors because of the highly advanced and technological medical care they provide to patients, need to consider the consequences of their acts and omissions while they treat patients. HCPs have an obligation to make decisions based on the patient's informed choices and decisions. In so doing, they focus on the potential effects – 'consequences' of their medical interventions (acts) as well as medical non-intervention (omissions) on the patient. They have a duty to protect the patient's safety and interests by exercising due diligence in decisions made, i.e. what is good, right, beneficial and fair to the patient as opposed to what is ethically bad, wrong, harmful and unjust to the patient. It seems appropriate for purposes of this study on patients' rights to integrate Sen's philosophy in the discussions around the protection and fulfilment of patients' rights in subsequent chapters.

Further, consequentialism, as in some other ethical theories, sets out criteria for choosing what to do; and among these are moral principles and actions. The moral principle grounding consequentialism obligates us to consider the interests of all those affected by our choice amongst the available options and to choose the option which we believe will result in the best consequences. As Pettit states,

Consequentialism argues against the complacent attitude of minding only your own moral business-your own intuitive part-never asking after the overall effects of that posture (Pettit, 1997: 168).

Suppose, for example, that research is needed on a particular sexually transmitted infection (STI). Public health researchers engage numerous men as subjects in this research. The subjects include 399 men who have the advanced active infection and a control group consisting of 201 men who do not (Jones, 1993). For their participation, the subjects are provided with free physical examinations (a luxury in the area in which they live as it is bereft of medical care) and hot meals on examination days. This study carries on for 40 years. At one stage in the research, the drug penicillin is invented and marketed. It is a cure for this STI. It is initially given to the research subjects, albeit in inadequate doses. However it is stopped and replaced by aspirin. The purported research aim was to scientifically document the physical and mental course of this major infectious disease on humans (ibid). At first glance, “if [this research] is the *only* way in which to save a *much* larger number of humans and there were no other adverse moral effects, then experimentation (or killing non-aggressors) would be morally permissible, and perhaps even morally mandatory” (LaFollette, 2007: 24).

The scenario above refers to the infamous Tuskegee Syphilis Study⁶ which started in 1932. The question is whether this study or research can be morally defended from a consequentialist perspective. First we will place this in the social context of its conception. ‘Social Darwinism’ was rife in America at that time. For example, in 1932, the Third International Congress on Eugenics was held at the American Museum of Natural History, and its theme was, “A Decade of Progress in Eugenics” (Osborn, 1934: 29-30). This particular sociological perspective may have served as a particular myopia when it came to the protection of humans in research. The scientific curiosity (albeit racially motivated) of the medical researchers may also have lent itself to starting this research in a Black population following the research done in Oslo, Norway in 1928 on a study of untreated syphilis in a White community (Harrison, 1956: 70). Some of the persons involved in the research may have acted in good will, while others followed the bureaucratic process with

⁶ The Tuskegee Syphilis Study is also known as The Tuskegee Syphilis Research and the Tuskegee Syphilis Experiment.

no moral reflection (Brody, 2005).⁷ A timeline of events may be helpful towards understanding the issues and the chronology of the Tuskegee Syphilis Study (Jones, 1993)

Table 1: Tuskegee Syphilis Study Timeline

Date	Event
Nov. 1929	The Rosenwald Fund, a private philanthropic foundation, appropriates \$50,000 to finance syphilis control demonstrations by the US Public Health Service (PHS) with African Americans in six different communities in six different southern states, one of which is the town of Tuskegee, the county seat of Macon County, Ala.
Jan. 1930	The PHS begins its syphilis control demonstrations in Tuskegee and other communities in the South.
Oct. 1932	The PHS returns to Tuskegee, where it previously uncovered an infection rate of 35% among those tested, to study the effects of untreated syphilis in a select group of African American males. The men are not told the purpose of the study or the effects of syphilis on human beings.
May 1933	Spinal taps are performed on the subjects of the study without the procedure or its effects being explained to them.
June 1933	Taliaferro Clark, who originated the study, retires from the PHS. Raymond Vonderlehr, who is intent on continuing the study, succeeds him.
Nov. 1933 – Mar. 1934	PHS officers return to Tuskegee and add a group of approximately 200 African American men to serve as controls for the study, again without explaining the study to them.
May 1935	The Milbank Memorial Fund, another private philanthropic foundation, gives the PHS a grant of \$500 to pay burial stipends to the men as an incentive for them and their families to consent to autopsies on the men when they die. The grant is extended in subsequent years.
1937-1938	The PHS sends mobile units into Macon County to treat people for syphilis, but

⁷Consequentialists though do not place any weight on the good or ill intent of an agent when judging the morality of an act.

	Treatment is withheld from the men in the study.
1942-1943	The PHS intervenes with the local draft boards in and around Macon County to secure deferments for the men in the study in order to prevent them from receiving treatment from the armed services upon induction into military service.
1943	The PHS starts treating patients who have syphilis with penicillin in several medical centres in the United States.
1947	The Nuremberg Code is articulated to protect human subjects from unethical and illegal medical experiments and studies.
1952	The PHS attempts to improve its record-keeping and diagnostic standards for the study.
1958	The PHS distributes certificates of appreciation and small cash payments to the men in the study.
1964	The Declaration of Helsinki, which stipulates that researchers must obtain informed consent from their subjects, is issued by the World Medical Association.
1966, 1968	Peter Buxtun, a PHS employee in San Francisco, Calif., raises strong moral objections to the Tuskegee Study.
Feb. 1969	The PHS convenes a blue-ribbon panel to review the Tuskegee Study, and the panel recommends that the study be continued, with one panellist in dissent.
July 1972	Peter Buxtun tells a newspaper reporter about the Tuskegee Study and the press breaks the story.
Aug. 1972	In response to public outrage, the Department of Health, Education and Welfare (HEW) appoint a panel to investigate the Tuskegee Study.
Feb./Mar. 1972	The US Senate holds hearings on human experimentation; the Tuskegee Study is given prominent attention.
Mar. 1973	HEW officially ends the Tuskegee Study by authorising treatment for the survivors.
July 1973	Attorney Fred Gray files a \$1.8 billion class action lawsuit against the United States, HEW, the State of Alabama, the State Board of Health of Alabama, and the Milbank Fund, as well as certain individuals in their private capacity.
Dec. 1974	A settlement is reached in the lawsuit.

1975	The US government agrees to treat the wives and children of the men in the Tuskegee Study.
1997	President Bill Clinton apologises for the Tuskegee Study. Source: Jones, 1993: 89, Figure 8.1

Source: Jones, 1993: 89

Source: Jones, 1993: 89

The supposed aims of the study were: 1) to follow the natural course of syphilis; and, 2) to document its unimpeded physical and mental course in a Black male population in order to gain knowledge about the disease in this particular racial population. In particular, the study aimed to answer the question if Black male populations reacted to syphilis in the same way as did White male populations. At the time the study commenced, syphilis was prevalent in the USA, particularly in the south amongst the poor, rural, unemployed and uneducated Black population. In the area from which the study's subjects were drawn, there was a critical lack of medical care and medical facilities. When the study began when there was no cure for syphilis, i.e. it was incurable at that stage. We recall that our question is whether we can morally defend this research from a consequentialist perspective. We keep in mind that what counts in our consequentialist moral reasoning must focus on the "overall happiness or misery of those affected by our decision" (Gillon, 1995:20).

Facts and conjecture continue to unfold concerning the Tuskegee Syphilis Study. We now know that there was blatant racism involved fed by social Darwinism, the eugenics movement, as well as fear and myths surrounding people who 'looked different' from the majority in society. Eugenics became the descendant of social Darwinism, which has had a lasting impact (often evil) on modern society. Over five million Jews were killed in the Nazi Holocaust, 375,000 supposedly 'inadequate' people were sterilised - all this in the name of a 'science' of eugenics, one deeming Jews and others to be biologically inferior to the Aryan race (Dickens, 2000)

It is no surprise that studies that were both evil and unethical were conducted during the eugenics movement era. The Tuskegee study “not only embraced Alabama’s unjust social protocols, but distilled them to the point that inadequate care became no care – simultaneously cloaked in a web of lies to make participants believe they had been freed from unjust treatment” (Levine, *et al.*, 2012: 104-105). During the course of the forty year study, three-quarters of the subjects died of syphilis (Jones, 1981: 154). Hundreds of the subjects suffered complications as syphilis took its natural course. As syphilis is a STI, wives and partners also were infected and, in turn, many children were born with congenital syphilis.

We now also know that there was a strong push for American dominance in the scientific world so the moral compasses of those engaged in this research might have been skewed. We now know that there was a point in the study when there was a proven cure for syphilis. Not only was this cure denied, but wilful deceit was engaged to assure that to the best of the PHS’s ability, subjects could not access the curative drug penicillin. In August 1972, in an Ad hoc Department of Health, Education and Welfare (HEW) hearing the study was deemed as “ethically unjustified” arguing that penicillin should have been given to the subjects

(Department of Health, Education and Welfare, 2000:166).

We now know that documents *indirectly* related to the study were excluded from the 1969 blue-ribbon panel’s consideration. Such excluded documents according to Roy (1995), point to the use of the Tuskegee subjects simply as a source for their bodily fluids, particularly their ‘bad blood’.⁸Roy (*ibid.*) writes: “Syphilis could only cultivate in living beings. As in slavery, the generative ability of the body made the Tuskegee subjects real property and gave untreated syphilis and the sera of the Tuskegee subjects immense commercial value

⁸ Because it was believed that the subjects of this study could not understand medical terms, they were told that it concerned their “bad blood” – the local colloquialism for syphilis (Brandt, 1978:7).

... Published protocols exploited the Tuskegee Syphilis Experiment to invent and commercialize biotechnology for the applied science of syphilis serology” (Roy, 1995:56).

We also know that specific ethical and legal research ethics guidelines came into place during the Tuskegee Syphilis Study, namely the Nuremburg Code (1947) and the Declaration of Helsinki (1964). Both these documents articulated the protection of human subjects in research emphasising the idea of obtaining their informed consent to participate. Although the list of faults could be added to, at least the following are blatantly clear: racism, moral myopia or the failure to see the wrong in one’s actions, violation of informed consent, deception, paternalism, double standards, maleficence, scientific hubris, ignorance and greed. We understand that for every action there are consequences. When we attempt to undertake consequentialist reasoning we should consider which consequences morally matter. LaFollette (2007) writes, “If we consider only the consequence, then we will eventually and perhaps often act immorally.” (LaFollette, 2007: 24). Now, I shall try to unpack only a few of the points raised in consequentialist deliberation.

Can we say that since the rural, poor, and uneducated Black population had no access to proper medical treatment anyway, then syphilis would have taken its natural course on them so the study would not have made any difference to their medical outcome? We are unable to answer this question. Most likely, before the advent of penicillin, many would have died. However, with the advent of a cure, the outcome may have been quite different. However, this relates to short-term consequences. Long-term consequences of the Tuskegee Study have resulted in a continuing suspicion amongst many African Americans that they will be used for ‘experiments’ under the guise of medical attention (Jones, 1981: 155).

Consequentialists consider in their reasoning how many interests are involved. In this way of thinking, the more interests involved the greater weight it should have on our moral decision. In this regard, the predominant short-term interest appears to be the interests of the PHS as opposed to the study’s subjects. This is intuitively unsettling. It is unsettling because it defies the moral idea that all people are of value and that the vulnerable sick

should be aided in as much as it is possible to do so. It seems that the PHS in this experiment were advancing a political (racism) rather than a scientific agenda of conducting research that is ethical. In addition, in 1948 during the study, the *Universal Declaration of Human Rights* was adopted by the General Assembly of the United Nations. It is clear that the tenets of this declaration – human dignity shared by all individuals regardless of race, religion, creed, nationality, social origin or sex, their civil liberties, and their rights were disregarded. These may serve as examples of 'adverse moral effects' which would make the research impermissible.

Concerning weighing interests in the long term, as Levine, *et. al.*, state,

We suggest that the fundamental structure of the Tuskegee experiment – legally mandated decisions which systematically expose African Americans (and now other minority groups) to conditions outside the boundaries of the best medical evidence – has been preserved through continuing and legally anointed social experiments which are either clearly or possibly unethical and to which the PHS remains partnered. PHS acquiescence puts it outside the boundaries of medical evidence; outside the boundaries of the ethical values of autonomy, justice, beneficence, non-maleficence, caring and solidarity; and outside of medicine itself. (Levine, *et. al.*, 2012: 124-125)

We are obliged as LaFollette (2007) writes to consider, “a) which consequences we should count, b) how much weight or consideration we should give those that do count, and, c) how we should use these considerations when deliberating” (LaFollette, 2007:25). Consequentialist theories are often applied to healthcare policies, particularly in public healthcare. We recall that our question is whether we can morally defend this research from a consequentialist perspective. In this section, the researcher has tried to show that consequentialism in the light of evidence cannot be used to justify this research. Consequentialism as a theory, particularly in considering how much weight we should award interests (necessary for deciding the moral course of action) is fraught with difficulties. If Consequentialism were to be taken seriously in this regard, it would have been difficult for Consequentialists to view the research as unjustifiable since in the consequentialist it is the majority of Americans who would stand to gain from the findings of

the experiment. The difficulty posed by Consequentialism hinges on the fact that, Consequentialists do not place any weight on the good or ill intent of an agent when judging the morality of an act but its outcome (consequences).

1.6.2. Utilitarianism

Utility has played a major role in political and moral philosophy. Utilitarianism is considered as a sub-category of a group of consequentialist theories. A classical utilitarian position is that only utility consequences (happiness, good, pleasure) and numbers make a moral difference. The classic proponents of utilitarianism were Jeremy Bentham, John Stuart Mill (1806-1873) and Henry Sidgwick (1838-1900).

Utilitarianism is based on the value of utility, or the theory commonly known as "the greatest amount of happiness for the greatest number of people". It arose in response to a time when it was felt that the government of England was interfering too greatly in the private lives of its citizens. Utilitarianism is a theory that involves maximising and collectivising utility (conceived as a good/happiness/pleasure).

In the political arena utilitarianism would require that governments should maximise the total net sum of happiness of all their citizens. Natural rights theory, on the other hand, considers each individual's interest.

Jeremy Bentham (1748-1832) was a lawyer, politician and philosopher who expounded classical utilitarianism. He argued that the actions of each individual are motivated by a calculation of pleasure and pain. In the context of politics, Bentham, as Shestack (1998:214) puts it: "argued that every political decision made should also be based on the calculation of utility; maximise the net utility and produce the greatest amount of happiness/good/pleasure (utility) over pain".

One of utilitarianism's main features is that it tries to be fair or impartial. The "classical utilitarianism calculus does not permit any favouritism, i.e. privilege based on mutual feelings, family relationships or shared nationalities" (Olen and Barry, 1999: 37).

As Olen and Barry write:

The assailants of utilitarianism seldom have the justice to acknowledge, that the happiness which forms the utilitarian standard of what is right in conduct is not the agent's own happiness, but that of all concerned. As between that of others, utilitarianism requires him to be as strictly impartial as a disinterested and benevolent spectator (Olen and Barry, 1999: 38).

A problem with utilitarianism is "the way in which it dismisses the influence of the past on determining the morality of actions and thus prevents people from acting with integrity" (Williams and Smart, 1973: 98-100). Critics of utilitarianism may also claim that it does not respect individuals' rights to make their own choices about how they want to live their lives. Because it is the end that matters, individually held values maybe subjugated to the "happiness of the greatest number of people". Shestack (1998: 213) notes that "values such as impartiality, happiness, liberty, self-worth, and respect all involve behaviour; unknown in a metaphysical sense but rather are recognised and acted upon".

Hedonistic utilitarians, such as John Stuart Mill, held epicurean views about consequences. Consequentialists claimed that an act is morally right if and only if that act maximises the good, that is, if and only if the total amount of good for all minus the total amount of bad for all is greater than this net amount for any incompatible act available to the agent on that occasion (ibid). Hedonism then claims that pleasure is the only intrinsic good and that pain is the only intrinsic bad.

Together these claims imply that an act is morally right if and only if that act results in the greatest happiness for the greatest number (Sinnott-Armstrong, 1992: 399-421). In this sense, it appears that utilitarians argue that the relative amount of happiness or pain brought about by human actions is the most important indicator of moral worth.

One could also hold that an act is right if it maximises respect for or minimises violations of certain specified moral rights. According to Sinnott-Armstrong, such theories are sometimes described as a utilitarianism of rights (ibid).

This approach could be built into a total consequentialism, with rights being weighed against happiness and other values, or alternatively, rendering the violations of rights insignificant could be lexically ranked prior to any other kind of loss or harm (Rawls 1971:42). In this instance, a weighting or priority ranking⁹ of the different relevant values engaged when formulating own principles is established. The value that has high lexical priority over another trumps the second high-ranked value. Rawls (ibid) writes that such “a lexical ranking within a consequentialist moral theory would produce the result that nobody is ever defensible in violating rights for the sake of happiness or any value other than rights although it would still permit some rights-damages thus avoiding or preventing other rights violations”.

Utilitarians claim that only consequences matter because the greatest balance of happiness over unhappiness is sought and that all individuals’ happiness counts equally. All other aspects of an action are ignored, including the question as to whether there might not perhaps be something inherently wrong about actions, irrespective of the consequences they might have. Van Niekerk (2011: 22) notes that, based on the foregoing statement, looking only at consequences makes the theory radical or even crass to a certain degree. For example, utilitarianism defends the idea that acts such as lying, stealing and torture can sometimes, depending on their consequences, be right, and that there is therefore nothing inherently wrong about them; all that matters is that they bring about the desired ends.

Despite its flaws, utilitarianism has been an exceptionally influential moral theory. It is prominent in the history of ethics and also in the province of moral deliberation concerning public policy. In application to human rights, the main criticism of utilitarianism is that it fails

⁹Rawls favours what he calls “lexical priority rankings” (Arneston, R. John Rawls’s Theory of Justice, Notes for philosophy 167, Spring, 2008)

to recognise individual autonomy; “it fails to take rights seriously in that it does not recognise the distinction between individuals” (Rawls, 1971:187).

1.7 Ronald Dworkin (1931-2013): Attempting to reconcile natural rights and Utilitarianism

As is common in philosophy, older theories are often reconsidered and revised in the light of new thought and information. Ronald Dworkin (1931-2013) makes a significant contribution to this in his many works. In his 1977 work, *Taking Rights Seriously*, he presents a reconciliatory attempt to unite natural rights and utilitarianism. Dworkin proceeds from the premise that all governments should treat their citizens with equal respect and care. Without this moral premise, no valid discussion of rights can take place (Dworkin, 1977:80). Dworkin follows this thought through with the utilitarian principle of egalitarianism.

Dworkin argues that the government may use wide interventionist functions to achieve the advancement of social welfare. He considers that the primary purpose of the law is to ensure that a political community acts in a clear and principled way to all of its members.

This dissertation, however, does not aim to provide any in-depth analysis of the legal arguments Dworkin presents but to attempt finding where law and moral principles meet (if they do at all) for purposes of advocating for patients’ rights. Dworkin draws a distinction between rules and principles as can be seen in extracts from the paper he presented at the Massachusetts Institute of Technology (MIT) in Spring 2012. According to Dworkin (ibid) “rules are applicable in an all-or-nothing way” the all-or-nothing application of rules means that if the facts a rule stipulates are given, then either the rule is valid, in which case the answer it supplies must be accepted, or it is not, in which case it contributes nothing to the decision (Dworkin, 1967: 25). Dworkin describes a principle as: “a standard that is to be observed, not because it will advance or secure an economic, political, or social situation deemed desirable, because it is a requirement of justice or fairness or some other dimension of morality” (Dworkin, 1967: 23). On the one hand, Dworkin argues that rules exist only after the case has been decided, in which event the court cites principles as its

justification for adopting and applying a new rule; on the other hand, he emphasises that principles have an element that rules do not exhibit – they have weight or importance (Dworkin, 1967: 29). A quotation from the United States of America's former Chief Justice, Sir Earl Warren in *A Biography of Earl Warren* by Ed Cray (1997) seems to capture the credence that ethical and/or moral principles demonstrate as opposed to rules as follows:

In a civilized life, law floats in a sea of ethics. Each is indispensable to civilization, without law, we should be at the mercy of the least scrupulous; without ethics, law could not exist (Cray, 1997: 395).

Ethical principles thus, have a useful role to play in bioethics as far as contemporary bioethical contests are concerned: when conflicting principles have to be applied to resolve a case, the one who must solve the conflict has to take into account the comparative weight of each (Dworkin, 1967: 27). In biomedical ethics, the weight of a case rests in its 'ethical justifiability' or 'the best interest of the individuals who will be affected by the outcome of the case' (more benefit than harm), the case that can be more ethically justified thus has more weight as opposed to the one that has 'grey areas' or cannot be ethically acceptable. It is also important to note that it is critical to apply what is called 'rigour' in the use of moral principles to settle a complex case. It is against this background that this dissertation prizes ethical principles highly. This is, however, not to claim that legal rules are not important but to say Dworkin's argument on principles is found attractive to this study on patients' rights.

1.8 Kant: Rationality, duty, the good will and human dignity and worth

For the 18th century German philosopher Immanuel Kant, the central defining feature of a human being is rationality. Kant's conception of rationality is partially based on the Enlightenment concepts of the universe or natural order as following universally valid laws or principles. The Enlightenment was a time of great cultural, scientific and philosophic evolution (i.e. Descartes, Newton, Leibniz, Locke and Galileo). It was a time of questioning, seeking, and attempting to answer all of life's questions with the focus on the idea of 'the rational man. As Kant stated, "Everything in nature works according to laws"(Kant [1797] 1996: 59).

Concerning living during the Enlightenment period, he writes:

Enlightenment is man's release from his self-incurred tutelage. Tutelage is man's inability to make use of his understanding without direction from another. Self-incurred is this tutelage when its cause lies not in lack of reason but in lack of resolution and courage to use it without direction from another. Sapere aude (Dare to know/Dare to be wise.) Use your own reason –that is the motto of enlightenment (Kant [1784] In: Beck, 1963:3).

Kant's complex works in philosophy cover many areas and discuss many deep, varied, and complex topics.¹⁰ Kant's great intellect continues to challenge philosophers and thinkers in contemporary times. In what follows, a few of Kant's ideas are offered as an analysis in so far as they are relevant to the purposes of this thesis.

1.8.1 Kant: Reason, Good Will, and Duty

For Kant, morality is something that human beings can self-prescribe simply because they are rational. By rational, Kant refers to the human capacity for reason. Because of this capacity for reason, each human individual is intrinsically a holder of dignity, value and worth, thus deserving of respect.

As rational beings, Kant argues, each human individual has the capacity to will the moral law, the capacity to act autonomously and the capacity to choose freely. In decision-making, rational individuals are offered the choice of many possible principles, but they should reject all principles that "cannot accord with the will's own enactment of universal law" (Kant [1797]1996: 60). According to Kant, the human will provides an ultimate action-guiding principle, a moral law that tells us what matters most and how to act accordingly. An individual's *will* is for Kant a power that is given to humans to choose a course of action based on principles (laws), and a *good will* is a disposition present in all rational humans "to adopt and act on the right sort of policies (i.e. maxims)" (Johnson, 2009:37-39). The human will binds itself to moral law, "experiencing the law's commands as absolute and expecting

¹⁰Naragon (2006) provides a list of the dates and topics of Kant's many writing.

as reward neither happiness nor heaven, eschewing both sensuous and divine incentives"(Kant [1785]2003: 401).

In saying that an individual acts autonomously (which is done in accordance with pure reason) Kant refers to a rational individual's capacity to choose freely his or her own course of action, to make his or her own choice. Because an action is right or wrong according to reason, individuals who reason have the capacity to know what is right or wrong. For Kant, actions are universally judged right or wrong (good or bad). All rational human beings are thus considered moral agents; as such we are held to be morally responsible for our actions.¹¹

Kant was a deontologist, the first philosopher to put the concept of duty (Gr. *deon*) at the centre of moral philosophy. He is considered the archetype of modern deontological or formalist theorists.¹² Differing from natural rights theorists, Kant makes no moral appeal to a Supreme Deity to justify actions. Kant emphasises duty, as a rational principle, which is on the one hand attractive, but creating problems to determine the morality of an act, or promote patients' rights (on the other hand). Langlois (2009) argues, "A philosophically adequate theoretical basis of human rights requires an account of moral reasoning that is consistent with the concept of rights, but does not necessarily require an appeal to the authority of some super-human entity in justifying an individual's claim to certain fundamental rights".(Langlois, 2009:14-15). Kant may provide such an account.

Kant proposed that moral goodness consists in the performance of duty for its own sake, that is, as opposed to requirements imposed upon an individual in ordinary social life (Norman, 1983: 95). Kant presents two views concerning the type of actions made by moral agents: those performed in accordance with duty and those performed from duty.

When an individual acts in accordance with duty, the action is performed as commanded by duty but if it is done because of inclination; the action is based on emotion, it pleases the

¹¹Others who may lack the rational capacity for moral reasoning are sometimes referred to as moral subjects or moral patients.

¹²Ethical formalism generally results in the use of principles or their derivative rules to guide decision-making.

person or is in his or her interests. According to Kant, action performed by inclination alone has no moral worth. Although individuals sometimes act from inclination (i.e. feelings, impulses, self-interest), for Kant, such inclinations can and ought to be overcome by acting from duty.¹³

Acting from duty means that an action is performed because it is an individual's duty to do it. Duty is performed for its own sake and Kant argues that only actions performed out of duty have moral worth. This is necessary in Kant's thesis because this is the only way an action can have an objective basis.

1.8.2 Kant and his Categorical Imperative

Kant argues that an individual's rationality (capacity for reason) is the basis of moral law. As this is so, he develops universal rules to guide moral actions. These rules Kant calls 'maxims' and because they are based on every individual's capacity for reason, they apply universally. Maxims are universalisable, according to Kant, because any rational individual *when considering the issue* would reach the same conclusion. For Kant, the only mark of an action's moral worth is not the outcome achieved by the action (as in consequentialist theories), but the agent's motive behind his or her action. Kant's famous statement concerning this is:

There is, therefore, only one categorical imperative. It is: Act only according to that maxim by which you can at the same time will that it should become a universal law (Kant, [1785] 2003:402).

There are different types of imperatives. Some rules, Kant asserts, appear to apply universally but, in reality, they are limited to a particular time, place, and circumstance. Hypothetical imperatives are rules that aim to achieve an instrumental good (ibid). They tend to follow an 'if ...'then' construction. For example, if I want to be healthy, then I should

¹³ Kant's idea of acting out of inclination as opposed to acting from duty has been criticised by many thinkers, for example, Anscombe, E., "Modern Moral Philosophy" (1958), Hegel G.W.F *The Philosophy of Right*, translated by S.W Dyed, sect. 135, and Schopenhauer A., *The World as Will and Representation*, translated by E.F.J. Payne (1958).

exercise; if I want good grades, then I should study. For Kant, hypothetical imperatives, as they are confined to an agent's situation and a particular time, lack universal scope. As such, there is no moral duty to follow them.

Kant's Categorical imperatives, on the other hand, refer to moral rules, the duties a rational individual must do or follow universally. For an action to be moral, it must be done in accordance with the three formulations of the categorical imperative. Kant ([1785] 2003) articulates these maxims as follows:

1st Maxim: "Act only according to that maxim whereby you can, at the same time, will that it should become a universal law without contradiction." (ibid: 402).

2nd Maxim: "Act in such a way that you treat humanity, whether in your own person or in the person of any other, always at the same time as an end and never merely as a means to an end" (ibid: 422).

3rd Maxim(*Conclusion*): "Therefore, every rational being must so act as if he were through his maxim always a legislating member in the universal kingdom of ends" (ibid: 433-434).

In simpler terms, Taylor interprets Kant's categorical imperatives as:

- (a) For a rule to be a rule, it must be consistently universalisable.
- (b) For a rule to be a moral rule, it must be such that, if all men follow it, they would treat each other as ends in themselves and never as means only.
- (c) For a rule to be a moral rule, it must furthermore be capable of being self-imposed by the will of each person when he is universally legislating (Taylor, 1975: 5)

The importance of these considerations emerges within Kant's introduction of the idea of the intrinsic nature of human dignity in his moral theory. According to Kant, only humans have the capacity to make their own decisions, set their own goals, and guide their own conduct by reason. If all human individuals are intrinsically valuable, then all human individuals should be worthy of respect (treated as ends in themselves and never as a

means to an end). As such, it is an objectively valid principle that every individual should be treated as a rational being with an autonomous will and dignity and as an end in him/her (Van Zyl, 1997:174).

The important point being made here can be highlighted with a counterexample of treating an individual as a means to an end: Dr A wanted very much to be appointed as the chairperson of the National Cancer Committee (NCC). He knew that the final decision would be made by the National Advisory Board (NAB). He quickly became 'best friends' with Dr X, head of NAB and ingratiated himself to her in many ways. When Dr A was appointed chairperson, his goal was reached and he no longer had any time for or interest in Dr X. She was used as a means to an end rather than an end in herself.

To treat a human individual solely as a means, Kant argues, is to treat him as a thing that can be valued strictly in terms of his usefulness. For example, slaves are commodities bought and sold for a fee. Slaves thus have no intrinsic value or worth; they are only of instrumental value, valuable as a means to an end.

Among Kant's central themes are the ideals of equality and the moral autonomy of rational human individuals. As Sandel (2009: 107) puts it, "[Kant believed] ... every individual is worthy of respect, not because human beings 'own themselves', but because they are rational beings, capable of reason and also autonomous beings, capable of acting and choosing freely". Kant's moral theory thus bequeathed to contemporary human rights theorists some notions of the intrinsic value of the human individual and the ideal of a potentially universal community of rational and intrinsically valuable individuals autonomously determining the moral principles needed to secure the conditions for equality and autonomy (Nickel, 2005: 385-402).

The strength of Kant's moral theory is that it bestowed a solid foundation for the idea of 'human dignity'.¹⁴ His theory offers moral laws that (may) hold universally, regardless of

¹⁴. Kant's moral theory can in my view be summarised simply as 'respect for human dignity.'

culture or social standing. The latter does not ignore the inflexibility¹⁵ of Kant's maxim but envisages the importance of human dignity, regardless of circumstances or consequences, especially as it pertains to the patient-health professional relationship. Some of the basic principles underscoring patients' rights are, for example, justice as in fairness, autonomy, respect, and beneficence. Kant's moral theory is thus critical for any study on patients' rights as special human rights emanating from a professional relationship between, for example, a patient and a doctor (patient-doctor relationship). Kant's theory, however, has been criticised by many philosophers, most famously Virginia Held (2006), Held maintains that utilitarianism and Kantian ethics are impartial and are built on the liberal model of social relations between strangers (Held, 2006:80). According to Held impartial moral theory gives no moral worth to personal relationships such as the one with family and friends and has this to say –

... To the impartialist, impartiality always trumps partiality after all ... (Held, 2006:70)

Held's views on Kant's theory were, however, met with counter-criticism from Kantian philosophers who argued that her stance was unconvincing and in some respects self-contradicting. For the purposes of this study, Kant's ethics are the appropriate moral theory to guide discussions on patients' rights. Held accepts that the ethics of care (her main theses) may not in itself provide sufficient theoretical resources for dealing with issues of justice (Held, 2006:17).

1.9 Neo-Kantian Social Contract Theory: John Rawls' Theory of Justice

In modern human rights theory, a significant contributor was the 20th century philosopher John Rawls (1921-2002). His complex theory was published in his famous work, *Theory of Justice* (1971). Rawls's work is quite intricate and in what follows, only a brief description of the main points he makes will be raised.¹⁶ Rawls' basic assumption is that a society is a

¹⁵ Kant's theory provides moral laws "maxims" which according to Kant must be universalisable, i.e. they must be the sort of thing that would be followed by all rational people irrespective of the consequences of the 'action' – An action is good if and only if it is motivated by duty, regardless of the consequences.

¹⁶ There is a great amount of literature both in favour of and against Rawls' *A Theory of Justice*. For example, see Wolff R. 1977, *Understanding Rawls*; Daniels N. (ed.) 1975, *Reading Rawls*; Sandel MJ. 1982,

communal effort or arrangement to advance the good of all members of society. "Justice is the first virtue of social institutions," says Rawls (1971:36). Accordingly, people's inequalities of birth, natural endowments and historical circumstances are undeserved and in a society where the cooperative nature of action to promote justice is taken seriously, every effort should be made to make equal the unequal situation of people who have been disadvantaged by what seems to be lotteries of life. Rawls perceives some of the advantages that people have over others as arbitrary (what Van Niekerk (2011) calls "accidents of biology and history" from a moral point of view and hence believes that these should be redressed. For Rawls, the idea is to redress the bias of such contingencies in the direction of equality (Rawls, 1971: 100-102).

A second central claim of Rawls's theory is that all essential economic goods and services should be distributed equally unless their unequal distribution works to everyone's advantage in that society. This distribution of goods, according to Rawls, ought to be the result of a social contract to which all who are affected by its contents should contribute equally (ibid). According to Rawls, the key principles underlying the social contract are as follows:

- 1) Each person has a right to the most extensive basic liberty compatible with the same liberty for others, and 2) inequalities in the distribution of wealth and power are just only when they can be reasonably expected to work to the advantage of those who are worst off. (Rawls, 1971:102).

For Rawls, justice does not require equality in social position, but it does require that people share one another's fate. Norman Daniels, a 20th century American theorist, summarises Rawls's theory as follows:

Firstly, there is what Rawls calls the "main idea". This is, according to Daniels (1975: 236), "the striking claim that principles of justice do not rest on mere intuition, yet are not to be

derived from utilitarian principles or from any other teleological theory holding that there is some form of good to be maximised.”

Secondly, he argues that the principles of justice are to be conceived as those that free and rational persons, who are concerned with furthering their own interests, would agree should govern their forms of social life and institutions if they had to choose such principles from behind a “veil of ignorance”. By this Rawls means ignorance of their own abilities – their psychological propensities, conceptions of good, status and position in society and the level of development of the society of which they are to be members (ibid).

Rawls calls this the “original position”. With this hypothetical situation, Rawls tries to show that if men and women are rational, and act only in their own self-interest, i.e. if they have to make choices without knowing their own position in society, they will choose his two principles of justice so as to ensure the best possible results for them even if they were the worse off in society.

Presenting a contemporary version of the social contract theory, Rawls thus contends that in an original position, a group of rational and impartial people will establish a mutually beneficial principle of justice as the foundation for regulating all rights, duties, power, and wealth (Rawls, 1971: 505). He proceeds with a ‘thought experiment’. Parties select principles that will determine the basic structure of the society in which they will live. This choice is made behind a ‘veil of ignorance’, which would deprive participants of information about their particular characteristics: ethnicity, social status, gender, crucially, and their conception of ‘the good’. This forces participants to select principles of impartially and rationally.

Rawls believed that his account of social contract-based justice avoids the problems of utilitarianism. Moreover, the response of a rational person based on this ‘original position’ would be to secure only two basic principles of justice: Firstly, a schedule of basic rights such as liberty and welfare rights, and secondly, equality of opportunity. A general conception of Rawls’s theory is that all social primary goods, liberty and opportunity, income

and wealth, and the basis of self-respect, are to be distributed equally unless an unequal distribution of any or all of these goods is to the advantage of the least favoured (Rawls, 1971:505).

Rawls argues that these social goods are what any rational person wants and will want regardless of his plan of life or his place in the social scheme of things. He further argues that the natural goods (health and vigour, intelligence and imagination) are only indirectly under the control of society, although their possession is influenced by the basic structures of society. In the same vein, Rawls insists on equal sharing by society of all burdens and benefits. As far as natural duties and obligations are concerned, Rawls emphasises support for just institutions, mutual respect, mutual aid, beneficence, justice as in fairness, and fidelity (promise keeping).

Rawls's theory seems not to require any appeal to human nature at all; rather, it is concerned with finding what conditions are relevant in the determination of what is just (Fisk, 1983 54). Incorporating his Neo-Kantian perspective, Rawls's theory developed around reason, autonomy and equality. Rawls argues that moral considerations, such as individual rights and distributive justice, depend less on social factors, e.g. individual happiness and mainstream interests, than they do on Kantian conceptions of individual value, self-respect and autonomy.

For Rawls, any philosophy in which the right to individual autonomy legitimately outweighs the demands of rational moral principles is unacceptable. Rawls claims that courageous and conscientious actions do not deserve admiration, except if they concur with moral principles derived from reason (Rawls, 1999: 221-222).

Rawls stresses that his work presents a moral-political conception of justice –“a moral conception worked out for a specific subject; namely, the basic structure of a constitutional democratic regime” (Rawls, quoted in Beauchamp and Childress, 2001: 352) rather than a comprehensive moral theory. This theory, the dominant moral and political ideology of our

time reflected in these principles, is of course a form of 'liberalism', a more egalitarian liberalism: justice as in fairness is at its epitome.

The rightness of considerations of justice in contemporary thought is also reflected in the work of other contemporary thinkers. Habermas, for example, in describing social justice states that systems of rights and protections (private and individual autonomy) will necessarily be postulated in order to institutionalise frameworks of public deliberation (more specifically, legislation and constitutional interpretation) that render principles of social justice acceptable to all affected – in consultation with others (Habermas, 1994: 111). According to Fraser (1997: 11-40), justice amounts to that set of principles that has been established in practice and rendered legitimate by the actual support of affected citizens (and their representatives) in a process of collective discourse and deliberation.

Rawls's theory provided a way around traditional contract theorists such as John Locke, who considered the state of nature in a generalised form, which is viewed as a way to concentrate on the natural. Based on a Lockean theory of nature, what humans do in the contract position is held to be expressive of what they are by nature, rather than expressive of what they have become *à la* Rawls because of the contingent situation in which they find themselves (Fisk, 1978: 53).

It is critical at this point to mention that Rawls' theory does provide some bases for human rights, and states as follows: "a just world order is perhaps seen as a society of peoples, each people maintaining a well-ordered and decent political (domestic) regime, not necessarily democratic but fully respecting basic human rights." (Rawls, 2003: 13). Human rights espoused by Rawls include but not limited to rights such as – "the right to an adequate standard of living, including "food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age ..." (ibid).

Rawls' theory seems to be consistent with social justice. In the same vein, if practice or result does not link up with any of Rawls' principles, it can be concluded that it is not

consistent with social justice. Something is not consistent with Rawls' notion of social justice - it interferes with any person's indefensible claims to equal basic rights. Rawls theory is thus relevant to this dissertation.

1.10 Moral Rights and Legal Rights

As shown, the history of concepts found in human rights theory includes ancient and modern philosophers and thinkers who put forth theories from, for example, considerations of justice to that of intrinsic human value; from early thoughts on natural rights as a gift from God to rights such as that of life, liberty, and the pursuit of happiness as human entitlements. These and other moral claims have evolved to be known as universal human rights, which serve as the grounding for the social order of all peoples. In contemporary human rights theory, these and other moral claims are referred to as universal human rights and are used as the basis for instituting universal human rights standards.

In their publication, *Principles of Biomedical Ethics*, Beauchamp and Childress (2001: 355) define a right as a "justified claim that individuals and groups can make upon other individuals or upon society; to have a right is to be in a position to determine by one's choices, what others should do or need not do". If the right is legal, then the claim must be supported by legal principles and rules, if moral, then the right finds grounding in moral principles and rules (ibid: 357-358). Yet, as we have seen, moral rights appear to be the basis of all legal rights. In practice, a number of moral rights are increasingly verbalised as lawful regulations, which are guaranteed by states. In this way, law becomes an instrument for the inclusion of moral rights for peoples.

The difference identified to exist between moral rights and legal rights is of fundamental importance for grasping the source and possible application of human rights. What then are moral rights? According to the *Internet Encyclopedia of Philosophy*,¹⁷ "moral rights are rights that, it is claimed, exist prior to and independently from their legal counterparts". The

¹⁷<http://www.iep.utm.edu/hum-rts>, accessed 09 February 2015.

existence and legitimacy of moral rights is therefore not considered to be dependent upon the actions of judges and politicians (ibid).

Legal rights, as the name implies, are those rights found within existing legal codes and enjoy recognition and protection by law. Legal rights can thus be exercised only in a specific jurisdiction, e.g. the National Health Act (Act. No. 61 of 2003) cannot have effect in say, the United Kingdom (UK); its application is limited to the Republic of South Africa. Legal rights, therefore change when one moves from one country to another.

Moral rights are the same irrespective of the country one resides in, culture or race, suffice it to say, that the claim on moral rights is the same no matter where you are. Even if moral rights are not be legally grounded and recognised as such, they remain absolutely valid and morally compelling, for example, the local and international resistance to the apartheid system in South Africa could not have been sustained by appealing to legal rights since no such rights existed (legal political rights for non-white South Africans). Nonetheless, the opposition to apartheid South Africa was a rights-based approach lamenting the gross violation of the fundamental moral rights of the larger South African population –blacks. There are, however, disputes related to the legitimacy and validity of moral rights (it is not within the ambit of this study to delve deeper into contestations about whether human rights can be universalised or not since that argument would call for another dissertation). A point that is uncontested thus far is that human rights originate as moral rights and derive their legitimacy as long as the concept of moral rights is legitimised. In South Africa, basic human rights are enshrined in the Constitution of the Republic of South Africa (Act 108 of 1996) as the Bill of Rights. According to Liebenberg (2002: 36), the Bill of Rights gives citizens “the full protection of the courts”. Human rights such as the patient’s rights in South Africa are therefore justiciable in so far as they can be grounded in moral rights. The idea of moral rights forms the basis of this dissertation.

1.11 Concluding Remarks

Although international law has established a conventional system of human rights, a philosophical understanding of the evolution of the moral grounding of human rights is not just an academic exercise. There are many philosophical theories that clarify and support the idea of human dignity and worth, and that offer thoughts concerning the grounding or re-conception of ways in which justice and equity may become part of the human experience. As Anthony Langlois (2001) puts it, the historical development of human rights has depended on the conviction that rights exist as moral demands that need to be translated into legal and institutional contexts in order to be effectively protected and policed.

Moral demands are fundamental to any laws, agreements, or institutions, and are the impetus for their creation. However, as will be shown in this study, the ability to claim rights, or to argue for them both in philosophical and practical terms is often most important to people when they do not have a well-functioning legal and institutional context in which to claim rights.

Uleman (2010:20) supports this thought: “the longings answered by a moral theory may also be historically and culturally specific born of particular struggles or circumstances or even mere restlessness.”¹⁸

In opening the conversation concerning moral theories and human rights, questions may arise that call for mindful reflection. Some of these questions might involve “aspects such as the nature of derogations or exceptions, the priorities to be afforded to various rights, the question of the hierarchical relationships in a series of rights, the question of whether rights ‘trump’ competing claims based on cultural rooting, and similar problems” (Shestack, 1998: 204).

Since the dynamic notion of human rights appears at this time to be mainly in the international law arena, answers to moral questions may be “relegated by pragmatic compromises, legal rulings, and interpretations” (ibid). This chapter has been devoted to a

¹⁸For example, the apartheid struggles in the case of South Africa.

discussion of a number of moral theories that can provide a foundation for human rights. The next chapter will give an overview of human rights from the international legal perspective, highlighting relevant declarations, conventions and other documents as a means to generate a broader understanding of the origins and importance of patients' rights.

Chapter 2

From human rights to patients' rights

... Whatever term we use to describe our times, we cannot avoid looking at power and connections if we hope to understand, and thus prevent, human rights abuses. And when we look at and listen to those whose rights are trampled, we see how political rights are intertwined with social and economic rights, or, rather how the absence of social and economic power empties political rights of their substance (Farmer, 2005: 16-17).

2.1 Introduction

Historically, the idea of rights emerged from the West. Langlois (2001: 12) tells us that "the language of rights did not appear out of a vacuum, but developed gradually through Western political history, reaching its first golden age in the European Enlightenment". Before the Enlightenment, social, moral and political values were considered relative to an objective moral order- the natural law - which was above all people. The 'objective moral order' was Christianity. Parishioners had particular duties associated with being members of the Church (ibid). Such duties were, under natural law, obligations first to the teachings of God as presented through the church. Another duty derived from natural law is a duty to others, because as humans we are 'created in the image of God'.

According to White, (1985: 1-2), the idea of rights "was given its widest currency by John Locke though it did not originate with him". Both seventeenth and eighteenth century philosophers "bequeathed the concept of rights to modern liberal democracy and rights theorists" (ibid). What 'rights' might be or even mean as claimed in the Enlightenment era over time grew more refined and served to lay the groundwork for 'natural rights' or 'the rights of man'. From these ideas came what are now called 'human rights'. Many documents were drafted "in the final decades of the 1700s, which are the early rhetorical and legal masterpieces of rights politics" (Fields, 2003: 22). They were created under the influence of a long chain of political events and in Langlois' (2001: 13) words, "the

intellectual ferment of the Enlightenment". The 'reasonable man' replaced the word of God as the highest authority. Thus, there gradually occurred a severing of the frame of natural law and its related Christian duties as the basis for certain obligations to others. Rather than relying on natural law, thinkers started to look to basic humanity from which the idea of rights could take shape, i.e. how our moral nature might serve to help develop the notion of human rights. In addition, social changes that considered the 'moral autonomy of the person', added substance to the idea of fundamental, inalienable rights, which were called 'natural rights' or those rights derived from our own humanity (Haakonssen, 1991: 61). "Human rights – *droits de l'homme, derechos humanos, Menschenrechte* (The Rights of Man) – are literally the rights that one has because one is human", writes Donnelly (2013:7). Understanding the idea and history of human rights is essential to appreciate the debates and problems that arise when we try to theorise human rights in general and patients' rights in particular.

This chapter, continues with the identification of some key points found in the development of the idea of human, health, and patients' rights. A human rights framework, because it is grounded in standards and processes based upon international law, differs from a bioethical view. For example, Beauchamp and Childress (1979: 48) tell us that patients' rights include the right to "privacy, confidentiality, information (informed consent) and professional care and treatment". These rights may be viewed as derivatives from the ethical duty that all HCPs have to respect the dignity and worth of their patients. In contrast to this, Cohen and Ezer (2013) state: "Human rights principles require that services to patients meet the standards set out in international and regional human rights norms and agreements." Both approaches, it may be said, look to the good of patient care and overlap. Indeed, as Beauchamp and Childress note, "Patient rights such as the right to privacy, confidentiality and freedom of choice are themselves not completely economic issues but civil and political in nature." The foregoing raises questions such as what then are 'rights'? What does it mean to 'have a right to (X)...'? To be a 'rights holder'? To be an 'addressee'? What international and national documents attempt to ensure justice for rights-holders?" First, definitions of some of the common terms used in the language of rights are needed.

2.2 Terms often used in the language of rights

Continuing the argument on the notion of 'rights' Donnelly (2013:13) regarding the meaning of having or possessing a right defines the term 'right' from two central aspects: 1) moral and political rectitude and 2) entitlement. According to Donnelly, when we speak of rights in the first sense we speak of 'the right thing to do', of something being right as opposed to being wrong. In the latter, at least in general terms, we speak of someone having a right (ibid). This work, focuses on the entitlement (political sense) aspect of rights. Rights as entitlements mean that if one is said to have the right to something, e.g. some goods or some service, she 'holds' that right and is, therefore, referred to as a 'rights holder'. The interesting thing about having a right is that the claim to the 'goods' or 'services' generated from it must be directed to a certain 'individual or 'party' that is obligated to address the claim. It is hoped that the identification of an individual or party can ensure that the rights holder receives the goods 'due' to her or access services to which she is 'entitled'. The individual or party charged with fulfilling the duties and responsibilities to address or fulfil the rights claim is an 'addressee' or an 'obligation bearer'. Rights to goods and services are typically regarded as claim rights or entitlements that are valid against others with corresponding obligations. O'Neill (2005: 430) tells us: "rights are seen as one side of a normative relationship between rights-holders and obligation-bearers."

Rights as viewed in an applied ethics perspective are best viewed as justified claims that individuals and groups can make upon others or upon society. Because moral principles and rules establish duties and obligations, rights are viewed as claims justified by moral principles and rules.

Dworkin (as cited in Donnelly, 2013: 27) explains the relation between the rights-holder and addressee as follows: "to have a right to x is to be entitled to x. It is owed to you, belongs to you in particular. And if x is threatened or denied, right-holders are authorised to make special claims that ordinarily trump utility, social policy, and other moral or political grounds for action." Nickel, however, warns that rights often involve "complex relationships such as

who has the right, and when it can be applied" (ibid: 27). Because of this, Nickel suggests ".it is helpful to have a detailed analysis of the parts of a fully specified right" (ibid: 23). With this in mind, the rights as set out in the Bill of Rights of the Constitution of South Africa may not meet Nickel's criteria of "fully specified rights". Rather, the rights included are broadly stated. For example, consider one of the rights:

Everyone has a right to access basic health care services including reproductive health.

The right to access basic healthcare services to an average South African implies that one has access to all the necessary components found in an effective and efficient healthcare service. However, this right does not specifically state that a patient accessing a healthcare service has the right to receive any such services that exceed those considered 'basic'. On the one hand, it was prudent of the authors of the Bill of Rights to use the term 'basic' because it can be interpreted in different ways and can change over time. On the other hand, perhaps if it had been more detailed, patients could understand the meaning of this right better. As I understand it, to have the right to access to healthcare means all are equally free to enter the healthcare system; that patients have a right to access basic healthcare services, however, is something different.

2.3 Defining features of human rights

Nickel (2007: 7) writes, "human rights as we know them today are the rights of the lawyers, not the rights of the philosophers". He further states that the term 'human rights' is not just another label for the historical ideas of natural rights (ibid). The development of important human rights documents followed political and social changes after the end of both the first and second World Wars. Formulated first as rights declarations, they were followed by international human rights treaties. Human rights treaties share general characteristics. Nickel (2007) describes such characteristics as the "defining features of human rights" as follows:

- (a) mandatory norms with right-holders, addressees, and scopes;
- (b) universal in the sense of protecting all people;
- (c) high priority norms with strong justifications;
- (d) not dependent for their existence on recognition by particular governments or on legal enactment at the national level;
- (e) international standards of evaluation and criticism that are not restricted by national boundaries;
- (f) political norms whose primary addressees are government rather than interpersonal standards;
- (g) numerous and specific norms dealing with matters such as security, due process, liberty, equal citizenship, and basic welfare;
- (h) minimal standards that constrain rather than replace legislation and policy-making at the national level (Nickel 2007: 25).

The background to patients' rights in this study is grounded in human rights and the human rights approach South Africa has adopted in its Constitution (Act, 108 of 1996). For purposes of this dissertation it is important that the features of 'human rights' should be highlighted so that this section forms a link to the subsequent section wherein natural and modern human rights are discussed.

2.4. A note on natural and modern human rights

Human rights as viewed today are not bound to a particular philosophical system or ideology. As a way to gather support for the human rights movement, philosophical underpinnings of human rights were sketched broadly but vaguely, in for example, the United Nation's Universal Declaration of Human Rights of 1948. Philosophical foundations may still be seen in statements such as "all humans being are" born free and equal in dignity and rights" and that we all "have equal and inalienable rights" (Nickel, 2007: 7-8). While the groundings of human rights may be difficult to cite clearly in moral philosophy, as Freeman (1994: 514) notes, "they can be derived from equal concern and respect for human

persons". Although the idea of natural rights is no longer the basis for human rights, some vestiges of this notion still remain.

The underlying idea of human rights is to prevent threats to an acceptable moral or minimally good life for people globally. Present in most democratic constitutions, a country's Bill of Rights at least generally follows from the traditional idea of Lockean natural rights (Wellman, 2011: 4). Although their influence upon the way we understand human rights is not denied, the idea of natural rights is, in fact, quite different from modern human rights. According to Nickel (2007:10), "modern human rights are specific and numerous, not broad and abstract like 'life, liberty, and property' which were the cornerstone for natural rights".

2.5. Generations of rights

According to Du Plessis (1993: 27), the term 'generation' as in 'generations of rights' denotes chronology rather than hierarchy. It refers to "growth in the awareness of various categories of rights and does not prioritise certain categories in relation to others"(ibid). The three generations of rights are: 1) civil and political rights (*liberté*); 2) economic, social, and cultural rights (*égalité*); and 3) (newly called) solidarity rights (*fraternité*) (Claude & Weston, 1992: 18).

2.5.1 First-generation rights (civil and political rights)

Civil and political rights are first-generation rights (blue rights or negative rights). They are different from moral, cultural, or religious rights, and they follow mainly from the Anglo-American legal tradition. First-generation rights refer to actions that the State should not take and are usually codified into law, e.g. the United States' Bill of Rights and the English Bill of Rights. Negative rights are premised on the traditional liberal-democratic idea of individual freedom from interference or coercion by the state or by other individuals in clearly defined private spheres, the argument often put forth by J.S. Mill. Negative rights correlate with duties to refrain from doing things to others. Civil and political rights consider that all citizens are entitled to freedom from interference, provided their actions are not harmful to others (ibid). Isaiah Berlin calls them "negative freedoms, the freedom to act

without undue constraint"(Berlin, 1969: 28). These early statements of rights were individualistic and libertarian. Because they were the first to be articulated, they are often referred to as first-generation or classic rights (ibid: 29). The protection of first-generation rights calls for as little government interference as possible (Du Plessis, 1993: 27).

2.5.2 Second-generation rights (economic, social and cultural rights)

Economic, social and cultural rights are considered second-generation rights (red rights or positive rights). According to Toebe (1999: 316-317), development of the idea of economic and social rights owes much to a speech given in 1941 by then US President Franklin Roosevelt. Reflecting the ideologies of the time, his 'Four Freedoms' speech included 'freedom from want' – a freedom that relates to socio-economic concerns (ibid).¹⁹ Second-generation rights have been recognised and are protected in modern constitutions and international law (BMA, 2001: 28). Second-generation rights acknowledge that more than freedom from interference is necessary for people to live well. Berlin (1969: 32) tells us that people require 'positive liberty'. By this he means that individuals need access to economic and social resources, e.g. education, healthcare, food and shelter, in order to flourish (ibid). Economic and social rights represent claims on the state for the provision of basic services and are explicitly recognised by international law. The promotion of second-generation rights cannot be realised without government taking decisive steps and interventions, it seems, since these rights require specific resources (human, material and monetary).

2.5.3 Third-generation rights (collective rights)

Third-generation or green rights are classified as positive rights (fraternity, and solidarity or group rights) and highlight the communal characteristics of humans. These rights attempt to broaden human rights to include issues such as the recognition of minority groups, social identity, the environment and particular cultural issues. These rights are often provided for by dedicated UN human rights instruments such as the *Declaration of the Right of Peoples*

¹⁹ President Franklin Roosevelt's other three freedoms are – freedom of speech, freedom of worship and freedom from fear.

to Peace, the *Stockholm Declaration* and the *Right to Development*. This category of rights is the most controversial and least institutionalised (WHO – Promotion of Patients' Rights, 1995). Second-generation rights and third-generation rights cannot be fulfilled without government intervention (Du Plessis, 1993: 27).

2.6. The South African Constitution and the Bill of Rights: duties and obligations

International human rights development in the form of treaties, conventions and declarations precipitated the changes that took place in South Africa, beginning at the inception of a democratic government in 1994. South Africa's transition is widely considered as a move from social injustice to social justice. A measure, at least in part, of social justice is the acknowledgement of human rights as a concept often described in South Africa's political arena as "the idea of our time" (Heyns and Brand, 2004: 25). It came as no surprise when a number of social and economic rights were included in the Constitution of the Republic of South Africa (RSA) (Act 108 of 1996) as presented in Chapter 2 of the Bill of Rights (hereafter the Bill). Moreover, the Bill gives citizens "the full protection of the courts" (Liebenberg, 2002: 36). Among the socio-economic rights that are protected are the right to access to adequate housing (section 26(1)), to health, sufficient food and water, and to social security (section 27(1)). There are, though, limitations to the duties of the state.

Except for children's rights to basic nutrition, shelter, basic health care and social services (section 28(1) (c)), the general socio-economic rights provisions are subject to internal limitations. The internal limitations require the state to take only reasonable legislative and other measures within its available resources to realise the rights progressively (section 26(2) and section 27(2)). Section 7(2) of the Bill provides a description of the nature of duties and obligations imposed on the state by such rights that "the state must respect, protect, promote and fulfil the rights in the Bill of Rights". In South Africa, all socio-economic rights, like all other rights in the Bill of Rights, are subject to the general limitation clause in section 36, which states the following:

The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open democratic society based on human dignity, equality and freedom, taking into account all relevant factors.

The obligation to respect human rights means that the state has a negative duty not to interfere with the existing enjoyment of rights. For example, in the context of a right to healthcare, if the state, without proper justification or procedure, discontinued or withheld basic treatment or healthcare services enjoyed now, this would be interfering with an existing right.

The duty to protect requires government to protect individuals from violation of their rights by third parties not related to the state, for example, corporate entities, this is called horizontal application (discussed further in subsequent sections) of the Bill of Rights. For example, a waste management company may dispose of medical waste which includes hazardous biologic material that can cause contamination of water sources and pose health hazard and/or illness in surrounding communities. As Mbazira (2006: 4) states, the duty of government in this regard is to regulate potentially harmful activities of third parties. By adopting and enforcing laws and regulations. It then becomes critical that over-and-above the laws government must provide for mechanisms to investigate and punish by levelling charges against perpetrators and ensure that remedies for victims are in place (ibid). This is a positive duty imposed by the Constitution against the state.

The obligation to promote also imposes a positive duty on the state to ensure that people are aware of their rights; it compels government to promote the rights through educating the people on how best to enjoy their rights. Dissemination of information becomes pivotal in this regard. To promote the right to health government should create awareness on how to prevent the occurrence of certain diseases such as HIV and AIDS and what people should do as soon as they realise they have contacted the disease. Key policy issues should be shared through publication to all key stakeholders including potential patients and patients afflicted by certain diseases.

Concerning patient rights, this suggests that the state should ensure that sufficient awareness about patient rights and responsibilities as stipulated in the PRC (1999) are effectively promoted. (this argument is returned to in subsequent chapters). The obligation implies that the state must ensure the full realisation of the rights as provided in the Bill of Rights. Human rights create obligations, usually on governments. The Bill of Rights in the Constitution of South Africa (Act 108 of 1996) relates solely to state law and the conduct of organs of state (section 7(1)). At all levels of government, citizens of the country are thereby protected against legislative, executive and administrative acts by the state that violate their basic human rights.

The duty to fulfil rights necessitates that government takes positive steps to ensure the realisation of rights in real practical terms. The duty requires government to take on measures that make it possible for those in need to access goods and services. Fulfilment of rights expects the state to provide material goods and services when needed, for example, the provision of food, water, medical services and creating and effectively implementing programmes that promote rights. Fulfilling socio-economic rights is the most arduous of all obligations since it requires huge amounts of resources (human and material).

The Constitution though does not provide the duties and obligations of citizens *per se*. However, since all South African citizens and people who live in it have human rights, they have a duty to uphold the values enshrined in the Constitution. Civilians also have an obligation to respect others' rights because they in turn want their rights to be respected. It is also encouraging that the National Department of Health's (NDoH) Patients' Rights Charter (1999) has a section on 'Patient's Responsibilities' (listed in a subsequent section). The Minister of Basic Education (DoBE), Ms Angie Motshekga, launched the Bill of Responsibilities Campaign for the Youth of South Africa on 23 March 2011. The DoBE's Bill outlines seven responsibilities that flow from each of the rights enshrined in the Constitution of the Republic of South Africa as follows:

My responsibility

(a) in ensuring the right to equality,

- (b) in ensuring the right to human dignity
- (c) in ensuring the right to life
- (d) in ensuring the right to family or parental care
- (e) in ensuring the right to education
- (f) in ensuring the right to work
- (g) in ensuring the right to freedom of expression.

The Bill concludes by stating that –

I accept the call of this Bill of Responsibilities, and commit to taking my rightful place as an active, responsible citizen of South Africa. By assuming these responsibilities I will contribute to building the kind of society which will make me proud to be a South African (Constitution of South Africa, Act. 108 of 1996)

This shows that citizens have duties and obligations towards all the rights in the Constitution of South Africa.

2.6.1 Vertical and Horizontal application of the Bill of Rights

Vertical and horizontal application of the Bill applies to individuals and corporates or business entities known as non-state agencies (NSA). The individual in relation to the government is known as the vertical operation of the Bill, the Bill then protects citizens from things done to them by the government. The horizontal operation of the Bill applies to matters between ordinary people or business; it protects people from things done to them by other people or business (Constitution of the Republic of South Africa, Act. 108 of 1996, Chapter 1). The rights enshrined in the Bill currently cannot be applied horizontally to private institutions such as hospitals. Private organisations therefore make own internal rules which may be contrary to the Bill. Conversely, an internal act that has an effect on private and public interests and violates rights outside the institution is no longer an internal ruling, it is unconstitutional. This viewpoint strengthens the ‘horizontal’ application of the Bill. The horizontal application of rights and in particular socio-economic rights is both a developing

and contested legal area locally and internationally. Pieterse (2007: 158-159) argues that “private entities are just like the state in that they are capable of harming the realisation of socio-economic rights. Because of this, certain obligations should be levelled against private sector corporations” (ibid). His argument is grounded in the constitutional guarantee of the right of everyone to have access to healthcare services. Pieterse (2007: 160) contends that “justiciable socio-economic rights ultimately require the reconstruction of the tenets of both the public and private law spheres whilst highlighting anew the artificiality of their separation, i.e. horizontal application of obligation also towards private institutions”. As the scope of this study does not include legal debates of this magnitude, the terminology used in addressing the realisation of socio-economic rights in the context of resource shortages – the progressive realisation of rights will be discussed.

2.6.2 Progressive realisation of Rights in the Bill

The principle of progressive realisation is articulated in certain human rights treaties, such as the International Convention on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of the Child, in relation to some of the obligations contained in them. States that are “parties to these treaties are bound by such obligations” writes Asher (2004: 22). Supporting the idea of progressive realisation of rights, Article 2 of the ICESCR stipulates that the state has the obligation to take:

...steps individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognised in the present Covenant by all appropriate means, including particularly the legislative measure (ICESCR, Art 2).

According to Judith Asher (2004: 22-23), “the principle of progressive realisation is particularly important for those countries where the full realisation of socio-economic and cultural rights such as the right to health, for example, is a difficult and complicated process requiring both resources and time”. The principle of progressive realisation “is essential to the practical implementation of the right to health, particularly in developing countries where

resources are scarce” (ibid). Asher argues that progressive realisation allows for a degree of variation in how states fulfil their duties. However, she insists that governments should not consider flexibility as an excuse or delay tactic. Rather, governments should move “expeditiously and effectively towards the full realisation of the right to health and other human rights” (Asher, 2004: 23).

Liebenberg (2010: 53) states that the court interprets ‘progressive realisation’ to mean “the dismantling of a range of legal, administrative, operational and financial obstacles which impede access to the rights and the expansion over time of such access, to a larger number of broader range of people”. Nonetheless, if Sections 26 and 27 of the South African Bill of Rights are interpreted as placing a strong obligation on the State to ensure that everyone has access to at least a basic level of the relevant socio-economic rights, ‘progressive realisation’ would refer “primarily to the State’s obligation to gradually improve the quality of goods and services to which people have access until the goal of full realisation of the rights is achieved” (Liebenberg, 2010: 187). Clearly, if South Africa is serious about ensuring that the state meets its obligations to respect, protect, promote and fulfil the basic rights of its people in general and socio-economic rights in particular, it is obliged to be pro-active and define concepts such as ‘minimum core’, ‘progressive realisation’ and similar ones in the context of the Constitution.²⁰

The Constitution of the Republic of South Africa places the primary responsibility for creating a framework within which socio-economic rights can be realised on the State. In theory, backed with our Constitution’s Bill of Rights as well as our country’s adoption of human rights treaties, one might be tempted to believe that there are good reasons to think that patients’ rights are realised in South Africa. When viewed from the perspective of some Constitutional Court rulings, it is clear that the issues involved in patients’ rights are quite complex. For their realisation, rights documents, treaties and declarations require a tremendous amount of education, action and public support. In the following section records

²⁰ In South Africa’s Constitutional Court Cases presented herein, it is clear that government departments either ‘misunderstand or misinterpret’ the concepts of ‘minimum core’, ‘progressive realisation’ or plainly choose to ignore them.

from the Constitutional Court, as it serves as the final arbiter for the realisation of rights in South Africa are examined.

2.7 South Africa's Constitutional Court Cases – Socio-economic Rights

How socio-economic rights are interpreted by the public, press, academics, and the courts is worth a pause. This is because each person or entity viewing them may have a different, and perhaps valid, point to make in the discussion. Liebenberg (2010: 80) proposes a substantive approach to the interpretation of socio-economic rights. She argues that “the interpretation of socio-economic rights should involve engaging with the actual impact of social and economic deprivation of disadvantaged groups” (ibid: 82). Then she suggests these findings “should be considered in keeping with the values and interests underpinning these rights” (ibid: 80). This, according to Liebenberg, requires “a consideration of the context both of the rights themselves and the circumstances in which particular groups allege a violation of their rights”. Agreeing with Nickel (1980), she points out that the textual setting of the relevant rights within the framework and social context must be taken into account (Liebenberg 2010: 80). When interpreting the Bill of Rights, Liebenberg argues that “the court, tribunal or forum must promote the values of human dignity, equality and freedom as provided by Section 39(1)(a) of the Constitution” (ibid).

The Constitutional Court of South Africa has affirmed the interdependence and interrelatedness of all rights (Liebenberg, 2010: 52). According to Liebenberg, a substantive approach to human rights interpretation is concerned with the social and economic conditions and relationships that are needed to ensure the full and effective enjoyment of rights (ibid). Looking at some of the important court cases may provide insight into how the judiciary interprets and responds to particular cases concerning socio-economic rights.

2.7.1 *Soobramoney v Minister of Health*

It took some time before social and economic rights were litigated in South Africa. When the first challenge was launched, the court, according to Davis (2004: 4), approached the issue with great caution.

In *Soobramoney v Minister of Health (KwaZulu-Natal)* 1997 (12) BCLR 1696²¹, the appellant was a diabetic who suffered from renal failure. He asked to be admitted to a state hospital for dialysis treatment but did not meet the hospital's eligibility criteria. He sought judicial relief, claiming that he had a right to receive treatment in terms of section 27(3), namely the right to emergency medical treatment. The court held that this right could not be construed outside of the context of the availability of health services generally (*ibid*). It thus found that the hospital authority could not be expected to provide treatment to all patients matching the appellant's profile. However, the court held in this judgment that the government is under an obligation to show that it has acted rationally and in good faith in making budgetary and policy decisions that affect people's access to these rights. Hence, the court was slow to interfere with decisions made by the KwaZulu-Natal Minister of Health, in the context of scarce resources and compelling medical demands.

2.7.2 The Government of the Republic of South Africa and Others v Grootboom and Others 2000

In 2000, the court heard another case of relevance: *The Government of the Republic of South Africa and Others v Grootboom and Others* 2000 (1) BCLR 1169 (CC) (*Grootboom*)²². In this case, the court set out a framework for South African jurisprudence on socio-economic rights (Davis, 2004: 5). The background of this case concerned the eviction of 900 squatters from informal homes they had erected on private land. Many of the litigants had applied for subsidised low-cost housing from the municipality but had been on the waiting list for years. The question for decision concerned whether the measures already taken by the State to realise housing rights in terms of section 26 of the Bill of Rights were reasonable.

²¹*Soobramoney v Minister of Health(KwaZulu-Natal)* 1997 (12) BCLR 1696

²²*The Government of the Republic of South Africa and Others v Grootboom and Others* 2000 (1) BCLR 1169 (CC) (*Grootboom*)

The court imposed an obligation on government at national, provincial and local level to “provide relief to homeless people living in intolerable conditions or crisis situations” based on section 26 of the Bill of Rights proclaiming the right of everyone to “access to adequate housing”. The court ruled in favour of the ‘Grootboom camp’ community. Judge Yacoob insisted that the courts can and must ensure that the State fulfils its unqualified constitutional obligations. This means the authorities cannot or should not ‘ignore’ the plight of those whose rights are in peril. Many South Africans viewed the court decision as “a watershed ruling of profound importance to the millions of South Africans who still live in great poverty” (ibid: 7). However, the court warned that the obligation of the state to fulfil that right is conditional. The reason for its being conditional is that the Constitution states that the state is obligated to take “reasonable measures within its available resources, to achieve the progressive realization of the right of all citizens to adequate housing”. In other words, the Constitution does not oblige the state to go beyond its available resources or to realise these rights immediately.

The Court insisted that the concept of reasonableness meant more than an assessment of simple statistical progress and that evidence had to be provided to show that sufficient attention had been paid to the needy and most vulnerable within the community (Grootboom, par. 44). According to Davis (ibid: 5), they were to be “considered a priority in the development of any sensible and constitutionally valid housing.” The court was invited to follow the minimum core approach of the United Nations Committee on Economic, Social and Cultural Rights in its General Comment 3 (GC3), to the effect that there was “... at the very least a minimum essential level of each of the rights” (GC3, par. 10). It further acknowledged that “it may be possible and appropriate to consider the contents of a minimum core to determine whether measures taken by the state were reasonable” (ibid).

The court felt that it was not provided in this case with “sufficient information to determine what would comprise the core in the context of the Constitution of the Republic” (Grootboom, par. 33). Instead, the court adopted the “test of reasonableness to hold that

the internal limitation did not permit the state to sacrifice the interests of those in desperate need in favour of medium-and long-term goals” (Grootboom, par.43).

In August 2008, seven years after the ruling had been made by the Constitutional Court, Irene Grootboom died before getting the benefit of the right to adequate housing. As written in *The Mail & Guardian*:

Irene Grootboom died in August 2008, penniless and homeless in her shack in Wallacedene. It is an image at odds with the photograph of her we publish in this edition: in it she spreads her arms in victory. She smiles, perhaps thinking of the home that might one day be hers. The Grootboom judgment to which she lent her name has become shorthand for one of post-apartheid South Africa’s major pro-poor victories. It gives extra muscle to the Constitution’s socio-economic rights – specifically the right to shelter – by compelling the government to take action. The ruling has set precedents for other judgments on the socio-economic rights of South Africans. That Grootboom died in her shack, her victory unrealised, at the beginning of women’s month should shame us all and goad the government into renewed commitment. Her death is a poignant symbol of the development failures of a middle-income country with a budget surplus, which for eight years could not provide proper shelter for a woman whom the Constitutional Court ruled it should immediately house. (*Mail & Guardian* of 8 August, 2008)

Only eight days after her death, Irene Grootboom’s family was allocated a low-cost house. Irene Grootboom’s case clearly illustrates the existing problems faced by the courts and society concerning the realisation and enforcement of socio-economic rights. Despite all the declarations on human rights, international covenants, regional instruments and domestic constitutions embracing the human-rights approach in general and health care in particular, gaps can still be identified in the realisation of rights and enforcement of socio-economic rights mainly by the poorest of the world. According to Liebenberg (2002: 36), "without access to at least a basic level of shelter, nutrition, education and health care, the foundational constitutional values of human dignity, equality and freedom have a hollow ring".

2.7.3 The *Minister of Health and Others v Treatment Action Campaign (TAC) and Others* 2002 (10) BCLR 1033 (CC) (TAC)

The Court's next encounter concerning socio-economic rights was the case of *Minister of Health and Others v Treatment Action Campaign (TAC) and Others* 2002 (10) BCLR 1033 (CC) (TAC).²³ This was a High Court case launched by TAC, which argued that the government had a duty to offer Nevirapine under the constitutional right to health treatment. The TAC demanded that the government provide a comprehensive national plan that prevents mother-to-child HIV infections, including services such as voluntary counselling, testing and providing a formula substitute for breast milk. Judge Chris Botha ruled in favour of the TAC, a milestone thus far. The bold judgment instructed the government to devise a plan for the provision of Nevirapine to pregnant mothers by the end of March 2002 (SAFLII 2002).

The court referred to the so-called Grootboom land case in the Nevirapine judgment. According to *The Sunday Independent*, "... in legal terms, the government had the right to lodge an appeal against the High Court judgment and allow the Constitutional Court to be the final arbiter". In moral terms, such action would be indefensible. All the Court did was to instruct the government to do what almost every expert and citizen had been calling for: the National Ministry of Health should supply and administer the best proven and affordable treatment for HIV and AIDS to save lives (ibid). Clearly, the reason for taking the issue to the High Court was to use constitutional instruments to ensure that the government would put in place policies that were in the best interests of the people.

Despite the aforesaid, and subject to the provisions of the Bill of Rights, a few days after the judgment was passed, government took the Nevirapine battle to the Constitutional Court. In its appeal, the Department of Health's legal adviser lamented: "the judgment raises many questions since the court order does not stipulate how long we (DOH) should provide Nevirapine" (ibid). The then National Minister of Health, Dr MantoTshabalala-Msimang,

²³ *Minister of Health and Others v Treatment Action Campaign (TAC) and Others* 2002 (10) BCLR 1033 (CC) (TAC).

claimed: "the order also failed to take into account budgetary constraints the DOH will incur about the provision of Nevirapine to pregnant mothers." (The Minister of Health and Others v Treatment Action Campaign (TAC) and Others 2002 (10) BCLR 1033 (CC) (TAC). In addition, she highlighted the lack of infrastructure for counselling and ongoing support services as major stumbling blocks and urged that the court should take all these issues into consideration in its rulings.

There was a great outcry over the Department of Health's appeal; for example, the TAC reacted as follows:

At the core of the court case were human rights, the rights of women to dignity and health care and the rights of children to life. The government's lack of a structured and coherent policy for the prevention of mother-to-child transmission (MTCT) goes against those rights ... The result of the appeal will be the loss of time, money and lives. While the appeal process takes place, more babies will contract HIV (*The Sunday Independent* of 13 April, 2002).

The Nevirapine debate, according to *The Sowetan*, was "raging" as far as socio-economic rights were concerned. This case was also the subject of intense debate in social, political, human rights and legal circles. The obligation of the State to fulfil these rights is unconditional. The Constitution stipulates:

... the State is obligated to take reasonable measures within its available resources to achieve the progressive realisation of the right of all citizens to access basic health care services ... (Constitution of the RSA, Act 108 of 1996).

The Constitutional Court found that the government's MTCT policy was "rigid, inflexible and unreasonable" (Liebenberg, 2002:16). Moreover, the finding that it should be amended "without delay" resulted in a victory for civil society through the realisation and enforcement of socio-economic rights (ibid). According to Liebenberg, the judgment vindicated the Constitutional Court on the Grootboom ruling and sent a clear message that government "must take reasonable measures with available resources to achieve the progressive

realisation of socio-economic rights”. The court found it was “under a duty to hold government to the Constitution and ensure that the values of human dignity, equality and freedom are realised by all South Africans” (ibid: 18).

2.7.4 Khosa and Others v Minister of Social Development and Another; Mahlaule and Others v Minister of Social Development and Another (Khosa/Mahlaule) 2004 (6) BCLR 569 (CC).

A different type of court encounter involving socio-economic rights is found in the cases of *Khosa and Others v Minister of Social Development and Another; Mahlaule and Others v Minister of Social Development and Another (Khosa/Mahlaule) 2004 (6) BCLR 569 (CC)*.²⁴ These cases involved a constitutional challenge to certain provisions of the Social Assistance Act 59 of 1992 and the Welfare Laws Amendment Act 106 of 1997, including provisions that had not yet been brought into force. These provisions restricted access to social assistance to South African citizens only, thus excluding permanent residents such as the elderly and children, who would have qualified for social assistance, but for the requirement of citizenship (Davis, 2004: 3-4). The court ruled “that the exclusion of permanent residents from the social security scheme was unreasonable and inconsistent with section 27 (social grant assistance) of the Constitution” (ibid: 5).

2.7.5 General Comment on South African Constitutional Court Cases on Socio-economic rights

International human rights documents (declarations and treaties) are on the face of it generally ‘powerful’. However, human rights documents or declarations in any guise do not have the capacity to adjudicate in disputes or in the face of coercive activities. It is for such and similar reasons that national governments must accept the serious obligation to ensure that human rights are respected, promoted, protected and fulfilled (Beitz, 2009: 24). One way of ensuring respect for rights is through the court system. Rights as articulated in Bills

²⁴*Khosa and Others v Minister of Social Development and Another; Mahlaule and Others v Minister of Social Development and Another (Khosa/Mahlaule) 2004 (6) BCLR 569 (CC)*

of Rights have what Nickel (2007: 25) terms a “mandatory character”, i.e. they provide a basis for complaint and in this manner they ‘empower’ the claimants. From the High Court rulings, we can see some progression towards the realisation of socio-economic rights, yet we also recognise that much more work needs to be done.

2.8 The Emergence of Patients' Rights

Many declarations and affirmations are instrumental in highlighting the need for and recognition of patients’ rights. Many international documents, such as declarations and national constitutions in their Bills of Rights refer frequently to a right to healthcare. The formalisation of patients’ rights gained momentum from the right to health grounded in ideals and practices found in international law.

2.8.1 Introduction

The World Health Organization (WHO), Constitution of 1946, declares that:

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic, or social condition (Constitution of the WHO, 1946: 1).

The *Universal Declaration of Human Rights* (UDHR) (1948) includes “everyone's right to a standard of living adequate for the well-being of himself and of his family (Article 25(1)). According to Article 12(1) of the ICESCR, parties to the covenant “recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”. Article 12(2) (d) states further that this *inter alia* impels governments to create conditions “which will assure to all medical service and medical attention in the event of sickness”. State parties that sign and ratify this treaty are legally bound by the conditions laid down in the treaty, i.e. by ratifying the treaty they bind themselves to respect the ideas contained within the treaty.

The *African Charter on Human and Peoples' Rights* (African Union, 1981), for example, imposes certain rights and duties on states to legislate the vertical (government) application of socio-economic rights within the realm of constitutional and legal provisions, or frameworks (Gawanas, 2009: 136-137). Moreover, The *African Charter* also imposes duties on members of society. Article 27 states: "Every individual shall have duties towards his family and society, the State and other legally recognised communities and the international community." This, points to the recognition in the *African Charter on Human and Peoples' Rights* of second-generation right and duties, as well as individual responsibilities (ibid: 155).

The UDHR (1948) recognises "the intrinsic dignity and the equal and unalienable rights of all members of the human family" (WHO, 1990). It is in the "concept of respect for persons and the fundamental dignity and equality of all human beings that the notion of patient rights finds grounding" (ibid). According to the WHO, the UDHR recognises the inherent dignity and the equal and inalienable rights of all members of the human family. The understanding and recognition in the UDHR of the inherent dignity that all human beings have by virtue of being human seems to serve as the bedrock for the patients' rights ideology, i.e. the kind of duties and obligations that both the HCPs and government owe to the patient as a human being. James Nickel states:

These rights exist in morality and in law at the national and international levels. They are addressed primarily to governments, requiring compliance and enforcement (Nickel, 2005:385).

The WHO Draft Declaration on the Rights of Patients (March 1990, revised August 1990) suggests that shared social, economic, ethical and political considerations gave rise to patients' rights internationally (Morgan, 1996: 22). Asher (2004: 9) tells us that patient rights can be considered a subset of the right to healthcare, thus falling under socio-economic rights. However, the idea that patients could or even should have rights is a modern conception. Here it should be noted that the health rights movement arose in response to questions from society concerning the role that doctors ought to play in their healthcare.

That the Human Rights movement would and did take a legal bend was not the original thought.

2.8.2 Changing perspectives in the 'doctor-patient relationship'

Throughout human history, there have been those who are ill and those who treat them. Those who treat the ill have always held a particularly high place in society as being “special, somehow gifted in matters of healing” (BMA, 2001: 14). The ancient version of the Hippocratic Oath was the first written document that set out particular ‘ethical’ rules of medical practice for its followers. The field or discipline of medical ethics would come much later. Medical ethics was created by the medical profession primarily to guide the decisions and regulate the actions of its members. It was formulated in the language of duties, tacitly assuming both the benevolence and importantly, the authority of doctors. In the 1940s, particularly following the Nuremberg Trials, it became evident that some doctors fell very far short of the qualities expected of them. The idea that all doctors in all places at all times acted for the good of their patients was publicly challenged.

In the 1960s, first in the United States (USA), social changes occurred and among all the fervour of the times 'rights-talk' became commonplace. The medical fraternity was not immune. Challenges to the doctor as the only authority in matters of one's life and death gained momentum. This was accompanied by the introduction of new medical rights laws in the USA, as well as in other countries. The idea of a kind physician telling his patient what to do and how to do it ('Doctor knows best') was under interrogation. The idea that patients should have a voice in their own healthcare (patients' rights) only arose during the last 50 years McLean, 1989 (as cited by Neary, 2002: 120). Meanwhile, the 'old' medical ethics were debated and considered by society. “This led many to conclude that the locus of medical authority ought to lie with patients rather than physicians” (BMA, 2001: 14).

Traditionally, codes of medical ethics were drawn up by the profession itself to safeguard its honour and reputation. Benevolence, duty and service to mankind were and are consistently reiterated as the key elements of medical practice (BMA, 2001: 15).

Since the 1960s the contributions of philosophers, lawyers and other professionals to the development of codes of medical ethics have ensured the incorporation of the concept of patient rights. In this way, the paradigm for healthcare ethics has gradually been expanding. Earlier paradigms emphasised the HCP's obligations to his or her patient. In the latter part of the twentieth century, the paradigm's focus expanded from the HCPs obligations to include "the source of that obligation: the rights of patients" (Schyve, 1996: 13). According to Schyve, this expansion arose from three sources:

1. The idea that a person does not forfeit his or her universal human rights by virtue of having become a patient; every patient has the right to be treated with respect as an individual. Both the atrocious experiments on patients in World War II and sociological studies on the inevitable loss of dignity that accompanies routine medical care emphasised the need for respect of persons in health care;
2. The realisation that a patient who participates in his or her own healthcare from decision-making to therapeutic activity, is more likely to have a desirable outcome than is the person who does not participate; and
3. The advent of consumerism in health care, in which key elements of a supplier-customer relationship have been recognised as part of the clinician-patient relationship (i.e., the choosing and using of a service, irrespective of paying for it) (Skyve: 13).

Viewed in this perspective, patients' rights may be seen as basic human rights of a special nature emanating from a special relationship between the patient and the doctor (as an HCP). The old paternalistic model of the doctor-patient relationship, in which the doctor made all decisions and was the sole keeper of information and knowledge, was replaced. A new autonomous model came into being in which a patient is supported by a doctor or HCP to participate actively in matters concerning his or her own healthcare and treatment. As a way of formalising the idea, hospitals began to support and promote the rights of their patients through a variety of institutionalised norms and bills of rights.

2.8.2.1 The rights of hospitalised patients

The USA led the field in the area of patients' rights. In 1973, the American Hospital Association (AHA) published the first document in the USA to express the rights of patients while in hospital – a Patient's Bill of Rights. The AHA's Patient's Bill of Rights originally contained 13 listed rights. It was revised in 1992 with the deletion of the 'therapeutic privilege' clause that permitted the disclosure of information regarding a patient's condition. The Bill became a model for American hospitals. Wilson-Silver (1997: 213-220) lists these rights as follows:

- (1) the right of a patient to considerate and respectful care;
- (2) the right to obtain from his/her physician complete recent information concerning his diagnosis, treatment, and prognosis in a way the patient can be reasonably expected to understand,
- (3) the right to receive from his physician informed consent prior to the start of any procedure and treatment, except in emergencies,
- (4) the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his action,
- (5) the right to every consideration of his privacy concerning his medical care programme,
- (6) the right to expect that all communications and records pertaining to his care should be treated as confidential,
- (7) the right to expect that within its capacity a hospital must make reasonable response to the request of the patient for services,
- (8) the right to obtain information,
- (9) the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care of treatment, the right to expect reasonable continuity of care
- (10) the right to examine and receive an explanation of his bill regardless of the source of payment,
- (11) the right to know what hospital rules and regulations apply to his conduct as a

patient,

- (12) the right to be informed of hospital policies and practices that relate to patient care, treatment, and responsibilities.
- (13) the right to be informed of available resources for resolving disputes, grievances, and conflicts, such as ethics committees, patients representatives, or other mechanisms available in the institution.
- (14) the right to be informed of the hospital's charges for services and available payment methods (ibid: 213-220).

According to Davis and Aroskar (1983: 49), the AHA's Patient Bill of Rights reflects public acceptance of the shift from "the paternalist model of physician-patient relationship to an autonomous model". The AHA's Patient Bill of Rights expresses what all patients should expect while hospitalised, while concurrently providing a clear way in which hospitals express their commitment to patients (Wilson-Silver, 1997: 213-220). As a result of the AHA's Patient Bill of Rights, many individual states in the USA developed their own particular patients' rights bills. Of note is the US State of New Jersey, which enacted legislation that supported, based on public policy, that "acute care hospitalised patients had certain specific rights" as well as "mechanisms in place to enforce such rights" (ibid: 213).

In the late 1980s the State of New Jersey passed its version of the Patient's Bill of Rights. The Bill of Rights includes both a list of individual rights, and information expanding and explaining each right stated in the document. The rights include: (1) the right to access to care; (2) the right to be free from discrimination; (3) the right to be introduced to any healthcare provider by name in addition to the use of name badges; (4) the right to receive confidential treatment; the right to and the procedure for obtaining a copy of medical records; (5) the right to provide informed consent; (6) the right to decline participation in medical research or treatment administered by medical or healthcare students; (7) the right to be informed of the facility's policies and procedures regarding the withdrawal and withholding of life support; (8) the right to be informed of the right to transfer care from practitioner or facility, and the procedure to accomplish it. Other rights, such as patients being provided with appropriate medical follow-ups and nursing support upon discharge, as

well as the discharge appeals procedure, the right to receive a copy of the hospital's billing rates and an itemised bill, and the right to be provided with assistance when applying for health insurance payment and charity care, are also included. The scope of a patient's rights under the New Jersey legislation is all encompassing and as it was legislated, it became mandatory New Jersey Statutes Annotated (1989).

In the US, in an effort to promote more of a 'partnership' (understanding that good healthcare requires effort on the part of HCPs, and patients, the Patients' Bill of Rights was replaced by the AHA in 2003 by the 'Patient Care Partnership' (Johns Hopkins Sheraton Library, 2003). While the underlying duties and obligations as noted above remain, greater focus is placed on the idea that for optimum benefit, patients and the entire healthcare team should work together.

2.8.3 Other declarations of note concerning the rights of patients

Other declarations of note concerning the rights of patients include for example, the World Medical Association's (WMA) Declaration of Lisbon. In September 1981 the 34th Assembly of the WMA met in Lisbon and approved a statement on the rights of the patient. It is referred to as the Declaration of Lisbon and states some of the principal rights that the medical profession seeks to provide to patients, (a) the patient has the right to choose his physician freely, (b) the patient has the right to be cared for by a physician who is free to make clinical and ethical judgments without any outside interference, (c) the patient has the right to accept or to refuse treatment after receiving adequate information, (d) the patient has the right to expect that his physician will respect the confidential nature of his medical and personal details, (e) the patient has the right to die in dignity, (f) the patient has the right to receive or to decline spiritual and moral comfort, including the help of a minister of an appropriate religion (Breen, *et al.*, 1997:12).²⁵

²⁵There are no major shifts from other declarations on patients' rights – all patients' rights charters and patient's bill of rights seem to be grounded in the principles of respect for patient's human dignity and respect for individual autonomy.

2.8.3.1 The United Kingdom Patient's Charter

Of more recent vintage, is the United Kingdom's Patient's Charter. In 1991, the UK National Health Service (NHS) launched a citizens' charter and the Patient's Charter. The Patient's Charter contained a series of 'rights' that referred to the patient's entitlement to care in the NHS, namely: (1) the right to receive healthcare based on medical need and no other factor; (2) the right to be registered with a general practitioner (GP), and to be able to change from one GP to another without difficulty; (3) the right to emergency treatment; (4) the right to a second opinion under certain circumstances, and (5) the right to provide informed consent. There is no mention of the right to refuse medication or treatment, even though this is implicit in the concept of informed consent. There is a right of access to one's health record and assurance that staff will keep those records confidential, and finally there is the right to decline to participate in medical research and medical training. This final right regarding medical research may be grounded more strongly in the desire to comply with the *Declaration of Helsinki*.

The Patient's Charter, towards its conclusion, does specify how to complain and who to contact within the NHS. Wilson-Silver (1997: 218) highlights that these rights are at present "not protected by a law which is regulated or empowered by government and in a sense there is no benefit or satisfaction in asserting that patients have certain rights, while at the same time providing no enforceable follow-through or credible means of redress".

These are only a few examples of the ways in which the idea of a patient's human dignity are currently being expressed in international documents.

2.8.3.2 The South African National Patients' Rights Charter (1999)

In 1996, The South African National Patients' Rights Charter (PRC) was enacted. This was conceived in order to ensure the realisation of the right to access to healthcare services. Such services are guaranteed in the Constitution (Act No. 108 of 1996). As an organ of the state, the Department of Health is morally and legally obliged to uphold, promote, protect

and fulfil this right, and in November 1999 it issued, in pursuance of this obligation, South Africa's PRC.

The PRC contains second-generation rights including: (1) the right to a healthy and safe environment; (2) the right to participation in decision-making; (3) the right to access to healthcare; (4) the right to knowledge of one's health insurance or medical aid scheme; (5) the right to choose health services; (6) the right to be treated by a named healthcare provider; (7) the right to confidentiality and privacy; (8) the right to informed consent; (9) the right to refuse treatment; (10) the right to a second opinion (11) the right to continuity of care; and (12) the right to complain about health services. The question, however, that arises from vertical and horizontal application of patient rights is: If patients have rights, do they also have duties or obligations, and what can be done to make these both understood and practiced? The PRC has a section stipulating patients' responsibilities corresponding with patients' rights.

Every patient has the responsibility to:

- 1) take care of his or her health;
- 2) take care of and protect the environment;
- 3) respect the rights of other patients, health workers and healthcare providers;
- 4) utilise the healthcare system optimally and not abuse it;
- 5) know his or her local health services and what they offer;
- 6) provide health workers with relevant and accurate information for diagnostic, treatment, rehabilitation, or counselling purposes;
- 7) advise the health providers of his or her wishes with regard to his or her death;
- 8) comply with the prescribed treatment and rehabilitation procedures;
- 9) enquire about the related costs of the treatment and rehabilitation and to arrange for payment (National Patients' Rights Charter, 1999)

In South Africa, as far as enforcement of these rights is concerned, two institutions, the Constitutional Court and the South African Human Rights Commission, are given an explicit

role. The rights as defined are justiciable and consequently have 'hard protection' offered by legally binding decisions of the South African courts. In this way, the Constitutional Court serves as the final arbiter in the realisation and enforcement of patients' rights in South Africa.

2.9 Conclusion

In this chapter some of the common terms used in rights language are identified, as well as ways in which different disciplines look at the idea of patients' rights. The discussion of the Constitutional Court cases identified that the notion of rights in general, quite apart from the rights of patients, is quite complex; and that no right can be viewed as standing alone. Because the human rights movement took a legal path, while keeping many medical and ethical principles, some of these differences are briefly highlighted in a historical context. The Patient's Charter (UK) and the patient's Bill of Rights (USA) are provided to see what these documents comprise compared to the PRC (1999, SA). The link between human rights and patients' rights as 'special rights emanating from a professional relationship between HCPs and the patient – e.g. doctor-patient relationship' is pointed out. The duties as well as obligations of public institutions/hospitals and HCPs including the responsibilities that patients themselves bear due to the rights that they have are spelt out.

In chapter 3, some perspectives concerning patients' rights that should be considered when arguing for the effective enforcement of the rights that patients have or are owed by government and HPCs will be investigated.

Chapter 3

Perspectives on patients' rights

3.1 Introduction

The exploration of theoretical perspectives in Chapter 1 paved the way for framing the practicalities of the clinical encounter with moral reflections in which values and principles are integrated. Codes or statements of ethical principles have existed to guide medical practitioners for almost 2500 years (Breen, Plueckhahn and Cordner, 1997: 3). The basis for the principles contained in the modern codes originated in Greece through what is usually termed the Hippocratic Oath (*ibid*). Codes of ethics are common guidelines, which health professions such as medicine and nursing have accepted to use in making ethical decisions. They are contained in various codes or pledges (Pera and Van Tonder, 1996: 6). Their purposes are to ensure that the community receives the highest standards of care and to prevent health professionals from abusing the trust and power granted to them by the community, these high expectations from healthcare professions by the greater public call for ethical professionals.

When the theoretical standpoints are conceived and understood in the manner described above, largely they can only enrich the discourse and the application of a rights-based approach to health care. In clinical settings, conflict between ethical principles occurs; ethical theories and moral judgments become contestable (Benn, 1994: 6-8). Consequently, no ethical theory or decision-making method yields unequivocal conclusions which convince

everybody; too many different beliefs, philosophies, cultural backgrounds and life experiences influence views of right or wrong and this creates what are called 'ethical dilemmas'.

According to Moodley (2011: 41), an ethical dilemma often involves conflict between ethical principles. Often one speaks of the ethics or morals of an individual or a group or one refers to a set of rules or body of principles. According to Davis and Aroskar (1983), each society, religion, and professional group has its own principles or standards of conduct, and as persons concerned with being reasonable in their conduct, people rely on these standards for guidance (Davis and Aroskar, 1983: 2-3). Davis and Aroskar argue that not to seek guidance from such principles or rules would mean that people would most likely engage in unpredictable behaviour and therefore would be considered unreliable, so that others could not count on them in daily social interaction, particularly in the healthcare system.

In the healthcare environment, ethics as a mode of enquiry help health professionals to understand the moral dimensions of human conduct and to investigate matters of human concern. From these statements, it seems that principles and theories taken from ethics and applied in the healthcare setting give people ways to reason through an ethical dilemma or problem systematically. As Davis and Aroskar put it:

If one's object is to discover unambiguous answers to an ethical dilemma quickly and effortlessly, then most likely he will be bewildered by the complexity of these dilemmas. Furthermore, he will most surely experience disappointment if he expects instant truth, for one does not mine ethical dilemmas as easily as one mines diamonds, but a concern for ethical principles may prove to be the more valuable of the two endeavours (Davis and Aroskar, 1983: 3).

To this end, meaningful and constructive discussion of practical ethical problems and dilemmas is possible when conceptual frameworks developed throughout the history of ethical reasoning are used to examine the facts (scientific objectivity) and values (patient care) in question. More often, such discussions may lead to a degree of consensus, or at least to mutual understanding of divergent views. For example, assuring that the rights of

patients are protected requires more than educating policy makers and health providers; it requires educating citizens about what they should expect from their governments and their healthcare providers, in terms of the kind of treatment and respect they are owed.

In recent times, many of those responsible for teaching ethical principles to medical students have emphasised four generally accepted basic moral obligations relevant to medical practice (Breen, *et al.*, 1997: 7). This has provided a simpler framework for discussion and application of ethical principles in clinical practice, that is, in the doctor-patient relationship. Beauchamp and Childress (1994: 58-103) provide a principle-based framework which is also referred to as the 'four principles'. This framework is used for resolving ethical problems that confront healthcare practitioners. Duties flow from principles that are *prima facie*, that is, they can only be overruled by other, stronger moral considerations. Each principle is binding unless it clashes with an equal or stronger obligation (Beauchamp and Childress, 1994: 33-36). The principles have to be interpreted in terms of existing social practices and they may be balanced or may differ between contexts. For example, the principle of autonomy in an individualistic, Western liberal perspective will differ significantly from that of other cultures in which the idea of decision-making is placed within a community or with the head of a family.

The four principles are as follows:

1. Beneficence (the obligation to provide benefits and balance benefits against risks).
2. Non-maleficence (the obligation to avoid the causation of harm).
3. Respect for autonomy (the obligation to respect the decision-making capacities of autonomous persons).
4. Justice (obligations of fairness in the distribution of benefits and risks).

Breen, *et al.*, (1997: 7-8) state that the motivation behind the principle approach is to approach moral problems by applying one or more of the four basic moral principles. These principles are meant as action guides that operate at quite a high level of abstraction, but can be further specified in terms of more specific guidelines (*ibid*).

Most ethical theories (as discussed in Chapter 1) and many moral judgments are contestable. Some norms, values or principles are sufficiently widely agreed for codes of professional practice to be based on them. The codes are derived from moral principles already generally agreed on by the community, but are more restrictive than the norm. Medical ethical codes provide guidelines to help deal with the moral dimensions of medical practice. These codes do not in any way override the personally held ethical and religious beliefs of doctors on difficult moral issues such as abortion, sterilisation and euthanasia (Breen, *et al.*, 1997: 6). The theories alone cannot solve medical problems, as there might be mutually exclusive decisions, each of which violates certain principles while supporting others (Benn, 1994: 6-8). As Benn puts it:

We are often faced not with the question whether or not to violate a certain theory or principle, but which possible alternative violates it more or less (1994: 7).

In practice then, while codes of ethics have limitations and cannot provide answers to day-to-day moral dilemmas because they cannot cover every possible circumstance as far as wide-ranging ethical dilemmas are concerned, they do, however, provide a framework of general rights (for example, patients' rights); duties, values and policies that govern professional practice (Thompson, Melia and Boyd, 1988: 57-58). Meaningful and constructive discussions of practical ethical reasoning are used to examine the facts and values in question. Such discussions may lead to a degree of consensus, or at least a mutual understanding of divergent views in the realisation and enforcement of basic human rights, in particular patients' rights.

Health professionals make judgements that involve human lives and have an impact on the wellbeing of patients, families and others. Many of the situations in which such judgments are made involve relationships in which there is conflict between human needs and moral values or in which the interests of individuals are in conflict with those of a group (Davis and Aroskar, 1983: 39). Judgments in the ethical/moral realm are primarily concerned with what

is 'right' or 'good' for the patients or for developing policy in areas that raise ethical questions, such as orders not to resuscitate, refusal of treatment, or obtaining adequately informed consent (ibid). In healthcare ethics today, the conceptual framework most widely used in analysing medical ethical or moral questions is that of the principles of bioethics (Beauchamp and Childress, 2001: 397). As Van Niekerk (2011) puts it:

The basic idea behind this approach is that moral problems can best be approached (though not always solved) by applying one or more of four basic moral principles to them (Van Niekerk, 2011: 37).

In the clinical setting, in order to make clinical decisions that are both ethical and legally acceptable, clinicians or health professionals have to employ one or more of the four basic moral principles to ensure that patients' rights are both realised and enforced. Moodley (2011) asserts that the dominant principle that emerges in decision-making may depend on various factors, for example, when a patient is able to make his or her own decisions, respect for autonomy is dominant (Moodley, 2011: 41). It is important to acknowledge at this point that the respect for autonomy principle provides an analytical framework that assists in organising thoughts on many of the ethical problems encountered in both medical practice and medical/health research.

This chapter focuses on one of the four principles, namely 'respect for autonomy', from which stems the ethical rules in medical ethics – informed consent, confidentiality and privacy. It is hoped that the examination of ethical principles in this study will provide some direction as to the extent to which patients' rights to autonomy, respect, informed consent, confidentiality and privacy (the four principles in patients' rights) are dealt in the South African public health institutions and facilities. This chapter will focus firstly on a conceptual analysis of the principles informing patients' rights; secondly on some of the philosophical/theoretical underpinnings of these principles; and thirdly on the application of these principles to medical ethics in everyday practice.

3.2 Autonomy

3.2.1 Definition

Autonomy is like baldness. We know what perfect baldness consists of, but we use the word 'bald' to describe people who have lost a substantial amount of hair. It would be idle to attempt a precise definition of how many hairs, or what proportion of hair, a person must have lost in order to be correctly described as bald (Lindley, 1986, as cited by Tauber 2005: 84-85).

When one follows a variety of sources on 'autonomy', it seems that in the end autonomy appears among the principles of medical ethics as an extrapolation from the political-judicial culture in which it evolved. In this study, definitions from various authors and sources are used to ensure some degree of understanding and conceptualisation of autonomy as a concept, so that its philosophical interpretations also become accessible.

A typical dictionary definition offers 'independence' and 'freedom' as synonyms for autonomy. These concepts are similarly abstract, context-dependent and complex, with many functions and meanings of their own (Tauber, 2005: 83). Autonomy is the condition of being self-directed, of having authority over one's *choices* and *actions* whenever these are significant in the direction of one's life (Oshana, 2003: 100).

Beauchamp and Childress (1983) state this as follows:

The autonomous person determines his or her course of action in accordance with a plan chosen by him or herself (Beauchamp and Childress, 1983: 59).

Most importantly, persons who are autonomous are parties to ongoing social relations that enable them to direct their lives with a minimum of interference (Oshana, 1998: 81-102). An autonomous person is able to meet his/her goals without depending on the judgments of others as to the goal's validity and importance. Kane argues that "one is autonomous when one is an independent source of activity in the world" (Kane, 1998: 206). Consequently,

when one traces the historical evolution of autonomy philosophical, political, or social environments, such narratives provide a variety of interpretations, each dependent on the cultural or conceptual setting in question, demonstrating that autonomy is 'a complex story'

In this study, the value of autonomy as expressed by Kant as respect for the unconditional worth of a person is the chosen definition. Kant's conception of persons as rational individuals capable of making choices according to moral principles that could be willed universally valid for everyone (his categorical imperative discussed in Chapter 1 of this dissertation) is highlighted. Against this background, the study seeks to understand better how *autonomy* is used and understood in everyday parlance, and more specifically, how it is applied in the clinical setting.

In bedside care, autonomy stands for the proposition that an adult with the capacity to decide has a full and perfect right to determine what may be done to his body. It consequently seems that respect for autonomy in general is important, but most particularly in medical ethics. This view reflects a strand of ethical thought, associated with Kant but including many modern writers who are not Kantians, according to which respect for autonomy is a basic moral principle. Peter Singer, a moral and political philosopher, begins his argument by stating that 'autonomy' means the capacity to choose, to make and act on one's own decisions (Singer, 1993: 99). He goes further and provides an exposé on this line of thinking – "respect for autonomy", as follows:

Rational and self-conscious beings presumably have this ability, whereas beings who cannot consider the alternatives open to them are not capable of choosing in the required sense and hence cannot be autonomous. For example, only a being who can grasp the difference between dying and continuing to live can autonomously choose to live. Hence, killing a person who does not choose to die fails to respect that person's autonomy, and as the choice of living or dying is about the most fundamental choice anyone can make, the choice on which all other choices depend, killing a person who does not choose to die is the gravest possible violation of that person's autonomy (ibid).

Singer's view as far as it concerns autonomous choice and a being who can grasp the difference between living and dying is fundamental to the importance of his theory's contribution to this study (Singer, 1993: 99-100). In the application of autonomy to a clinical setting (patients' rights), there could be some other views and contradictions of Singer's line of thinking as presented herein. However, in view of the limitations of this study, which constrains one to focus on the principle of autonomy, an in-depth engagement on Singer's view on respect for autonomy is not attempted.

The implication is that, when an individual makes a similar declaration about some sphere of his/her²⁶ own life, she, too, is denying that anyone else has the authority to control her activity within this sphere; she is saying that any exercise of power over this activity is illegitimate unless she authorises it herself.

As a way to lend more power to the principle of autonomy, its philosophical origins are traced by borrowing from Kant and the utilitarian views of autonomy in medical ethics.

3.2.2 Kant's autonomy

The different uses of the term reflect two origins of the concept of autonomy in modern thought. The value of autonomy expressed as respect for the unconditional worth of a person is based on the view of autonomy expounded by Kant (Tauber, 2005: 83-85). Kant argued that persons are rational individuals capable of making choices according to moral principles that could be willed universally valid for everyone. Based on this capacity, Kant further argued that persons ought to be treated as ends in themselves and never as means to the ends of others. In this view, to be an autonomous agent is to be self-legislating in terms of valid moral principles that the individual would will for everyone. Respecting autonomy in this sense is to respect this capacity in other persons and to allow them to make choices according to the principles that they would will or legislate for themselves (self-determination). When one respects persons in this manner one treats them as an end in themselves and not as a means to one's own ends or the ends of others (Fry, 1987: 40).

²⁶ "Her" is used throughout the study but implies both male and female.

Moreover, central to Kant's ethical theory is the claim that all persons are owed respect just because they are persons, that is, free, rational beings. For Kant, to be a person is to have a status and worth unlike those of any other kind of being: it is to be an end in itself with dignity (Kant, 1785/1996, 4: 429). Kant further argued that the only response that is appropriate to such a being is respect. Respect is the acknowledgement in attitude and conduct of the dignity of persons as ends in themselves (ibid). Kant calls this distinctive worth, which only ends in themselves possess. For him, in his theory of value or dignity is the supreme value; thus ends in themselves are to be valued morally above all entities. Kant's concept of an end has several meanings, but for the purposes of this study, the researcher will restrict herself to an explanation of Kant's theory on respect for the unconditional worth of the individual.

3.2.3 Mill's liberty

The value of autonomy expressed as respect for individual thought and action (liberty) is based on the view of the 19th century philosopher John Stuart Mill. As a utilitarian, Mill believed that autonomous thought and action are beneficial to the welfare of individuals and the welfare of the state (Mill, 1996: 13). Mill argued that persons have the right to make autonomous choices of any type according to their personal convictions. Other persons in this view cannot interfere with this right as long as the choices made do not limit the freedom of choice of others and do not harm others. According to Mill, it is in the public interest to allow persons to have the opportunity to make individual choices in this manner in order that they might develop their full potential and contribute to the state. In effect, Mill would even argue that one role of government is to foster social conditions that allow the development of a person's character to choose according to self-determined plans developed by the individual (Fry, 1987: 40). Mill emphasises a plan of action in accordance with the principles chosen by the individual. Mill argues that in the part which merely concerns the individual, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign (Mill, 1996: 13-15). According to Mill, the only

part of the conduct of anyone, for which he is accountable to society, is that which concerns others.

Arising from these two moral philosophies, according to Beauchamp and Childress (1983: 79), the principle of autonomy assumes two components, namely (1) *respect for the unconditional worth of the individual* (Immanuel Kant) and (2) *respect for individual thought and action* (John Stuart Mill).

In moral and political philosophy, the notion of respect for persons commonly means a kind of respect that all people are owed morally just because they are persons, regardless of social position, individual characteristics or achievements, or moral merit.

In this sense, the idea is that persons as such have a distinctive moral status by virtue of which one has special categorical obligations to regard and treat them in ways that are constrained by certain inviolable limits. This is sometimes expressed in terms of rights (for example, patients' rights): persons, it is said, have a fundamental moral right to respect simply because they are persons. It is furthermore commonly accepted that persons are owed or have a right to equal respect (respect for patients' rights).

In this way, the human faculties of perception, judgment, discriminative feeling, mental activity, and even moral preference, are exercised only in making a choice. According to Mill, he who chooses his plan for himself employs all his faculties. He must use observation to see, reasoning and judgment to foresee, activity to gather materials for decision, discrimination to decide, and when he has decided, firmness and self-control to hold to his deliberate choice (choosing voluntarily). The researcher understands Mill's philosophy to be that: "Individuals are the best judges of their own interest, and the reason for not interfering, with a person's voluntary acts unless it is for the sake of others, is consideration for his liberty." (Mill, 1996: 75-76) .Against this background, individuality or autonomy is too important a characteristic for persons to be without. Since it is that element of persons upon which all other forms of freedom are grounded, including the freedom to act; autonomy cannot be something that one is at liberty to dismantle.

3.2.4 Autonomy in medical ethics

Autonomy has become more important as social values have shifted to define medical quality in terms of outcomes that are important to the patient rather than medical professionals (Tauber, 2005: 59). When an individual is able to make their own decisions especially relating to matters of life-and-death he is said to be 'autonomous', this implies that one has the capacity to make decisions (free from any psychiatric condition, he is mentally healthy). Against this backdrop, autonomy may be viewed as a general indicator of health. Many diseases, for example are characterised by loss of autonomy (mental incapacity). This makes autonomy an indicator of both personal well-being and of the well-being of the profession – by considering autonomy as a gauge parameter for (self) healthcare, the medical and ethical perspective both benefit from the implied reference to health. The patient is not a scientific entity, nor a technological object, nor a unit of financial value (ibid). The patient should be medicine's primary concern, and patient autonomy should consequently become medical ethics' governing philosophical principle. In this way, autonomy usually trumps other contenders (beneficence, justice and non-maleficence). Wolpe (1998) states this as follows:

For better or worse ... autonomy has emerged as perhaps the most powerful principle in American bioethics. It forms the basis of much theory and much regulation, and has become the 'default' principle ... Indisputably ... (Wolpe, 1998: 43).

The principle of autonomy, because of its mainly Western interpretation, has become a point of discussion worldwide. By virtue of the paradigm shift in medical ethics, which in the modern era has developed into what is called, "the ethics of care" (Tauber, 2005: 57), patients now expect to participate in collaborative consultation with the HCP. Contemporary medical ethics or ethics of care have successfully forced a realignment of patient's rights (patient autonomy); that is, people must be informed of medical decisions affecting their care. This new dynamic has reduced physicians' power, which hitherto seemed sacrosanct. This line of thinking seems to have laid the foundation for respect for patients' autonomy.

To say that doctors, nurses and other HCPs ought to respect autonomy is to assert a principle of autonomy as a guideline for action on the part of the health professionals. It is a broad principle in that it is binding on all healthcare professionals. For example, saying that the nurse respects the autonomous decisions of patients implies that she follows the correct procedures for obtaining informed consent from the patient before initiating procedures or treatment involving the patient. The treatment offered must be one that the patient would choose, or that is congruent with the course of action that he would want implemented on his behalf. I will discuss this in a later section of this chapter.

The assertion that nurses ought to respect autonomy also presents autonomy as a *prima facie* principle, which is to be followed unless it is overridden by another moral principle of greater weight or standing (ibid). For example, it may not always be possible to allow patients to make their own decisions or to follow the course of action that they have chosen. This is because their choice might be perceived as dangerous to other parties. Furthermore, the ability of the person to make autonomous choices might be in question, such as "in the case of impediments to a person's control that may consist of inner, psychological obstacles, for example, neurotic compulsion, excessively low self-esteem, weakness of will or addiction"(Feinberg, 1973: 13). In such circumstances, the obligation to prevent harm to others, Feinberg suggests, carries greater weight than does the obligation to respect patient autonomy (ibid: 14-15).

Additionally, persons who have diminished autonomy are incapable of acting according to a plan of action that they have chosen. For example, "a small child, an individual afflicted with Alzheimer's disease or an insane person lacks the rudimentary ability to be self-governing" (Oshana, 2003: 103). In such cases then, the state carries the obligation to protect and enhance the integrity and autonomy of individuals with 'diminished autonomy'.

Psychiatrists are often asked to evaluate the capacity of patients for making end-of-life decisions. Common practice in clinical settings is that persons with delirium or clinical depression are considered incapable of making decisions regarding end-of-life plans. Refusal of treatment for this group of persons and/or patients seems both impractical and

unethical. Strict standards governing consent, decisions and refusal of treatment takes into consideration persons or patients compromised by their physical or mental state (Fowler and Levine-Ariff, 1987: 195). On the other hand, Ryan (2010: 26-27), argues that persons who have the psychological capacity to make end-of-life decisions have the right to refuse treatment and choose to die if that is what they want. In such cases, Ryan contends that psychiatrists should be part of protecting that right.

These cases must be distinguished from circumstances faced by persons who possess the general capacity for self-determination, but who are prevented for various reasons from living autonomous lives. An imprisoned individual, for example, lacks the freedom to interact with others in ways that afford her control over the direction of her life. She also lacks a range of options, which are expected of one who can direct their own life. (A classic South African example is that of a political activist, Steven Bantu Biko, who could not exercise self-determination while in police custody).

As a principle guiding healthcare ethics, respect for autonomy does not apply to patients who are incapable of acting autonomously. For this reason, the obligation to follow the principle of autonomy does not apply if the patient is a young child or is comatose, severely mentally retarded or mentally ill. Obviously, it may be a difficult principle to follow in critical care settings. This is because the use of technologies may reduce the patient's ability to make his or her own decisions. Such technologies include, for example, the administration of potent medications that affect judgement and the use of 'induced comas' as part of life-saving attempts. Often, autonomy is compromised by disease or the inability of the patient to physically articulate decisions. In these circumstances, Fry (1987:42-43) points out that biomedical ethics helps assure the basis of autonomy: "The respect-for-persons model, which is of course the least well-developed of all the models, is protected when patients are substantially non-autonomous."

The respect-for-persons model views the patient as possessing certain human characteristics that need respect. His or her human dignity is respected regardless of whether or not the patient is self-determining or autonomous. It is at this stage that the

nurse's advocacy role asserts itself. The nurse keeps the basic human values of the patient in mind and acts to protect his dignity, privacy and self-determined choices, when applicable. Murphy (1998) argues that the nurse's patient-advocate model supports the moral authority of the nurse to make decisions for and with the patient, and to help the patient obtain the best possible care. The advocacy role assumed by nurses is based on the reality that "because the nurse spends more time with the patient, has a more continuous and caring relationship with the patient than any other member of the healthcare team, and is capable of developing a more insightful relationship with the patient he or she is, therefore, the best person on the healthcare team to act in the role of advocate for the patient" (Murphy, 1983: 9-24). The goal of advocacy, in this sense, is to promote the autonomy, self-actualisation, and individual uniqueness of the patient.

Alfred Tauber notes that in the reality of healthcare practice:

While autonomy remains an aspiration in the clinical setting, a fair appraisal shows that its attainment requires accepting "varying degrees" of autonomy or, better, "respect" for personal choice, as a substitute for full patient participation in decision making. (Tauber 2005: 125)

Tauber contends that one should acknowledge that autonomy is a flexible concept exhibiting different 'degrees of freedom'. In the highly technical arena of contemporary medicine, the power relationship between doctors and patient is profoundly asymmetrical. In his view, "patients simply agree to delegate varying degrees of their freedom and entrust their care to others out of deference to superior knowledge and technical expertise" (ibid: 126-130). Tauber suggests that it is precisely at this point that "current medical ethics fail to make the appropriate adjustment of modifying a restrictive definition of autonomy and complementing it with expanded physician responsibility" (ibid). This topic is revisited in subsequent chapters.

The principles of autonomy, beneficence, justice, and non-maleficence each claim consideration in healthcare settings. In Western societies, it is the principle of autonomy

though that usually takes precedence over the other principles. Autonomy or the duty to respect the autonomous decisions of others has "emerged as the most powerful principle in bioethics in general and, in particular in patient's rights" (Tauber, 2005: 61).

3.3. Informed consent

3.3.1 Introduction

Tauber (2005: 64) claims that "the belief that one could do almost anything to a patient, as long as one ensures that she upholds the principles of beneficence and non-maleficence is obsolete, i.e. such a belief were radically revolutionised over the last century. Sharing of commodities, in this case medical knowledge, requires a fundamental reshaping of the doctor's sociology of knowledge, namely, how it is used and to what end (ibid). In the 21st century, it seems that globally, paternalism has lost its hold in the healthcare arena.

Since the Nuremberg Code (1947) and the Declaration of Helsinki (1964) as well as other guidelines and declarations concerning ethical conduct in research were articulated, the imperative to obtain consent from a research participant for medical and other interventions has been a priority. In South African in particular, although the principles of such international codes are not enforceable, research ethics committees view them as binding. Van Oosten (2000: 7) tells us "... failure to observe the provisions of these guidelines may, in given circumstances, render a medical practitioner liable to (i) disciplinary action by the Health Professions Council of South Africa (HPCSA) and/or the academic or other institutions concerned; and/or (ii) civil action and/or criminal prosecution, provided the requirements of the delict or offence in question have been satisfied."

Informed consent as a requirement for lawful and ethical medical research is clearly identified in section 12 (2) (c) of the Constitution of the Republic of South Africa (Act. 108 of 1996), which stipulates:

[e]veryone has the right to bodily and psychological integrity, which includes the right ... not to be subjected to medical or scientific experiments without their informed consent.

According to Van Oosten (2007: 7), "the use of the word 'their' in section 12 (2) (c) makes it patently clear that the only person who is capable of giving consent to medical research is the research subject ... and surrogate consent to medical research is out of the question". Van Oosten further points out that "section 12(2) (c) is clearly out of step with current local and international medical research ethics" (ibid). This point will be revisited later in this chapter.

In clinical medical practice, *informed consent*, first received attention only in the early 1970s. Recently, the focus shifted from the physician's or researcher's obligation to disclose information to the patient's or subject's understanding and consent (Beauchamp and Childress, 2001: 77). Informed consent is both an ethical and a legal requirement. Doctors and other HCPs must ensure that informed consent forms are documented and are part of a patient's records. Ethical considerations for doctors include, for example, the assurance that their patients are sufficiently informed about any proposed treatments including any risks or benefits. Medical practitioners must be satisfied that patients understand and freely consent to such measures (Breen, *et al.*, 1997: 26-27).

"*First party consent*", is based on the principle of autonomy (Crump 1987: 237). The principle of autonomy grounds the rights of individuals to make a voluntary non-coerced choice concerning whether to participate in a research project. In research, the *principle of autonomy* also protects the individual concerning his or her right to withdraw from the research at any time without prejudice. Individuals may also make the decision to participate in research that involves risk. Concerning such decisions, because autonomy represents the principle of respect for persons, all individuals must be provided with the necessary information about a particular medical treatment and/or research regarding all possible risks. Without information a patient or research participant will not be able to make 'informed' choices and thus respect for autonomy is thwarted.

If autonomy is diminished, as in the cases of, for example, an unconscious patient, mentally incompetent persons, or small children, they have the right to additional safeguards (ibid). One way of providing safeguards to non-autonomous persons requires securing the consent of the patient's kin or guardian. This Crump (ibid: 237) terms "*second party consent*". Second party consent grounds its ethics in the principle of beneficence –actively doing good for one's patient or research participant. This principle establishes an individual's right to protection from harm. "Guaranteeing this principle involves first giving a fair assessment of known risks and benefits then monitoring the person's response to the treatment or study (if consent is given)" writes Crump (1987: 237).

The principle of justice (as in fairness) is involved in both first and second party consent. In research, for example, this principle grounds the idea that research participants should be recruited from a variety of groups. Selecting participants from a variety of groups helps to ensure a measure of protection for vulnerable groups such as those vulnerable to coercion, i.e. individuals who are economically or socially disadvantaged.

Informed consent, as an exercise in autonomy, embeds the patient's responsibility for making any delegated decisions. According to Tauber (2005: 135-136), the physician's responsibility is to fulfil the professional obligations so contracted, but the underlying and directing mandate remains the patient's. If this is violated, civil injury may be claimed. Although informed consent is based on respect for autonomy, the law has evolved to protect related rights and duties derived from this principle. Informed consent arose from the common law of torts, namely from cases of civil injury resulting from intentional or negligent actions inflicted by another (Faden and Beauchamp, 1986: 23-29). While the right of privacy and protection from battery are complementary legal elements, the law concerning negligence has been the dominant theory of liability informing the doctrine of medical consent (Tauber, 2005: 135). According to Faden and Beauchamp, in the clinical setting, medical negligence, as applied to informed consent,

assumes that there is a professional duty of due care to provide patients an appropriate disclosure of information before obtaining authorisation for treatment ... Lack of informed consent is treated as professional negligence in essentially the same respect as is careless performance of a surgical procedure (Faden & Beauchamp 1986: 29).

Requirements for consent are based on the principle of autonomy and are grounded in the idea that respect is due to the individual (Elliston, 1996: 37). Breen, *et al.*, (1997: 26) challenge the notion that this procedure arises principally from respect for the autonomy of the patient, but in essence, the forces behind this shift in emphasis were autonomy-driven. According to Breen, *et al.*, (1997), doctors who fail to inform their patients fully about their condition, treatment options or the material risks of treatment may be sued on the grounds of negligence (*ibid*). The doctor may be guilty of assault should she or he touch the patient without consent, in this case, the doctor may be charged with civil or criminal offense.

This means that a doctor must always focus on procedures, practices and treatments that are in the best interests of the patient. For example, anything done in relation to the health care of a person who lacks the capacity to make his or her own decision about that matter must be (1) reasonable and (2) in the best interests of that person. The point of 'best interests' will be revisited later in the study.

3.3.2 What then is 'informed consent'?

Crump (1987: 237) defines informed consent as "the knowing consent of a competent individual who is able to exercise free power of choice without undue inducement or any element of force, fraud, deceit, or any other form of coercion. Informed consent can also be given by an individual's legal representative if the individual is not competent to consent personally".

Paul Ramsey (2002: 5) provides an interesting explanation of informed consent as follows: "the principle of informed consent is a statement of the fidelity between a man who

performs medical procedures and a man on whom they are performed.” The key elements of valid informed consent are discussed in the following subsections.

3.3.3 Elements of valid informed consent

Adapted from Breen (1997), for consent to be valid, it needs to:

- (1) Be freely given; this includes avoiding putting pressure on a patient through failure to provide sufficient time for the patient to consider matters.
- (2) Involve disclosure by the doctor of the relevant (material) issues.
- (3) Be specific for the proposed procedure(s). The catch-all phrase "any other procedures which may be deemed necessary" (ibid: 28) should only be used in regard to unforeseen and urgent problems, and if it is used, a note should be made of the matters discussed in relation to this phrase.
- (4) Be given by a person who is competent to consent. Under ordinary circumstances, a husband does not have the legal power to give consent on behalf of his wife, a wife on behalf of her husband or children on behalf of their parents”(Breen, *et. al.*, (1997: 28)

According to Brock (2008: 607), a valid informed consent has three distinct components: *consent must be informed, voluntary, and given by a competent person*. Evidently, for the consent to be valid, the following conditions must be met: adequate information, voluntarism, and competence. In the following sections each of these three conditions is discussed in more detail.

3.3.3.1 Information

A doctor or researcher is obligated to provide appropriate information in an understandable form to both outpatients and in-patients (in the case of a doctor) and to each potential participant (in the case of a researcher). For doctors, the critical issue is to ensure that patients, for example, are able to make an informed decision about various treatment modalities presented and discussed between themselves and the physician. This applies to

researchers and their participants as well. Both have the responsibility to invite and answer any questions that rise concerning their treatment regimen, investigative procedure or research details. A major difficulty both doctors and researchers face is in deciding how much and how detailed the information should be. Brock (2008: 607) suggests that details about potential risks and benefits should take priority. The condition of adequate information thus revolves to a large extent around the issue of information disclosure.

There are common standards used for the disclosure of information to patients and research participants.

(a) The *reasonable person* standard of information disclosure

This standard, according to Pullman (2002: 116), requires that researchers "disclose as much information as any reasonable person would expect to have in order to make an informed decision whether or not to participate in a clinical trial. This standard is largely considered a compromise between the professional practice standard and the subjective person standard".

(b) The *professional practice* standard of information disclosure

The professional practice standard requires researchers to "disclose only as much information as other researchers working in the field would normally disclose" (Beauchamp and Childress, 1994: 148-149).

(c) The *subjective person* standard of information disclosure

The subjective person standard requires that the "information given be that which the specific patient or research participant feels is necessary for her to gain an informed understanding of, and appreciation for, that to which he or she is asked to consent" (Pullman, 2001:117).

Also, the differences between the therapeutic and research situation may permit a different standard of informed consent in each context – this complicating the situation even more (ibid).

In the case of researchers, "the professional practice standard is considered inadequate in that it puts prospective research subjects at the mercy of the research community" (ibid). Some ethicists recommend the subjective person standard as the preferred standard from a moral point of view (Beauchamp and Childress, 2001: 149-150). According to Beauchamp and Childress (2001), "legally, this standard puts the researcher at the mercy of the research subject's bitter hindsight" (2001: 150).

Clearly, there is no unanimity in the application of these standards. Nonetheless, Tauber (2005) argues, that the three disclosure requirements are applied in medical therapy rather than research: the professional practice standard, the reasonable person standard, and the subjective standard (ibid: 135). These are all highly contested, since the courts have not applied precise criteria. "The appropriate standards exhibit heterogeneity in practice" (ibid). There remain on-going debates in research and clinical practice concerning these three standards when applied to the idea of a 'valid informed consent'.

Ethical defence for the use of the subjective standard in clinical practice is sometimes offered because "this standard directs the doctor to tailor the information provided to any known special concerns or interests of the patient in question" (Brock, 2008: 608). This standard, Brock argues allows for the "individuation of information to the needs and concerns of individual patients, at least to the extent that they are or can be known". A signed consent form, however, is not sufficient proof of ethically valid consent if an appropriate informed consent process has not taken place.

Brock (2008: 609) argues that informed consent is an ongoing process, a dynamic process both in therapy and research, not the single event of signing a consent form. There are many discussions regarding informed consent. The main criticism concerns whether patients have sufficient technical, medical, and scientific knowledge to understand the terms used by doctors and researchers. However, it is clear that the patient's level of understanding of medical intervention or high technology does not necessarily have to be that extensive. What is ethically expected is that patients are informed about how their health and lives are likely to be affected, both positively and negatively, by the research or

treatment. "Whatever reasons, compelling or otherwise, one may offer for not providing the necessary information to patients to enable them to make informed decisions and choices about their medical care, can never be sufficient grounds for denying patients the right to make decisions on their treatment and care" (Ramsey, 2002: 10).

3.3.3.2 Voluntariness

The importance of voluntariness in informed consent has a place in medical-legal history. In-voluntary use in research was the point raised in 1914 in the landmark US case, *Schloendorff v Society of New York Hospital*. It raised the issue about medical paternalism and a patient's voluntary choice to treatment or investigations. The issues raised concerning non-voluntary treatment, for example, in cases where patients are considered especially vulnerable, such as the mentally incompetent, pointed to specific concerns about non-voluntary medical treatment. As the court ruled in this case, due to mental incompetence, a patient cannot make an informed decision, it is wrong to take advantage of such persons, and mentally compromised persons should not be denied their basic human rights.

To have the freedom to choose implies that one makes a choice that is voluntary, meaning that a patient or research participant must be removed from any element of undue inducement, force, fraud, deceit, coercion, or manipulation.

This requirement places responsibility on the doctor to ensure that the patient's consent is in fact voluntary, i.e. given without inducement or coercion. The word 'coercion' has a history that is complex both linguistically and philosophically. According to the *Stanford Encyclopedia of Philosophy* (Spring 2006), the concept of coercion has two different faces, corresponding to the two parties (coercers and coerced) usually involved. One can identify reasons why a coerced sometimes does or refrains from doing something. Due to its complicated history, coercion is linked to many complications such as diminishing the targeted agent's freedom and responsibility. In this way, coercion is also viewed as wrongdoing or violation of rights (ibid). It involves threats that may be real or implied, psychological or physical, and sometimes these have devastating effects.

On the other hand, coercion can be useful in areas such as politics to entrench a state's legitimacy and sovereignty, and it can be used by governments in the function of justice and the state. Because of its alleged utility, on the one hand, and its potential injurious effects on the other, coercion is a contentious issue both from a political (social life) and ethics viewpoint. There is a general belief that coercion is not always unjustified. Philosophers (such as Aquinas (1920 [1273]), Hobbes (1651), Locke (1823 [1689]), Kant (1996 [1797]) and 20th century philosophers such as Nozick (1969), O'Neill (1991) and Berman (2001), to name a few) started paying more attention to coercion as a concept in the 1970s with a special focus on its 'usefulness' and 'harmfulness' (ibid). For fear of doing disservice to the many and varied robust views about the notion of coercion, this study focuses on the 'damaging' effects that coercion might have in ethics with an emphasis on informed consent. In medical ethics coercion may be seen as some kind of pressure imposed on the coercee's will. Feinberg highlighted that by using pressure the coercer seeks to obtain a symbolic "consent" to some harmful or dangerous activity from the coercee (1986: 198). Feinberg (1986) provides a useful description of the role of the coercer namely that the coercer threatens to "cause or fail to prevent some consequences that (the coercee) finds unwelcome" and "gives some evidence of the credibility of the threat"; and "has actively intervened in (the coercee's) option network, to acquire control of the relevant option-switches; in particular he can close tight the conjunctive option that consists of (the coercee's) noncompliance with the demand and (the coercee's) avoidance of the threatened unwelcome consequences" (Feinberg, 1986: 198).

This requires the coercer to demonstrate his power, and to actively use it to prevent the coercee from finding ways to avoid the forced choice. Although Kant gives more attention to the importance of coercion for guaranteeing the rights of citizens, he maintains that coercion is a hindrance to freedom and that coercion is similar to all violations of a person's rights (Kant, 1996 [1797]: 232).

If coercion obstructs an individual's freedom as far as informed consent goes, the patient will not be free to make their own choice about whether to give consent or not. She may consent against her because he/she has been 'forced' to choose to consent (forced choice). This is ethically unacceptable since patients or research participants have the right to

decide or make free choices to consent to medical treatment or participate in a research project. Coercion differs from mere disapproval, emotional manipulation or persuasion. The bone of contention in ethics as far as coercion is concerned is that it usurps the agent's will to consent, thus interfering with the freedom of the coercee. Manipulation has usually been a side-issue in philosophical thought which is focused on the worrisome issues of freedom and unfreedom, such as coercion and exploitation, or psychological unfreedom in free will literature. The meaning of manipulation as defined in *The Concise Oxford Dictionary* means to manage a person or situation to one's own advantage, especially unfairly or unscrupulously. Kantian ethics seem to provide a clear line of argument and objection to manipulative tactics because, in Kant's view, such tactics tantamount to using an individual as a means to someone's ends in this manner, the manipulee as Greenspan (2003: 155), states: "does not necessarily share the optional ends served by the tactics but the manipulator". What is wrong with manipulation is that it involves violation of the autonomy of the manipulee. When someone violates an individual's autonomy, he/she shows a basic failure to respect that person's capacity to set and pursue his/her own ends. Coercion and manipulation therefore do not have any space in biomedical ethics or in clinical care and research involving human beings.

The following example shows how coercion impacts on patients

A physician out of science curiosity wants to conduct a study on a condition that the medical world is still grappling with in terms of its origins and effective treatment, and wishes to include his hospitalised patients in this research project. One of his patients, Betty, has heard of the 'disease' but has only a vague idea about it and feels uncomfortable about participating in the research. For days the physician, in collaboration with the nurses, is at pains to try to coerce Betty to sign the consent to participate in the project. Both the physician and the nurses keep reminding Betty how knowledgeable they are about the disease and how disappointed they would be should Betty not consent to the research project. In the end, Betty thinks that if she does not participate, then her physician will discontinue her monthly treatment for hypertension. Patients may sometimes think that their care will be compromised if they do not accept their physician's call to participate in a research project. This way of thinking may not be a fact but may be based on assumptions

and suspicions that are not well founded. It is against this background that physicians should take the necessary steps to reassure, inform and explain their objectives to patients. In this way, doctors can avoid untoward negative effects in their relationship with their patients.

When one deliberately misinforms participants about research and puts unwarranted pressure on the decision maker this is aimed at coercing potential research participants or patients to make a choice they would not make if fully informed and choosing freely according to their own choices grounded on the values they hold. Ramsey (2002: 11) states this clearly:

To have the freedom to choose – to choose voluntarily, means that a patient or research participant must be removed from any element of undue inducement, force, fraud, deceit, coercion or manipulation.

3.3.3 3 Competence

For informed consent to be ethically valid it is also a requirement that the person must be competent to make such consent; this is the *sine qua non*. In this respect there seems to be a crucial link between autonomous choice and competence. As Moodley (2011: 44) states, “informed decision-making in healthcare rests on the pre-condition that a patient is competent to consent”. When patients or participants in research do not have this competence they do not have the capacity to arrive at a choice that fits their values and interests, even if relevant information has been made available and no involuntariness is present.

According to Moodley (2011: 44), the terms ‘competence’ and ‘capacity’ are often used in decision-making in healthcare and are regularly used interchangeably. In this respect, it is critical to establish whether a patient is competent to consent in order to balance the conflict that exists between respecting autonomy and acting beneficently, that is, in the best interest of a cognitively impaired patient and/or incompetent patient (ibid). That there is such tension is well recognised and it is beyond the scope of this study to provide more than an outline of this debate.

The question is: What decision-making capacities are needed for competence? The answer to this question is provided by Dan Brock (2008: 610) as follows: "The first are capacities for understanding and communication. Capacities for understanding relevant information are needed to permit an informed choice, and capacities for communication are needed both for the process of becoming informed and to communicate a choice once it has been made." The second are the capacities "for reasoning and deliberation". This will most often be an 'if/then' construction of reasoning; if I do this, then that will happen. Part of deliberation entails the capacity to consider different courses of action so that they can be compared and then a choice made. The third capacity involves having 'aims and values'. Aims and values serve as the basis for selecting one course of action over its alternatives.

The evaluation of competence, Brock argues, should focus on the exercise of these various capacities in the person's reasoning about whether to participate in the research project at hand, not simply on the outcome of that decision process – whether consent is given or refused. The competence evaluator should therefore look for serious defects in the participant or patient's decision-making process and not merely focus on whether the patient or subject has arrived at a decision that others consider correct, rational, or the best (ibid).

Typically, adults are presumed to be competent to decide about participation in research unless proven otherwise, for example, individuals who are comatose or suffering from advanced dementia, the mentally ill or mentally handicapped (ibid). Elliston (1996: 29-34), states this as follows: "the adult patient of sound mind is taken as the benchmark for determining whether people are to be legally recognised as having capacity and competence to determine their own medical treatment." In the infamous *Schoendorff v Society of New York Hospital* (1914), in the medical malpractice action, Judge Benjamin Cardozo stated this:

Every human being of adult years and sound mind has a right to determine what should 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 (*Schoendorff v Society of New York Hospital* (1914) 105 NE92, 93).

In South Africa, consent to medical interventions by institutionalised mentally ill patients is governed by section 60(A) of the Mental Health Act, (Act No. 18 of 1973) – referred to as ‘the Act’ – which provides that where a patient is on account of mental illness "incapable of consenting to medical treatment or an operation, the following persons, in order of precedence, may give written consent to the treatment or operation: a curator, the patient’s spouse, a major child or a (presumably major) brother or sister (Section 60A (1) and (2) of the Act). In the absence of such persons or where such persons cannot be found after reasonable enquiry, based on the provisions of the Act (Section 60A (2) and (3), the superintendent of the hospital where the patient finds himself or herself may give written consent to the required treatment or operation if he or she has reasonable grounds for believing that the patient's life is being endangered or that the patient's health is being seriously threatened by his or her condition and that the patient's condition necessitates the treatment or operation in question. Children are presumed not to be competent to make that decision and so others, typically parents, must decide for them (providing surrogate/proxy consent); in the case of older children, their assent to participation is, according to Brock (2008: 610) naturally required.

For example, in the case of a child under the age of 18 years the consent of the parent or guardian is required. In terms of the Children’s Act (Act No. 38 of 2005) and the Choice on Termination of Pregnancy Act (Act No. 92 of 1996), certain exceptions to this rule exist, such as the age of consenting to medical treatment and surgical operations of children, which has been lowered from 21 years to 18 years, which means that people over the age of 18 years have full legal capacity. In this sense, children may consent to their own medical treatment or to the treatment of their children if:

- (a) They are over the age of 12 years;
- (b) They are of sufficient maturity and have the mental capacity to understand the benefits and risks, and social and other implications of the surgical operation; and,
- (c) They are duly assisted by their parents or guardian (Section 129(2)).

Also, the Children's Act provides for consent by children to HIV testing as a special provision if the following conditions are fulfilled:

- (a) If such a test is in the best interest of the child; and,
- (b) If the child is 12 years of age or older, or the child is under the age of 12 years and is of sufficient maturity to understand the benefits, risks and social implications of such a test (Section 130 (1) and 130(2)).

Consent to HIV testing may also be given on behalf of children by a parent or caregiver; provincial head of social development and a designated child protection organisation arranging the placement of the child, where the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test (ibid).

A child who is over the age of 12 years may, according to the Children's Act, consent to contraception such as condoms. In the case of other contraceptive methods where normally they should get the consent of a parent or caregiver they can only consent provided the child is at least 12 years old, proper medical advice is given to the child and the child is medically examined to determine on medical grounds whether a specific contraceptive should not be supplied to the child (section 134(2)). The Choice on Termination of Pregnancy Act, (Act No. 92 of 1996) allows girls of any age to consent to the termination of pregnancy without a parent's or guardian's consent.

The South African Medical Research Council's Guidelines on Ethics for Medical Research, which are based on the guidelines and reports of the Royal College of Physicians (1990), make the following provisions in terms of which the elderly may be included as participants in medical research: Firstly old age, as such, does not render a person incapable of consenting to medical research. In the absence of any indication to the contrary, elderly patients are, therefore, generally assumed to be competent to consent to research. Secondly while it is permissible to involve the elderly in research, consideration should be given to the possibility of mental deterioration and diminished ability to comprehend in the elderly, and also to their dependence and vulnerability (Van Oosten, 2000: 17).

Since children and the elderly are the most vulnerable groups as far as health care in general is concerned, and in particular medical treatment and research, this study pays special attention to these groups in terms of ethically and morally acceptable processes and procedures for obtaining consent.

The Act goes into details in addressing various technical and process issues affecting the elderly, pregnant women, the dying and minors in research, whether therapeutic or non-therapeutic. However, that there are such complexities is well recognised and it is beyond the scope of this chapter to provide more than a general outline of the debates on such issues, as given.

3.3.3.4 Concluding remarks on informed consent

In the case of people who cannot consent for themselves, in particular children whose consent form is signed by the parent or legal guardian, a fundamental principle is that the medical treatment or experiment must be in the child's best interest (benefit). It would be unethical to consent to submit a child to procedures believed not to be in the child's best interest. .

For the process of obtaining informed consent, a contractual relationship must exist between the person who performs these procedures and the patient. However, this does not imply a 'legal contractual agreement' used in business, politics, etc. The contract denotes a tacit 'contractual' relationship between HCP and the patient which is grounded on respect and trust. This seems basic to a cooperative enterprise or what one can call a 'collaborative' working relationship. Abraham Lincoln (as quoted by Ramsey 2002: 6) had this to say concerning political covenants among men that: "no man is good enough to govern another without his consent". This also applies to the requirement of consent in the relationship between those who perform medical procedures and those who are patients – "no man is good enough to experiment upon another without his consent". The same can be said of the doctor-patient relationship. No man is good enough to cure another without his consent (Ramsey, 2002: 6-7).

In medical treatment, however, there is one clearly definable exception to the requirement for expressed consent, which does not weaken the general rule governing medical practice by consent alone. This is the class of cases in which consent may properly be assumed or implied when individuals are in extreme danger and cannot themselves consent explicitly.

Thus, consent lies at the heart of medical care as a joint adventure between patient and doctor. It lies at the heart of man's continuing search for cures to all man's diseases as a great human adventure that is carried forward jointly by the investigator and his subjects. Stripped of the requirement for reasonably free and adequately informed consent, experimentation and medicine itself would soon become inhumane.

3.4. Confidentiality and privacy

3.4.1 The ethical aspects of confidentiality

Confidentiality is another important aspect of fidelity as far as information about patients is concerned. From the time of Hippocrates, the idea of confidentiality has been central to patient care and treatment. In South Africa, according to the National Health Act (Act 61 of 2003) all patients have a right to confidentiality and this is consistent with the right to privacy in the Constitution (Act 108 of 1996). The notion of confidentiality has been a foundation of healthcare ethics and hence, it is one of the longest-standing maxims in healthcare codes of ethics (Temkin and Temkin, 1967: 6). It is another way of respecting the patient's autonomy. As Moodley (2011: 48) puts it, doctors explicitly or implicitly promise their patients that they will keep confidential the information provided to them. The relationship between doctor and patients is based upon and necessitates mutual trust; in order to be correct in his diagnosis, the doctor has to assume and trust that the patient is disclosing all facts relevant to his or her condition. Logically, the patient likewise trusts that the doctor will respect the knowledge to which he has been made a party and not disclose it to others.

In the 4th century BCE, Hippocrates, a thinker, philosopher, doctor and great advocate for ethics in medicine, captured this principle in the Hippocratic Oath as follows:

In my attendance of the sick, or even apart there from, whatsoever things I see or hear, concerning the life of men, which ought not to be noised abroad, I will keep silence thereof, counting such things to be as sacred secrets (Temkin and Temkin, 1967: 6).

This obligation for professional secrecy has since been repeated in the World Medical Association Declaration of Geneva as:

I will respect the secrets which are confided in me, even if the patient has died (Plueckhahn and Cordner, 1991: 4).

The International Code of Medical Ethics (ICME) of 1983, in its section of duties of physician to patients states that: “a physician shall respect a patient’s right to confidentiality” (ibid: 2). From the foregoing statement, it can be deduced that, confidential information is being perceived also by the World Medical Association as sensitive information as judged by the patient. Moodley argues that patients are unlikely to divulge highly private and sensitive information that is needed for their optimal care (ibid).

In this way, confidentiality can be perceived as the need to keep such personal information within proper confines. The patient’s assumption of ‘secrecy’ could seem justified in certain respects, that is, he or she must have a reasonable expectation that this sensitive information will not be disclosed to others.

The concept of confidentiality is frequently discussed within the scaffold of privacy. However, there are some differences between the two. Privacy relates to aspects of a person’s being into which no one else should intrude. When patients share private information with their practitioners, they choose to relinquish some aspects of their privacy. Essentially, patients have a reasonable expectation that such information will only be shared with specific people to further their welfare and not with anyone else. The notion of confidentiality involves a relationship, whereas privacy does not.

Central to patient-professional confidentiality is trust, if patients do not get the sense that health professionals will keep personal information shared with them by their patients secret, the patients will probably be unwilling to provide the information necessary for their care.

In many cultures, privacy and confidentiality are considered fundamental to human dignity. Respect for human dignity also implies the principles of respect for privacy and confidentiality. Fried states this as follows:

While we might not mind if a person knows a general fact about us, we might feel that our privacy has been invaded if he knows the details (Fried as cited in Beauchamp and Childress, 1979: 212).

When people grant others access to their personal histories or bodies, they necessarily surrender some of their privacy. However, they also retain some control over information generated about them, at least in the diagnostic and therapeutic context and in research. For example, health professionals generally are obligated not to disclose any information to third parties such as insurance companies and prospective employers about patients unless the patients have been consulted and have granted permission for any such information to be released. Confidentiality is thus a subset of informational privacy and prevents re-disclosure of information that was originally disclosed within a confidential relationship.

When people gain access to protected information without consent, one is legally and morally justified sometimes to say that their access infringes one's right to confidentiality and at other times to say that it infringes our right to privacy.

An infringement of a person's right to confidentiality occurs only if the person (or institution) with which the information was shared in confidence fails to protect the information or deliberately discloses the information to someone without first party consent. By contrast, a person who without authorisation enters a hospital record room or computer databank violates rights of privacy rather than rights of confidentiality (Beauchamp and Childress

2001: 304). In this sense, only the person (or institution) that receives information in a confidential relationship can be charged with violating the rights of confidentiality. Accordingly, Beauchamp and Childress (1979: 211) emphasise that the core self with its secrets is at the centre, choosing to grant others access to that information in accordance with the kinds of relationships it wants to establish, and a professional relationship forms an integral part of a professional ethic.

Exceptions to maintaining confidentiality are provided for by the National Health Act No. 61 of 2003, section 14, which states that: “the patient consents to the disclosure in writing, a court order or any law requires the disclosure, and non-disclosure of the information represents a serious threat to public health” (ibid).

Based on the foregoing deliberations, it can be concluded that it is universally accepted that doctors and all other health professionals owe a duty of confidence in respect of information concerning their patients, which they acquire in their professional encounter with patients. In a study conducted by Jones (2003) to assess the importance patients place on medical confidentiality one of the findings is that: “patients generally recognise that breaches of confidentiality may deter patients from seeking further treatment, but none the less, many patients will support disclosure to protect third parties” (Jones, 2003: 352). From this finding from Jones’ (2003) study, it might be fair to draw the conclusion that upholding confidentiality between health professionals and patients in certain instances, borders around both deontological and consequential theories.

Deontologists, in appealing to intuition, would, according to Brown and Gannon (1996: 218-219), argue that confidentiality should be treated as part of the general principle of patient autonomy. Consequentialists regard confidentiality as a necessary prerequisite to obtaining full and frank disclosure from the patient, thus ensuring effective identification and treatment of disease (ibid). From this, it seems that preservation of confidentiality would serve as a motivation for clients and/or prospective patients to seeking health professionals’ help or care. Naturally, even outside the healthcare system, a reasonable person wants to keep privacy to any information that is personal. The healthcare environment is one that requires

personal information to be shared with the doctor so that he or she is well informed to make a diagnosis on the patient. Without such crucial information it might prove difficult if not impossible for the doctor to make the right diagnosis and to provide appropriate care and treatment.

3.5 Conclusion

The foregoing discussions of perspectives on respect for patient's autonomy, informed consent, and confidentiality and privacy no doubt necessitate that in clinical care, the complex and highly technical nature of professional functions requires an astute knowledge of values important to professional practice. The principles of autonomy, informed consent, confidentiality and privacy have been discussed in terms of their meanings, origins, and moral dimensions. What is critical is how health practitioners fulfil their roles in promoting, protecting and preserving these values in the clinical setting.

For example, as Fowler and Levine-Ariff (1987: 41) state:

Respect for autonomy is a specific principle regarding principles of conduct that can be willed by the individual that results in a principled plan of action chosen and followed by the individual.

When autonomy is configured in the web of social relationships, choices become negotiated in the light of those relationships and not artificially situated in an enclave of individual isolation. In short, decision-making (self-determination) may be regarded as cooperative or selective. Uncertainty, as well as fear of the unknown, abounds at every step of medical treatment. Communication between doctor and patient is not only impaired by the barriers posed by medical jargon, or the knowledge base of bioscience, but also by the fear and anxiety that may overwhelm a sick patient (Tauber (2005: 141).

Sickness itself may rob the patient of his rational faculties and may also blur the distinct beliefs and values that are so necessary to the exercise of autonomy, and consequently,

has the potential to affect all the other principles that are basic to medical treatment and care – respect for the patient, informed consent, confidentiality and privacy. In addition to these formidable obstacles, the bureaucratic nature of modern medicine, as well as various forces that dehumanise the patient, converge to make the free exchange of ideas and options often difficult, if not impossible. The sick devote enormous energies to their illness, recovery and countless other new issues, which, in most cases, is the reason why patients might, as Tauber (2005: 142) writes, “not crave the decisional authority the autonomy paradigm envisions for them”.

In the next chapter, as a way to assess whether there is a correlation between theory and practice as far as the recognition and enforcement of patients’ rights in South Africa is concerned, an analysis of a case study (an empirical study) in the form of an *ethics audit* undertaken at the CHBH in 2001 is presented. The question is whether there is any correlation between theory (Constitution of the RSA, National Health Act, National Patients’ Rights Charter, International and Regional Human Rights Instruments) and practice (clinical setting or medical care) as far as the recognition and enforcement of patients’ rights in South Africa’s public health sector institutions is concerned.

It is at this point critical to mention that the CHBH Ethics Audit was carried out by the Ethics Institute of South Africa (EthicSA). The researcher was at that time an employee of EthicSA serving as both project manager and fieldworker. Interviews with various role-players and stakeholders resulted in a large amount of raw data. Some of these data were included in the EthicSA’s final publication. The remaining raw unpublished data were analysed in the course of this work as a case study. Permission to use the ethics audit as a case study (findings and data) for this dissertation was requested and granted by the then chief executive officer (CEO) of the CHBH, Dr Reg Broekmann (Appendix 1). Permission was also granted by EthicSA to use the raw data of its ethics audit in this study.

Chapter 4

Patients' rights in the South African public healthcare system: An ethics audit at the Chris Hani Baragwanath Hospital

4.1 Introduction

From the outset, it should be noted that the discussions, dialogue boxes and main findings of the Chris Hani Baragwanath Hospital Ethics Audit (hereafter 'audit') are adopted directly from both the focus group interviews (unpublished data) and the formal published ethics

survey (audit). The unpublished data were derived from focus group interviews conducted as part of the Audit. The formal published Audit was conducted by the Ethics Institute of South Africa (EthicSA) in 2001 by Landman, Mouton and Nevhutalu.

The problem that this dissertation endeavours to investigate is two-fold. Patients' rights should be recognised and enforced as part of good ethical practice. The first issue was to evaluate any corollary between theory and practice concerning the recognition and enforcement of patients' rights in South Africa. This was the question that led to the empirical study (audit). Secondly, various media reports as well as surveys already conducted in Gauteng public hospitals,²⁷ pointed to numerous problems that also included flaws in the recognition and enforcement of patients' rights. While these reports and surveys emerged independently from one another, almost in an *ad hoc*, issues-related manner, the CHBH audit was done systematically as a comprehensive case study. A critical analysis of this case study revealing a gap between theory and practice, and an identification of the actual problems (gaps) preventing the realisation of patients' rights in the South African healthcare system will be presented in this and the subsequent chapter.

The goal of this chapter is to establish whether or not there is any discord between theory and practice, i.e. whether or not there is any correlation between theory and practice as far as the recognition and enforcement of patients' rights in South Africa's public health hospitals are concerned. To this end, a brief background concerning the objectives of the audit, research design and methodology, the sample profile as well as key findings of the audit is provided. Information is used from both the formal EthicSA publication and from previously unpublished results of focus group surveys.

In conclusion key findings of the study are presented and a position is taken regarding the correlation or lack thereof between what the Constitution and the Patients' Rights Charter states, and what is actually occurring in the clinical setting, i.e. a focus on the practical

²⁷ Several surveys and audits of hospitals (national) and in the Gauteng province were conducted in 1996, 1998, 1999 and 2000 respectively. A Health Systems Review was also conducted in 2000 by the Health Systems Trust (HST).

realities as far as the realisation and enforcement of patients' rights in South Africa's public health sector hospitals are concerned.

4.2 Objectives of the CHBH ethics audit

The objectives of the CHBH ethics audit were stated as follows by Landman, *et al.*, (2001: xii-xiii):

- (i) To identify the key ethical issues and problems that 'live' in the minds of the various 'actors' in the hospital.
- (ii) To establish what the general working environment is like at CHBH, and the possible effects that factors in that environment might have on the personal and interpersonal conduct of employees.
- (iii) To describe in detail the 'ethics culture' at CHBH by identifying the salient attitudes, beliefs and values employees hold and the way in which these affect every day conduct in the hospital.

4.3 CHBH ethics audit: Research design and methodology

The research design and methodology of the audit consisted of three major phases developed to realise the objectives.

First phase: Focus group interviews

Focus group interviews were conducted in April 2001. These were conducted in keeping with the first objective – the identification of key ethical issues as viewed by hospital participants.

Focus group participants were derived from "five main categories of health personnel, namely, central hospital management, doctors, nurses, allied health professionals, and support staff. A sixth group consisted of patients. Each group comprised of 8-12 individuals, except for the management group that consisted of four individuals. The main purpose of the focus group interviews was to gather initial information that would reveal trends indicative of ethical problems in the organization. The main categories for the questionnaire were developed based on the data gathered during these interviews" (Landman, *et. al.*, 2001: xiii).

Second phase: Questionnaire Development

The second phase of the study involved designing and constructing of questionnaires for the pilot study. This resulted in six questionnaires, one for each sub-group, that were distributed to the hospital in July 2001. Results of this pilot study were captured and analysed statistically. "This led to changes to all versions of the questionnaire. As a final check, the revised questionnaires were sent to a panel of experts for comments. The final versions of the six questionnaires were completed early August 2001" (*ibid.*).

Third phase: The ethics survey

The main component of the ethics audit was a sample survey conducted at CHBH. A stratified multistage sampling design was used. Approximately 1200 questionnaires were hand-delivered with the help of staff and under my supervision (as one of the authors of the CHBH ethics audit report). This took place during the latter part of August to early September 2001. Based on information relayed from the hospital to the research team, we stratified the participant population into six categories, as mentioned above.

4.4 Motivation for choice of qualitative research paradigm

The focus groups interviews were conducted with five categories of health personnel and a patient group (in-patients and out-patients). They took an average of 1.5 hours. Focus

group interviews were audio-taped and verbatim transcripts were produced. Raw qualitative data from the focus-group interviews were captured in MSAccess, and hand-coded. The subsequent analysis is presented in three 'acts', namely, Act 1, Act 2 and Act 3 (Unpublished raw data, Brigitte Smit, University of Pretoria).

Act 1: Each group was analysed and coded separately, to facilitate the audit trail and to pinpoint selected views and perceptions from the various groups or stakeholders. Each group was given an identification code as follows: management (m), doctors (d), nurses (n), allied health professionals (ah), support staff (so) and patients (p) (ibid).

In terms of analysing the actual data this normally started with a line-by-line analysis, typically within a paragraph, during which every line of the transcribed interview was searched for key words or phrases which would give some insight into the phenomena or behaviour under study (Goulding, 2002: 76). Beside or below the paragraph, categories or labels were generated, and added to a growing list.

Act 2: Constructed codes from the analysis were grouped into labels, clusters or categories. In this study, the term categories is used to refer to the various codes developed during the data analysis. The individual categories were examined more closely and, typically, a slightly more abstract category was attributed to several incidents or observations. These categories were intended to serve as the basis for a thematic analysis, which would be transparent and open to interrogation at a later stage.

Act 3: The data generated by the six focus-groups were analysed as a hermeneutic unit. The hermeneutic tradition of the German scholars Wilhelm Dilthey and Max Weber share with phenomenology an emphasis on the "subjective understanding or interpretation" (Verstehen) (Babbie and Mouton, 2001: 20), of human action. The hermeneutic endeavour or intertextuality is a strategy whereby patterns and differences were sought across transcripts (Thompson, 1997). This strategy of interpretation, Thompson believes, must broaden the analysis to include a wider range of considerations, which helps the researcher

arrive at a holistic interpretation. For example, in this study, codes were presented in conjunction with quotations, which facilitated the search for verbatim evidence.

In the following section, the core categories from the data analysis that were directly linked to basic patients' rights are listed in chronological order. Then, descriptions are given of how each category was discovered and, lastly, the problems that serve as obstacles for the realisation of patients' rights are identified. Finally, a critical analysis is provided of the identified problems.

During the process of data analysis, core categories and sub-categories emerged through the use of the three Acts described above. The identification of problems contributing towards the prevention of the realisation of patients' rights within the South African healthcare system is based on a careful cross-examination or interrogation of the information (phrases, words, verbatim statements or quotes) that compose the core categories and their sub-categories.

4.5 Findings from focus group interviews

The journey into the realisation or non-realisation of patients' rights at the CHBH begins by paying special attention first to the focus group interviews as the first phase of the audit – the qualitative data. These data are analysed to address the question of whether patients' rights are protected and fulfilled, and what the actual situation is at CHBH concerning the acknowledgment and compliance with international instruments and charters on patients' rights.

The basic assumption underlying the empirical study is that patients' rights are regularly violated in South African hospitals. This assumption is supported by the following evidence:

First, there were serious allegations from the media that public sector hospitals are in dire straits; “30% of hospitals are in a serious crisis” (*Mail & Guardian*, 3 March 1999). Almost on a daily basis, the media reported on alleged misconduct by doctors and other HCPs.

Second, there was a “severe shortage of staff, particularly if we take into account the daily admission rates of up to 140%. This shortage is related to an exodus of both doctors and nurses to overseas countries that offer them decent salaries and a good working environment, as well as more safety against possible HIV infection. Third, very high nurse-patient ratios, escalating up to 1:35, which make it impossible for nurses to cope with patients' health care demands” (*The Mail & Guardian*, 2 – 8 February 2001). Fourth, “professional and clinical neglect of patients by both nurses and doctors have been reported, as well as verbal and physical abuse of patients by nurses culminating in sub-standard patient care. It is in particular post-operative patients and patients in emergency care units and those in transit to hospitals (for example, patients falling to their deaths from ambulances) which are notable. Other factors such as indiscriminate budget cuts by government exacerbate the problem” (Jewkes, *et al.*, 1998: 1781-1785). Lastly, the National Patients' Rights' Charter (the Charter) was launched in November 1999, however, the charter seemingly remains poorly understood by some doctors and nurses as well as poorly implemented (if any implementation takes place at all) based on media reports.

4.5.1. Attitudinal issues (money, patients and staff)

'Attitudinal issues' as a core category was identified following a line-by-line analysis of the focus group interviews. Each line of the transcribed interviews was searched for keywords and phrases as well as verbatim statements giving some insight into the study phenomena, i.e. what lives in the 'minds' of the different 'actors' as far as CHBH as a public sector hospital is concerned. The statements, phrases and verbatim transcriptions from the interview data, are typical responses from the six focus groups to questions asked by the facilitators, e.g. questions to gain more insight about group members' thinking or feelings about CHBH as an institution generally. Questions asked were, for example:

Why did you choose to work at the CHBH? And, what is it like to work at CHBH?

It emerged that a major problem area is the negative attitudes that cut across all categories of health personnel at CHBH who have an obligation to render effective and high-quality

patient care that is supposed to be based on fundamental human rights. These negative attitudes create an environment that is described by members of the different focus groups as "unconducive" and contrary to the ideal of a healthcare milieu that is caring and compassionate. For example, some of the problems mentioned as the basis of the negative attitudes of staff are strained working relationships between doctors and nurses, nurse-to-nurse, doctor-to-doctor, nurse-to-patient and doctor-to-patient. A careful examination of this problem (negative attitudes), indicates that the 'negativity syndrome', however, is not of the staff's own making but a systematic problem.

Data analysis points to two major problems: (1) Serious staff shortages (all categories, but with nurses being the most affected); and, (2) a seeming lack of a "deeper understanding and appreciation" of the magnitude of the problem (staff shortages) by Management of CHBH and consequently the Government (Gauteng Department of Health).

These problems, no doubt result in the following manifestation regarding patient care:

Compromised standards of care because of poor communication and unhealthy relationships between staff and between staff and patients; and, 2) Infringement of patients' rights such as the right to respect, to information and informed consent, to confidentiality and privacy, and the right to refuse treatment. This claim of infringement of the patient's rights is clearly depicted in the qualitative data presented in Box 1.

Box 1**Attitudinal issues**

Nurse: "There are actually serious attitude problems that cut across all Categories of workers"

Nurse: "Attitudinal problems cause huge conflicts, you are working with colleagues that react negatively to almost everything; and on the other hand, you still have to give high standard of care to your patients"

Allied health professional: "Working at CHBH is a challenge because we come with a positive attitude to uphold CHBH values, but somewhere down the line, because of all the attitudes issues highlighted, somehow

the environment is not conducive, we get stressed and our morale goes down and this affect patient care negatively”

Allied health professional: “Some medical practitioners feel indifferent to patients”

Allied health professional: “Patients are seldom greeted as if they are no persons”

Allied health professional: “Polite communication. Call patient by name. Make him/her feel good or like a human being. Respect (patients’) religion, race, culture, behavior, wishes, fears, etc. Be patient.”

Nurse : “Nurses and doctors are working against one another”

Doctor: “Management has little understanding of the realities in Bara.”

Allied health professional: “Government is bureaucratic, therefore, management at CHBH is seen as an extended arm of government.t”

Support staff: “At CHBH nobody cares! “

Patient: “My observation is that, CHBH has a serious shortage of staff.”

Nurse: “The professionals’ attitudes go down to their patients. Patients become submissive, they cannot demand care they deserve.”

Doctors and nurses are the backbone of a healthcare system, if the working relationship between these two groups of HCPs is unhealthy; it is unlikely that the core ethical values and standards underpinning professional practice can be effected in an acceptable and professional manner. (Box 1 gives some of the quotes that confirm this observation and assessment of the situation).

Thus, it seems in situations where relations are strained and the environment is stressful only the strong can survive. Health professionals are in a strong position because of their expertise and position they hold in the clinical setting and therefore they will survive or win. Patients are vulnerable; they are weak because of their illnesses that require the care, treatment, and support of doctors and nurses. In that sense a patient's chances of 'survival' in this situation are narrow; they cannot speak. The following quote from a nurse at CHBH confirms this:

The professionals' attitudes go down to their patients. Patients become submissive; they cannot demand care they deserve (Professional Nurse, *CHBH focus-group interviews*, April 2001).

From the data, a myriad of issues and problems including patient-related and staff-related matters are raised.

4.5.2 Resource shortages (human, material and financial)

Resource shortages as a core category emerged from the interview data from statements and verbatim transcriptions of the text. At the same time that the category or cluster was generated, it was reviewed and was attributed to several incidents and observations. For example, as illustrated by a quote from one of the nurses:

There is no money, not enough doctors, nurses, medicines, linen and equipment (Professional Nurse. *CHBH focus-group interviews*, April 2001).

This category includes human and material resources. Qualitative comments pertaining to these issues are listed in Box 2.

Box 2
Resource shortages

Allied health professional: "CHBH is characterized by shortage of resources related to lack of funding and budget cuts which escalates each year".

Patient: "Due to shortage of staff patients die at night with no one taking care of them at night".

Nurse: "Two nursing sisters to 40-60 patients: Feeling de-motivated."

Doctor: "Huge workloads, HIV/AIDS epidemic without resource."

Doctor: "Intensive Care Unit (ICU) not enough beds for critically ill patients, if beds are available there is no nursing staff."

Doctor: "20 burn cases arrived, only 3-4 can be handled, there are not enough ventilators."

Doctor: "80 to 100 women die every year at Bara due to pregnancy-related complications which are either mismanaged or negligence related to staff shortages."

Doctor: "Because nurses and doctors are stretched to the limit, and are stressed, they leave South Africa for Saudi Arabia, the United Arab Emirates and the United Kingdom (UK) where there are better working conditions and remuneration."

The data highlight the shortage of resources as a major problem resulting from complex issues such as a small and continuously *shrinking* budget (a financial practice that has become a norm since the inception of a democratic government in 1994). The situation (shortage of staff in general and, in particular, nurses) is exacerbated by the fact that, once a post is vacated it becomes frozen. As a consequence, the working environment at the CHBH becomes intolerable and not conducive to quality patient care, and, seemingly from the statements and verbatim transcriptions, health professionals are left with not much choice but to go and work abroad. This more than ever before in the history of South African healthcare has contributed to a situation of unwarranted exodus of nurses and doctors to overseas countries such as the UK and Saudi Arabia (in the case of nurses) and

Canada (in the case of doctors). This major problem (resource shortages) is overarching – first it is staff shortages; second material resource shortages such as linen and medicines, and thirdly it is shortage of financial resources and facilities e.g. ventilators.

Staff shortages result in increased nurse-patient ratios, e.g. two professional nurses to 50 patients (in adult wards) and two to 65 (in children's wards). Linen shortages imply that patients do not have sufficient and necessary linen including bed linen, sleeping attire, theatre attire and towelling materials for major surgical operations. Medicine shortages mean that patients may not get the correct amount of medication they need, e.g. the patient may get only a 5-day instead of a 15-day supply, if any medication is available at all). In the case of emergencies that require admission into ICU, because of the shortage of high-tech machines such as ventilators or defibrillators, such patients are indirectly 'sentenced to death' by authorities who are charged with the responsibility to give quality care to every patient.

The latter argument begs the question: *What then are the effects of resource shortages on patients' care?* As evidenced from the analysed data, the answer is: *Compromised service delivery, poor performance and sub-standard patient care.* The qualitative data in Box 3 spells this out:

Box 3**Effects: Staff shortages and non-functional equipment**

Allied health professional: "With shortage of linen, there is no human dignity. Patients are left to lie in the bed naked with no nighties, lying on their own soiled linen."

Doctor: "Patient abuse as well as aggression from the nurses is so rife especially in maternity Wards where disrespectful remarks are made to patients, e.g. Oh, you have eight children, why the hell did you still get this one."

Doctor: "We apply half-hearted measures to treat our patients; this affects us because this is not what we have been trained to do. We get frustrated because we have to sacrifice our patients, we have to sentence them to death due to shortage of equipment and medicines."

Doctor: "People are dying because of the lack of money and not because they cannot be treated."

Doctor: "High-profile surgical cases with VP-Shunts cannot be operated due to lack of appropriate equipment. They have to wait for up to six months before they get operated and by the time they do, their disease conditions have deteriorated and have already complicated."

Allied health professional: "CHBH needs staff, facilities and budget, with resource shortages, everybody is stressed and everybody loses it here, in the end, standards of care are compromised."

The major problem in this regard is a serious shortage of resources (human and material). This has serious and devastating effects on patient care which can be presented in two scenarios as follows: Firstly, service delivery is compromised and characterised by low quality and standards of care, a generalised lack of organisational performance, unnecessary and unexpected deaths from disease conditions previously unheard of (such as maternal deaths of 80 to 100 pregnant women per annum) and infringement, if not violation, of basic patients' rights. Secondly, resource shortages have a negative impact on the healthcare personnel, e.g. aggressive behaviour towards patients, disrespect of patients' human dignity, frustration leading to low morale and severe stress (physical and emotional).

In the final analysis, the situation has made patient care difficult, if not impossible. Thus, some of the HCPs, in their quest for a 'healthy' working environment, opt out of CHBH to healthier work environments abroad.

4.5.3 Incidents of misconduct (unethical conduct)

This category was found in the data wherein specific focus was on unacceptable behaviour or conduct of the professionals towards patients. The data comprised behaviours that are considered 'unethical or immoral' and, therefore, generally undesirable in the day-to-day interactions between human beings and, specifically in the healthcare environment between the doctor, nurse, other HCPs and patients. Sound professional practice is based on core ethical values and standards that serve as guiding principles to actions taken by all healthcare personnel towards patients. When these core ethical values are disregarded, there are serious concerns from all stakeholders in health care. In spite of the concerns, however, infringements and violations of these fundamental ethical principles are a

common occurrence in South Africa's public health sector hospitals as illustrated by the following quotation:

Respect for the patient as a human being is non-existent at CHBH
(Doctor: *CHBH focus-group interviews*, April 2001).

Members of the different focus-groups were asked the following question: "*How would you describe the work ethic and professional ethic at CHBH?*" From this question, it was possible to establish through further probing the existence of instances of ethical misconduct with reasons offered for some of the misconduct.

Box 4

Work – and professional ethic

Doctor : "Can ethical standards be taught if students see all the unethical practices by doctors and other members of the health professions?"

Doctor: "Depression: people (psychiatric patients) are strapped down; next morning they are smelly and stinky."

Doctor : "Inhumane and unethical behaviour in ward 20."

Patient: "Patients sleep with a corpse the whole night, nurses come in the evening, take report from the day staff but 'disappear' at 23h00."

Nurse: "Mortuary services are bad; bodies may not be collected for 24 hours."

Patient: "Medical student supervision is very poor, they are left alone and they carry out procedures such as intravenous therapy (IV therapy) wherein they sometimes hurt patients, therefore, "ba ithuta ka rona" English translation "they treat us like guinea pigs."

Management: "We have staff members who come to work only on the 15th of every month when they come to collect their salaries, and they disappear again until the 15th of the following month."

Management: "Confidentiality at CHBH is not maintained, e.g. a doctor informed a patient that he was going to take blood to test her for HIV, the patient requested the doctor not to inform anybody (including herself) about her HIV status, but, the doctor went ahead and informed his colleagues."

Patient: "Mothers are not informed about their children's diseases, prognosis and treatment regimen."

These quotations on patients' rights illustrate clearly the concern expressed by healthcare personnel and patients about violation of these rights and the absolute need for re-establishing a culture of respect for patients and their rights. The impact that misconduct has on standards of care is highlighted by the quotes.

The main finding is that the extent of misconduct, as reported by staff, is serious and points up to a situation that does not promote professional and responsible patient care. Some of the most important points that emerged are the following: (1) There is strong evidence that patients' rights are abused (confirmed by staff and by patients themselves); (2) professional negligence in patient care is rife as evidenced by, among other indicators, maternal mortality rates of between 80-100 mothers *per annum*; (3) patient abuse (physical and verbal) verbatim reports from staff themselves and patients, but, also verbal abuse of nurses by patients (Landman, *et al.*, 2001: 66-67).

The Audit report went on to state: Data analysis suggests four groups of possible reasons for observed instances of misconduct: Lack of punitive measures – no real or visible disciplining of misconduct occurs (as reported by the majority of staff), working conditions – heavy workloads lead to inadequate attention to care (considered a major problem by staff), and language barriers, lead to misunderstanding and possibly abuse" (ibid).

Significantly, however, the five most common patients' rights recognised in declarations and the literature (Neary, 1999 and Wilson Silver, 1997) are the rights to *respectful care*, *information* (regarding the caregiver's name, diagnosis, treatment options, and prognosis), *informed consent*, *confidentiality of private information*, and *refusal of treatment*. The patients' rights enshrined in the PRC are – (1) a healthy and safe environment, (2) participation in decision-making, (3) access to health care, (4) referral for a second opinion, (5) continuity of care, and (6) complain about health services. Based on the findings on qualitative data of the focus group interviews, it remains largely doubtful that the realisation of patients' rights at the CHBH can prevail. The data reveal to what extent the relationship between staff and patients is characterised by abuse (staff abusing patients and patients abusing patients) and professional negligence. This is perhaps the most serious finding of

the focus-group interviews since it concerns the basic rationale of an institution devoted to the care and healing of human beings.

The fact that staff report instances of abuse of patients, and staff abuse by patients, is an indication of seriously deteriorated relationships. This section vividly illustrates the severity of problems at CHBH.

Patients, for instance, described incidents where confidentiality of information had been breached by doctors; and nurses verbalised that they have witnessed incidents where informed consent had not been obtained.

4.5.4 Disciplinary issues

This category was found in the data during the coding process (open, axial, and selective), by analysing statements, concepts, and comments from members of the various stakeholders participating in the interviews. The aspects addressed in the interviews revolved around observed instances of staff misconduct as well as the steps taken by management to remedy the unacceptable behaviour. In fact, the high level of misconduct at the hospital seems to flow from the lack of discipline as illustrated by the quotes below:

Box 5
Disciplinary issues

Management: "The CEO has no power to discipline staff, systems need to be in place and offenders immediately punished."

Management: "Work ethic is very poor, people do not do the work they have been employed for."

Nurse: "Disciplinary measures are missing."

Management: "People can be absent from work for many days but still come to collect their pay cheques on pay day".

Doctor: "Bara is a good place for bad doctors; it is hidden and nobody really cares."

Management: "A doctor hired a hit-man to kill a porter who owed him R800, the doctor is still working at CHBH and no disciplinary measures were taken against him."

Management: "Disciplinary measures at CHBH are extremely ineffective."

This section clearly illustrates the severity of the lack of discipline at CHBH at the time of the Audit. The statements or comments (quotes) listed above, suggest the following major problems: "(1) lack of disciplinary measures, i.e. there is no visible disciplining of misconduct; (2) inadequate attention to clinical care (perceived by staff and patients as being related to heavy workloads and staff shortage); and, (3) the extent of misconduct as reported by staff is serious and points to a situation not conducive to professional and responsible patient care, the healthcare environment presents barriers to professional practice and professional fulfilment" (ibid). There are good reasons to support the argument that patients' rights are being violated.

4.5.5 CHBH working environment (buildings, wards and security)

Qualitative data related to perceptions by staff and patients with regard to three aspects of the environment, buildings, wards and security arrangements were analysed. Box 6 presents some of the quotations:

Box 6

CHBH working environment

Doctor: "The physical working environment at CHBH is demoralising."

Doctor: "Surgery and casualty wards look terrible."

Management: "Bara is like a town of 5000 staff."

Nurse: "The physical environment is appalling to say the least."

Nurse: "Bara used to be clean, but, now the condition is appalling."

Allied health professional: "There is a difference in how wards appear – adult and paediatric wards, adult wards are dirtier."

Allied health professional: "There is lot of intimidation, there is no discipline."

Management: "Poor economic and social status of patients perpetuates the condition."

Nurse: "Working conditions are hard and frustrating."

Support staff: "It is stressful to come to work, one feels completely demoralised."

Support staff: "Wards are freezing cold, lifts do not work."

Support staff: "Staff steal blankets and tea bags and sell them at the squatter camp."

Nurse: "We have serious security problems, we get robbed within the hospital premises. There are gun fights within the hospital."

Doctor: "In some of the wards, the ceiling is falling apart, and the paint on the walls is peeling off."

Patient: "Corpse lay in the ward all night."

Patient: "The toilets are dirty, patients do not flush."

Patient: "Male cleaners in female wards, we have no privacy."

Patient: "We have no blankets, night attire or cutlery."

4.6 Three summary conclusions

Three summary conclusions from focus group interviews can be drawn as follows:

- (1) Significantly, the data analysis reveals the physical environment that is unacceptable as viewed by staff and patients alike. Thus, the environment at the CHBH is not conducive to sound professional practice, such an environment presents barriers to practice and professional fulfillment. Professional virtues and excellences can either be supported or nourished by the environment or they can be thwarted and diminished. For HCPs, virtues and excellences are those habits which “affirm and promote the values of human dignity, well-being, respect, health, independence, and informedness” (Nursing World, Ethics & Human Rights, 1998). Based on the views of both staff and patients, the healthcare environment at CHBH neither affirms nor promotes the realisation of patients’ rights.
- (2) The shortage of linen is regarded as the second major problem by staff as well as patients. From the patients’ quotes in Box 6 above, it is evident that the patients ‘feel’ that their human dignity or respect is not being taken seriously at CHBH.
- (3) “There is a lack of confidence in the capacity and ability of security staff to ensure a safe environment” (Landman, *et. al.*, 2001: 27-28).

The PRC states categorically that a patient has a right to a healthy and safe environment:

Everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection (*National Patients’ Rights Charter*, November 1999).

An unsafe environment is therefore a violation of patients’ rights. The survey revealed that patients' right to a healthy and safe environment at the CHBH have been violated.

4.6.1 Effect: Compromised service delivery and poor performance

This category emerged from the responses from the focus-groups to questions related to their views regarding possible effects each of the problems (attitudinal, resource shortages, incidents of misconduct, disciplinary procedures and working environment) they thought would cause to CHBH as an institution in general and, in particular, to HCPs in their daily job performances. A careful analysis of the statements and comments indicate their concern about compromised service delivery and poor job performance, as illustrated by quotes in Box 7.

Box 7

Effects: Compromised service delivery and poor performance

Doctor: "We apply half-hearted measures to treat our patients, this affects us because this is not what we have been trained to do, and we are frustrated because we have to sacrifice our patients, we have to sentence them to death."

Allied health professional: "Many patients are dying of HIV AIDS, we are not even sure what advice to give to mothers with HIV/AIDS regarding breast-feeding because of lack of clear policy guidelines from government."

Doctor: "Since free antenatal care was announced by the media, there has been triple attendance at Bara; staff cannot cope with the large numbers of pregnant women."

Doctor: "Ambulances bring patients whether there are beds in the trauma unit or not."

Management: "Many are leaving, nurses are stretched to the limit and, they leave for the UK and Saudi."

Doctor: "Sisters are stretched beyond belief."

Doctor: "Staff swearing at each other: A sign of stress."

If one divides problems into different categories, namely, those related to attitudes, resource shortages, professional and clinical misconduct, lack of disciplinary measures and the general working environment, resource related problems – linen and staff shortages are regarded as the most serious problem at the hospital by both staff and patients.

The results also reveal that the relationship between staff and patients is characterised by abuse and negligence, instead of the expected mutual respect. The report of instances of abuse of patients by nurses and the abuse of nurses by patients, is perhaps the most serious and worrying finding of the study (Landman, *et. al.*, 2001: 65). These incidents cut across

fundamental aspects of patients' rights such as: incidents of verbal and physical abuse; breach of confidentiality of information; professional negligence; and, substandard clinical care.

4.7 Summary of findings from the ethics survey – the 'audit'

Key findings of the CHBH Ethics Audit (Landman, *et al.*, 2001) and the salient points that relate to the categories as reported on in this dissertation from the qualitative data (focus group interviews) are as follows: Safety and security, Professional values, Leadership and Management, Human resources (conditions of service), Misconduct and standards of care, Problems and sources of stress, and Patient perspectives.

Attention here is focused on patient perspectives as they pertain to patient respect, professionalism of doctors and nurses and caring. In the audit the salient points regarding patient perspectives were summarised as follows:

- The vast majority of patients (70%) agreed that giving money to staff for treatment was wrong.
- A similar proportion of patients (71%) agreed that hospital staff did not have sufficient time to treat them properly.
- Language barriers between staff and patients are a serious problem given that three-quarters of patients said that such barriers posed difficulties for mutual understanding. A similar proportion of patients (72%) indicated that they had had problems understanding what doctors had told them about their illness.
- Nearly two-thirds of patients (64%) claimed that they had not been told or informed what was wrong with them and why they had received certain kinds of medication.
- There seems to be better communication between patients and nurses, with 62% of patients indicating that they found it easy to understand what nurses told them about their illness. By contrast, almost three-quarters of patients (72.5%)

sometimes found it hard to understand what doctors tried to communicate to them about their illness" (ibid).

The overarching impression is that most patients are not well informed about their illness, or the reason for the treatment or medication they receive, which are basic patients' rights (ibid). As the audit identified, lapses in ethical professionalism and poor organisational structure related directly to breaches of patients' rights.

With examples such as improper care due to time constraints, language barriers with consequent misunderstanding of their treatments and diagnosis, it is clear that patients' rights to information and inclusion in decision-making for their care and treatment have been violated. It is also unlikely that respect for patient autonomy can follow if patients do not understand the language a doctor uses. Language barriers are a serious barrier to a good doctor-patient relationship.

The audit findings placed one area of concern into perspective that the focus group interviews touched on but not at the level at which the ethics survey put it – the problems related to patients with HIV and AIDS. Box 8 presents verbatim transcriptions of what both the patient and HCPs said about patient care issues such as general patient care, problems encountered with patient admissions, discharge, and the care of patients with HIV and AIDS.

Box 8

Patient care and the HIV and AIDS pandemic

Female student radiographer at X-ray department for three years: “The patients are discharged without being better in their condition, more especially when the patient is HIV positive; they discharge them because there is this thing that he is going to die so there is no use to keep him in the hospital. This is wrong.”

Female doctor at CHBH for five years: “Home-based AIDS care is needed to relieve the hospital of the burden of terminal patients coming to hospital for admission and care.”

Male doctor at CHBH for two years: “Admission of HIV patients and their treatment needs review and protocol to serve resources.”

Female nurse at medical, surgical, maternity, paediatric, orthopaedic and St. Johns’ Eye Hospital for 13 years: “Community must be taught how to take care of full-blown AIDS patients and very frail patients, to minimise admissions due to shortage of staff, and so that quality care can be rendered. Before discharge, relatives to be informed and be taught how to take care of the patient at home.”

The qualitative data illustrate clearly the concern expressed by the HCPs themselves, nurses and doctors alike, with regard to the violation of patients’ rights. These concerns also emphasise the need to re-establish a culture of respect for patients’ rights in the South African healthcare system.

One of the qualitative quotations related to HIV and AIDS patients reads as follows:

The patients are discharged without being better in their condition, more especially when the patient is HIV positive; they discharge them because there is this thing that he is going to die so there is no use to keep him in the hospital. This is wrong.

This quotation reveals that patients with HIV and AIDS at the CHBH are both stigmatised and discriminated against. The stigma and discrimination can easily be detected from, for example, phrases such as: “... *more especially when the patient is HIV positive*” and “*going to die*”. This gives the impression that only patients who are HIV positive die, yet death is every living being’s fate.

Stigma and discrimination are interrelated, reinforcing and legitimising each other. According to UNAIDS Best Practice Collection (2005: 11), stigma lies at the root of discriminatory actions, leading people to engage in actions or omissions that harm or deny services or entitlements (e.g. patients' rights) to others. Discrimination can be described as the enactment of stigma and, in turn, discrimination encourages and reinforces stigma. Discrimination is a violation of human rights. The principle of non-discrimination, based on recognition of the equality of all people, is enshrined in the *Universal Declaration of Human Rights* and other human rights instruments (ibid). As far as the *equality* of all people is concerned, the South African Constitution, section 9(2) states:

Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken (Constitution of the Republic of South Africa, 1996: 7).

The values highlighted above prohibit discrimination based on race, colour, sex, language, religion, political or other opinion, property, birth or other status. In addition, the United Nations Commission on Human Rights has resolved that the term 'or other status' used in several human rights instruments "should be interpreted to include health status, including HIV and AIDS", and discrimination on the basis of actual or presumed HIV-positive status is prohibited by existing human rights standards. Moreover, the PRC also shares the same sentiments with other internationally recognised human rights standards documents by stating that:

Everyone has the right of access to health care services that include: provision for special needs in the case of newborn infants, children, pregnant women, the aged, disabled persons, patients in pain, persons living with HIV or AIDS patients (*National Patients' Rights Charter*, November 1999).

4.8 Concluding remarks

A critical analysis of the CHBH ethics audit findings reveals that various aspects of patient's rights such as informed consent, respect for dignity, a safe environment, and treatment, were being violated at the hospital. Based on this evidence, it seems both objective and fair for this study to point out that what is happening in the clinical setting at the CHBH is definitely not in keeping with the values enshrined in South Africa's Bill of Rights, and in the international and regional human rights instruments and documents. There is therefore no correlation between theory ('charters' and 'service pledges') and practice as far as the realisation of patients' rights are concerned at CHBH. Patients' rights to respect, promotion of well-being, privacy, confidentiality, informed consent, are normally non-negotiable – in theory that is. Yet, there are strong indications that these basic rights are not practiced as they should be in the CHBH (Landman, *et. al.*, 2001).

Landman, *et al.*, summarise this as follows:

Given the nature of its mission, a hospital should embody the highest *human values* with the aim of optimal professionalism and quality patient care. Further, because a hospital is an organisation, one would expect a commitment to other *organisational values*, such as good staff relations, a good organisational work ethic, and the like. In short, one would expect to find the 'usual' organisational values, and, in addition, values peculiar to a 'hospital' (Landman, *et al.*, 2001: 11).

In chapter 5 subsequent case studies, research studies and media reports on patients' rights and hospital conditions conducted after the CHBH audit are presented. These show that even though the CHBH ethics audit was conducted in 2001, its findings still hold and can be referred to without any fear of contradiction or doubts.

Chapter 5

Recent Patients' rights surveys and grey literature reports on violations of patients' rights in the South African public health hospitals and facilities

Dr Mengele came into the barracks every day after roll call. I would have to say that, as children; we had some kind thoughts for him because, after all, had it not been for him; we would have surely been condemned to death. We did not have, however, any love, affection or loyalty for him. Nor did he have any for us. The only way I can describe the relationship is in a scientific way. Any scientist who is conducting experiments on laboratory animals has some concern for the animal. A type of caring develops; a relationship begins. We knew that we were alive because of the experiments. We obviously wanted to continue to live. We knew that our fates lay in his hands. Thus, we were his guinea pigs. (Eva MozesKor, one of Mengele's child research subjects in Auschwitz, 1944, as cited in the BMA, 2001: 205).

5.1 Introduction

In this chapter some reports published after the CHBH ethics audit (2001) to gauge the implementation of the will be presented. The first is a report titled: *“Operationalising health as a human right: Monitoring tools to support implementation of the Patients’ Rights Charter in the health sector”* which includes two provincial case studies (London, *et al.*, 2006). This is followed by a 2010 research report in which violations of patient’s rights are identified, and then few recent media reports on various aspects of health care affecting the realisation and enforcement of patients’ rights in public health hospitals and other facilities. These indicate that problems such as respect for patient autonomy, as highlighted in the CHBH Ethics Audit still exist 13 years later.

5.2 Monitoring tools to support implementation of the Patients’ Rights Charter

In 2006, the University of Cape Town (Health and Human Rights Programme (UCT HHRP, School of Public Health and Family Medicine), and the University of the Witwatersrand (Centre for Health Policy, CHP) undertook a collaborative research project. This case study report was supported by the National Department of Health (NDoH). The project aimed to explore options towards the "development of an implementation tool for the Patients' Rights Charter, as part of the operationalisation of the right to health in South Africa" (London, *et. al.*, 2006: ii).

The objectives of this report were to:

- (a) "Review the literature for international models and experiences in using Charter-based approaches to realising the right to health and comparing them to the South African Charter.
- (b) Review the state of current implementation of the Patients' Rights Charter in the public sector in South Africa, including:
 - Describe the process of implementation at that stage, including resource inputs provided by the Department of Health to support the Charter's implementation,
 - Characterise monitoring tools in place to support the Charter's Implementation,
 - Describe awareness and utilisation of, and attitudes towards the Charter among users and providers, and potential factors to promote awareness and utilisation,
 - Identify obstacles to compliance with the Charter,
 - Make recommendations for overcoming any gaps or obstacles in the implementation of the Charter and the realisation of its provisions,
 - Develop indicators suited for monitoring the implementation of the Charter
- (c) Develop and pilot a tool based on the above for monitoring the implementation of the National Patients' Rights Charter" (ibid).

This research project was organised in two stages - a Literature review and a Comprehensive case study analysis.

5.2.1 Literature Review

The Literature review would re-examine national and international practices regarding the application of the PRC. Telephonic interviews with managers at national level in eight provinces were conducted to explore the contents and processes of implementation, existing monitoring strategies, levels of awareness, utilisation, attitudes amongst users and HCP as well as obstacles to implementation (ibid: iii).

5.2.2 Comprehensive Case Study Analysis

Comprehensive case studies were conducted in the Western Cape and Limpopo provinces. In-depth focus group interviews were piloted across a variety of service providers, s, managers, support staff and community members. The main aim on the two case studies was to gauge the implementation of the Patients' Rights Charter at existing healthcare facilities.

Some of the key issues that emerged from both the literature review (national level) and the case studies (provincial level) are presented in the following sections.

5.2.2.1 Key Issues that surfaced at National level

Six major findings emerged at National level; however, in this study only two will be discussed – (i) discordances between national, provincial and local responsibilities made it difficult to ensure accountability and to effect implementation, (ii) widespread conflation of the Charter with other quality assurance programmes, particularly with Batho Pele. This is probably linked to poor understandings of human rights as they relates to health (London, *et. al.*, 2006: iv).

Discordances between national, provincial and local responsibilities made it difficult to ensure accountability and to effect implementation.

The Constitution of South Africa (Act. 108 of 1996) provides for three distinctive spheres of government, and each of these spheres has both legislative and executive power. These

government spheres are co-dependent, interconnected and distinct. When it comes to planning and programme implementation, it is critical that the powers and functions of these spheres are taken into consideration, i.e. 'careful' and 'nuanced' to avoid conflicts or 'discordances'²⁸ between these areas of interest. The discordances frequently stem from aspects such as 'accountability' and 'implementation'. Accountability, among other behaviours, encourages collaboration with partner spheres to share best practices, ensures that officers take ownership of and responsibility for decisions and actions within their sphere of accountability, and also when one is accountable they do not 'shift' blame for their actions and omissions. When a new programme such as the application (implementation) of the patients' rights charter is introduced and there has been no consultative process or discussions between, for example, national and provincial government departments, it becomes difficult as to which sphere is responsible for the successful implementation of the programme and this puts the value of 'accountability' into jeopardy, i.e. it is not clear which government department has to ensure that the programme is successfully implemented, and also that it is effective and efficient. Based on this, it might not come as a surprise that the patients' rights charter has not been well implemented in South Africa (ibid). It is important for the spheres of government when a new programme is introduced to know whether or not a particular project falls within their competence area. London, *et. al.*, (2006), summarise this as follows:

Surprise visits by the Member of Executive Council (MEC) and the executive management tended to reinforce the view that the Charter was less a tool to improve quality of care but to hold health workers accountable for their inadequacies and reflected a role for which the Charter was not intended (London, *et. al.*, 2006: v).

Widespread conflation of the Charter with other quality assurance programmes, particularly with Batho Pele. This is probably linked to poor understandings of human rights as it relates to health

Introducing programmes that are more or less related could be confusing to HCPs, more especially given the current shortage of staff at many of South Africa's public hospitals.²⁹

²⁸This is how London *et. al.*, (2006) describe 'conflicts'.

²⁹ From various survey reports and grey literature on the state of South Africa's public hospitals.

Such projects or programmes may be viewed as ‘add-on’ instead of being ‘at the core’ of service delivery, for example, patients’ rights. The *Batho Pele* principles are: consultation, service standards, access, courtesy, information, openness and transparency, redress, and value for money (Department of Public Service and Administration, 1997). There appears to be a close link between the values of Batho Pele and the ones enshrined in the patients’ rights charter (1999), and thus the seemingly “poor understanding of human rights as they relate to health” (London, et. al.; 2006: xiii) .

Both threats and opportunities concerning human rights implementation were identified in this report. Opportunities arise from “access to resources and institutions, and a generally heightened awareness and willingness to engage with human rights which can assist in realising rights” (ibid). According to London, et. al.; (2006: v-vi) threats, according to the report, result from the “overuse of rights in ways that may not necessarily be appropriate or reflect correct understandings of rights, as a result of which rights can be “cheapened” or turned into vehicles for interests” (ibid).

5.2.2.2 Case Reports

The aim of the two case studies conducted in the Western Cape and Limpopo served to engage stakeholders and role-players in their associations with health facilities as well as respective community members concerning implementation of the PRC. This included measuring impediments to the Charter’s implementation. It was identified that implementation of the Charter necessarily involves training in human rights. “Ineffective human rights training programmes for healthcare professionals (henceforth HCPs) represents a challenge as far as effective implementation of the Charter is concerned. The inadequate human rights education may also be complicated by the past unsuccessful execution of the Charter” (Batho Pele) (ibid).HCPs may develop a sense of unease with the topic of human rights following the so-called ‘unsuccessful execution ‘unless sufficient ground work has been done to secure a firm and united position concerning the importance of patients’ rights (ibid).

5.2.3 Discussion

For the success of the Charter's implementation, a prerequisite is that HCPs first and foremost need to understand the history and notion of rights and the idea of human rights. Without this essential knowledge, it seems unlikely that HCPs working in health facilities can appreciate the value of the role the Charter is meant to play, i.e. promoting and protecting patients' autonomy, dignity, confidentiality and privacy. It is through the supporting of human dignity and value that HCPs can actualise Patients' Rights. The British Medical Association writes,

[The]...teaching of medical ethics appears to assume great importance in maintaining doctors' awareness of patients as individuals. Clearly, since few had had any real experience of ethics training (BMA, 2001: 492).

The importance of "maintaining awareness of patients as individuals" (ibid) has relevance to respecting human rights. In South Africa use of 'rights language' is a relatively new concept that gained popularity with the dawn of democracy. It should not be assumed that every member of society understands a right-based approach, especially in the healthcare environment. Hence familiarising doctors, nurses and other allied health professionals with the tenets of human rights would help to improve efforts in the implementation of the Charter.

A sense of 'inadequacy' that some HCPs develop due to a lack of proper information, training and debriefing by top management brings untoward antagonism towards the patients' rights ideology, let alone its implementation. Although the factors discuss herein are not direct or obvious patients' rights violations, they nonetheless have the potential to undermine the value of patient's rights. Consequently, this could lead to actual violations of patient's rights. In their ignorance about human rights in general and in particular patients' rights, HCPs may manifest various forms of resistance, negative attitudes towards patients, verbal and non-verbal patient abuse. Sebokedi wrote,

... some of the ways providers framed the PRC revealed power issues directly, such as nurses and managers saying the charter was being used as a tool to intimidate health workers (Sebokedi, 2002: 60).

It is important that HCPs receive training in the field of human rights. The BMA (2001) argues “while doctors would not necessarily share the same cultural norms or views (in certain instances) about medical ethics; they should nevertheless be aware of the obligation to respect the health-related human rights specified in international instruments that their governments had legally ratified (and local documents such as charters)” (ibid: 498).

The rights of patients remain the same, be it at national, provincial or local spheres of government. 'Discordances' reported in the areas of accountability for enforcement and oversight of patients' rights is a deep concern. If and when there is a gross violation of patient's rights, it is unlikely that any of the government spheres will take responsibility or accountability. Cases of patient negligence are not uncommon in South Africa's public health institutions. For example, there is a lack of clarity of roles and responsibilities between provincial and municipal health services. South Africa has seen cases where patients have been moved from pillar to post between the former and later spheres of government and patients have lost their lives due to this poor coordination of services. Uniformity or cordial working relationships between national, provincial and local governments are pivotal to successful implementation of any government programme. Mutual cooperation has the potential to improve accountability across the three spheres of government. In the case of patients' rights, someone must assume the responsibility for both the actions and omissions of health professionals.

Any programme or project that is implemented without prior agreement between the three spheres (national, provincial and local) of government concerning monitoring and evaluation systems is doomed to fail. There must be an agreement amongst all key stakeholders as to how a new programme will be measured, i.e. assessment of its effectiveness (short-term) and its impact (long-term). A case in point is the complaints

management system at public health facilities. Some facilities do have effective systems to manage patients' complaints, some do not have any complaint's management systems and, therefore, the implementation of patients' rights will differ. Where there is a complaint management system, patients stand a chance to have their concerns addressed. Addressing patient concerns will lead to a better chance of implementation of the Charter. "There is a high possibility that through the complaints management system, patients' rights will be realised when corrective measures (redress) are taken and re-enforced" (London, *et. al.*, 2001: iv).

5.3. Research Report: "*Midwives' experiences of managing women in labour in the Limpopo Province of South Africa: A research study*" (Maputle and Hiss, 2010).

This study was conducted in 2010 at a tertiary care hospital in the Limpopo Province. The purpose of this study was to explore and describe the midwives' experiences of managing women during labour (Maputle and Hiss, 2010: 6).

Maputle and Hiss (2006) present qualitative research aimed at discovering what resides in the minds of all role players – the midwives managing women during labour and women in labour regarding the entire care continuum, i.e. experiences. "An exploratory, descriptive, contextual and inductive design was applied in this qualitative research study" (*ibid*). Twelve (12) midwives participated in this study. Individual unstructured interviews were conducted and data analysis was done through an open coding method.

The outcomes of this research report appear to identify direct violations of patients' rights. In the following section, some of the conclusions that serve as classical examples of breaches of the rights of patients are discussed.

5.3.1 Findings from the Research Report analysing midwives' experiences of

managing women in labour.

The findings of this research report identified:

1. “Limited mutual support, responsibility sharing, decision-making and dependency,
2. Lack of information-sharing, empowering, autonomy and informed choices,
3. Limited open communication and listening,
4. Non-accommodative midwifery actions; and
5. Limited human and material infrastructure” (ibid).

5.3.2 Discussion

In order to make the findings meaningful, salient points about the experiences of midwives as they manage women in labour are presented as follows:

Midwives indicated that during labour women did not verbalise that they would like to participate in decision-making, yet talking, discussing and making decisions requires a collaborative working relationship between midwives and women. It is the midwives’ responsibility and duty to invite women to participate in their care and informed decision-making, the PRC provides that patients should make decisions for their care (including women in labour/childbirth) against this backdrop, it seems critical that mutual respect, understanding, HCPs honouring of professional duties and obligations as well as information to patients so that they are enabled to make informed choices and decisions during labour is pivotal to childbirth management. Midwifery care is particularly stressful when women are not participating effectively in their care during labour and this has a potential to lead to complicated labour since some of the most crucial developments in labour and facts may be lost along the way due to the women’s lack of useful participation (of course this cuts across all healthcare settings and not only midwifery care).

A quote from one of the midwives who participated in the study: “Most women who are in labour look confused and don’t listen to the instructions carefully. They are anxious and don’t co-operate” (ibid). Two issues can be extrapolated from this quotation – (i) that it is to

be expected that women in labour are apprehensive most of the time, (ii) that the midwife has a duty to ally the anxiety of the woman that is in labour. It sounds as if the midwife in this regard negates her responsibility to provide sufficient information regarding labour and instead seems to be blaming the woman for being 'confused'. When a patient's anxieties (fear of the unknown) have been sufficiently allayed it is uncommon that she/he acts 'confused'. The patient has the right to information.

Midwives (nurses) thus have a duty to inform and encourage women in labour (patients) to take part in the responsibility for their care (Fowler and Levine-Ariff, 1987). Concerning this case, the midwives had a responsibility to explain what was happening to their patients in a clear, understandable manner – that is, without using medical or scientific jargon. When medical procedures are communicated to patients in a way in which they can be understood, this opens the path for patients to take informed choices and decisions. When patients “do not understand the medical terminology, they are at risk for errors that can result in adverse health outcomes” (Maputle and Hiss, 2010: 8-10).

The issue of language as a barrier to communication that is both meaningful and useful is not only a problem in midwifery care but the entire healthcare environment as discussed in earlier chapters. It is a concern that the midwives referred to women in labour as being 'difficult' and 'unable to follow instructions' (Maputle & Hiss, 2010: 10), instead of sympathising with the women and that they do so because of language problems. It seems it should be incumbent upon the midwives to try and improvise means to compensate for the 'language barrier' by, for example, getting colleagues who speak the same language as the women to interpret. Child birth is an intricate process and cannot be left to chance, i.e. everything has to be done appropriately and conscientiously for the sake of both the women and her unborn child. Part of acting in the best interests of one's patient, when framed in a rights perspective, includes not only acting in the best interest of 'good health' for one's patient, but also ensuring that patients can participate in their rights. This approach would necessarily involve that HCPs understand 1) asymmetrical power relationships and 2) a rights-based approach to healthcare. In this way, the importance of encouraging patient participation in healthcare rights could be enhanced.

Women in labour were also denied their rights to choice on what their wishes are regarding their deliveries, such as the presence of the spouse during the delivery of their babies. This is clearly a violation of the right to choose and right to be respected as persons with their own values and beliefs. One of the midwives had this to say about the women's choices and preferences:

The presence of a companion/partner during childbirth is an obstacle to a good relationship. It is very difficult to establish contact with the mother in the presence of the father who at times displays a negative attitude, worry or is aggressive." (Maputle and Hiss, 2010: 7).

Women in labour are like all other patients, they have rights, i.e. such as the right to respect for their autonomous choices. If a patient is granted autonomy, she or he has the right to choose or determine what is to be done to her or his body. There is no reason that the right to autonomous choice should 'evaporate' during labour and delivery. So, patients in labour should be given the opportunity to participate in and thus assume some responsibility for their care. In this study, it appears that the midwives ignored (at least) or were unaware of the basic and fundamental rights of these women. Even if the women were ignorant of their rights, the midwives still have the obligation to ensure that their patients were engaged with the fundamentals of exercising their rights. Exercising rights means that the women become part of the decision-making processes concerning their care during labour and child birth. These rights are not negotiable.

The study also alluded to the shortage of resources – human and material. This finding links well with the findings of the CHBH Ethics Audit of 2001. Shortage of staff, linen, medicines, etc. is a serious problem in many of South Africa's healthcare institutions and facilities (already discussed in previous chapters). The shortages militate against good patient care and acceptable professional practice because the nurses, for example, may be overwhelmed by the load of work they face and do not have enough time to pay

attention to details of their care, this is not to say that sub-standard care is acceptable but to highlight the potential effects that staff and other resource shortages may cause.

Based on the findings on midwives' experiences of managing women in labour, it might be important to suggest that over and above the National Patients' Rights Charter (1999), the country needs charters for special vulnerable patients such as women in labour and psychiatric patients. (this is included in Chapter 8 as a recommendation).

In the London, *et al.*, (2006) report, we learned that HCPs need training in human rights. We may also assume that rural women need to have a tremendous amount of education and training concerning their rights – as humans in general, as women in particular, and when in the healthcare arena, their rights as patients. Patients generally do delegate a varying degree of their freedom to those who are medically trained; they do so in trust. Part of returning and encouraging trust in the HCP-patient relationship is the promotion of patients' rights.

Perhaps the reluctance of HCPs to engage patients in 'rights talk' is a result of the professionals' misinterpretation or fundamental lack of knowledge concerning patients' rights. London, *et.al*, write that there is:

... the overwhelming sense in which patients' rights has become interpreted as a threat to health care providers, and competes with their rights as workers (London, *et.al.*, 2006: v).

Based on this, it is clear that there is a sense in which HCPs feel disenfranchised and uneasy about the rights that patients have, namely that they can claim certain rights from health services. The doctor, for example is no longer viewed as the sole arbiter for the treatment and care of the patient, and the voice of the patient must be included in discussions and decisions. Paternalism's long journey has unceremoniously come to a halt. This undoubtedly sends some uncomfortable signals to HCPs who always had the last say in the clinical setting. Moreover, a shift from paternalism is bound to cause some

degree of anxiety and fear of the unknown as far as health professionals are concerned. No one amongst the HCPs can start to guess the route that health services will take with the advent of a rights-based approach being introduced to healthcare services.

HCPs are the custodians of the ethical principles, values and virtues related to healthcare. The Oath or declaration that they take when they graduate represents a public affirmation that they will promote and support the right and proper care, the dignity and worth of their patients – such ideals form the bedrock of patients' rights.

In conclusion, it is of great concern that seven years after the NDoH launched the PRC, key HCPs such as doctors verbalise their ignorance about patients' rights. It is also alarming that nine years after the launch of the Charter, nurses do not acknowledge the obligation that they have to inform patients about their care and ensure that patients form part of the decision-making process concerning issues that impact on their lives.

5.4. Media Reports (Grey literature)

Thirteen years after the CHBH Ethics Audit was conducted, media reports continue on a daily basis, to describe the conditions of public hospitals in South Africa as 'appalling', 'shocking', or, putting it more strongly, as being in 'dire straits'. The situation prevailing in these hospitals is a cause for concern for the country (Dr Aaron Motsoaledi, National Minister of Health, (*Pretoria News*, 15 September, 2012). Violations of patients' rights range from physical, verbal and sexual abuse of patients by and of nurses and doctors. Some of the major characteristics of the 'decay' in the country's hospitals includes but is not limited to sub-standard care, unprofessionalism, harsh working conditions and environment, particularly doctors and nurses. In South Africa, ignorance about health rights among the poor and uneducated remains glaring, and people therefore may fail to notice that their rights have been infringed or violated for as long as they do not know what is right or wrong as far as their care is concerned.

There is growing interest among the South African public and government alike that the violation of patients' rights in public health institutions is untenable. The current South African Minister of Health Dr Aaron Motsoaledi described one of the hospitals in Gauteng and lamented "healthcare has collapsed" (*Pretoria News*, 15 September 2012). The 'collapse' that the Minister spoke of included shortage of linen for patients, lack of surgical outfits for surgeons and theatre nurses, electricity cut-offs, shortage of medicines (particularly chemotherapy for cancer patients), as well as dysfunctional X-ray machines, and special X-rays such as those used for radium therapy (*ibid*). All these are essential resources that patients and especially patients with special needs (cancer) require but they are not available.

This raises the question: Do patients in South Africa's public hospitals have 'access' to health care? There is no doubt that there is access to hospitals, but that is not the same as access to treatment. This is a worry and may be an indicator that patients' rights are not realised in many hospitals. The 2007 public hearings of the South African Human Rights Commission highlighted ongoing violations of the right to access healthcare services. This raises the question: Do patients in South Africa's public hospitals have 'access' to health care? There could be no doubt that there is access to hospitals, but that is not the same as having access to medical treatment. This is a worry and may serve as an indicator that patients' rights are not realised in many hospitals. The 2007 public hearings of the South African Human Rights Commission highlighted ongoing violations of the right to access healthcare services. A media launch of the South African National Health and Nutrition Examination Survey (SANHANES-1) took place on 6 August 2013. This study was conducted by the Human Sciences Research Council (HSRC) between 2011 and 2013. It highlighted that "waiting times were much longer in the public health sector when compared to the private sector" (*ibid*). The SANHANES report also indicated that such long waiting period (as an access problem) "was of great concern since it would be indicative of shortage of health professionals (doctors and nurses in particular)" (*ibid*). Clearly, SANHANES-1 claim closely relates to the findings of the CHBH Ethics Audit on as far as human and material resource shortage is concerned.

Moreover, the media regularly report on alleged misconduct by doctors and other HCPs. On 1 February 2012, *The Sowetan* described hospitals in South Africa as: "Hospitals of no return". On 15 November 2011, the same newspaper reported a shameful case at one of Limpopo Province's hospitals where a male nurse was caught raping a mentally ill patient. People with such frailties have always been dependent on nurses and others for assistance. The nursing profession has in past decades filled in the gap that is created when one is sick and helpless, and they have done so efficiently. As far as this unfortunate and shameful incident of a nurse raping a patient is concerned, all that can be said is that one can only hope it was the doings of one person's twisted mind. Rape is a criminal offence, a gross violation of a patient's rights and a shame to the profession.

In a presentation at the occasion of the Marilyn Lehana Caring Awards Ceremony, Johannesburg, South Africa (17 January 2001), Prof. Willem Landman described the caring nature of nursing in three broad philosophical ways as follows:

First, nurses care by defending patients' human rights, such as the rights to life or to access to health care. This is based on the Declaration of the International Council of Nurses (1998).

Second, nurses care by promoting the good or best interests of others. They do so by preventing disease, by relieving pain, by comforting, by rehabilitating, by advocacy.

Third, nurses care by living the good or moral life, by embodying the virtues of compassion, sympathy, or empathy. They do not defend human rights and promote best interests mechanically or dispassionately, but they do so from having feelings that identify from within with the other in need (Landman, 2001. Unpublished Paper).

In June 2011 *The Sowetan* and *Pretoria News* newspapers revealed that the State had been sued for R235 million for alleged negligence of patients at various public hospitals that resulted in the death of patients. On 18 July 2012, while millions were celebrating Mandela Day, a woman gave birth in her shack and cut the umbilical cord herself while waiting for paramedics. In August 2011, the Human Rights Watch (HRW) report on

accountability for maternal health care in South Africa, reported serious problems with maternity care in the Eastern Cape Province. Amongst other findings was the reported a range of maternity care failures, patient abuse and substandard care of maternity patients in public health facilities in the Eastern Cape. According to the HRW, such activities carried out by midwives put women and their new-borns at risk of both maternal and neonatal death and injury, and violate the rights to respectful and dignified care (Human Rights Watch, 2011: 21-22). Labour and childbirth are unique experiences in a women's life – joyous and painful. Women at this stage are vulnerable and anxious; midwives provide a source of solace and support to women in labour. It must have been both traumatic and unusual for the woman referred to by *The Sowetan* and *Pretoria News*, first to have given birth alone and second, to be in the predicament of having to cut the umbilical cord of one's child. This report links with the findings at CHBH where it was learnt through focus group interviews that women in certain instances had no choice but to deliver alone without the attendance of a midwife (Landman, *et al.*, 2001).

On 27 July 2012, a mentally deranged patient killed a 90-year-old patient in a hospital in North West Province (*The Times*, 27 July 2012). An elderly patient ought to have been protected by the hospital, i.e. nurses and other HCPs. Instead this vulnerable, weak and helpless human being was not safe in what should be 'a safe environment' as promised by the PRC. All these cases and the many more uncited, constitute a rude awakening to South Africa's health system and a grave sign of patients' rights violations that seem to be continuing unabated.

5.5 Conclusion

This chapter has shown that effective implementation of PRC has not been occurred. It is crucial for all HCPs to be taught about rights-based approaches to healthcare. Moreover, HCPs should understand how the environment – the context of the hospital setting may hinder or help patient decision-taking choices – promote or hinder violations of patients' rights. Importantly, it is practically impossible for HCPs to be able to pinpoint situations of human rights abuse in general and more specifically patient's rights if they have no

knowledge of such. Education of HCPs concerning human rights remains a key element in their ability to understand and promote patients' rights. It is quite worrisome that in a case study conducted in 2009, to assess provider's response to the PRC in South Africa, Raphaely found that one of the major concerns from HCPs was that: "some perceived patients who refused treatment as abusing or taking advantage of the system" (Raphaely, 2009: 43). Clearly, from this statement there can be no doubt that there is some degree of 'ignorance' from HCPs regarding the PRC and issues of rights as a whole. HCPs do not understand or appreciate the fact that patients have the right to be respected, they have a right to autonomy (self-determination), and they have a right to participate in decisions that affect their lives.

The findings of the CHBH Ethics Audit (Landman, *et.al*, 2001) are still relevant 13 years after it was conducted. The results from the CHBH Audit, the report from London *et al.*, (2006), research reports and media such as newspaper articles all point to severe problems within the healthcare system. Many of the problems relate to mismanagement, lack of care, and the absence of combined will on the part of society to support and actively promote the idea that each person is of value. From a historical perspective, one might imagine that human rights would form part of the 'culture' in our country. However, it appears that there is much that needs to be done to strengthen the realisation and enforcement of patients' rights in South Africa. In the final Chapter, 'Conclusions and Recommendations', recommendations on how some of these findings may be mitigated are given.

In Chapter 6, a critical analysis is done of the findings of the CHBH ethics audit, as well as subsequent case studies in Western Cape and Limpopo province with the aim to exploring the operationalising of health as a human right. The aim is to try and identify the actual problems that prevent the realisation of patients' rights within the South African healthcare system (hospitals and other health care facilities such as community and healthcare centres). It is within the context of this study that a correlation between theory and practice as far as patients' rights are concerned in South Africa is found.

Chapter 6

Problems preventing the realisation of patients' rights within South Africa's public hospitals

6.1 Introduction

In chapter 4, unethical conduct taking place at the CHBH was identified. These transgressions range from the environment, organisational culture, leadership, staff attitudes, interpersonal relationships and general misconduct to patient care-related issues. All of this culminated in a situation where patients' rights are perceived to be infringed and even grossly violated. The behaviour and attitude of HCPs in general and, in particular, nurses pose an impediment to the actualisation of patients' rights at the CHBH. There has been a significant gap between the promise of access to basic healthcare services and the delivery thereof.

Respecting the right to health care (patients' rights) applies mainly to government laws and policies and requires that states refrain from undertaking actions that inhibit or interfere (directly or indirectly) with people's ability to enjoy the right to health (Asher, 2005: 35-36).

At CHBH patients' rights to *autonomy, respect, informed consent, confidentiality and privacy* are also breached. In this chapter some of the problems that contribute to hindering the realisation of patients' rights will be critically analysed. This applies not only to CHBH, but can be generalised to the South African healthcare system as a whole. This is not only because the CHBH is the largest hospital in South Africa but also on the African continent; it also follows from the subsequent surveys and grey literature discussed in Chapter 5.

The next section, begins by identifying the problems that contributed to the demise of patients' rights at the CHBH. This is followed by a critical analysis of the problems, with

special focus on the impact that such problems have in this setting concerning the realisation of patients' rights.

6.2 Problems preventing the realisation of patients' rights within the South African healthcare system

6.2.1 Under-supply of medicines and shortage of hospital linen

The under-supply of medicines and shortage of linen pose a serious problem in a hospital. At the CHBH these problems have featured frequently, and it is an area of grave concern to both management and staff, which has also been highlighted in previous surveys conducted in other Gauteng Hospitals. From the outset, this does not sound right if one knows and understands the obligations that a hospital has regarding patient care. For example, according to Schyve (1996: 16), a hospital has an ethical responsibility to the patients and community it serves. Guiding documents such as the organisation's mission statement and service charter provide a consistent, ethical framework for its patient care and business practices. The CHBH displays all of these documents on the walls of all its service units including the outpatient department, casualty and pharmacy. But obviously a framework alone is not sufficient. To support ethical practices and operations as well as fair treatment of patients, a hospital has a code of ethical behaviour (the CHBH has the Public Service Code of Conduct) and operates according to it. An under-supply of medicines and shortage of linen cannot be in keeping with the mission and service charter of the hospital.

This raises the following question: Why is there an under-supply of medicines and shortage of linen at the CHBH? Or put differently, what are the possible reasons for the under-supply of medicines and shortage of linen?

The reasons for the under-supply of medicines in descending order of importance are:

- Decreasing healthcare budget,
- HIV and AIDS patients (pandemic),

- Influx of non-South African patients,
- Theft of medicines from hospital stocks by staff,
- Over-ordering of medicines by ward sisters (professional nurses).

The factors were identified from the raw data of the CHBH focus group interviews as 'key themes' and they formed the sub-categories of the survey questionnaire. Research participants were requested to rate them in descending order of importance as reasons for under-supply of medicines. To summarise this, Landman, *et al.*, (2001) had this to say:

In the case of both an under-supply of medicine and a linen shortage, cuts to the healthcare budget were cited as the most important reason for these problems (Landman, *et al.*, 2001: 26).

The implications of the under-supply of medicines and a shortage of linen are easy to understand. The CHBH ethics audit report reveals that some patients are discharged and go home without the necessary prescribed medicine, while some patients receive insufficient medicine. Yet, taking home medicine when a patient is discharged is a patient's right, and so is getting appropriate and sufficient medicine when this is prescribed. When a patient does not get the treatment as prescribed, the right of the patient to treatment, as stated in the PRC, is not respected.

The PRC states:

Everyone has the right of access to healthcare services that include:

Treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof (PRC, 1999: 1).

The phrase above, 'access to healthcare services', does not imply only physical access; it also means access to treatment, i.e. medicine. Failure on the part of a hospital to ensure that the patient gets the kind of access referred to, namely access to medicine, precludes the realisation of patients' rights in a hospital. The emphasis placed on services provided to

non-South African patients or even attributing the under-supply of medicines to them does not sound logical and is a cause for concern. There is danger in this, because if such utterances are allowed to continue discrimination on the basis of nationality could occur. In that way, the principle of respect for human dignity may be lost. What is important in this regard is for the state to ensure that people understand that while citizens of the Republic have a right to access health care so do foreign nationals who find themselves within the borders of the Republic of South Africa.

According to the Charter of the Fundamental Rights of the European Union (2000/C 364/01), Art 1, any violation of the majority of fundamental human rights and freedoms also breaches the respect and protection of human dignity. This is the case in areas such as health, extreme poverty and the treatment of illegal aliens or foreigners whose legal status has not yet been clarified. Yet, all patients, according to the Charter, “have the right to a *positive disposition displayed by health care providers that demonstrate courtesy, human dignity, patience, empathy and tolerance*” (ibid). Also, the World Medical Association’s *Declaration of Lisbon on the Rights of the Patient* (2005), section 1 (a)-(f), states among other moral rights that patients have the right to be treated without favouritism and without discrimination and that they have the right to dignity. Discrimination robs patients of their dignity and prevents the actualisation of patients’ rights. The issue of foreigners or non-South Africans raises concerns about hatred for foreign nationals. Foreign nationals, once they are in the country, have a right to access health care just like any South African. An emphasis on ex-patriots as far as health services is concerned strictly speaking, could lend itself to different kinds of connotations (negative) such as discrimination, xenophobia, etc.

The issue of linen shortages thus needs to be taken seriously when it comes to the implementation of patients’ rights. Linens sensitive since in-patients’ bodies are in constant contact with linen, and linen may be regarded as symbolic of cleanliness, comfort and personal caring. The mismanagement of the supply, cleaning and security of linen in a hospital undermines the values of good patient care and seems to be stripping patients’ right to dignity.

6.2.2 Unacceptable physical (buildings) environment and unsafe security arrangements

The physical environment is regarded as unacceptable because the buildings at CHBH are seen by hospital management, staff and patients (in- and out-patients) as dirty, unsafe and unattractive (Landman, Mouton & Nevhutalu, 2001: 21-22). These quantitative results are, according to Landman, *et al.*, (2001), borne out by qualitative remarks made in response to the open-ended questions of the survey.

The dirty toilets, bathrooms, ward floors and ceilings in some of the wards that threaten to collapse are not conducive to a caring environment. A hospital is supposed to be a home away from home to patients. Baillie (2007: 30-31) states that “staff behaviour and the hospital environment impact patients’ dignity, and threats to patients’ human needs can lead to loss of dignity”. To this end, providers of health care are expected to uphold patients’ rights and focus on the patients’ needs of a therapeutic environment, which is clean, fresh, and warm and promotes the healing process. According to Berglund and Saltman (2002: 633-666), therapeutic relationships need the human touch to bring them to life and to develop rapport with clients. The physical environment at the CHBH and South Africa’s public health institutions in general fall short of the ideal and this is an affront to the realisation of patients’ rights.

When it comes to the reasons for this dismal state of the physical environment of the CHBH, the audit revealed the following:

- The hospital is dirty,
- Unsafe,
- Unattractive,
- Depressing.

Landman, *et al.*, (2001: 19-21).

6.2.3 Safety and security at CHBH

Security at CHBH was a recurring theme during the focus group interviews, and the reason for this was cited as the lack of adequate safety measures. The violent social conditions in the country make security a top priority. Disregard for others' or the state's material possessions (through theft, pilfering, reckless handling or destruction) and violence against the person (such as verbal or physical abuse, assault, etc.) are wholly antithetical to what a hospital as an institution is supposed to stand for. Issues such as the right of admission, searches upon leaving hospital premises, identifying marks on equipment, installing surveillance cameras and introducing effective punitive actions need to be explored. As a means to enhance patients' fundamental rights as stated in the WHO Charter of 1995 as follows:

Everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection (WHO Charter 1995: 1-6).

All categories of staff at CHBH attribute the lack of safety and security to the following reasons:

- Perceptions that security staff at CHBH are not well-trained,
 - That, in fact they are part of the problem than the solution,
 - Screening of visitors is poor,
 - Government negating the responsibility to ensure a safe environment for employees.
- (Landman, *et. al.*, 2001: 27-29).

6.2.4 Staff shortages

Staff shortages are a major problem not only in South Africa, but are also a global phenomenon (*HRH Strategy 2012/2013 – 2014/2016*). A major category of concern in this regard is professional nurses who leave the country looking for better salaries and working conditions in foreign countries, such as the UK, Australia, New Zealand, Canada and the United Arab Emirates. Nurses are the backbone of the healthcare delivery system in any country (developed and developing countries). They are with patient's 24 hours a day, while medical practitioners and other HCPs spend on average of 15-20 minutes at a patient's bedside. Nurses work long hours and are overloaded with a nurse-patient ratio ranging from 1:60 or more at CHBH, while the acceptable nurse-patient ratio as per WHO norms is 1:6. It seems very unlikely that with such workloads nurses would be in a position to give nursing care that is of a high standard to all patients, yet patients deserve even personalised care.

During night duty, a single nurse attends to almost 60 patients. This leads to burnout among the nursing staff, which results in poor attitudes to patients and work. This is compounded by the negative attitudes of the community, including senior government officers, as well as nurses (focus group interviews of the CHBH ethics audit, 2001).

Staff numbers should thus be reviewed with a view to an increased budget allocation, which would include incentives (financial and non-financial) for nurses, recruitment strategies and an occupation specific dispensation (OSD).

The principle in such a review process should be quality patient care which conforms to acceptable universal standards of care. It is also critical that the available staff should be distributed optimally. The provision of a conducive environment and/or an enabling milieu cannot be over-emphasised. Such an environment promotes employee productivity, job satisfaction and professionalism across the board. Importantly, some sectors of the hospital (such as general admissions and discharge, casualty admissions, and the pharmacy or dispensary) seem to experience particularly acute staff shortages, and such shortages appear to be at the root of many other problems in the hospital. Landman, *et al.*, (2001: 96-

97) recommend that "clerical staff must be appointed in admission wards, such as ward 20³⁰, on a 24-hour basis" (Landman, *et. al.*, 2001: 96-97).

In conclusion, when nurses are over-worked and short-staffed, undoubtedly they eventually experience burnout, affecting their performance. This change in mood and morale will, in turn, affect their relationship with their patients with consequent compromising of patients' rights. Accordingly it can be understood why the World Health Regional Office for Europe (1994) observed that "nurses' attitudes and behaviours pose an impediment to the actualisation of patients' rights in many countries".

6.2.5 Lack of a patients' rights culture

The quotations in this dissertation on patients' rights illustrate clearly the concern expressed about the violation of these rights and the absolute need for re-establishing a culture of respect for patients and their rights. By their own admission, doctors and nurses at CHBH lack respect for patients' rights and apparently violate them self-consciously.

Patients' rights are an integral part of human rights. They promote and sustain beneficial relationships between patients and HCPs. As Hunt (2005: iii) has observed: "Health professionals – doctors, nurses, pharmacists, technicians, administrators and others – and their professional associations have an indispensable role to play in the vindication of the right to health."

In South Africa, the apartheid system of government was a process of dehumanisation; it reduced the majority of the country's people to objects or physical entities in almost every sphere of their lives. In the healthcare arena, the focus was on the disease and not the patient, their families and communities. As London (2011: 87-88) rightly puts it, "imperceptibly, medicine also became dehumanised". South Africa is now a democratic state that is politically free and redress of the injustices of the apartheid system is due to all the people of the country. Against this backdrop, South Africa's transition is widely

³⁰ Ward 20 is an obstetric ward where pregnant women in labour are admitted for delivery at the CHBH. It has been reported in the survey that the admission process as well as care leaves a lot to be admired and hence this ward is singled out in the audit report.

understood as a move from social injustice to social justice. One component, a partial measure of social justice though, is the acknowledgement of patients' rights as an integral component of human rights. Health-care professionals can become important instruments for entrenching human rights and as a consequence thereof, patients' rights language in a hospital setting.

It is worrisome that the patients' rights culture at CHBH needs to be re-established to the extent that the situation is described as an "absolute need" (Focus Group Interviews at CHBH, 2001). Health professionals ought to be both the advocates and custodians of patients' rights in the clinical setting. For example, the nurse is viewed as the defender of patient rights against an impersonal healthcare system that violates patients' rights. According to Fry (1987: 42), nurses have the responsibility of informing the patient about his or her rights in the hospital (for example, discussing the 1999 National Patients' Rights Charter), making sure the patient understands these rights, and knows how to exercise them within the healthcare system. From this, it is reasonable to expect that nurses should also be the appropriate person to whom the patient reports infringements of his rights.

Murphy (1978: 9-24) argues that the patient-advocate model of nursing supports the moral authority of the nurse to make decisions for and with the patient, and to help the patient obtain the best possible care. This model is based on the premise that the nurse spends more time with the patient and has a more continuous, caring relationship with the patient than any other member of the healthcare team and is capable of developing a more insightful relationship with the patient.

The question that arises is: What are the critical issues at CHBH that contributed to the gap between these ideals and reality? This is approached by presenting the following challenges generally faced by healthcare workers in South Africa's public hospitals as well as at CHBH in particular.

It would be dangerous to turn a blind eye to the numerous challenges facing health professionals in the public healthcare system that could constrain effective patient care

(patients' rights), if one aims to bring reality closer to the ideal. Low medical literacy and/or health literacy seems to be at the core as far as patient-provider relationships are concerned. Of course, low literacy is omnipresent in South Africa, but poorly considered and recognised. As Landman, *et al.*, (2001) put it: "Doctors and nurses alike consistently mentioned the language barrier from the broad perspective of lack of mutual intelligibility. Colleagues are often used as interpreters, but given the staff shortages, this could pose yet another challenge" (Landman, *et. al.*; 2001: 67).

Data from the ethics audit highlight that lack of confidentiality and disrespect for patients' dignity might be attributed to overcrowding in many of the wards at the CHBH and that this aggravates the perceived violation of patients' rights.

Time constraints mean that healthcare workers often cannot devote the large amount of time needed, for example, to obtain informed consent from each patient. HCPs in this country recognise that different cultural norms and beliefs should be respected, but it is often difficult to establish what these are. Where the doctor cannot speak the patient's language and where many medical conditions, such as HIV and AIDS, are clouded in superstition, according to Ojwang, Ogutu and Matu (2010: 107-108), it will "require ongoing dialogue between HCPs and patients to ensure that the patients' beliefs are recognised. The large number of patients and little time to attend to them are a potential threat to efficient and satisfactory service and in a sense they pose impediments to the realisation of patients' rights". These problems raise the following questions:

1. At what point in the healthcare system do resource shortages permit sub-standard care and professional neglect of patients?
2. Put differently, one can ask at what point in the healthcare system do resource shortages permit the infringement or violation of patients' basic and fundamental rights?

To begin to answer these questions, the statement made earlier in this chapter on South Africa's transition from the apartheid system of government to a democratic government is useful: "South Africa's transition is widely understood as a move from social injustice to social justice" (Heyns and Brand, 2004: 37). The violation of socio-economic rights was

major part of apartheid era injustice. The Constitutional recognition of such rights "is thus an attempt to ensure that the same causes of conflict will not present themselves again in future" (ibid).

The judges of the South African Constitutional Court found legitimate reasons for overruling the majority government in the *Grootboom* and *TAC* cases on the basis of the human rights provisions of the new Constitution. However, there is a deeper foundation for doing this, namely the concept of human rights itself, and this includes socio-economic rights (patients' rights). According to Heyns and Brand (2004: 39): "the state and society can never have the jurisdiction to violate human rights". The same applies to any government institution or organisation." It is therefore the role of the courts to protect these rights and to prevent people, if they believe there is no other alternative, from taking matters into their own hands. The courts represent guardians of the continuous transition towards the full recognition of human rights, in other words the courts are the final arbiters of human rights.

Resource shortages are not a sufficient reason to deny patients the opportunity to realise their rights. The socio-economic rights clauses in the Constitution impose a minimum core duty on government to provide a basic level of services to the poor. Liebenberg states this as follows:

Government should not be able to evade this core duty by invoking resource constraints and the latitude of "progressive realisation". It would thus be easier for poor people to prove that these rights had been violated (Liebenberg 2002: 36).

Against this background, it is clear why HCPs should be aware of patients' rights as set out in both international and local documents such as the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the National Patients' Rights Charter (1999).

Established patients' rights to respect, promotion of welfare, privacy, confidentiality, informed consent, and the like, are non-negotiable. There are strong indications that even these basic rights are not practised adequately at CHBH. Relevant documents setting out

these rights are the PRC and Nurses and Human Rights (International Council of Nurses, 1998) (Landman, *et al.*, 2001: 103-104).

This section is concluded by borrowing from Landman, *et al.*, (2001) as follows:

All public health institutions should consider constituting hospital or institutional ethics committees, as opposed to health research ethics committees (public authorities often confuse the two), that would serve as advisory bodies on ethical issues, including clinical practice, to which all stakeholders, including patients, can appeal. More importantly, patients should be made aware of all their rights and their responsibilities upon admission, or at the bedside when appropriate, and they should have access to formalised complaint procedures without fear of victimisation (Landman, *et al.*, 2001: 103-104).

6.2.6 Management and leadership – ineffective and weak

When the management and leadership of an organisation are viewed as ineffective and weak, key areas of the organisation, such as its culture, staff relations, organisational values and professional values are affected negatively. This has a spill-over effect on other critical functional areas. For example, it affects the organisation's capacity and ability to discharge its functions and obligations. In this way, the hospital's obligation to respect, protect, promote and fulfil patients' rights is hindered and as a consequence thereof, patients' rights actualisation becomes practically impossible.

Professional values such as compassion for the patient, confidentiality of patient information, respect for the dignity of the patient and empathy are lost. Disciplinary mechanisms are both lacking and reflect favouritism, and staff morale is low. Given the unhealthy working environment depicted by the findings of the CHBH audit, emotional reactions and responses that are adverse to the patient could follow and trigger a rift from the professional's ethical and moral ideals. HCPs may find themselves in very disconcerting positions when challenged to maintain the duty of compassion and concern for patients while faced by situations that undermine this.

Despite such obstacles, in the last two decades, some shifts have occurred that represent an expansion of patients' rights into a major consideration of organised healthcare (Schyve, 1996: 14). In South Africa, the first national emphasis on this organisational obligation was reflected in the PRC in the section on 'Access to healthcare', which states:

Everyone has the right of access to healthcare services that include:

- Receiving timely emergency care at any healthcare facility that is open regardless of one's ability to pay;
- Treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;
- Provision for special needs in the case of new-born infants, children, pregnant women, the aged, disabled persons, patients in pain; persons living with HIV and AIDS patients;
- Counselling without discrimination; coercion or violence on matters such as reproductive health, cancer or HIV and AIDS;
- Palliative care that is affordable and effective in cases of incurable or terminal illness;
- A positive disposition displayed by health care providers that demonstrate courtesy, human dignity, patience, empathy and tolerance; and
- Health information that includes the availability of health services and how best to use such services and such information shall be in a language understood by the patient. (National Patients' Rights Charter, 1999)

It is apparent that poor management and weak leadership of the CHBH with the concomitant low professional values, poor staff relations, and low morale do not favour the ideals or aspirational values enshrined in the Charter. For example, it is difficult to picture a nurse who has lost professional values or professional ethics as being courteous to his or her patients. Examples of disregard for the rights of patients are many and varied. For

instance, to enable the patient to give voluntary informed consent, the patient has the right to clear, concise, understandable information about his or her condition and proposed procedures, which includes information on the probability of success, the possibilities of any risk or problems that might arise, and significant alternatives to the proposed treatment. Should there be any lingering question, the patient has the right to refuse treatment.

However, the qualitative comments given by staff at CHBH, give a sense that patients and staff are afraid to report any ethical misdemeanours. For example, a comment by a radiographer reads:

Patients must not be scared to report unsatisfactory treatment. Staff shouldn't be scared to voice out if not satisfied. That is, management must be approachable, and responsive (Focus Group Interviews, CHBH Ethics Audit, 2001)..

Clinical performance, i.e. failure to maintain standards and disrespect shown to certain patients by senior members, according to reports by staff at CHBH, influences how subordinates behave. Poor patient management occurs and, despite assaults on patients by nurses and patients assaulting nurses, no disciplinary measures are taken against aggressors. Nurses and doctors behave unethically and no disciplinary measures are taken against them. Organisationally, these problems point to two things: poor management and weak leadership. These block the realisation of patients' rights. A line-by-line analysis of focus group interviews at the CHBH reveals that patients who fought nurses were patients who according to the nurses were "non-compliant" as far as hospital policies and regulations were concerned. When a patient is non-compliant he usually does not cooperate with, for example, the management programme prescribed by the practitioner. It is unthinkable that the chief executive officer (CEO) can manage such a big hospital with its complexities without being granted full authority and powers to be able to run the hospital without constraints. The famous excuse given by senior political officers in this regard for over-controlling is to always invoke the policies of government such as, for example, the Public Finance Management Act (Act 1, 1999).

We know, however, that in South Africa the aim of many guidelines, Acts and policies is to encourage one to think, i.e. look at various options when faced with a challenging situation to ensure that such a guideline and/or policy is well implemented and it is effective.

Ethical challenges are a part of our lives. In some cases, according to Schyve (1996: 15), the challenge derives from "a conflict between the interest of the patient and the success, at least in the short term, of the organisation". In healthcare settings, conflict may also be represented by conflicting ethical principles, such as the good of the individual versus the good of the community. The question is: How should a healthcare organisation ethically respond to such challenges? The organisation could try to resolve the challenge by telling the patient to observe the principle of *caveat emptor* - this is a doctrine that often places the burden to reasonably examine property before purchase and take responsibility for its condition on the buyer³¹. In the context of healthcare, however, *caveat emptor* would imply that the patient bears the responsibility to ensure that the care and treatment he or she receives is his or her responsibility, i.e. the patient takes responsibility, for example, for the complications arising from his or her treatment and care. This is something that is not viable, and thus unwelcome in the healthcare arena. Most HCPs and patients would find this not only unsatisfactory, but unethical. Organisations could avoid the question and rely on the personal ethics of each professional and administrator in the healthcare system to do the 'right thing'. The administrators could report unethical behaviour to the HPCSA or other governing body. In practice, however, some individuals who are involved in the management of healthcare organisations appear not to place a great amount of emphasis on promoting high ethical standards. It is acknowledged that most people have occasional ethical lapses, and knowing the 'right thing' can be difficult when ethical principles conflict.

6.2.7 Lack of emphasis on patients' responsibilities

In terms of section 36 subsection (1) of the Constitution, the rights in the Bill of Rights may be limited only "in terms of the law of general application to the extent that the limitation is

³¹ (<https://www.law.cornell.edu/wex/caveat-emptor>. Accessed Sept 8 2015).

reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including –

- (1) the nature of the right;
- (2) the importance of the purpose of the limitation;
- (3) the nature and extent of the limitation;
- (4) the relationship between the limitation and its purpose; and
- (5) less restrictive means to achieve the purpose.

Placing emphasis only on patients' rights and not on patients' responsibilities is an omission that could prove detrimental to the full realisation of patients' rights. Assuming patients' or clients' responsibilities as reflected in the Charter empowers the patient and is in keeping with the principle of autonomy, because it has the potential to boost and enhance a patient's self-esteem.

According to the CHBH ethics audit report, patients steal hospital linen and also assault nurses. These are clear indications that patients do not know the obligations that the Charter imposes upon them or they may not understand what the obligations mean to them. Hence ongoing re-orientation and education about the patients' rights charter seems crucial.

The PRC states:

Every patient or client has the responsibility to comply with the prescribed treatment or rehabilitation procedures.

In the *Financial Mail* of 12 July 2002, Liebenberg stated:

... Without access to at least a basic level of health care in South Africa's healthcare system, the foundational constitutional values of human dignity have a hollow ring (2002: 36).

This responsibility is crucial because one can recognise and ensure the realisation of some if not all of the patients' rights as listed, but as long as the patient does not take the responsibility to take care of his or her right, 'all efforts will be in vain'. Over-and-above access to health care, patients need to be encouraged to take responsibility for their health as well as that of their families (in the case of adult patients).

6.3 Concluding remarks

An organisation such as the CHBH, and any other public hospital for that matter, has an ethical responsibility to its patients (ensuring the realisation of patients' rights) and the community it serves. Guiding documents such as the mission statement and service charter/pledge provide a consistent, ethical framework for its patient care and business practices.

The core duty or obligations imposed by the Constitution on government (public institutions) should form the basis for progressive improvement in the quantity and quality of the rights enjoyed by citizens over time.

In this chapter some of the actual problems preventing the realisation of rights within the South African healthcare system, based on the raw excess data from the ethics audit conducted at CHBH have been identified and analysed. In the next chapter, the implications of the problems identified in this chapter will be scrutinised, and the idea of patients' rights will be reassessed.

Chapter 7

Patients' Rights revisited

7.1 Introduction

Having traced both the theoretical and moral underpinnings of human rights in general and patient's rights in particular, revisiting patients' rights as specified in the PRC (1999) seems to be in order. Fundamentally, findings of the CHBH Ethics Audit (2001), the two case studies in the Western Cape and Limpopo provinces (2006), the research study to assess the midwives' experiences in managing women in labour, and various media reports serve as beacons for revisiting patients' rights.

The main purpose of this chapter is to rethink patients' rights within the context of the practical realities facing public health hospitals and facilities. Whether patients' rights as they stand in the PRC are 1) relevant to the basic moral principles espoused in biomedical ethics literature, and 2) in the spirit of the Bill of Rights (enshrined in the Constitution of the Republic of South Africa Act, 108 of 1996) will be critically evaluated.

Some of the key findings concerning the position of patients' rights in South Africa's public health institutions including reaffirming patients' rights and responsibilities as presented in the PRC are restated in the following section.

7.2 Restating some key findings on the state of patients' rights in public health institutions

The results of audits, case studies, research studies and media reports were not limited to the following findings:

- (1) Time constraints due to staff shortages resulted in inadequate time to treat patients well;
- (2) Language barriers between patients and HCPs represented a severe hindrance to mutual communication;
- (3) Poor or complete lack of proper information about patients' diagnosis and treatment resulted in poor patient care;
- (4) Health professionals' lack and/or limited knowledge and understanding of human rights in general and specifically patients' rights was identified as one of the key problems in actualising patients' rights;
- (5) Occurrences of patient abuse (verbal and physical) were noted;
- (6) Patient exclusion in decision-making concerning their treatment and care;
- (7) Breaches of confidentiality and privacy of patients remain common;
- (8) Linen and medicine shortages persist;
- (9) Staff shortages persist countrywide;
- (10) Disrespect of patient autonomy and dignity commonplace.

Various sources, including surveys, audits, case studies and grey literature repeated some of the problems as highlighted above, such as patient abuse, resource shortages (linen, medicines, and food) that characterise the state of patient care (patients' rights) in many of South Africa's public healthcare institutions (hospitals) and facilities (community clinics and healthcare centres) in general.

7.3 Patients' rights in the National Patients' Rights Charter (1999) reaffirmed

To ensure the realisation of the right to access to healthcare services as guaranteed in the Bill of Rights (The Constitution of the Republic of South Africa Act No. 108 of 1996), the NDoH proclaimed the PRC as a common standard for achieving the realisation of the right to health care (National Patients' Rights Charter, 1999). The patients' rights are listed as follows:

A healthy and safe environment

According to this right, *“everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection”*. This first right as it appears in the PRC appears practical and is in keeping with many constitutions and rights declarations calling attention to the ways in which the environment affects human health and vice versa. One of the difficulties is that if a HCP tried to explain the meaning of this right to her patient, it is doubtful if she would succeed. This is because the terms and concepts (e.g. environmental danger, pollution and ecological degradation) are not present in the many local languages (vernacular). This is not to say that HCPs should not try to explain the meanings. A finding relevant to the right to a safe environment comes from the CHBH Ethics Audit (2001):

...both staff and patients consistently indicated that the hospital is dirty, unsafe, and unattractive (Landman, *et al.*, 2001: 21).

The right to a safe environment would include the duty on the part of hospitals and healthcare facilities to ensure that medical waste is disposed off properly by licensed medical waste companies, to report and insist on follow up on leaking water taps, broken toilets and any sewerage problems. Hospital infection control committees as well as staff should ensure proper techniques for theatre and hand-washing to contain nosocomial infections. Patients should thus also be educated concerning hygienic techniques when needed. Staff and patients should ensure that they do not personally contribute to littering and environmental degradation.

Participation in decision making

This right is described in the PRC as follows:

Every citizen has the right to participate in the development of health policies and everyone has the right to participate in decision making on matters affecting one's health (National Patients' Rights Charter, 1999: 1).

The first part of this right "... *Every citizen has the right to participate in the development of health policies...*" appears consistent with the ideal that citizens should participate in government processes and policies that affect their lives as part of participative democracy. On a practical level though, it is quite difficult to imagine that a patient would begin to understand that she has a right "to participate in the development of health policies". This is because one must consider, for example, literacy levels, understanding of medical jargon, transportation and costs to policy meetings or discussions; much less a general understanding of what is included in 'policy development'. Concerning the second part of the right to participate in decision making it is stated: "... *(and) everyone has the right to participate in decision making on matters affecting one's health*" (ibid). In consideration of this, the cultural diversity present in our society must be considered. In some of our societal traditions the 'doctor' or 'inyanga' has always decided for the patient, therefore, how this right is phrased becomes crucial. This, of course, is not to propose that decision making should be negated but it is to suggest that the phrasing of this right should be such that it appeals to the patient's emotions and reasoning. Taking part in one's healthcare decisions 'now' as opposed to time immemorial when such decisions were made by another, should be backed by good reasons for why it is better that mutual decisions are made. A meaningful engagement with the patient regarding this right is important, not just a compliance act where the HCP does not take an effort to double check with the patient to ensure that s/he understands what is expected when one says: "you are part of the decision-making process". As Landman, *et al.*, (2001) stated:

... one's overarching impression is that most patients are not well informed about their illness, or the reason for the treatment or medication they receive (2001: 89).

The 'denial' of patients being allowed to make decisions in relation to their treatment and care clearly shows disrespect for their autonomy and dignity. Despite the complexity of problems faced by the healthcare system, there is no excuse to deny patients their right to

self-determination. Cognisant of common problems such as language barriers, educational disparities that may exist, as well as workloads, between HCPs and patients, it remains a non-negotiable imperative that a patient's right to participate in decisions about treatment, risks, possible alternate therapies, costs, and so forth should be maintained.

From the research and case studies conducted on patients' rights and the exploration on the implementation of the PRC, it was unclear what the real problems were preventing the involvement (at least meaningfully) of patients in decision making. Not knowing precisely the cause of the apparent disengagement of the patient from his care, whether due to the language barriers, staff shortages or the attitudes of HCPs is worth further research. Concerning patients, low literacy is omnipresent although poorly acknowledged when documents such as the PRC are crafted. Regardless of the difficulties, HCPs have an ethical duty to advocate for their patients for their right to be included in decisions that affect their health. In cases where autonomy is compromised, e.g. children, the comatose, severely mentally challenged, or mentally ill, the "respect for persons principle is protected through advocacy by HCPs" (Fowler and Levine-Aruff, 1987: 41-40). Health institutions should thus lead the way in ensuring the realisation and enforcement of the right to participate in decision making on matters affecting one's health.

In the PRC patients' rights are formulated as follows:

Access to healthcare

Everyone has the right of access to healthcare services that include:

- i. *receiving timely emergency care*
at any healthcare facility that is open regardless of one's ability to pay;
- ii. *treatment and rehabilitation*
that must be known to the patient to enable the patient to understand such treatment or rehabilitation and consequences thereof;

iii. *provision for special needs*

in the case of new-born infants, children, pregnant women, the aged, disabled patients in pain, person living with HIV or AIDS patients;

iv. *counselling*

without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV and AIDS.

v. *palliative care*

that is affordable and effective in cases of incurable or terminal illness;

vi. *a positive disposition*

displayed by healthcare providers that demonstrates courtesy, human dignity, patience, empathy and tolerance.

The areas covered by this right seem appropriate; however, other key areas of access such as: distance from the health facility, financial resources, operating times of the health facility and availability of doctors, nurses and other members of the allied health professions should have been included under the right to access healthcare. If one is admitted to hospital but does not have a doctor in attendance then 'access' is not complete. As an in-patient, the relevant HCP, medications, treatment and care are rightfully expected. Here the inclusion of a recent media report regarding orthopaedic patients at Pelonomi Regional Hospital has relevance:

- (1) That, 34 patients with fractured bones have been lying on trolley beds in the hospital's casualty referrals section while waiting for beds;
- (2) That a further 64 orthopaedic patients who have already been admitted to hospital are still waiting for surgery – some for as long as a month (*Sunday Times*, 25 May 2014).

This strengthens the argument that: being admitted to hospital without getting the necessary medical interventions does not translate to 'access to healthcare'. Hence, the areas highlighted in terms of access above seem to be omitted in the PRC. There is no benefit for anyone to 'access' healthcare facilities and hospitals if there are no HCPs, treatments, drugs, clean linen, safe environments, and so forth.

Emphasis should also have been placed on the role of Medical Schemes. For example, medical schemes should not forbid starting of treatment without pre-authorisation in emergencies. It would be useful if patients were informed that in emergency situations pre-authorisation is just a delay in urgent and vital life-saving medical care and treatment.

There is no disagreement that special consideration is due to those whose needs are exceptional. It is incumbent on the healthcare system to make provisions for vulnerable groups. As far as special needs are concerned, a neglected part of our population consists of the rural elderly. Many of the rural elderly witnessed their children dying from HIV/AIDS and are now the caregivers of these grandchildren. Poor eyesight, hypertension, diabetes, certain types of cancer, and 'chronic diseases of the elderly', should be prioritised within our healthcare system. Some Western countries have enabled additional patient rights for specific groups within their population. This step may be premature for South Africa, however, special consideration of vulnerable groups through special rights over-and-above the PCR could enhance and promote their recognition and enforcement.

Knowledge of one's health insurance/medical aid scheme

A member of a health insurance or medical aid scheme is entitled to information about that insurance or medical aid scheme and to challenge, where necessary, the decisions of such health insurance or medical aid scheme relating to the member.

The great majority of South Africans do not belong to any health insurance or medical aid scheme. On 29 June 2011, *BusinessLIVE* provided a report from the Board of Healthcare Funders of Southern Africa that highlighted that "84% of South Africans have no medical aid

cover, this translating into only 3.5 million citizens having medical aid cover". We can see that "many low and middle income earners' families are at risk by not having medical cover or sufficient health cover" (ibid). However, following the launch of South Africa's National Health Insurance (NHI) in 2012 it is hoped that every citizen will have health insurance, and be able to have knowledge of his or her health insurance. The Department of Health thus already has a responsibility to ensure that every member of society is conversant with the NHI.

Choice of health services

Everyone has a right to choose a particular healthcare provider for services, or a particular health facility for treatment provided that such choice shall not be contrary to the ethical standards applicable to such healthcare providers or facilities, and the choice of facilities is in line with prescribed service delivery guide lines.

The choice of a healthcare provider for services represents an ideal. Given the human resource shortages in public health facilities, this is difficult, if not impossible, to realise. Also, choosing one's own healthcare provider implies a good understanding of the choices available. As far as medical-related choices are concerned, a certain level of literacy is imperative, let alone a basic understanding of medical terms, technology, etc. Given the fact that South Africa's adult literacy level stands at 93% according to the United Nations Development Programme's Human Development Report (2014) this poses a problem as far as the right to choose is concerned. Decisiveness on the part of government is needed to develop mechanisms and strategies to ensure that those who enter our public health facilities are empowered to make choice about health services and providers.

Be treated by a named healthcare provider

Everyone has the right to know the person that is providing healthcare and therefore must be attended to by a clearly identified healthcare provider.

This seems like the normal day-to-day practice where people introduce themselves to each other when they first meet. Interestingly, though various studies conducted to assess the implementation of patients' rights identify that patients are unhappy concerning poor interpersonal relationships between themselves and HCP. It is difficult to imagine that basic human etiquette such as greeting others, introducing self, and wearing a name tag or other form of identification would be ignored in the healthcare fields. Certainly, the right to know the name of the person providing healthcare and for the HCP to wear some form of identification is reasonable. This right involves all personnel under hospital management as a duty to ensure and create an environment that is friendly and conducive for positive staff and patient relationships.

Confidentiality and privacy

Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or an order of court.

Respecting and maintaining confidentiality and privacy of patient information forms part of respecting a patient's integrity and dignity. When confidentiality and privacy are ensured patients develop trust for both the institution and HCP. Without this trust, the professional-patient relationship can be jeopardised.³²

Informed consent

³²A detailed discussion of this ethical principle is presented in Chapter 3 of this dissertation – "*Perspectives on patient's rights*".

Everyone has the right to be given full and accurate information about the nature of one's illness, diagnostic procedures, the proposed treatment and the costs involved, for one to make a decision that affects anyone of these elements.

This right is quite comprehensive and relevant. The essence of informed consent as a concept has been thoroughly discussed Chapter 3. However, of great importance in consenting is 'health literacy'. It is probable that many South African adults are deficient in literacy skills. All HCPs should be aware that as the American Medical Association (AMA) (2007: 12) puts it:

... (A)t each step, opportunities arise for miscommunication, misunderstanding and possible harm – to the patient, provider and health care system.

There may be many persons who become involved in a patient's care. As others become involved, they also share the patient's information. The only constant, is the patient. Proper communication with the patient thus serves not only to inform her about the roles different HCPs are playing in her care, but it also adds to her knowledge concerning her illness. Without communication, understanding, knowledge, and being respected as a person, no patient can make an informed choice.

Refusal of treatment

A person may refuse treatment and such refusal shall be verbal or in writing provided that such refusal does not endanger the health of others.

The concept of 'refusal of treatment' is a relatively new term in the vocabulary of many South Africans, especially black Africans. This is because traditional medicine entrenched the powers of the healer to make treatment decisions for the patient. There was absolutely no way that a patient or family member could make a decision concerning any aspect of what I refer to as 'a traditional agreement' to care and treatment. The level of authority and respect vested upon the 'inyanga/healer' seems far beyond that accorded a medical

practitioner. All cultures change, therefore the role of the 'inyanga/healer' will change as well. Yet, since the majority of South Africans still consult a traditional healer prior to a 'Western/orthodox' HCP, then we need to sensitively view this right in terms of our many cultures and traditions.

Be referred for a second opinion

Everyone has the right to be referred for a second opinion on request to a health provider of one's choice.

Unfortunately this right seems enigmatic. Only a small percentage of the population (middle-class) patients have the knowledge that there is what is called, 'second opinion and/or referral'. The great majority of South Africans using public hospitals cannot fathom raising questions concerning their prescribed diagnosis or treatment. Most patients seeking healthcare in public hospitals either concede to the 'prescribed' treatment, seek another healthcare facility which might offer a different choice, opt for traditional healers, or simply abscond from the healthcare system. Additionally, the right to a second opinion infers that there is another HCP available, or that arrangements can be made to transport the patient to another facility where a HCP is available. With delays in patient transport and inter-facility communication, many obstacles to implementation of this right are present. This right therefore levels a serious obligation towards HCPs to serve as reliable and loyal advocates of their patients who can assist them in making this choice for second opinion or referral – a task that might prove onerous given the shortage of HCP in public sector hospitals. Referral in itself is beneficial in a healthcare system that is functional, but in a system that is faced with a myriad of operational problems, it can be a serious challenge.

Continuity of care

No one shall be abandoned by a healthcare professional worker or a health facility which initially took responsibility for one's health.

On the face of it, this right seems to be encouraging to patients. However, given the myriad of difficulties faced by the healthcare system, it may be challenging if not impossible to realise this right at this time. Perhaps it would have been prudent for the NDoH to have added something like: 'if possible or preferably'. It is doubtful if many of the patients even remember the HCP who initially took responsibility for their healthcare. With the lengths of internships, and the general movements of HCPs in and out of public healthcare facilities, continuity of care is a right and an ideal we should all strive for, but at this time, it is not realised.

Complain about health services

Everyone has the right to complain about healthcare services and to have such complaints investigated and to receive a full response on such investigation.

Twelve years after the launch of the PRC in 1999, it does not seem this right has been taken seriously by both patients and health authorities. Based on what is reported in the newspapers daily, if patients complained about health services and these complaints were investigated, government would be inundated with cases of negligence, law suites, and so forth. Empirical studies³³ persistently point to a lack of a national uniform and coordinated complaints management system. The National Department of Health therefore recently launched the National Complaints Management Protocol for the Public Health Sector of South Africa (May 2013). This should have a positive impact on the rights of patients to complain.

The main objective of the protocol is, according to the NDoH Office of Health Standards Compliance, to ensure that, in setting up a National Complaints Protocol, the perspective of both the complainant and the public health sector should be considered, i.e. the health sector must be clear on why they need a protocol and it must be understood why

³³ London, *et. al.*, (2012). Filling the gap: A learning network for health and human rights in the Western Cape, South Africa. Human Rights Watch, 2011, "Stop making excuses", accountability for maternal health care in South Africa. Sebokedi L.M. 2002. Patients' Rights Charter: The impact on the quality of care.

complainants make their grievances known (National Department of Health, Office of Health Standards Compliance, May 2013).

7.4. Patients' Responsibilities.

Ten patients' responsibilities are mentioned in the PRC as follows:

- "Taking care of one's health
- Protecting and caring for the environment
- Being respectful of the rights of other patients as well as healthcare providers
- Taking care of health records such as clinic or hospital cards
- Providing healthcare providers with relevant and accurate information for diagnosis, treatment, rehabilitation and counselling
- Complying with prescribed treatment and/or rehabilitation requirements
- Obtaining knowledge about local health services
- Enquiring about costs of treatment and rehabilitation and making appropriate payment arrangements
- Not to abuse the health care system but to use it properly
- Advising health care providers with regard to his/her death." (PRC, 1999)

Focus group interviews from the CHBH Ethics Audit (2001), however, identified that patients infringe on the rights of other patients and HCPs. For example, theft of hospital property such as blankets, linen and medicines by patients was reported by both patients and HCPs. Theft of hospital property is also of great concern and impacts on society as replacements are costly both morally and fiscally. One only needs to look at news reports on hospital conditions to see how conditions in many developing world hospitals are dire. This has partially been due to mismanagement and the inability of ordinary citizens to accept that they have a responsibility to care for their healthcare facilities. It is fitting that along with rights concurrently there are duties or responsibilities. Media reports³⁴ have pointed out that some patients on Antiretroviral (ARVs) therapy, after collecting their

³⁴ Chinouya, *et al.*, (2014). 'Some mix it with other things to smoke': Perceived use and misuse of ARV by street thugs in Tshwane District, South Africa. *Daily News* 4 January 2012, SA high on list of drug traffickers. *SABC News* 14 July, 2015. *Pretoria News* 12 August 2013. Drug thugs rule Pretoria CBD.

monthly supply, sell them to drug lords who use them to manufacture illicit drugs. This is self-destructing since the patient will not be taking her treatment, thus her disease condition will deteriorate leading to premature death. Additionally, this impacts on society as the drug-trade increases.

Government can do everything in its power to ensure that patients' rights are realised and enforced, but the patients also have to play their part. The issue of patient's rights calls for a mutually beneficial relationship between healthcare establishments and patients based on respect. However, in view of the ongoing violations of patients' rights in public healthcare facilities and hospitals, this study suggests that there should be an emphasis on the duties and obligations that all citizens (with a special focus of HCPs) have to ensure the enhancement of the Constitution and, in particular, the Bill of Rights. These are included in the Recommendations section in the final chapter.

7.5. Concluding remarks

In this chapter the PRC is revisited showing that while of good intent, that a great amount of work is needed before the rights outlined can be realised. Education of patients and HCPs may be the key to realisation of the PRC. The rights as presented in the PRC are grounded in respect for persons. Overall, the rights are practical and can be used by both HCPs and patients to promote and enhance HCP-patient relationships, particularly because they conform to South Africa's Bill of Rights. All of the patients' rights share a common ground in the quest for an educated, respectful, dutiful and honourable society, promoting the dignity and well-being of all citizens.

Chapter 8

Conclusions and Recommendations

8.1 Introduction

It is clear from this study that the violation of patients' rights in South Africa's public sector hospitals has affected people in a way that should not be ignored. South Africa is a signatory to the International Covenant on Economic, Social and Cultural Rights. In addition to this formal commitment, South Africa has entrenched socio-economic rights as justiciable rights in the Constitution (Act, 108 of 1996), enshrined in the Bill of Rights. Other measures, including the creation of domestic human rights institutions such as the South African Human Rights Commission and the Constitutional Court to have been put in place. It is, however, disheartening to note on a daily basis how generalised patients' rights violations have become. This appears particularly true in public hospitals where the poorest and most vulnerable people in the country seek healthcare services. For example, in August 2011 Human Rights Watch (HRW) reported:

The verbal and physical abuse, denial of care, neglect and delays, and some cases of treatment without informed consent that patients experienced in Eastern Cape public health facilities, sometimes for extended periods of time (especially during the particularly vulnerable periods immediately before, during, and after childbirth when women are under the control of health facilities) can amount to cruel, inhuman, or degrading treatment (HRW, 2011: 61).

In this final chapter the reports, case studies, and documents highlighted in earlier chapters are engaged with further for the purpose of developing a possible way in which the PRC can be enhanced within the South African healthcare system. A strategic policy framework for the effective implementation of the PRC is developed and suggested. The recommendations encompass both policy and process dimensions.

8.2 Policy Frameworks

Despite the many initiatives that have been taken to advocate, develop and emphasise patients' rights, it appears that much of this effort has been in vain. As Legemaate (2002: 723-724) observed: "it is quite evident that the existence of legislation, case law or charters in the area of patients' rights does not guarantee that these rights are or will be successfully implemented in everyday practice."

The report by London, *et al.*, (2006), *Operationalising health as a human right: monitoring tools to support implementation of the Patients' Rights Charter in the health sector* included wide-ranging recommendations to the NDoH. Some of these included ways to "improve management capacity, style, and systems aimed at building trust both within and outside of the healthcare system" (2006: 122-124). The report identified three areas which hold potential for further development: "(1) broad management strategies, (2) technical inputs or interventions, and (3) areas specific to the PRC" (*ibid*). Despite advances made in each of these areas, six years after the study infringement and violation of patients' rights continue unabated.

Speaking at the NDOH quality seminar (November 2012), the Director-General for Health, Ms Precious Matsoso, said:

Lack of infrastructure and the long distances to hospitals are two of the challenges faced by rural communities and communities in informal settlements that have to be addressed. Patients from these communities could use the last of their money to travel to a hospital, only to be told they have to come back the following day, due to lack of resources (commonly medicine). Those people then have to borrow money so that they can travel back to the hospital the next day.

The implementation of patients' rights requires specific actions, expertise and community input (community participation). This is critical because it allows the voice of the community to be heard in policy negotiations and/or development (Friedman, 2006: 12-13). The ideas

to have a constructive dialogue with all key stakeholders. For example, Legemaate (2002: 723) argues, “since it has been shown that legal interventions, such as legislation, will always have to be embedded in and/or supplemented by non-legal policy measures” he advocates for a “broad and well-considered implementation policy, including items at various levels i.e. legislation, patients and patients’ rights organisations, health providers and health institutions, contextual conditions”. Such a strategy, according to Legemaate (ibid), “calls for a multidisciplinary approach, involving input from the areas of law, ethics, medicine, the sciences, etc.”

London, *et. al.*, (2006) present another position. “The best strategies to strengthen the implementation of the Charter will be generated through discussion among those working within the health system rather than imposing a simple tool to support implementation, which would ignore the dynamic role of relationships and “software” within the health system” (p. vii). This ‘software’ intervention as described by London, *et al.*; is “... the one that addresses issues such as management styles, communication approaches, values and organisational culture as a framework to be used to ensure better understanding of the Charter as opposed to the ‘hardware’ intervention” (2006: vi-vii). The ‘hardware’ intervention refers to “legal frameworks, structures, organisational charts, resource allocation and technical skills development” (ibid). Because the PRC is not a legal document, there is no way in which it can be legally enforced. The rights and responsibilities of patients are dependent on the goodwill of the government, community, patients, HCPs, hospital and healthcare facility administrators, clerks, suppliers, and so forth moving in tandem towards its realisation.

If one takes the analogy of the housing policy and relates it to the implementation of the PRC, it seems the same mistake may be repeated by addressing issues relating to patients’ rights which may not necessarily be of any consequence to the most vulnerable communities. The sense that one gets is that for effective and successful implementation of the PRC, there has to be a consultative process of broad-based stakeholder engagement, based on trust, respect and commitment, in an atmosphere that is non-confrontational.

The question is, how do vulnerable communities view the PRC? Is it meaningful to them? Recognising there is a consistent gap between various policies and the preferences of the most vulnerable in our society calls for increased dialogue. Friedman (2006: 12) states this:

Research and observed behaviour over the past decade has revealed a consistent gap between anti-poverty policy and the preferences of the poor. Research finds that years were spent finding ways to offer poor people something they did not want (Friedman 2006: 12).

Cognisant of all the studies conducted by various experts in South Africa with recommendations of various magnitudes and approaches to the implementation of the PRC in South Africa (as discussed earlier in this study), the recommendations in this study focus on both 'software' and 'hardware' interventions, as defined by London, *et. al.*, (2006).

8.3. Proposed Approaches:

8.3.1 Community Participation

There are many debates about the usefulness of a 'structured' consultative process between government and the public. Friedman (2006) in writing about representativeness between government and the public, highlights "that the structural problems inherent in identifying a single organisation, which could claim to represent large and diverse social constituencies (let alone entire communities), were evident in the manner in which participants were chosen by a government ministry charged with reconstruction and development" (Friedman 2006: 13). According Friedman, "while this is hardly a recommended method of ensuring inclusive participation, it is difficult to imagine an alternative, which would ensure even a semblance of representativeness" (ibid). The processes and planning involved in community participation is a valid point when introducing any new idea. However, as noted, it relies on sensitive and careful analysis of the communities. Although there are hurdles to overcome, community participation when successful; certainly represents a positive step towards 'participative democracy'. The community-based HIV Counselling and Testing (HCT) Campaign is an excellent example of

this. In 2010 the NDoH launched a community-based HIV and Counselling and Testing (HCT) Campaign. The goal was to test 1.5 million (annually) South Africans for HIV, TB, hypertension and diabetes. This community-based approach was expected to assist in improving health-seeking behaviour, as the testing is accessible beyond the traditional health systems setting. This project was one of the NDoH's key priorities in the reorganisation of health services, i.e. making interventions and programmes available in the community (Department of Health, Annual Performance Plan 2011/12-2013/14). This campaign involved a wide range of stakeholders, for example, the NDoH, provincial health departments, CSOs, NGOs, traditional leaders, communities, etc. This campaign was hailed as a huge mobilisation campaign in terms of community participation.

This campaign has brought about massive changes in how the HIV and AIDS programme is run in South Africa by virtue of working closely and collaboratively with communities. From its inception in 2010 to date, 20 million people have been tested for HIV infection and 1.7 million people have been put on antiretroviral treatment (Personal communication with Dr Thobile Mbengashe, then Chief Director: HIV and AIDS at the National Department of Health, South Africa, 8 January 2013).

It is against this background that this study suggests that the development of a strategic plan for the effective implementation of the PRC also must involve communities. The idea is to have a strategy that is both robust and resilient. A policy is considered robust when it keeps performing well under different possible perceptions of the problem, the system and alternate future development. Resiliency is "the capacity of individuals, organisations and nations to survive and thrive amidst ongoing change, disruption and adversity" (Rutter, 2000: 651-658). Stakeholder involvement increases the robustness of the preferred policy (ibid).

According to Rutter (2000: 653), three types of rationales are commonly cited in literature in favour of stakeholder involvement in policy decisions: "a democratic, a substantive, and a pragmatic rationale". The substantive rationale, which has bearing on community involvement, is based on the idea "that relevant expertise is not limited to professionals and

public officials, and that participation of stakeholders will provide essential information and insights” (Bijlsma, *et. al.*, 2007: 2-5). Successful stakeholder participation in policy analysis leads to the formulation of more robust policy.

8.3.2. Cooperative and adversarial models

South Africa has spent the last 21 years dealing with a legacy of poor and inequitable access to healthcare. Hence, as a way to recommend the effective implementation of patients’ rights based on this study, a co-operative model as opposed to an adversarial one is suggested. When a co-operative model becomes a standard in human and patients’ rights advocacy, respect for patients’ autonomy follows. The adversarial model, on the other hand, introduces the ‘us’ and ‘them’ notion, i.e. patients vs. HCPs. The key in this regard is engaging in a constructive dialogue between all key stakeholders, public and private sectors, civil society organisations, communities, health rights advocates, and so forth. “Critically important is the fact that one cannot determine which patients’ rights are more important because they are all indivisible and therefore equally important. The caveat in this regard is that it is wise to give leaders a choice to prioritise what needs to be done and this prioritisation has to be rational, i.e. they have to give reasons why this and not that. The key is to allow individuals to give reasons that are scientifically and morally backed as opposed to arbitrary, (Personal Communication with Paul Hunt, then UN Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, August 2004).

8.4. Recommendations

The following recommendations are premised on the conviction that both the infringements and violations of patients’ rights identified from all sources in this work represent broad and interrelated failures of government and its healthcare institutions. The lack of fiscal accountability, results in aspects of healthcare provision being compromised such as linen, medicines and staff (shortages). The failure of service delivery, a point emphasised in the earlier Batho Pele project, appears to be at the root of many other problems in the public

hospitals. One of the major problems is that no effective oversight mechanisms to monitor general healthcare systems and, in particular, the implementation of patients' rights, are in place. Human Rights Watch states this as follows:

... underlying this problem are shortcomings in accountability and oversight mechanisms that authorities use to monitor health care system performance, identify failings and needs, and make timely interventions (Human Rights Watch, August 2011: 2).

Recommendations are presented in the following section:

8.4.1 Recommendations to the National Department of Health (NDoH)

8.4.1.1 Recommendation 1:

The Department of Health should, as a matter of urgency, facilitate the development of a national health strategy for the implementation of the Patients' Rights Charter with a wide ranging Programme of action or Implementation Plan

Health professional associations, organisations and NGOs have an important role to play in contributing to a national public health strategy as well as an associated plan of action that the NDoH has a core obligation to adopt and put in place. The ICESCR General Comment 14 stresses that "authorities should collaborate with civil society, including health experts, in designing the national strategy and in adopting a policy framework that can give effect to it". Since its launch in 1999, the PRC has had no national programme of action and/or an implementation plan – this could be an explanation for the PRC's implementation failures so far.

Key to this envisaged strategy is that all the themes identified by the CHBH Ethics Audit and other findings by various researchers referred to in this study should be used (if the stakeholders responsible for the strategy development are in agreement) to serve as 'strategic pillars/priorities' for the strategy. The strategy must have well-set objectives, indicators, targets to be achieved, activities and measurable outputs with timeframes

(monthly and quarterly) for reporting on progress made as far as the implementation of the PRC at the level of service delivery (provincial and local levels) is concerned. Even in times of resource constraints, governments are required to monitor the extent to which the right to health is realised or not realised, and to devise strategies and programmes for its promotion.

NGOs can contribute to the process of designing and implementing a national public health strategy for the implementation of the PRC including a programme of action by, for example:

- “helping to establish priorities for the national strategy. This might include contributing baseline studies, community-based studies or position papers, or by submitting their conclusions to relevant authorities or for publication in the appropriate professional journals or in the media;
- ensuring that the plan of action takes account of existing gaps in the government’s compliance with its obligations arising from the right to health;
- identifying reasonable steps to close these gaps;
- identifying the resources available to meet government obligations, with emphasis on core obligations, and the most cost-effective way of allocating those resources;
- helping to establish the national targets (benchmarks) to be achieved in relation to each indicator and the time-frame for their achievement;
- participating in monitoring progress to achieve these targets;
- contributing to the design of appropriate policies by which the targets can be achieved; and
- identifying the most cost-effective way of using available resources to attain defined objectives in the strategy and plan of action” (Asher, 2004: 111).

8.4.1.2 Recommendation 2:

Lift the status of patients’ rights to a priority project and make it the fifth output in the health sector’s four outputs stated as: “effective implementation of the patients’ rights charter”

The PRC should receive the same attention as legacy programmes of the Department, for example, the charter should form part of the Negotiated Service Delivery Agreement (NSDA) for top management (national and provincial levels). Experience has demonstrated that once a project becomes the Minister of Health's service delivery agreement, it receives greater attention. An example of this is the HIV and AIDS Counselling and Testing Campaign.

8.4.1.3 Recommendation 3:

The implementation of the PRC should be included in the Monitoring and Evaluation (M&E) System of the NDoH to ensure effective management and monitoring of the implementation of the PRC

Human rights monitoring makes a distinction between *obligations of conduct* and *obligations of result*. Obligations of conduct refer to the state duties that focus on public policy priorities (which government can control immediately and directly). Obligations of result refer to state duties that focus on guaranteeing measurable outcomes, which may be influenced by many different factors, such as economic factors. Monitoring and evaluation should be used to identify areas of failures and weaknesses, with prompt remedial action.

8.4.1.4 Recommendation 4:

Create a directorate for patients' rights at both national and provincial levels

This newly established directorate would work with the Office of Standards Compliance (OSC) at the NDoH. The Department through its OSC has decided to contribute to strengthening the health system by enhancing public accountability through enforcing mandatory compliance to a set of national standards and norms and linking this compliance to the requirements for NHI in the long-term funding. These newly (when established) created directorates could leverage their work on the realisation of patients' rights to the compliance standards of the OSC in the Department.

8.4.1.5 Recommendation 5:

Provision of adequate and appropriate resources (human and material) in all hospitals and healthcare facilities need to be acted upon as a matter of high priority

The reports and resources used in this work demonstrated that the origins of the problems relating to patients' rights abuse and/or violations are complex. They may be identified in the poor conditions at the workplace, such as a shortage of staff, medicines, food and linen. It might prove difficult if not practically impossible for HPCs to protect, promote and respect patients' rights without these necessary means (resources). With increasing (e.g. HIV and AIDS admissions) numbers of very sick patients likely to become dependent on and dying in public hospitals, the demographics of such hospitals will increasingly take on a shape unlike that of hospitals in the past or in other parts of the world. It is the researcher's conviction that excessive workloads, shortage of staff, medicines, linen, food and non-functional equipment, compounded with unsafe working conditions and inadequate support by management can be considered forms of violations of patients' rights and are thus incompatible with good practice.

8.4.1.6 Recommendation 6:

The NDoH through its Directorate: Health Research and the respective statutory bodies (National Health Research Committee and the National Health Research Ethics Council) should facilitate and promote research and development, as well as public health research innovation on issues and policies concerning the implementation of patients' rights and best practices related to the promotion of patients' rights locally and internationally. Research should also focus on policy for public participation and/or community participation.

One of the social determinants of health is the creation of diffusion of knowledge. South Africa finds itself in the era of the knowledge society. There is a growing body of evidence showing that knowledge represents one major driving force for health progress. Research is a value in itself, an essential part of culture. Knowledge has an instrumental value as a means to improve health and is translated into evidence that provides a scientific foundation

for advocacy and decision making both in the delivery of health services and in formulation of public policies.

Despite all the best pieces of legislation (the Constitution (1996) and the PRC (1999) South Africa is yet to adopt a policy on how to engage communities to have a full say in the services they expect from government. Simply having democratic legislation without effective action, i.e. plans of action, will not make the realisation of the ideals enshrined in these documents a reality and this defeats the good spirit in which the Constitution was crafted. It is therefore critical that the Department provides leadership and support and appreciates the valuable role research experts can play in the effective implementation of the PRC by, for example, researching other models used to enhance the implementation of the PRC in other critical research areas, such as - Recommendation 7: “Create more community awareness of patients’ rights and responsibilities”, which are applicable to all groups of the population, in particular the vulnerable, children, women and the disabled and poor members of society.

The application of human rights protection should focus on vulnerable groups such as women, children, the elderly, refugees and stigmatised groups. All efforts directed at the enhancement of the implementation of the PRC must first consider these groups, since studies have shown that their rights are violated most severely in public hospitals and they commonly suffer abuse (verbal and physical). To this end, sanctions should be adopted that reflect the seriousness of any particular incident of the abuse of patients’ rights. Co-operation with other organisations having common goals in the campaign against violence is important. It could be considered to add the following to the patients’ responsibilities as stipulated in the PRC:

8.4.1.7 Recommendation 7:

The application of human rights protection should focus on vulnerable groups such as women, children, the elderly, refugees and stigmatised groups. All efforts directed at the enhancement of the implementation of the PRC must first consider these groups, since studies have shown that their rights are violated most severely in

public hospitals and they commonly suffer abuse (verbal and physical). To this end, sanctions should be adopted that reflect the seriousness of any particular incident of the abuse of patients' rights. Co-operation with other organisations having common goals in the campaign against violence is important. It could be considered to add the following to the patients' responsibilities as stipulated in the PRC:

Additional patients' responsibilities that could be incorporated into the PRC (1999) –

- Ask questions when you do not understand information or instructions. If you cannot follow through with your treatment plan, inform your doctor. You are responsible for the outcomes if you do not follow the care, treatment and service plan.
- Treat all hospital staff, other patients and visitors with courtesy and respect; abide by all hospital rules at all times.
- Report any infringement and/or violation of your rights as a patient to the relevant authorities and/or patients' rights ombudsman (should the recommendation for the establishment of a patients' rights ombudsman at public healthcare institutions be accepted).

8.4.1.8 Recommendation 8

The NDoH should lead the way in the development of a standard complaints management system that is culture-sensitive (in terms of methods of communication, language, etc.)

There must be clear guidelines to patients informing them on how to lodge a complaint when they are of the opinion that their rights have been infringed or violated. The guidelines should lay out the entire complaints procedure and names of appropriate authorities (name, address and contact details) and timelines when they can expect feedback on complaints they lodged. The guidelines should be written in simple language and preferably in all 11 official languages for ease of understanding. Posters, as well as radio and television slots, can be used for this purpose. The State has an obligation to respect, protect and fulfil the right to health. To ensure that these obligations are upheld, the NDoH has a duty to:

- Support and guide patients, should they wish to take their cases to court.
- There should be mechanisms for remedy and/or redress through courts, professional bodies, or the proposed ombudsman for health.
- Improve complaints processes and procedures laid down in complaints guidelines written in simple and straightforward language which is understandable, in all official languages (it is preferable that health facilities in areas where many foreign nationals live have multilingual interpreters who could assist them to understand what their rights and responsibilities are).
- Develop systems to assess patterns of complaint and use them to address systemic problems to avoid a recurrence of the problems.
- Create a favourable environment for patients to complain without fear of being victimised.

8.4.1.9 Recommendations 9:

The NDoH should consider the introduction of a transformation officer in all of its healthcare institutions

South Africa has a painful history of racial discrimination, with consequent disrespect for human dignity and rights. Many of the ethical misdemeanours reported at various public hospitals and facilities seem attitudinal rather than originating from the work environment. Attitudes can have a detrimental effect on service delivery. Based on the country's dark history and record of human rights violations, it seems fit that the work force be transformed into professionals of high repute who respect the dignity of the people they serve and the people with whom they serve. Members of the public also have to treat every health provider with respect, as well as treating fellow patients and their families with respect and courtesy. Workshop intervention may be useful in changing the attitudes of currently practising staff. The NDoH must double its actions and/or efforts to eliminate racism in the public healthcare system. The introduction of a transformation officer might go a long way in changing negative attitudes as well as stereotypes in public hospitals and facilities.

8.4.1.10 Recommendation 10

Authorities and/or top management of the NDoH should engage in open forum communication with facility managers and health workers.

Communication is vital for improving morale; HCPs should be given outlets to voice their concerns, and a belief that higher levels are willing to hear them out. “Bottom-up theory predicts that implementers’ expertise in the realities of implementation could offer valuable contributions to policy-makers” (Raphaely, 2009: 69).

8.4.1.11 Recommendation 11

The Department should consider developing and launching specific rights charters, e.g. women in labour, psychiatric patients.

Over and above the general Patients’ Rights Charter launched in 1999, in view of studies such as the one by Maputle & Hiss (2010) – “Midwives’ experiences of managing women in labour in the Limpopo Province of South Africa” discussed in Chapter 5 revealed that women in labour’s rights are either infringed or violated. A report by Human Rights Watch (2011) also reiterated some concerns about maternal health care in South Africa that women during labour were not being treated well. These are reasons enough to consider having such specific rights charters targeting specific groups of patients such as women (pregnancy and labour) as well as people with mental problems. Mental healthcare users are one of the most vulnerable, invisible and forgotten groups of people in our society (<http://www.capementalhealth.co.za/rights.html>, accessed January 18, 2016. According to Cape Mental Health, many of people with mental health problems face physical, sexual and psychological abuse, unfair denial of employment opportunities and discrimination in access to health care and other services (Cape Mental Health, 2016).

8.4.2 Recommendation to the public sector hospitals and other healthcare facilities

Public institutions and facilities should always ensure that any new policies and programmes introduced are communicated and familiarised to all employees. Face-to-face engagement with staff to clarify issues not well conceptualised by staff is a useful exercise. It is also critical that employees are encouraged to voice concerns, frustrations as well as recommendation on new programmes with the aim of improving implementation thereof. It is very likely that when people are not aware of the historical and contextual nature of human rights and are not aware that human rights become realised through the struggles of actual human beings experiencing practical instances of domination, then human rights are all too easily used as symbolic legitimisers for instruments of that very domination (disempowerment).

8.4.2.1 Recommendation 12:

HCPs at all levels should be thoroughly conversant with patients' rights as set out in all relevant documents.

HCPs (including doctors, nurses, pharmacists, technicians, administrators and similar professionals and their professional associations) have an indispensable role to play in the vindication of the right to health. Provided they are equipped with suitable training, they occupy a pivotal position enabling them to promote the right to health and identify alleged violations. Too often, their training encompasses ethics but not human rights. "While ethics are vital, human rights are both vital and binding." (Personal Communication with Paul Hunt, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 2004).

8.4.2.2 Recommendation 13:

Set up help desks in facilities to assist patients who wish to raise complaints.

Support patients in their attempts to assert both their rights and responsibilities by applying humane approaches that minimise conflict between patients and HCPs. This could be achieved by introducing a user-friendly system for lodging complaints and getting feedback without antagonising HCPs, for example, nurses.

8.4.2.3 Recommendation 14:

Establishment of hospital ethics committees in all public health institutions and facilities

The purpose of such a committee would be to encourage a culture of reflection and debate about the complexities of institutional and clinical decision making, and to advise in disputes. If the patient does not get satisfaction from the hospital ethics committee, the patient would be encouraged to seek the help of the health ombudsman (once such a position has been approved by the National Health Council). Ethics committees would help maintain professional practice and conduct through applying disciplinary measures and advice where necessary, this should be done more on colleague approach as opposed to adversarial. The ethics committee should serve as a source of support and guidance for ethical conduct of hospital workers across the board. The Committee should also a disciplinary body for unethical conduct of HCPs when necessary.

8.4.2.5 Recommendation 15:

Repairs, maintenance, replacement or upgrading of equipment is crucial across all of South Africa's public hospitals and facilities in view of aging and outdated equipment

The state of repair of equipment in hospitals, for example, CHBH, Charlotte Maxeke, Steve Biko and George Mukhari represent an indictment on the health sector's commitment to ensure "a long and healthy life for all South Africans" (Guide to Outcome Approach,

2010:13). Outdated equipment and ordering patterns, as well as late payment of service providers who service this equipment appear, to be a very important concern to a wide spectrum of employees.

8.4.3 Recommendations to professional regulatory bodies and professional associations and/or organisations

8.4.3.1 Recommendation 16:

Hospitals should be managed in such a manner that they protect the rights of HCPs (Doctors, Nurses and all Allied HCPs).

No form of abuse and violence against nursing personnel should be tolerated. This could range from passive aggression to homicide and sexual harassment. Such actions violate the right of nurses to personal dignity, integrity and freedom from harm. Yet such violence, including fatal stabbings and rape of nurses on hospital premises and in clinics, has become common in almost all provinces. Within the employment sector, nurses are a category of worker particularly at risk and thus attention must continue to be placed on eliminating all forms of abuse and violence against nursing personnel.

The leaders of both the nursing and medical professions have to acknowledge that deteriorating standards of care in all public health institutions across all categories of health professionals is a serious problem and an indictment to both the medical and nursing fraternity. It is crucial that processes to investigate this further and seek solutions should be embraced by the professional regulatory bodies (Health Professions Council of South Africa (HPCSA), the South African Nursing Council (SANC) and the Democratic Nursing Organisation of South Africa (DENOSA).

The HPCSA, SANC and DENOSA are organisations charged with the responsibility to ensure that doctors and nurses in South Africa deliver services of high standard and quality to all the people of South Africa. If a doctor or a nurse is found guilty of unethical behaviour

or unprofessional conduct, punitive/disciplinary measures should be taken against such a professional without fear or favour.

8.4.3.2 Recommendation 17:

Codes of ethics for doctors and nurses need to be enforced through disciplinary procedures so that health professionals are under no illusion that abuse of patients is sanctioned by higher authorities.

Established patients' rights to respect, promotion of welfare, privacy, confidentiality, informed consent and the like are non-negotiable. There are strong indications that even these basic rights are not practised adequately in health facilities and hospitals. Relevant documents setting out these rights are, for example: the National PRC of the national Department of Health (See Appendix 2), Nurses and Human Rights (International Council of Nurses, 1998) and the Health Professions Council of South Africa's guidelines for good practice in the health care professions (Booklet 3, 2008).

8.4.3.3 Recommendation 18: To the Health Professions Council of South Africa (HPCSA):

Inclusion of work and professional ethics in basic training of health professionals (all categories) to be mandatory at all training institutions.

Studies to assess the implementation of the PRC (1999) by London, *et al.*, (2006) and by Raphaely (2009) as discussed in this dissertation report that health professionals, in particular medical practitioners, admitted to being ignorant about ethics as a concept and a value against which health care is grounded. This is an irony since health professionals are guided by professional codes of ethics in their day-to-day treatment and care for patients. It is unsettling to note that doctors can be said to be 'ignorant' about ethics since the medical

profession is grounded on the Hippocratic Oath. Medical practitioners and nurses are the doyens of treatment and care which is based on the ethics of care and treatment. Admittedly, there are currently various levels of ethics training some in the form of continued professional development, however, the ethics training proposed in this study focuses on basic academic training of all categories of HCPs as mandatory curriculum component.

8.4.3.4 Recommendation 19: To the Democratic Nursing Organisation of South Africa (DENOSA):

Actively sensitise the public and the nursing community to the various manifestations of violence against nursing personnel. In addition to the particular points raised previously:

- Ensure access to counselling services for nursing personnel (victims and perpetrators of violence), including supporting nurses during reporting/compensation and claim procedures.
- Negotiate the introduction and maintenance of appropriate security measures and confidential grievance procedures in the work and learning environments.

Violence in the health workplace threatens the delivery of effective patient services and, therefore, patient safety. If quality care is to be provided, nursing personnel must be ensured of a safe work environment and respectful treatment. Excessive workloads, unsafe working conditions and inadequate support can be considered forms of violence and are incompatible with good practice.

8.4.3.5 Recommendation 20: To the South African Nursing Council (SANC)

Establish required competencies for continued professional development for nurses relating to human rights and patients' rights, and communicate such competencies to all stakeholders.

Nurses have an obligation to safeguard, respect and actively promote people's health rights at all times and in all places. This includes ensuring that adequate care is provided with the

available resources and in accordance with nursing ethics. The nurse is obliged to ensure that patients receive appropriate information in understandable language prior to consenting to treatment or procedures, including participation in research. The use of coercion or manipulation to obtain consent is unethical and constitutes a violation of human rights and professional codes of conduct. Nurses are accountable for their own actions and omissions in safeguarding human rights, while the SANC has a responsibility to participate in the development of health and social policy and legislation related to patients' rights.

8.4.4 Recommendations to Civil Society Organisations (CSOs)

8.4.4.1 Recommendation 21:

Public officials need to be lobbied to adopt legislative reforms to enhance the effectiveness of the PRC.

The CSOs should lobby public officials, such as parliamentarians and government officials (national and local levels), who are responsible for the adoption and implementation of legislation (e.g. legal reforms proposed in Chapter 5). For example, CSOs can lobby for the ratification of the ICESCR and its Optional Protocol by South Africa. In 1994, South Africa signed the ICESCR. By signing the treaty, South Africa indicated its intention to ratify and incurred an international obligation not to act contrary to the object and spirit of the treaty (ICESCR Ratification Campaign Driver Group, 12 October 2012). However, South Africa has since failed to ratify the instrument. States that ratify human rights treaties freely agree to assume responsibility for guaranteeing that people can enjoy the benefits of the right to health. It is therefore the job of CSOs to hold them to this responsibility.

The right to health and as a consequence, patients' rights, is relevant to the everyday lives of ordinary people and is therefore relevant to CSOs, because it is often their work that promotes and protects the health of individuals, local communities and poor, vulnerable, or otherwise disadvantaged groups.

For example, the Qwasha Project (Qwasha) engaged in climate justice dialogues that were made available as a sound compilation. This is essentially a series of ‘pavement broadcasts’ made on the streets, based on audio conversations, recordings of songs, life stories and interviews by the Qwasha collective-in-the-making. This approach proved useful to the extent that no two interviews were responded to in the same manner; hence a great variety of responses and perceptions were generated (Ndlovu, 2013: 180). The same approach/strategy could be used for socio-economic justice dialogues, aimed at the implementation of patients’ rights.

8.4.4.2 Recommendation 22:

Lobbying with government for the introduction of a patient or health rights ombudsman.

Civil society organisations should consider lobbying for the introduction of a patient or health rights ombudsman to protect and enforce the right to health (including patients’ rights) in South Africa as a matter of urgency, given the current state of patients’ rights violations in the country’s public health institutions. South Africa’s Constitutional Court cases on socio-economic rights discussed in Chapter 2 serve as strong evidence of the usefulness of engaging CSOs and NGOs in advocating for human rights broadly and patients’ rights in particular. The establishment of the office of a health ombudsman can go a long way in furthering legal action and seeking remedies for victims of violations. In this way, CSOs could hold government accountable by taking cases to court and ensuring redress.

8.4.4.3 Recommendation 23:

Carry out vigorous communication campaigns

Communication campaigns could include, but are not limited to radio, television, or newspaper campaigns, poster campaigns and public meetings, which are especially important where populations are functionally illiterate. According to Johannesen (2013: 32), previous research has shown that “mass media is the key source of information and the

main factor in shaping people's awareness of climate change". The same can be assumed about mass media's influence on people's awareness about socio-economic rights including patients' rights.

8.4.4.4 Recommendation 24:

Mobilise the public by promoting civil action, including letter-writing/e-mail campaigns, petitions and public demonstrations. Such civil action might be directed at the remedying of specific violations or the introduction of mechanisms to protect and enforce the right to health, by way of patient advocates (not necessarily a legal professional but a health professional with extensive experience in healthcare-related issues).

With an expansive Constitution, mobilised activism has often involved litigation in what has been referred to as the 'legal-activist' approach. In the well-known case of the TAC, activists mobilised around the right to health and mounted a successful legal challenge against the government's policy of restricting to pilot sites the provision of antiretroviral medication to pregnant mothers (to prevent mother-to-child transmission of HIV and AIDS) to pilot sites.

8.4.5 General Recommendations

8.4.5.1 Recommendation 25:

Embark on social transformation directed to meeting basic human needs and rights (environmental and social justice).

Involvement of communities in education programmes concerning their rights and responsibilities concerning what they consider important as basic needs as opposed to their desires or wants will promote an awareness of various approaches to social justice.

Environmental justice is seen by Cock (2004: 4) as a platform that holds the potential to collectively mobilise and vindicate unsatisfied social needs.

8.4.5.2 Recommendation 26:

Encourage government to respect, promote, protect and fulfil patients' rights. There is a need for increased vigilance, and for public to be informed about how new technology and experimentation can violate their rights as patients. Government should always be reminded about the obligation it has to respect, protect and fulfil patient's right to health care. Public television and radio stations should be used as platforms for disseminating such information, government institutions should develop pamphlets and posters that raise awareness in this regard. Government should develop a wide range of programmes targeted to enhance government's efforts in ensuring the realisation of patients' rights.

8.4.5.3 Recommendation 27:

Support educational institutions to introduce formal training with regard to professional conduct and work ethos

Various studies presented in this dissertation have shown that it is of great concern that health professionals stress their rights more than those of their patients. While it is true that health professionals also have rights, education concerning the asymmetrical power relationships that exist within the nurse-patient relationship will assist nurses in understanding and prioritising patients' rights over their own. A constant reminder is needed to HCPs to highlight that their professional conduct and practices might go a long way to reduce unprofessional behaviour or conduct that amounts to 'abuse' or 'violation' of patients' rights.

8.4.6 Recommendations: To the Courts

8.4.6.1 Recommendation 28:

The Courts should introduce transformative approaches to socio-economic rights litigations.

The fulfilment of the transformative potential of socio-economic rights will depend in part on the willingness of South African judges, practitioners and other participants in “socio-economic rights litigation to revisit and refashion many traditional concepts of liberal legalism that inhibit creative, innovative responses to socio-economic rights claims“ (Liebenberg, 2010: 36-37).

8.4.6.2 Recommendation 29:

The courts should develop a notion of rights that is empowering and recognises people’s agency in relation to the definition and meeting of their needs.

Liebenberg (2010: 53) argues that the courts should avoid interpreting socio-economic rights in ways that position claimants as passive objects of state bureaucracy. This requires a consideration of the context both of the rights themselves and the circumstances in which particular groups allege a violation of their rights.

8.5. Conclusion

The UNDHR (1948) recognises the inherent dignity and the equal and unalienable rights of all human beings and, in this way, it has been instrumental in enshrining the notion of human dignity in international law, providing legal and moral grounding for improved standards of care (WHO, 2003). The notion of patients’ rights was developed on the basis of this view of the person or individual. Human rights provide a principles alternative to the growing discourse of ‘patients’ rights that has evolved in response to widespread and severe human rights violations in health settings (Cohen and Ezer, 2003: 7).

The democratic government in South Africa ushered an arena that is underscored by a human rights approach, as evidenced by the Constitution of the Republic of South Africa (Act, 108 of 1996) with the Bill of Rights. In South Africa health care is a right of all individuals. It must be available, affordable and culturally acceptable, regardless of financial, social, political, geographic, racial or religious considerations. This includes the right to refuse treatment or nourishment, the right to be treated with respect, the right to informed consent, including being free of non-consensual medical treatment, and the right to confidentiality and dignity, including the right to die with dignity and to be free from pain, torture and other cruel, inhumane or degrading treatment. Health is a social value for which all sectors are responsible and accountable.

Instead of the humane and appropriate healthcare expected, patients and HCPs in the country's hospitals, in particular public institutions, encounter a range of abuses that disrespect basic human dignity and jeopardize health outcomes. The abuses range from pervasive violations of patients' rights to informed consent, confidentiality, privacy and discrimination. In the same vein, this study recognises HCPs as important actors, whose rights must be respected both as a matter of principle and for the benefit of the patient. The importance of a cordial and mutual relationship between patient and provider rights cannot be over emphasised. Providers are unable to provide high-quality care unless their rights are respected and they can work under decent conditions, such as a safe and secure work environment, and an acceptable staff complement with adequate medicines and linen.

What the South African health system needs today, is to search for what Julio Frenk (quoted by Sepúlveda, *et.al.*, 2006) calls the "diagonal"³⁵ – a strategy in which explicit intervention priorities are used to drive the necessary improvements into the healthcare system (Sepúlveda, *et. al.*, 2006: 2017-2027).

³⁵. According to Sepúlveda (*ibid*), the importance of the "diagonal approach" is *integration* and *coordination* between vertical interventions and community-based initiatives and health facilities or extension services.

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AAPPENDIX 1

PERMISSION TO USE DATA FROM THE CHBH ETHICS AUDIT



Tel: (011) 933 8145
Fax: (011) 933 1961
Cell: 083 395 3933
E-mail: chbara@mweb.co.za

*Office of the CEO
Chris Hani Baragwanath Hospital
P O Bertsham
JOHANNESBURG 2013
October 1, 2001*

The Operations Director
Ethics Institute of South Africa
P O Box 2427
BROOKLYN SQUARE 0075

Dear Ms. Nevutalu

PERMISSION TO USE ETHICS AUDIT MATERIAL FOR PHD

Your letter in this regard refers.

Thank you for requesting authorization to use information obtained from the ethics survey at Chb. I have no contradiction to your use of the information and I wish you well in your further studies.

Best wishes

Yours sincerely,

A handwritten signature in black ink, appearing to read 'R. J. Broekmann', written over a horizontal line.

Dr. R. J. Broekmann
Chief Executive Officer
/Ethics

APPENDIX 2

NATIONAL PATIENTS' RIGHTS CHARTER (1999)



Your right to dignity

PATIENTS' RIGHTS

Every patient or client has the following responsibilities:

- to take care of his or her health.
- to care for and protect the environment.
- to respect the rights of other patients and health providers.
- to utilise the health care system properly and not abuse it.
- to know his or her local health services and what they offer.
- to provide health care providers with the relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purposes.

- to advise the health care providers on his or her wishes with regard to his or her death.
- to comply with the prescribed treatment or rehabilitation procedures.
- to enquire about the related costs of the treatment and/or rehabilitation and to arrange for payment.
- to take care of health records in his or her possession.

This Charter is subject to the provisions of any law operating within the Republic of South Africa and to the financial means of the country.

Private Bag X828, Pretoria. 0001.
For further information call: (012) 312 0018

DEPARTMENT OF HEALTH



DEPARTMENT OF HEALTH

Patients' Rights

EVERY PATIENT HAS THE RIGHT TO:

A healthy and safe environment
 Everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal, as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection.

Participation in decision-making
 Every citizen has the right to participate in the development of health policies and everyone has the right to participate in decision-making on matters affecting one's health.

Access to health care
 Everyone has the right of access to health care services that include:

i. receiving timely emergency care
 at any health care facility that is open regardless of one's ability to pay;

ii. treatment and rehabilitation
 that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;

iii. provision for special needs
 in the case of newborn infants, children, pregnant women, the aged, disabled persons, patients in pain, persons living with HIV or AIDS patients;

iv. counselling
 without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV/AIDS.

v. palliative care
 that is affordable and effective in cases of incurable or terminal illness;

vi. a positive disposition
 displayed by health care providers that demonstrate courtesy, human dignity, patience, empathy and tolerance.

vii. health information
 that includes the availability of health services and how best to use such services and such information shall be in the language understood by the patient.

Knowledge of one's health insurance/medical aid scheme
 A member of a health insurance or medical aid scheme is entitled to information about that insurance or medical aid scheme and to challenge, where necessary, the decisions of such health insurance or medical aid scheme relating to the member.

Choice of health services
 Everyone has the right to choose a particular health care provider for services, or a particular health facility for treatment provided that such choice shall not be contrary to the ethical standards applicable to such health care providers or facilities, and the choice of facilities in line with prescribed service delivery guide lines.

Be treated by a named health care provider
 Everyone has the right to know the person that is providing health care and therefore must be attended to by clearly identified health care providers.

Confidentiality and privacy
 Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or an order of court.

Informed consent
 Everyone has the right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment, and the costs involved, for one to make a decision that affects anyone of these elements.

Refusal of treatment
 A person may refuse treatment and such refusal shall be verbal or in writing provided that such refusal does not endanger the health of others.

Be referred for a second opinion
 Everyone has the right to be referred for a second opinion on request to a health provider of one's choice.

Continuity of care
 No one shall be abandoned by a health care professional worker or a health facility which initially took responsibility for one's health.

Complain about health services
 Everyone has the right to complain about health care services and to have such complaints investigated and to receive a full response on such investigation.

APPENDIX 3

MISSION STATEMENT OF THE CHBH



CHRIS HANI BARAGWANATH HOSPITAL

MISSION STATEMENT

Chris Hani Baragwanath Hospital strives to:

- Achieve the highest level of patient care based on sound scientific principles and administered with empathy and insight.
- Train our work force to be the best equipped and motivated to serve the sick and injured.
- Maintain and defend truth, integrity and justice for all, at all times, to the benefit of patients, staff and the community.



life support equipment. Medical equipment, not under private maintenance contact is sent here for repair and servicing.

ORTHOPAEDIC CENTRE

The success of orthopaedic appliances or artificial limbs depends on the skill of an individual craftsman. This unit is a recognised training centre for students training as Prothetists/Orthoptists. The unit handle approximately 15 000 patients per year.

HOSPITAL LAUNDRY

The Chris Hani Baragwanath Laundry is considered as the largest single laundry in the country. It handles a staggering 1 500 000 items of washing per month. The current output is approximately 32 000 items per day.

Should you require any additional information about the hospital you may write to:

The Chief Executive Officer
Chris Hani Baragwanath Hospital
PO Bertsiam
2013
South Africa.

If you are a student and wish to do an elective period at Chris Hani Baragwanath Hospital you may write to:

University of the Witwatersrand,
Faculty of Health Sciences
7 York Road
Parktown
2193
South Africa

Or you may access our Webpage on:
www.chrisibanbaragwanathhospital.co.za

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2013

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DEPARTMENT OF NURSING

Despite staff and supply shortages, the high standards of care and training, constant dedication and unwavering enthusiasm of this department was kept at a high and professional level. Bara provides training for nurses at all levels of the nursing sciences, for both basic and post basic qualifications.

PHARMACY DEPARTMENT

The Pharmacy Department at Chris Hani Baragwanath Hospital is academically linked to Potchefstroom University and the University of the Witwatersrand. The speciality services rendered include: Total Parenteral Nutrition, Oncology, Therapeutic Drug Monitoring and Ward Pharmacists.

ALLIED MEDICAL SERVICES

PHYSIOTHERAPY
Physiotherapy is a service in which disease is treated through: Electrotherapy, Manual Therapy, Hydrotherapy, Exercises and Respiratory Modalities.

OCCUPATIONAL THERAPY
The main treatment method in this department involves participation of clients in purposeful activities which are relevant to their needs in daily life. The unit comprises three sections: Adult physical disability, Psychiatry and Paediatric disability.

SPEECH THERAPY & AUDIOLOGY
In this department management involves the diagnosis and treatment of communicatively disabled people. A community orientation programme has been adopted, which aims to increase awareness of communication problems, by training teachers, community health workers and parents.

SOCIAL WORK
The social worker is involved with the patient's psychosocial treatment. All spheres of the patient's needs are attended to, be it professional counselling for the patients and his/her relatives, or financial problems.

HUMAN NUTRITION
The Department of Human Nutrition prepares approximately 10 000 meals per day, and is divided into two sections: Clinical Dietetics and Food Service Management. This department's ultimate goal is to provide optimal nutrition to all patients through the combined effort of the clinical dietician and foodservice manager.

DEPARTMENT OF ADMINISTRATION

The Department of Administration is divided into three main sections: Finance, Human Resources and Patient Affairs & Auxiliary Services. Each of these sections are again divided into its own sub-sections

MEDICAL EQUIPMENT CENTRE

This department provides a specialist maintenance service for

life support equipment. Medical equipment, not under private maintenance contact is sent here for repair and servicing.

ORTHOPAEDIC CENTRE

The success of orthopaedic appliances or artificial limbs depends on the skill of an individual craftsman. This unit is a recognised training centre for students training as Prothetists/Orthoptists. The unit handle approximately 15 000 patients per year.

HOSPITAL LAUNDRY

The Chris Hani Baragwanath Laundry is considered as the largest single laundry in the country. It handles a staggering 1 500 000 items of washing per month. The current output is approximately 32 000 items per day.

CHRIS HANI BARAGWANATH HOSPITAL

INTRODUCTION

The hospital's name, Chris Hani Baragwanath was derived from two people. John Albert Baragwanath was a Cornish immigrant who settled in these parts during the late 1800's, and Chris Hani, a former South African freedom fighter, who was assassinated in April 1993.

Chris Hani Baragwanath Hospital is situated to the south west of Johannesburg, on the southern border of Soweto. The hospital grounds cover an area of 173 acres, and was recorded in the 1997 edition of the Guinness Book of Records as the largest hospital in the world.

Bara is one of 40 provincial hospitals in the Gauteng Province, which is financed and run by the Gauteng provincial authorities.

When it was opened in 1948, as a civilian hospital, it had 480 beds. The hospital has since grown to 3 400 beds. At present (2001) though, only 2, 600 beds are being used.

The hospital has a total staff establishment of $\pm 5\ 000$, and serves the Soweto community, and surrounding areas.

Being a specialist hospital, referrals for consultant treatment are received from all over the country, as well as from the surrounding African States.

Baragwanath is a training hospital for nurses, with a nurses college on the premises. It is also considered the largest teaching hospital associated with the Medical School of the University of the Witwatersrand. The hospital and the university jointly offer undergraduate and postgraduate medical training.

For the financial year 2001/2002 the hospital budget amounts to R766 995 823, and it is essential that the hospital authorities stay within this estimate in running the hospital.

CASUALTY & OUT-PATIENTS

The Casualty, Out-Patients & Short Stay Unit are functioning under continuous stress due to the high traffic experienced, and the unique & severe trauma cases seen here on a daily basis.

Although there was a decrease in patient numbers since the implementation of longer hours at the primary health care centres in Soweto, this department still handles an average of 300 patients per day. This number often doubles during weekends.

OBSTETRICS & GYNAECOLOGY

The hospital acts as referral centre to the community health clinics for all complicated cases seen, especially complications detected during pregnancy.

About 35 000 babies are born at Baragwanath and the Soweto Health Centres every year. This constitutes 25% of all babies born in all regions north of the Vaal River.

During 1997 Bara was chosen by the UNAids as one of nine sites world-wide where HIV/AIDS research is being conducted in the international search for an Aids vaccine.

All pregnant women undergo consented tests for HIV/AIDS, and, if found positive, will be referred for counselling and treatment. At present (2001) about 29% of the test group are found to be HIV positive.

DEPARTMENT OF PAEDIATRICS

The Department of Paediatrics is responsible for the medical care of neonates, and children up to the age of 12 years. The department's responsibilities can be divided into: **an ambulatory paediatric service, an inpatient service and a neonatal service**

The department also runs the MRC/University Mineral Research Unit which focuses on metabolic bone disease of particular relevance to the people of South Africa. The unit is funded by grants from the South African Medical Research Council and the University of the Witwatersrand.

BURN UNITS

(Johnson & Johnson Burn Treatment Centre)

More than 250 adult patients, and as many children, are annually admitted to Baragwanath Hospital with severe burns.

During 1991, the Johnson & Johnson Group of Company's provided the hospital with a R3 million ultra modern burn treatment centre.

The unit comprises, inter alia: Operating theatre & associated facilities, Skin care laboratory, Intensive treatment rooms and Dressing rooms with hydro-therapy baths for physiotherapy

DEPARTMENT OF MEDICINE

The Department of Medicine is the largest department in the hospital, with over 800 beds. They admit in excess of 2 500 patients and attend to over 7 000 outpatients per month.

Some of the units functioning within this department are:

RENAL UNIT

The Renal Dialysis Unit at Chris Hani Baragwanath is the largest single unit of its kind in Africa.

The unit comprises of: Acute Haemodialysis, Chronic Haemodialysis, Peritoneal Dialysis (PD), Inpatient services and Outpatient services

GASTRO-ENTEROLOGY UNIT

The Gastro-enterology Unit was founded in 1975. During the following 25 years the unit has established itself as one of the major gastro-enterology units in Africa. It is the only centre in Africa where the impact of urbanisation on GIT (Gastro-Intestinal-Tract) diseases have been studied in detail.

CARDIOLOGY UNIT

The unit is recognised for the training of medical and technical staff by the South African registering bodies.

Approximately 14 000 outpatients are evaluated per annum, of which some 280 are referred for surgery. After an absence of 15 years Cardio-thoracic surgery was once more introduced at Chris Hani Baragwanath Hospital during July 1999.

RADIOLOGY

The department of Radiology has all the modalities required for modern radiological investigations.

The main and casualty departments handle all the film reporting—casualty remaining open 24 hours a day, 7 days a week. The department performs approximately 324 000 radiological examinations annually.

RESPIRATORY UNIT

Approximately 800-900 inpatients are referred to the unit annually. A "walk-in" service for patients attending the clinic is available with the aim of obviating admission. The nursing staff provide asthma education.

PSYCHIATRY

This department consists of 4 adult wards with a total of 155 beds, as well as a paediatric psychiatric department. Students, including medical students, student nurses, primary health care nurses, social workers and occupational therapy students, are taught practical skills here in the field of psychiatry

DEPARTMENT OF SURGERY

There are 27 operating theatres in the hospital complex. An average of 44 000 operations and related procedures are conducted here each year. About 70% of the cases attended to are trauma related.

DEPARTMENT OF ANAESTHESIA

The department staffs 38 service points and administers $\pm 50\ 000$ anaesthetics per annum. This department is responsible for: Teaching of undergraduate students, Formal lectures to 5th year medical and 4th year dental students, Postgraduate Medical Officer training and Postgraduate examinations.

INTENSIVE CARE UNIT

The Bara unit is recognised as a Category 1 ICU and can thus cope with intensive therapy, ventilatory assistance, sophisticated cardiac monitoring & support and circulatory support at the highest level. The nursing contingent strives to maintain a patient/nurse ratio of 1:1. The ICU is recognised as a training centre for the Diploma in Intensive Care Nursing Science, and for clinicians specialising as Intensivists.

ORTHOPAEDIC SURGERY

All areas of orthopaedic subspecialties are provided for and the department is divided into six autonomous units: Trauma, Cold (Elective Surgery, Spinal, Hand and Paediatric Units).

ST JOHN EYE HOSPITAL

The St John Eye Unit provides a comprehensive ophthalmic service, and is the largest eye hospital in South Africa. An average of 4 000 eye operations are conducted, and more than 65 000 outpatients seen here per year.