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## TITLE:

# MOVING BEYOND INFORMED CONSENT TO DYNAMIC OR SHARED CONSENT: THE CLINICAL AND LEGAL FRAMEWORK OF A MORE PATIENT-CENTRED APPROACH

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## Dedication

*First and foremost, I wish to dedicate this mini-dissertation to the Almighty God, the reason of whom I am today, for giving me strength, guidance and His divine intervention in this academic endeavor;*

*To my loving husband Mr. Neil Mabeba, thank you Sthi for always believing in me and for your overwhelming, support morally and spiritually. You have been my inspiration and my soul mate;*

*To my children Rena, Londeka and Omphemetse Mabeba for your encouragement and eternal love. Thank you Cushie, Poensie and Momomo for seeing me as your role model and always wanting to follow my career path;*

*To my mother Mrs. MG Mkhize, a strong and gentle soul who taught me to trust in God, believe in hard work and that so much could be done with little. Thank you for your continuous care and love;*

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*I thank the Department of Public Law stuff for their support.*

# Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.

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3. I have not used work previously produced by another student or any other person to hand in as my own.

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# Abstract

Obtaining the consent of a patient is at the centre of medical practice and as such medical practitioners need to ensure proper patient's approval in the administration of medical services or prescription of medical products. Informing a patient about the medical implications involved in the procedure they are about to undergo is not sufficient as patient needs to be fully engaged. The transcendence beyond informed consent to shared or dynamic consent is the core focus of discussion in this work. It is argued in this work, that there has to be policy that deals with specifically with consent across a broader spectrum of the provision healthcare goods and services.

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# CHAPTER 1

## Introduction to Informed Consent and Shared Consent

### 1. Background

The principle of dynamic or shared consent is broadly praised for its ability to advance patient autonomy and reduce physician liability.[1] The doctrine of informed consent is criticized for its patent deficiencies in addressing the traditional problem of medical paternalism and increased rate of medical negligence. In medical law, it is as much a concern to reduce medical negligence as it is to enhance patient awareness and participation in medical decisions. The general consensus is that by properly addressing the latter, the former is likely to be automatically resolved, hence the growing endorsement of the principle of shared-decision-making in substitution of the doctrine of informed consent.[2] One can thus ask, can dynamic or shared consent lead to a fruitful participation of patients in their medical procedures, and subsequently reduce the rate of incidents of medical negligence? This is the principal question upon which this dissertation contemplates. In other words, this dissertation critically analyses shared consent in its endeavour to advance the rights of the patient as contained in section 12(2)(b) of the Constitution,[3] while subsequently addressing the problems that lead to medical negligence.

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[1] A.M. Stiggelbout et al, Shared decision-making: really putting patients at the centre of healthcare, *British Medical Journal* Vol. 344, No. 7842 (4), (2012), p 28. H. Manyonga *et al*, From informed consent to shared decision-making, *South African Medical Journal*, Vol. 104, No. 8, (2014), p 561.

[2] J.C. Tilburt *et al*, Shared decision-making as a cost-containment strategy: US Physician Reactions from a Cross-sectional Survey, *British Medical Journals – Open*, (2014), p 29 – 59. Available on: https://bmjopen.bmj.com/content/bmjopen/4/1/e004027.full.pdf. Accessed: 28 October 2018.

[3] The Constitution of the Republic of South Africa, 1996.

## 2. Assumptions

It is clear that there are specific issues that give rise to the dissatisfaction around the doctrine of informed consent as a guiding norm in the administration of the patient's consent in medical treatment. In order to achieve the desired objectives, this dissertation lists below, the assumptions that border the major inquiry of this work.

2.1. The doctrine of informed consent faces many difficulties, among others, the inability to improve the doctor/patient relationship, and neither can it resolve the problems that lead to the incidents of medical negligence.
2.2. There is a need to reformulate the doctrine of informed consent, or substitute it with another approach, in order to solve the biomedical-ethical challenges that result in increased medico-legal conflicts or disputes.
2.3. A more patient-centred approach could improve the doctor/patient partnership and foster an effective working network between health professionals, medico-legal practitioners and patients.
2.4. Any approach that seeks to place more responsibility in the hands of the patient's hands during the course of medical procedures/treatments, also takes into consideration the justifiable defences for medical professionals' invasion of the right to bodily integrity, namely necessity and emergency.

## 3. Research Questions

This dissertation covers a wide range of questions in relation to the doctrines of informed consent and shared decision of making. But more specifically, this work aims at addressing the below listed questions. The inquiry in this work seeks to evaluate the extent to which the doctrine of informed consent falls short of centralising patient autonomy in the doctor-patient interaction. These questions are fully addressed in the subsequent chapters to this one.

3.1. How will the patient benefit by employing shared consent as opposed to informed consent?
3.2. In what ways will shared consent reduce physician liability?
3.3. How will shared consent foster a balanced partnership between patients and doctors?
3.4. What professional standards and ethics need to be in place, for both medical and medico-legal practitioners, in order for shared consent to be effectively implemented?

## 4. Study Objectives and Limitations

The growing dissatisfaction against other models of doctor-patient communication, for example, motivational interviewing, has led to the pioneering of the principle of shared consent.[4] This research is motivated by the criticism against the doctrine of informed consent and the call to substitute it with shared consent. It is worth critically exploring the extent to which the doctrine of informed consent could not be redeemed from its deficiencies. In other words, whether there is a difference between informed consent and shared consent at all. If indeed shared consent entirely forms an improvement of the doctrine of informed consent, does it also necessarily lead to the advancement of the patient's autonomous rights as well as an effective doctor/patient partnership?

Save for the fact that this research does not incorporate clinical data and empirical observations, it will observe all medical law arguments as and when they expand into various areas of the law. As a matter of fact, "the principles and practice of medicine are relevant to most if not all branches of the law."[5] In other words, the discussion of the topic at hand incorporates various areas of the law, for example: delict, contract, legal

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[4] G. Elwyn *et al*, Implementing Shared Decision-making: consider all the Consequences*, Implementation Science*, (2016), p 2.

[5] P. Carstens and D. Pearmain, "*Foundational Principles of South African Medical Law*," (2007), p 4. Cf Strauss SA "Medical Law – South Africa" in International Encyclopaedia of Laws (eds Blanpain R and Nys H)(2006), para 42.

interpretation, family law, criminal law, constitutional law, administrative law as well as human rights.

## 5. Motivation and Rationale

### 5.1. Background

Lawsuits in medical negligence are based on contract and delict.[6] Unsurprisingly, the stemming point for contractual damages for most of the patients' complaints against the physicians is lack of informed consent prior to the medical procedure or treatment.[7] In respect of medical malpractice, claims against healthcare practitioners are instituted in terms of delict or breach of contract.[8] "The damages payable for breach of contract unlike those in respect of a delict, are usually calculated to place the plaintiff in the position in which he or she would have been but for the breach."[9] A claimant or plaintiff who wishes to institute a claim based in medical malpractice must prove the following:[10]

- *that there was breach of contract committed by the other contractant;*
- *damage;*
- *a factual causal connection between the breach and the damage;*
- *That for the purposes of the law he damage is close enough to the breach in that it was reasonably foreseeable or agreed to by the contractants.*

The test is whether damage was caused by the breach of the contract in question.[11] With respect to delict, the reasonable person test for negligence is used.[12] The question

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[6] J. Neethling and J.M. Potgieter (2015) *Law of Delict*. These authors provide a detailed contrast between delict and breach of contract, p 6–7.

[7] P.J. Moore, Medical malpractice: the effect of doctor-patient relations on medical patient perceptions and malpractice intentions, *Western Journal of Medicine* Volume 173, (2000), p 244 – 249.

[8] Carstens and Pearmain, (2007), p 335 – 341.

[9] Carstens and Pearmain, (2007), p 335.

[10] Carstens and Pearmain, (2007), p 335.

[11] Carstens and Pearmain, (2007), p 335.

is whether the reasonable doctor in the professional level of the defendant has foreseen the possibility of harm ensuing in his conduct, and whether he has taken the reasonable steps to prevent such harm from occurring.[13] When applying the reasonable doctor test, the question is whether the alleged negligent doctor has exercised the degree of care and skill and skill which a reasonable doctor, of equal professional level, would employ.[14]

Consent is historically connected to the Roman Law principle of *volenti non fit inuiria*.[15] The principle signifies that 'no harm is done to someone who consents to it'.[16] In the words of Carstens and Pearmain, "the practice of obtaining consent and informed consent has its history in predominantly in medicine and medical research" where the decision to either disclose or withhold information formed the daily experiences between the doctor and the patient.

The doctrine of informed consent is realized when the physician discloses information regarding the medical procedure or treatment to a competent person or patient, and that person voluntarily accepts or rejects the recommended medical path.[17] However, as observed in the case of *Stoffberg v Elliot*,[18] "the doctrine of informed consent in medical practice and medical law is often fraught with controversy."[19]

The controversies faced by the doctrine of informed consent include, among others: the uncertainty regarding the relevant health professional suitable to obtain it, for example

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[12] Carstens and Pearmain, (2007, p 624. *R v Van der Merve* 1953(2), PH H124).

[13] Carstens and Pearmain, (2007), p 624.

[14] *R v Van der Merve* 1953(2), PH H124).

[15] Carstens and Pearmain, (2007), p 875.

[16] Carstens and Pearmain, (2007), p 875.

[17] J.F. Merz and B. Fischhoff, "Informed Consent does not mean Rational Consent: Cognitive Limitations on Decision-making" 1990, *The Journal of Legal Medicine*, Volume, p 322.

[18] 1923 CPD 148.

[19] Carstens and Pearmain, (2007), p 877.

nurse or doctor; the health care professionals' unreadiness to embrace the patient autonomy; and the inability to determine where the harmonised balance lies as a result of the impact of a multi-layered approach which necessitates the interpretation of various provisions from applicable sources.[20] On that note, Kunneman and Montori argue that informed consent amounts to an establishment of "a minimal legal standard in which (1) clinicians disclose the risks, benefits and alternatives of a proposed treatment or procedure and (2) people accept or reject this procedure that has been identified to be the most relevant for them."[21] In other words, the doctrine of informed consent encourages doctors to disclose information with patients as opposed to discussing with them. A further growing concern from the clinicians' position is that this doctrine is an imposing legal concept by nature, and serves no interest in the advancement of medical practice, nor does it enhance the interaction between the doctor and the patient. As a consequence, there is a need to ascend beyond the doctrine of informed consent into the principle of dynamic or shared consent, which would enable both the physician and the patient to be the mutual co-authors of their partnership.

The principle of shared decision-making intends to move beyond mere compliance with "the legal standards established in local jurisprudence."[22] As Coulter and Collins put it:

> "*Shared decision-making is a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.*"[23]

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[20] Carstens and Pearmain (2007), p 877.

[21] Kunneman M and Montori M "When patient-centred care is worth doing well: informed consent or shared decision-making" *BMJ Quality & Safety*, 26 September 2016, p1.

[22] Kunneman and Montori (2016), p1.

[23] Angela Coulter A. and Alf Collins A., Making share decision-making a reality: no decision about me without me, *The King's Fund*, (2011), p vii.

In the light of the above authors' assertion, this research is triggered by the need to critically assess the place for informed consent in medical practice in the electronic age in which patients feel substantially knowledgeable about their rights, interests and preferences. Despite the excitement towards the birth of the principle of shared consent in the medical fraternity, the analysis in this research will critically examine the extent to which its implementation will come to fruition in communities where illiteracy, lack of access to information and other related factors may inhibit the patient from playing his role in partnership with the doctor.

## 5.2. Literature Review

When most people think about informed consent, "they probably think of consent to risks of personal injury from medical treatment and from exposure to dangerous products" or services.[24] This line of thought, among many patients, is rooted on the fact that the required standard of informed consent gives a patient, as a lay person, little or no room for an opinion on the medical treatment or procedure that he or she is about to undergo.[25] Often times, the medical professionals diagnose and then explain to the patient, in minimal terms, the condition and best medical path available. The patient must therefore sign on a piece of paper to accept the procedure in the face of the risks, or alternatively reject the procedure and suffer the consequences thereof. The case of *Afrox Healthcare Bpk v Strydom* is an example in which a patient argued that the hospital urged her to sign the consent form without informed consent.[26] In this context, the interaction between the doctor and the patient sounds very paternalistic and places the doctor in a position of authority. In such an interaction, patient autonomy is also curbed. Patient autonomy is realized when the healthcare practitioners comprehensively discharge their duty to provide a balanced information that allow their patients to determine their clinical choices.[27]

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[24] H.P. Schuck "Rethinking Informed Consent", *The Yale Law Journal*, Volume 103, (1994), p 902.

[25] H.P. Schuck, (1994), p 902.

[26] 2002 (6) SA 21 (SCA) [2002] 4 All SA 125 (SCA).

[27] Ames Dhai and David McQuoid-Mason, "Bioethics, Human Rights and Health Law Practice," *The South African Medical Journal*, (2011), 69–70.

Coulter and Collins argue that, "Shared decision-making explicitly recognises a patient's right to make decisions about their care, ensuring they are fully informed about the options they face."[28] On the same line of argument, Durand *et al* hold that, "There is considerable hope that sharing decisions with patients using good communication skills and tools that improve provider-patient communication and understanding of the harm versus benefit trade-offs would lead to lower litigation levels."[29] In other words, dynamic or shared consent promotes and heightens a patient-centred care, patient empowerment and evidence-based patient choice.[30] It is a collaborative effort in which patients and medical practitioners share not only information and intuition but the making of decisions.[31] In this line of observations, the pioneers of shared consent seem prepared to eventually eradicate medical paternalism and put more power in the patient's willingness to undergo any medical treatment or procedure.

The rejection of medical paternalism is also emphasized by the courts in view of patient's right as entrenched in section 12(2)(b) of the Constitution. In *Castell v De Greef*,[32] the court held that:

> "*It is clear for the patient, in exercise of his or her fundamental right to self-determination, to decide whether he or she wishes to undergo an operation, and it is in principle wholly irrelevant that the patient's attitude is grossly unreasonable in the eyes of the medical profession: the patient's right to bodily integrity and autonomous moral agency entitles him or her to refuse medical treatment. It would be equally irrelevant that the medical profession was of the unanimous opinion that it was in*

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[28] Coulter and Collins (2011), p 2.

[29] Marrie-Anne Durand *et al*, "Can shared decision-making reduce medical malpractice litigation? A systematic review," *BMC Health Services Research*, (2015), p2.

[30] H. Manyonga *et al*, "From informed consent to shared decision-making," *South African Medical Journal*, Volume 104 (2014), p 561.

[31] S.N. Whitney *et al*, "A Typology of Shared Decision-making, Informed Consent, and Simple Consent", *Annals of Internal Medicine* (2004), Volume 1(1), p 54.

[32] 1994 (4) SA 408 (C).

> *given circumstances the surgeon's duty to refrain from bringing the risk to his patient's attention.*"[33]

In the same spirit of the decision in *Castell v De Greef*, the courts continue to give emphasis on the patient's right to bodily integrity, as could be observed in the decisions such as *C v Minister of Correctional Services* and *Minister of Safety and Security v Xaba*.[34] The right to bodily and psychological integrity cannot be threatened by another unless the patient comprehensively gives his or her consent.[35] As such, the proponents of shared consent feel that informed consent has failed to reduce the incidents of medical negligence and to advance the rights of the patient. These proponents feel that informed consent is the legal process used to promote patient autonomy, seemingly with the aim to reduce physician liability, whereas shared consent is a widely promoted medical ethical approach.[36]

The Court of Appeal in the United Kingdom has also delivered similar pronouncements as the South African courts in favour of patient autonomy. In the case of *St George's Healthcare NHS Trust v S*, this Court held that, "an adult patient of sound mind has an absolute right to refuse any, or all, medical treatment including treatment necessary to save the patient's life."[37] This decision indicates that the call for a more patient-centred approach is an international one that is strengthened by the advancement of human rights across the world. So far, it seems that the patient's right to determine his or her clinical choices, as attached to the right to bodily integrity, trumps necessity and emergency as defences. Since all rights cannot be unlimited in terms of section 36 of the Constitution, it is submitted that an individual's right to bodily integrity can still invaded where its prevalence potentially endangers the life of the entire community.

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[33] South African Law Reports, Volume 4, (1994), p 409.

[34] *C v Minister of Correctional Services* (4) SA 292; *Minister of Safety and Security v Xaba* 2003 (2) SA 703 (D).

[35] Schuck (1994), p 902.

[36] S.N. Whitney *et al* (2004), p 54.

[37] [1998] 3 All ER 673 (CA). Cf A Grubb (2001) *Principles of Medical law*, 36.

By its very nature, shared consent emanates from the doctor-patient relationship. As already indicated above, "the traditional model of medical practice left little decision-making to patients. This has shifted to a model that now involves patients in directing their care."[38] Various factors have contributed towards the development in which information flows from medical practitioners to the point where the patient has control over his or her relationship with the doctor. The following are some of the factors:[39]

- Medical advances that changed the focus from curing infections to managing chronic diseases;
- The bioethics movement of the 1960s;
- Ideas such as patient-centred medicine;
- An increasingly knowledgeable public with access to information via the Internet.

## 6. Research Methodology

This research is a critical analysis of the unfolding move beyond informed consent and ascend into the practice of shared consent in which doctors and patients need to partner for medical procedures. The arguments that will be referred to in this research deals substantially with matters relating to informed consent, shared consent and to some extent the principles of beneficence and maleficence. Even more importantly, the arguments that will be cited in this research are critically concerned with the deficiencies of informed consent and its coveted substitution by shared consent in the light of the expansion of patient autonomy and minimisation of the incidents of negligence.

## 7. Structure

### 7.1. Chapter 1: Introduction

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[38] B. Steinhart, "Patient autonomy: evolution of the doctor–patient relationship," *Haemophilia*, Volume 8, (2002), p 442.

[39] Steinhart, (2002), p 442.

This chapter presents the general background to the topic at hand. It is in this chapter that key concepts that are central to this research are descriptively outlined, particularly the doctrine of informed consent and as well as shared consent.

### 7.2. Chapter 2: Informed Consent and Medico-Legal Framework

There is a generalizable consensus that the doctrine of informed consent is fraught with controversies.[40] In Chapter 2, this research will look into this doctrine and the problems that it faces. It will examine the scope and ambit of informed consent in the medicolegal framework in view of a patient's rights.

### 7.3. Chapter 3: Shared Consent in the Comparative Outlook

In this chapter, a patient empowerment and patient-centered approach is illustrated in the comparative sense by observing at other countries such as Canada and the United Kingdom, among others. This chapter comparatively analyses the benefits that shared consent presents in substitution of the 'deficient' informed consent. It is important to explore how shared consent would possibly deal with the problem of medical paternalism, professional negligence and how it would enhance patient's self-determination and advance his or her rights and interests.

### 7.4. Chapter 4: Issues of Contention relating to Consent: Discussion of Applicable Case Law

As the principle of shared consent promises to create an environment in which the doctor/patient partnership thrives, it is crucial to explore this principle in the light of the socio-economic challenges that many patient face: for example, lack of access to information sources and illiteracy. This chapter also critically analyses the doctor/patient partnership in view of the doctor's bio-ethical values that were imported into the

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[40] J.C. Tilburt *et al*, Shared decision-making as a cost-containment strategy: US Physician Reactions from a Cross-sectional Survey, *British Medical Journals – Open*, (2014), p 29 – 59. Available on: https://bmjopen.bmj.com/content/bmjopen/4/1/e004027.full.pdf. Accessed: 28 October 2018.

profession by the principles of respect for patient autonomy, beneficence and non-maleficence. As a matter of fact, both the medical and legal fraternities will need adjustment to accommodate this more patient-centred approach.

### 7.5. Chapter 5: Recommendations and Conclusion

After the four first chapters have looked into the deficiencies of informed consent, and the need to substitute it with shared consent, chapter 5 will draw conclusion based on the explored arguments from various authors, guidelines from policy documents, legal provisions, as well as rationales from case law.

## 8. Conclusion

Obtaining the consent of a patient is at the centre of medical practice. Failure to ensure proper patient's approval in the administration of medical services or prescription of medical products amounts to violation of the patient's bodily integrity. As clearly illustrated in this first chapter, informing a patient about the medical implications involved in the procedure they are about to undergo is not sufficient. A patient's opinion needs to be given room form part of the medical strategy or approach that will be employed in their treatment. Hence this chapter has clearly outlined that there is a need to transcend the mechanical spelling of procedure that a patient is to undergo, as a form of soliciting their signature for approval to what a medical practitioner has already made up his mind about. The transcendence beyond informed consent delineates shared or dynamic consent in which patient autonomy is entirely prioritised. It also delineates the amplification of an enhanced doctor-patient partnership that is centred on the patient's rights, and automatically total eradication of medical paternalism. As this chapter has specified, the chapters that follow will critically assess the inadequacy of the doctrine of informed consent, and why it is considered medically and constitutionally transformative to substitute the above mentioned form of consent with the principle of shared consent.

# Chapter 2

# Informed Consent and Medico-Legal Framework

## 1. Introduction

The basis of the regulations governing consent in the South African medical law and ethics can be derived from the constitutional provisions. The rights that embody and protect patient consent are contained in section 12 (2) of the Constitution. Section 12 (2) states that:

> *"Everyone has the right to bodily and psychological integrity, which includes the right – (a) to make decisions concerning reproduction; (b) to security in and control over their body; and (c) not to be subjected to medical or scientific experiments without their informed consent*."

The rights entrenched in section 12 (2) pertain to the so called "security and freedom of the person". Section 12(2)(b) in particular protects the autonomy of patients against involuntary medical treatment. Section 12(2)(b) enable the detailed provisions of sections 6, 7 and 8 of the National Health Act 61 of 2003 that govern patient consent in the South African health sector. This chapter critically assesses the legal provisions that guide administration of patient consent in South Africa. The work in this chapter aims at evaluating the extent to which the rights of a patient are given an attention sufficient enough to advance the transformative objectives of the Constitution in view of medical service provision in South Africa.

## 2. The Constitution and Legislation

The post 1994 South African legal framework is structured according to the Constitution. In other words, even the medicolegal regulations must comply with the values and principles set out in the Constitution. Section 2 of the Constitution state that: the "Constitution is the supreme law of the Republic; law or conduct inconsistent with it is invalid, and the obligations imposed by it must be fulfilled.” In the spirit of the supremacy of the Constitution, it follows that the health regulations that govern the relationship between the doctor and the patient must be consistent with the values and principles embodied in the Constitution. Not only do we observe the fact that the codification of the various health regulations are enabled by the Constitution, but we also need to ensure that the conduct of the health professionals reflects the said constitutional values and principles when discharging their professional duties. For the purposes of this work, the constitutional values and principles that must inspire the doctor-patient relationship can be summarised as follows:

- Section 9 – the right to equality;
- Section 10 – the right to have one’s inherent dignity respected and protected;
- Section 11 – the right to life;
- Section 12(2)(b) – the right to bodily and psychological integrity, specifically to have security in and control over one’s body;
- Section 14 – the right to privacy.

The rights mentioned above, among others, should be seen as the cornerstone that ought to inform the regulations and judiciary decisions with the aim of giving effect to the transformative aspirations of the Constitution, with the objective of achieving indiscriminative equality even within the provision of health care products and services. In view of a patient’s freedom, it is not hard to understand that consent to medical treatment is bordered by the above mentioned values and principles. As already mentioned above, a patient’s right to agree or refuse medical treatment is further expressed in details in sections 6, 7 and 8 of National Health Act.

Section 7 of the National Health Act governs the doctrine of patient consent to health service. Section 7(1) states that no patient or consumer can be provided with health services without their consent. The section further lists the exceptions under which health services can be administered to user without obtaining their informed consent. These exceptions can be summarised as follows:

(a) where the user is personally unable to give informed consent, such consent can be given on their behalf by a representative of their own mandate of nominated by the Court of law;

(b) where the user is personally unable to provide informed consent they may be represented by spouse or partner, and where the latter is not available by strictly following the list of: parent, grandparent, an adult child or a brother or a sister of the user;

(c) where the provision of a health service without informed consent is authorised in terms of any law or a court order;

(d) where failure to treat the user, or groups of people which includes the user, even without obtaining their informed consent, will result in a serious risk to public health;

(e) where any delay in the provision of the health service to the user might result in his or her death or irreversible damage to his or her health and the user has not expressly or impliedly or by conduct refused that service.

In view of the above listed exceptions by which a health service can be administered without consent of the patient, section 7(2) directs the health care provider to "take all reasonable steps to obtain the user's informed consent." Undoubtedly, the provisions of the above mentioned sections of the National Health Act embody the spirit of section 12(2)(b) as far as the promotion and protection of the right to bodily integrity are concerned. The direction of the provisions of sections 7(1) and (2) point to the fact that "informed consent means consent for the provision of a specified health service given by a person with legal capacity to do so" and who has been fully informed about the nature of his illness and the risks of various medical procedures available.[41]

## 3. Analysis of the Implications of Sections 6, 7 and 8 of the National Health Care Act in view of the Principle of Shared Consent

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[41] Sections 6 and 7(3) of the National Health Act.

It has already been indicated above that the discourse of a patient's consent is captured in sections 6, 7 and 8 of the National Health Act. The provisions of section 7, which contains the directives regarding the attainment of patient consent before provision of health care services, are clearly outlined above. In this part of the work, the objective is to critically evaluate the provision of section 7 as the cornerstone of the doctrine of informed consent in relation of the resultant implications in the practice of medicine. The aim is to display the legislative shortcomings in relation to the advancement of the patient's participation in medical decisions that affect his or her bodily integrity.

Looking closely in the above three mentioned sections, the emphasis seems to be on the need for the doctor to inform a patient about the benefits, threats and risks of some specific diagnosis. It seems to be the aim of the legislation that only the doctor must do his or her homework to ensure that a patient is informed. The Act does not put any directive to a patient to play her role in the nature of medical proceedings concerning her health. In other words, the focus of the National Health Act in relation to consent is somewhat still paternalistic in that the directives therein still expect the doctor to play a major role in the diagnoses and treatment of patients. The discontent with the provisions in these three mentioned sections is that they still apply the word “informed” which by nature suggest the flow of information from the doctor to the patient rather than the mutual meeting of ideas from both the doctor and the patient. Drawing from the the view of Moore and Nöthling-Slabbert, one can submit that the provisions in these sections embody traditional obligations based on beneficence principle that focused on ethics and scientific research.[42] The beneficence principle put emphasis on the hypocritical oath traditionally taken by medical trainees to swear that they will advance their practice for the benefit of patients and do their best to prevent harm in the process.[43] The closest that the National Health Act comes close to advocating for patient autonomy and shared consent is in section 6(1)(d) which provide that the healthcare provider must inform the

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[42] W. Moore and M. Nöthling-Slabbert, Medical information therapy and medical malpractice litigation in South Africa, *South African Journal of Bioethics and Law*, Vol. 6, No. 2, (2013), p 61.

[43] R. Gillon, Medical ethics: four principles plus attention to scope, *British Medical Journal* Volume 309, (1994), p 108.

user of their "right to refuse health services and explain the implications, risks, obligations of such refusal." From this line of authority, it can be submitted that the legislature envisioned the need to embrace patient autonomy. However, it should be noted that the sections in question mainly direct the medical professionals to "inform" the patient.

From the medical practice experience, it is submitted that shared consent goes beyond merely informing the patient of the diagnoses of their medical condition and the options and risks involved therein. In the words of Howard Manyonga *et al*, shared consent, which constitutes good medical practice, means that the medical practitioner should "check that the patient has understood the information provided and has been offered an opportunity to seek clarification."[44] In the South African context, it is worth noting that that level of the patient's education and their native language should be taken into consideration. In such a consideration, one can submit that the fundamental rights with regard to patient autonomy and bodily integrity are given a priority. This consideration, it can be added, transcend the traditional duty placed upon medical professionals to inform patients for compliance purposes only.[45] In this work, it is argued that informed consent is not adequate as it robs patients of the opportunity to make extra consultation and research in relation of the pending medical treatment they are about to undergo.

## 4. THE PROVISIONS OF THE HEALTH PROFESSIONS COUNCIL OF SOUTH AFRICA (HSPCSA)

The HSPCSA guidelines aim at entrenching the mutual relationship between the health care practitioners and their patients. This mutuality is sustained by the permanent

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[44] H. Manyonga *et al*, "From informed consent to shared decision-making," *South African Medical Journal*, Volume 104 (2014), p 561.

[45] C. Tay, "Recent developments in informed consent: the basis of modern medical ethics," *APLAR Journal of Rheumatology*, Volume 8, (2005), p 165.

acknowledgement by medical professionals that their trade is a “moral practice”.[46] In the context of the topic at hand, the moral practice concerned is the sharing of information to reach consent with a patient before administering medication and health care services. In view of information sharing, clause 7.1 of the HSPCSA guidelines states as follows:

> “*It is for the patient, not the health care practitioner, to determine what is in the patient's own best interests. Nonetheless, practitioners may wish to recommend a treatment or a course of action to patients, but they must not put pressure on patients to accept their advice. In discussions with patients, health care practitioners should:*
>
> *6.1.1 Give a balanced view of the options;*
>
> *6.1.2 Explain the need for informed consent.*”[47]

These guidelines strike a good balance in the process of information sharing by specifying that disclosing and sharing the necessary information is for the benefit of the patient, and not the doctor. These guidelines further emphasize that the health care professionals must declare potential conflict of interest in the process of information sharing.

To some very substantial extent, the guidelines also outline a process to administer the health care services to patients in emergencies with emphasis on the respect for patient autonomy. In emergencies, clause 8.1 of the guidelines directs health care professionals to provide medical treatment to patients who are unable to give consent only to the extent necessary to save life or avoid deterioration.[48] The above directive can be understood in view of the exceptions in section 7(1) of the National Health in which the patient nor any of the potential individuals that may represent such a patient in decision-making are unavailable. That said, it is worth noting that the provisions of the HPCSA guidelines are more advanced with regard to shared consent as compared to

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[46] HSPCSA, *Guidelines for good practice in the Health Care Professions*, (2008), p i.

[47] HSPCSA, (2008), p 6.

[48] HSPCSA, (2008), p 7.

those of the National Health Act. The provisions of the Act, as already argued above, put more emphasis on informed consent as opposed to shared decision-making.

One of the hinging points in the regulations is that the patient must understand the nature of diagnoses and options available to address his or her health issues. The patient must further understand the benefits and risks that come with each available option. The patient's right to refuse medical treatment must be emphasized in view of patient autonomy. The fact that the patient decides against any available option in the treatments discussed does not mean that they do not understand the options.[49] The patient's right to refuse medical treatment forms part of their rights to their to make decisions concerning their body. However, as Dain van der Rayden puts it, "the capacity to make autonomous decisions may" sometimes "be constrained temporarily by factors such as illness, ignorance, coercion or limiting conditions."[50] As already outlined, it is submitted that the National Health Act along with the HPCSA regulations have envisaged the potential for these constraints and thus require only legal or authorised representatives to decide on behalf of the constrained patients.

## 5. Conclusion

This chapter focused on the authoritative constitutional and legislative provisions that find application in the discourse of shared decision-making as well as the rights of the patient. In this chapter, it was clearly specified that section 12(2)(b) takes the centre stage with regard to medical treatment as well as an individual's rights to bodily integrity. Sections 6, 7 and 8 of the National Health act provide key directives with regard to obtaining informed consent from patients before provision of health care services or products. However, it was expressed in this chapter that the provisions of sections 6, 7 and 8 put emphasis on the word "informed", thus suggesting the flow of information from the medical practitioner to the patient. This work advocates for the emphasis on "shared decision-making" in which the medical practitioner and the patient

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[49] I. Kennedy and A. Grub, *Medical Law*, (2002) p 605.

[50] D van der Raiden, "The right to respect for autonomy Part 1 – What is autonomy all about?" *South African Journal of Occupational Therapy* — Volume 38, Number 1, (2008), p 27.

discuss the diagnoses as well as treatment options available for the patient. In such a discussion, the final decision lies with the patient as to whether to accept or refuse any medical treatment. The health care provider has a duty to take all the steps to ensure the availability of the necessary information to the client and to inform the patient of his or her right to make further consultation. The HSPCA guidelines are encoded in a much advanced tone in comparison to the provisions in the National Health Act. These guidelines provide that the medical practitioners must avoid conflict of interest and prioritize the interests of the patient throughout the process of information therapy and medical treatment. In conclusion, it is submitted that the South African legislation still need to be updated to capture the principle of shared decision-making in its essence.[51]

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[51] L. Pienaar, Investigating the Reasons behind the Increase in Medical Negligence Claims, *Potchefstroom Electronic Law Journal*, (2016), p 1 – 18.

# Chapter 3

# Shared Decision-Making in the Comparative Outlook

## 1. Introduction

In Chapter 2, the legal frameworks that regulate consent were critically discussed. The said legal frameworks are specifically limited to domestic application in the South African jurisdiction. However, it is indisputable that the advancement of patients' rights is a global discourse. In other words, other countries are also striving for an implementation or refinement of a more patient-centred approach in the light of the inevitable notion of fundamental human rights. As such, South Africa's medico-legal approach towards 'informed consent' or shared decision-making is worth a constructive comparison with approaches applied in other countries. In this Chapter, a patient empowerment and patient-centred approach is illustrated in the comparative sense by observing at other countries such as Canada and the United Kingdom, and the United States of America.

## 2. Shared Decision-making in Canada

"There is considerable interest for shared decision-making (SDM) within the Canadian healthcare system,"[52] and therefore the discussion of SMD in the Canadian context is justifiable. This said interest seems to be stemming from the fact that, "the legal obligation for doctors to fully disclose information enabling patients' participation in decisions has spawned professional codes and guidelines with a vision of patient's empowerment through the use of patient decision aid and SDM."[53] According to the report by France Légaré *et al* one proof that SDM has gained some remarkable recognition through increased funding in the healthcare system.[54] It follows that funding enables the healthcare system to invest in research and development in order to

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[52] France Légaré *et al*, "Shared decision-making in Canada: update, challenges and where next!" *German Journal for Quality in Health Care*, Volume 101, Issue 4, (2007), p 213.

[53] Légaré *et al*, (2007), p 213.

[54] Légaré *et al*, (2007), p 213.

formulate and implement programs to train medical professionals to manage patient consent and decision-making. From medical experience, it is submitted that the availability of funds is also key to securing equipments that are necessary to aid patients in the process of decision-making.

The right linked to patient consent and decision-making is contained in section 7 the *Canadian Charter of Rights and Freedoms (CCRF). Section 7 states that,* "[e]veryone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."[55] However ,consent is fully regulated through Canadian Health Care Consent Act of 1996. In other words, in Canada, patient consent is not regulated through the general Canadian Health Care Act of 1984. It is submitted that the fact that Canada has a specific Act to regulate patient consent simplifies the intensity of that country's current steps to develop a more patient-centred approach. It goes without a say that the Canadian position of having an entire Act regulating patient consent or decision-making is more effective than that of the South African one in which only three sections in the National Health Act 61 of 2003 regulate the said consent. The Canadian position is preferred in the light of the rights of patients.

As already argued above, the need to ensure the prioritisation of the rights of patients is in line with the project of the universal human rights. It seems that Canada's efforts are remarkably advanced. As France Légaré *et al* hold, [e]fforts to improve the health and welfare of each citizen in Canada, while at the same time ensuring that the society as a whole benefits, rest on the acknowledgment that human beings have the capacity to make the right life choices and highlight the need to respect people and their integrity when making such decisions."[56] One of the tests that may be used to evaluate a statutory compliance with the project of human rights is whether a statute in question provides the patient an option to refuse medical treatment.

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[55] Section 7 of the Canadian Charter of Rights and Freedoms.

[56] Légaré *et al*, (2007), p 213.

In terms of the guidelines by the World Health Organisation, consent must satisfy the following criteria in order to be valid:[57]

> a. *“The person/patient giving consent must be competent to do so, and competence is assumed unless there is evidence to the contrary.*
> b. *Consent must be obtained freely, without threats or improper inducements.*
> c. *There should be appropriate and adequate disclosure of information. Information must be provided on the purpose, method, likely duration and expected benefits of the proposed treatment.*
> d. *Possible pain or discomfort and risks of the proposed treatment, and likely side-effects, should be adequately discussed with the patient.*
> e. *Choices should be offered, if available, in accordance with good clinical practice; alternative modes of treatment, especially those that are less intrusive, should be discussed and offered to the patient.*
> f. *Information should be provided in a language and form that is understandable to the patient.*
> g. *The patient should have the right to refuse or stop treatment.*
> h. *Consequences of refusing treatment, which may include discharge from the hospital, should be explained to the patient.*
> i. *The consent should be documented in the patient’s medical records.*”

In view of the WHO guidelines as well as the Canadian position on the regulation of patient consent, it makes sense that South Africa should have a specific legislative document regulating the administration of patient consent.

## 2.1. Canadian Patient Participation in Decision-making

As already indicated above, patients hold the right to decide their fate. However, it is of paramount importance that patients are informed of their right to research their diagnosed condition and compare their findings with those of the medical practitioner.

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[57] Susan Friday, “Informed Consent and Mental Health Legislation: The Canadian Context,” *Vancouver/Richmond Mental Health Network Society*, (2005), p 1. See also WHO Resource Book on Mental Health, Human Rights and Legislation. *World Health Organization*, 2005, p 43-44.

Medical practitioners are also obliged to give information access to patients, hence it was outlined above that the availability of funds makes it possible for health institutions to strengthen the process of shared decision-making. It is submitted that patients should also be given an opportunity to choose the health practitioner they would prefer as an assistant in the process, e.g. physician, nurse or rehabilitation specialist. In Canada, it was found that most patient choose "counselling by a physician" as "their preferred method of receiving support prior to making health decisions."[58] In this context, Canadian patients' preference is based on expectation "that their health providers" ought to have "the necessary skills to ensure adequate decision support, or at a minimum, that they can direct them to trustworthy resources."[59]

However, it must be noted that making the availability of information to patients who cannot read or write places a difficult challenge in the hands of healthcare practitioners. Noting from an experience of the writer as a medical practitioner, South Africa still has a significant percentage of the population that cannot comprehensively read and write. In comparison to developed countries like Canada, illiteracy adds to the problem in which most South African patients are unable to process necessary information in relation to consent. That said, the healthcare system in developing countries should equip public institutions with resources to deliver and translate medical information in the language that suits various patients according to their literacy level.

## 2.2. Barriers and facilitators to implementing shared decision-making in Canada

One of the ways in which Canada has managed to improve the administration of patient consent is through research and development. Through research, Canada has been able to develop a "rapidly growing body of new knowledge regarding new decision-

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[58] Légaré *et al*, (2007), p 216.

[59] Légaré *et al*, (2007), p 216.

making models."[60] As already mentioned above, the availability of funds enables medical researchers in Canada to review relevant factors that could either be barriers or facilitators of "shared decision-making as a decision-making process jointly shared by patients and their health care providers."[61] As a result of the good research conduction around the topic of shared decision-making, Canada has been able to identify the said barriers and facilitators.

### 2.2.1 *A Brief Discussion of Predominant Barriers*

a. Lack of awareness

This refers to the inability to correctly acknowledge the existence of shared decision-making.[62] It is my view that proper training, especially among medical professionals, could help to eradicate this barrier.

b. Lack of familiarity

Given that medical information is technical by nature, most patients are unable to correctly answer questions about shared decision-making content, let alone conclude a comprehensive research of their diagnoses and the implications they carry. This similar barrier applies to medical practitioners as well, particularly where their part of professional role includes interpreting legal provisions which may be replete with legal jargon. As such, medical practitioners should also be equipped with basic skills to understand the legal implications of processes such as patient consent and rights.

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[60] France Légaré *et al*, "Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions," *Patient Education and Counselling Journal*, 73 (2008), p 526.

[61] Légaré *et al*, (2008), p 526.

[62] Légaré *et al*, (2008), p 528.

c. Lack of agreement with specific components of shared decision-making and Interpretation of evidence

This barrier relates to lack of beliefs among medical practitioners “that specific elements of SDM are supported by scientific evidence.”[63] This barrier echoes the challenges brought about by medical paternalism in which most medical practitioners held a view that patients cannot understand diagnoses that naturally require scientific knowledge.

d. Lack of expectancy

Some medical practitioners hold that the administration SDM will not necessarily enhance any better results as compared to pure informed consent in which diagnoses are announced and medical procedure is carried on the patient’s body for their benefit. Medical Researchers in Canada were able to note that this barrier motivates violation of patient rights as it does not take into consideration the fact that patients have a right to determine how they want their bodies to be treated.

e. Compatibility

There is misconception that SDM is difficult to understand and put into practice in relation to the available methods of clinical practice.

### 2.2.2 *A Brief Discussion of Predominant Facilitators*

a. Motivation

Motivation on the part of both stakeholders is based on the understanding that the more diagnoses, risks and benefits are discussed among stakeholders the

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[63] Légaré *et al*, (2008), p 528.

more the likelihood of arriving at the outcomes that are best suited to the rights and interests the patient.

b. Preferences of Patients

The facts that medical practitioners are obliged to listen to the patient's preferences, facilitates the need to properly administer SDM.

c. Avoiding Challenge to Autonomy

This facilitator relates to compliance. When health professionals understand the reasons to comply with specific medico-legal provisions, they are most likely to fulfil such requirements.

## 3 Shared Decision-Making in United States of America (USA)

The preceding section has outlined Canada's commitment to the development of the shared decision-making. The discussion has indicated that Canada has an entire Act that focuses on patient consent, and that Canada's ability to develop access of information to patients is due to good funding programmes in the healthcare system.

In the United States, President Barack Obama signed into law the Patient Protection and Affordable Care Act (PPACA; Pub. L. No. 111 – 148) and the Health Care and Education Reconciliation Act of 2010 (RCA; Pub. L. No.111 – 152). The purpose of the PPACA and the RCA, among other things, is to ensure that shared decision-making "is among delivery system reforms contained within the new Center for Medicare and Medicaid Innovation."[64] These above Acts were also designed to extend healthcare to most Americans that could not afford it through their own means.[65] In fact the PPACA is also popularly known as the Obamacare or the Affordable Care Act. As Frosch *et al* put it, the Obamacare also "authorizes a Shared Decision-Making Program to help patients

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[64] Dominick L. Frosch *et al*, "Shared decision-making in the United States: policy and implementation activity on multiple fronts," *German Journal for Continuous Medical Education*, (2011), p 306. Available online at www.sciencedirect.com: Accessed on 12 July 2018.

[65] Frosch *et al*, (2011), 306.

– in collaboration with their clinicians – make more informed treatment decisions based on an understanding of available options and each patient's circumstances, beliefs and preferences."[66] Similar to the approach in Canada, the USA also seems to be committed towards the effective administration of the shared decision-making. However, it is submitted that the Canadian approach is more preferred in that it involves a separate Act that deals with patient consent.

One of the advantages of the Obamacare is that it "establishes a program at the federal Department of Health and Human Services (HHS) for the development, testing, and dissemination of educational tools to help patients, caregivers, and authorized representatives understand their treatment options."[67] It goes without a say that there is a serious commitment of funds in the programmes and equipments in order to develop patient decision aids (DAs) in order to enable the unhindered prevalence of shared decision-making in the USA. Given the significance of SDM in the enhancement of the project of fundamental human rights, it is inevitable that countries invest resources in the development of a more patient-centred approach. It is submitted that the investment in patient consent should include the development of instruments in various medical fields to help patients have more options and take well informed decisions. These instruments should include, among others, decision analysis, option scales and decision support analysis tools. Medical researchers in the USA have been gathering information on the approaches from other countries such as Italy and France with a view to refining their SDM.[68] The sharing of information among countries is supported in this work, as SDM is still a relatively young approach and thus requires collaborative updates to ensure that it is universally embraced.

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[66] Frosch *et al*, (2011), 306.

[67] Frosch *et al*, (2011), 306.

[68] Frosch *et al*, (2011), 306.

As Glyn Alwyn *et al* observe, an effective implementation of SDM can best be achieved by ensuring that:[69]

- *“Decisions have to be made about the relevance of information, and this leads to a selection based on ‘what matters most’ to (most) patients when making decisions.”*
- *“Meticulous editing is needed to ensure that the language is concise, accessible and clear.”*

The above authors’ observation is supported because from the physician experience and point of view, patients are not interested in the complexity of medical technical language. So the language of discussion has to be concise and the information must be reviewed and simplified to help patients make input into the procedures and treatments with the full knowledge of what the consequences of what each option entails. It is submitted that the approaches in the United States and Canada seem to strive to arrive at the brevity and preciseness of information sharing between the doctor and the patient.

## 4 Shared Decision-Making in the United Kingdom (UK)

The National Health Service of the UK commits its agenda on the prioritisation of the enhancement of patient rights.[70] The National Health System (NHS) Constitution lists the following values as towards the development of a more patient-centred approach:

- *Working together for patients*

  This value commits the healthcare system of the UK to putting the rights of patients first. The system aims to involve patients, staff, families, caregivers,

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[69] Glyn Alwyn *et al*, “Option Grids: Shared decision-making made easier,” *Patient Education and Counselling Journal*, Volume 90 (2013), p 208.

[70] Angela Coulter *el al*, “Implementing shared decision-making in the UK,” *German Journal for Continuous Medical Education*, No. 105 (2011), p 300–304.

communities, and professionals inside and outside the NHS in order to meet the needs of patients and communities before organisational boundaries.

- *Respect and dignity*

  The NHS values every person – whether patient, their families or carers, or medical practitioners – as individuals, and respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits.[71] The system further takes the opinions of patients into serious consideration, and strives for honesty and openness about their abilities and limitations with respect to the patient needs.

- *Commitment to quality of care*

  Through this value, the UK system commits to earning the trust placed in it "by insisting on quality and striving to get the basics of quality of care – safety, effectiveness and patient experience – right every time."[72] In order to improve the system, the system encourages feedback from patients, families, caregivers, staff and the public at large.

- *Compassion*

  The NHS Constitution promises to ensure that compassion is central to the care provided and responded to. It further promises to afford humanity and kindness to each person's pain, distress, anxiety or need by going an extra mile and find time for patients, their families and carers.

- *Improving lives*

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[71] The NHS Constitution of the UK.

[72] The NHS Constitution of the UK.

The UK strives to improve health and wellbeing and people's experiences of the NHS. Through the NHS, the UK healthcare system aims to maintain excellence and professionalism to improve people's through quality clinical practice, service improvements and innovation. The system commits to creating inclusivity for everyone to play a role in uplifting the standard of healthcare in the UK.

- *Everyone counts*

  More like the systems of Canada and the USA, the UK system commits the maximization of resources for the benefit of the whole community. In other words, this includes commitment of funds to ensure the development of SDM.

In the spirit of the above mentioned values, and with reference to the UK citizens, the NHS system states that you have a right to:

> "[*A*]*ccept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests*."

The right to refuse treatment as contained in the NHS Constitution echoes similar sentiments as the wording of the section 6(1)(d) of the South African National Health Act 61 of 2003. The similarity of sentiments between the two is most likely due to the fact that the South African Healthcare approach is substantially influenced by the UK system. Unlike Canada, however, the USA, the UK and South Africa do not deal directly with patient consent from the legislative point of view. It seems that countries that do not encode patient consent in statutes leave more room for regulations to be developed at the local or institutional level.

One of the strengths of the UK approach towards the implementation of the SDM is the incorporation of Option Grids. As Elwyn *et al* explain, Option Grids refer to the "exploratory use of short decision support tools for patients" which may include "summary tables, using one side of paper to enable rapid comparisons of options, using questions that patients frequently ask (FAQs) and designed for face-to-face clinical encounters."[73] Elwyn *et al* clarify that the model of Option Grids "calls for two different types of tools to support shared decision-making: brief tools for use inside clinical encounters and more elaborate tools for independent use."[74] Brief Option Grids offer a supplementary approach to the ones in which 'patient decision aids' has been based on tools with high content levels, designed for patients to use independently," either before or after consultation with a health practitioner.[75] In the UK, it was reported that, Option Grids "stimulate choice talk and support option talk – therefore providing a visible and concrete platform for decision talk, in short: shared decision-making." It is submitted that South Africa's transitional approach from the informed consent to SDM should involve the use of Option Grids.

## 5 Conclusion

In this Chapter, South Africa's approach towards the development SDM was compared to that of Canada, the USA and the United Kingdom. It was outlined that the Canadian approach is more preferred because it has a statute whose sole purpose is to regulate patient consent across a wider spectrum of the provision of healthcare products and services. The model of the USA involves the analysis of models from other countries in order to review its federal approach towards the implementation of SDM. One of the advantages of the UK model is the use of Option Grids in which patients have a format of discussion with a health practitioner, and another separate one to be analysed and researched by patients independently. In comparison to South Africa, it was outlined that Canada, the USA and the United Kingdom invest substantial funds into their health systems with the aim of embracing the universal project of human rights. Indeed it was found that effective funding models allow investment towards better quality services. This Chapter recommends that the South African model should also seek ways to utilize

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[73] Alwyn *et al*, (2013), p 207.

[74] Alwyn *et al*, (2013), p 211.

[75] Alwyn *et al*, (2013), p 207.

the limited resources to effectively influence the implementation of shared decision-making.

# Chapter 4

# Contentious Issues relating to Consent and Discussion of Applicable Case Law

## 1. Introduction

As already discussed in the preceding Chapters, consent is one of the regular aspects of contention in matters relating to medical-legal disputes brought before the courts. In fact, the courts always inquire about consent in any disputes between the patient and the doctor. Even before the matter is taken to the court, the parties themselves almost always disagree about the consent with regard to the treatment or medical procedure that lead to the harm or damage from which the dispute would originates. However, the challenge to medical practitioners comes when the instructions to treat or operate on an individual flow from court orders. In such instances, medical practitioners may be unable to develop shared consent because the objective is to ensure that effective justice system is maintained, for example. In some instances, the doctors may act under urgency to terminate an unwanted pregnancy of a woman under the age of 18, even though such an individual does not truly capture the implications of shared consent. This chapter discusses some issues of contentious contention in which consent forms the basis of the procedure that a medical practitioner needs to carry out on an individual.

## 2. Consent and Termination of Pregnancy

Abortion or termination of Pregnancy is one of the contentious issues that still remain an ongoing subject of discussion in the society. Even though abortion is legalised since 12 November 1996 in South Africa, the discussion has always been about the age at which a woman should be allowed to terminate pregnancy, particularly young girls, without the company of parent or guardian. In view of the need to protect the woman's life, the other point of contention involves the stages of pregnancy at which is medically safe for a woman to terminate pregnancy. Section 5(1) and (2) of the Choice of Termination of Pregnancy Act 92 of 1996 state as follows:

> *“(1) Subject to the provisions of subsections (4) and (5), the termination of a pregnancy may only take place with the informed consent of the pregnant woman*.”
>
> “*(2) Notwithstanding any other law or the common law, but subject to the provisions of subsections (4) and (5), no consent other than that of the pregnant woman shall be required for the termination of a pregnancy*.”

In supplement to the above subsections, subsections (4) and (5) address the situations in which a woman seeking to terminate her pregnancy is incapable of giving consent either due to mental illness or continuous state of unconsciousness. In such situations, the provisions in the Act require the consent of either of the following people:

- Natural guardian;
- Spouse or legal guardian;
- Curator personae – may be appointed where any of the above is not available, subject to other requirement under the Act.

With regard to the situation where a minor seeks to terminate unwanted pregnancy, “a medical practitioner or a registered midwife, as the case may be, shall advise such minor to consult with her parents, guardian, family members or friends before the pregnancy is terminated: Provided that the termination of the pregnancy shall not be denied because such minor chooses not to consult them.”[76]

In view of the above outlined provisions, it is clear that a woman of any age can terminate pregnancy in South Africa.[77] However, the provisions of the Choice of Termination of pregnancy are read to together with those of other Acts, for example Child Care Act and the Children's that “provide for different ages of consent for medical and surgical procedures.”[78]

In this section, case law that deals with consent and termination of pregnancy is discussed.

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[76] Section 5(3).

[77] Section 1(1) of the Termination of Pregnancy Act clarifies this point by defining a "woman" as any female person of any age.

[78] David McQuoid-Mason, “Termination of pregnancy and children: consent and confidentiality Issues,” *South African Medical Journal*, Vol 100, N0 4, (2010), p 213.

### 2.1. *Christian Lawyers' Association v National Minister of Health and Others*[79]

Facts

Christian lawyers Association as the plaintiff instituted an action before the Court in which it seeks an order declaring some sections of the choice of Termination of Pregnancy Act unconstitutional. These sections were specified as sections 5(2) and 5(3) read with, the definition of "woman" in sections 1 and 5(1) of the Choice on this Act. The bases of this application to declare the said sections unconstitutional are as follows:

- The specified provisions of the Act should not allow women under the age of 18 years to choose to have their pregnancies terminated without –
  - (a) the consent of the parents or guardians;
  - (b) consulting the parents or guardians;
  - (c) first undergoing counselling, and (d) reflecting on their decision or decisions for a prescribed period. The measures in (a) to (d) are for the sake of convenience collectively hereafter referred to as parental consent or control.

The Christian Lawyers association motivated that young women or girls below the age of 18 years are not capable on their own, that is, without parental consent or control to take an informed decision as to whether or not to have a termination of pregnancy which serves their best interests. The following sections of the Constitution were presented by the Association as point of reference for the alleged unconstitutionality of the sections in the Choice Act:

- Section 28(1)(b): Every child has the right to family care or parent care.
- Section 28(1)(d): Everyone has the right to be protected from maltreatment, neglect, abuse or degradation.
- Section 28(2): A child's best interests are of paramount importance in [*17] every matter concerning the child.

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[79] 2004 (10) BCLR 1086 (T).

- Section 9(1): Everyone is equal before the law and has the right to equal protection and benefit of the law.
- Section 7(1): 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.

The defendants filed an exception against the plaintiff's particulars of claim on the ground that the particulars of claim do not disclose a cause of action.

Judgement

The court dismissed the plaintiff's claims and upheld the defendants' application of an exception. The Court held that the plaintiff's claims that young women are unsafe in the face of the provisions of the Choice Act are not correct. It further held that:

> "*Women or girls under the age of 12 are not unprotected for as long as they are incapable of giving informed consent. What is more, the legislation makes provision to ensure that all young women or girls below the age of 18 are encouraged to seek parental support and guidance when seeking to exercise the right to reproductive choice. The constitutional right of a pregnant child to family or parental care (section 28(1)(b)) is therefore not denied. It is accommodated but not imposed. It is given effect to under the Act in a manner that does not seek to negate other constitutional rights including the right to equality before the law, to equal protection and benefit of the law as well as the right to termination of pregnancy itself*."

In the light of the above judgment, it follows that the courts are more lenient to the rights of the recipient of healthcare goods and services when interpreting the law. This position is preferred because it is in line with the constitutional provisions with respect to healthcare administration.

## 3. Consent and the administration of Criminal Justice

The need for an effective criminal justice means that the police may not be hindered in the process to collect evidence or arrest suspects, for as long as such activities are carried out in a lawful manner. With respect to effective criminal justice, the Constitutional Court in *Democratic Alliance v President of the Republic of South Africa and Others* held that,[80] "the attainment of an effective criminal justice system is in turn vital to our democracy." The issue of contention arise when the need to ensure effective justice system, through collection of evidence from the body of a suspect, needs to be balanced with the right to bodily integrity. A good example is where the policy needs a suspect to undergo surgery so that they can test at whether the bullet lodged in the suspect's body puts him or her at a scene of crime. This issue arose in the case of *Minister of Safety and Security v Xaba*.

### 3.1. *Minister of Safety and Security v Xaba*[81]

Facts

In *Xaba*, a suspect who was admitted in a hospital as a patient had a bullet lodged in his body and refused to undergo an operation to remove it. The police had waited for the doctors to remove the bullet so that they can run tests to confirm if the bullet places the suspect at a scene of crime which involved hijacking of a motor vehicle. Since the suspect could not give consent for the doctors to perform the operation, the doctors could not act against the patient's will in fear of violating his right to bodily integrity as contained in section 12(2)(b). The Minister of Safety and Security applied for a rule nisi in which he sought to compel the suspect to submit himself for removal of the bullet. The applicants relied on section 27 of the Criminal Procedure, which provides power to the police officials to use force in certain situation, and section 37 which authorizes any police official take such steps as he may deem necessary in order to ascertain whether the body of any suspect or arrested person has any mark, characteristic or

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[80] [2012] ZACC 24.

[81] [2002] (2) SA 703 (D).

distinguishing feature or shows any condition or appearance. The suspect, Mr Xaba, refused to submit to the operation for the removal of the bullet based on section 12 which guarantees the right to freedom and security of the person, particularly the right to bodily and psychological integrity.

Judgment

The Court held that section 37(1)(c) was not intended to give police official the power to empower a medical practitioner to do an operation on the suspect so that he can access the bullet lodged in the suspect's body. However, the Court clarified that section 37(1)(c) only empowers the medical practitioner to perform specific procedures when so requested by the police official. Furthermore, the court held that section 37(1)(c) does not intend to allow a police official to empower a medical practitioner to perform an operation under general anaesthetic. According to the Court, this section only grants the general practitioner to perform certain activities on request by the police official limited to surgery associated with the taking of a blood, for example. The Court noted that confirmation of such power as granted in *Minister of Safety and Security v Gaqa* is wrong.[82]

From the above judgment, it is clear that consent is indispensable in the realisation of the right to bodily integrity. Although the rights in the Bill of Rights can be limited in terms of the law of general application such as legislation, the above judgment serves as proof in that the pursuit of such proof must be approached with a great caution. In the case of *Xaba*, it may seem that the Court unfairly ruled against the police minister from applying the provisions of sections 27 and 37(1)(c) in order to have the criminal justice realised. However, the position of unfair ruling would not hold water in the context of the facts of the matter.

### 3.2. *Minister of Safety and Security and Another v Gaqa*[83]

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[82] 2002 (1) SACR 654 (C).

[83] 2002 (1) SACR 654 (C)

## Facts

The Respondent, Mr Qaqa, was suspected to have been involved in a crime of scene where two men, Boesman and Bangani, were murdered through gun shots. The suspect was also shot and had a bullet lodged in his leg. The police official investigating the matter learnt from some informants that the suspect in question was involved in the murder of two men and had a bullet lodged in his leg. Due to fear of records that could lead to his arrest, the suspect never went to any hospital for any treatment or removal of the bullet from his leg. When he was arrested by the police at New Crossroads, at first the suspect said that he was injured with a screwdriver by someone who interfered with his girlfriend at the Zama Tavern, and that he was treated at GF Jooste Hospital. There were no records of his admission at GF Jooste Hospital. The police officials took the suspect to Dr Linda at Goodwood to have him examine the suspect's wounds. Dr Linda noted that the suspect's wounds were septic bullet wounds which were never professionally treated. The suspect later informed Dr Linda that he did not want the bullet in his leg removed. The suspect then changed his version and said that he was indeed shot by an unknown person in Gugulethu and that he could not report the incident as the perpetrator had apologised. Given that the informants had no credible evidence of the assailant of the two murdered men, the police had to rely on the evidence of the bullet.

Captain Frans Maritz of the Police Forensic Laboratory confirmed that if the bullet was removed he would tell if it was fired from the gun of one of the murdered victims. In his report, an orthopaedic surgeon, Frans Steyn, informed that the removal of the bullet would be relatively simple and safe to remove under general anaesthetic. The suspect then kept on changing his version of how he sustained the injuries in his leg, and further insisting that he was treated in GH Jooste Hospital whereby he is not sure if his friends reported him under the correct name. His last version was that he got shot at Strandfontein beach on 1 January 2002. The suspect objected to the removal of the bullet and argued that the bullet was not endangering any of his blood vessels or bone structure. He argued that it was unnecessary for the bullet to be removed and that the application to compel him to submit to the surgical removal of the bullet violated his constitutional rights.

## Judgment

Desai J observed that the proposed surgical intervention to remove the bullet from the suspect's leg, without his consent, would undoubtedly be a serious affront to the respondent's human dignity and an act of state-sanctioned violence against his bodily and psychological integrity. However, the Court held that there was little danger or any harm to the respondent when the bullet is removed. Desai J noted that the decision to go against the respondent's refusal to tender consent for removal of the bullet is based on the fact that the current matter involves serious crime of double murder. The limitation of the respondent's rights in terms of section of 36 of the Constitution made more sense to the Court. Desai J held that the interests of the community to punish crime were more important than the respondent's individual rights.

## Discussion of the Court Decisions in *Xaba* and *Gaqa*

The decision of *Gaqa* was handed down a year before the decision of *Xaba*. However, the two decisions provide two different precedents relating to the protection of informed consent. In *Gaqa*, the Cape High Court upheld the application to have the respondent submit to surgical operation in which a bullet that would serve as evidence in the murder to two human beings would be removed. It is clear that the surgical operation was violation of the respondent's right bodily and psychological integrity as contained in section 12(2)(b) of the Constitution. In *Xaba*, the Court declined to follow the reasoning in *Gaqa*. The only distinguishing factor is that the case of *Xaba* involved moto-vehicle hijacking whereas the case of *Gaqa* involved the murder to two men. "The severity of the crime, according to the judgment in *Gaqa* is a factor to be taken into account when being asked to authorise surgery on a suspect against his will."[84] In view of the above two decisions, it is clear that an individual's right to refuse to grant informed consent can always be limited in favour of the interests of the community to punish crime and to

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[84] Carstens and Pearmain, (2007), p 980.

ensure effective justice system. It is submitted that the decision of the courts are swayed by the circumstances and factors of each individual case. It is further submitted that, the doctors in such instances, have little room to ensure effective shared consent in that they are acting under compulsion to fulfil the court orders.

## 4. Conclusion

In conclusion, there are contentious instances in the South African society in which informed consent forms the crux of arguments before the courts. In such instances, the courts need to tread very carefully to balance an individual's constitutional rights against the interests of the community, for example for preservation of children's rights or ensuring an effective justice system. It is extremely difficult for medical professionals to ensure shared consent in that the instructions for doctors to treat an individual flow from the court. With regard to matters that involve termination of pregnancy, the courts are of the feeling that the fact that the system does not violate the rights of women under the age of 18 years because medical professionals are authorised by the law to terminate pregnancy even where such women do not want to involve their own families. In such instances, the medical professionals have a huge role to ensure that shared consent is administered before the procedure is carried out.

In *Xaba and Gaqa*, the question was also on whether the provisions of section 27 and 37 of the Criminal Procedure Act provide for medical intervention in which the police officials seek to extract evidence from the body of the suspect. The above two cases indicate that in some instances, as in the case of *Gaqa*, the interests of the community to punish criminals could be preferred against the individual's rights to bodily and psychological integrity. In other instances, like in the case of *Xaba*, the rights of an individual would weigh against other interests.

# Chapter 5

# Recommendations and Conclusion

## 1. Introduction

In the preceding chapters, some challenges with respect to the development of shared consent were outlined and critiqued. Most of these challenges were particularly observed in chapter 3 where the South African legislation that governs consent was compared to those of other countries. One of the major challenges outlined about the South African healthcare system with respect to the effective development of shared consent is lack of the entire Act that deals specifically with consent. In this chapter, some recommendations concerning the development of shared consent are suggested. This chapter also draws conclusion on the rest of the work.

## 2. Recommendations

It should be noted that some suggestions were outlined in the preceding chapters where challenges with respect to share consent were discussed. In this section, some additional recommendations that are considered pivotal for the development of shared consent are presented.

### 2.1. Encouraging Patient Participation

It is inevitable to engage patients in process to administer healthcare products and services as the engagement forms the cornerstone of health reformation. “Patient engagement is an increasingly important component of strategies to reform health care.”[85] Furthermore, research indicates that, “patients who do not understand or accept that they have an important role working with their provider to maximize their health are

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[85] J.H. Hibbard and J Greene, What The Evidence Shows About Patient Activation: Better Health Outcomes And Care Experiences; Fewer Data On Costs, Health Affairs, Volume 3:2, February 2013, p 207.

less prepared for provider visits than patients who are engaged."[86] The absence of active partnership between patients and healthcare providers not only leads to delayed medical care, but it can also trigger to less than ideal health outcomes and unsatisfied medical needs. As research further proves, "low patient engagement is also linked with increased medical costs and *lesser* preventive behaviours compared with patients with high levels of activation and engagement."[87] In other words, without patient participation, shared decision-making is unattainable.

## 2.2. Appropriate Use of Healthcare Resources

Before resources can be used, they first have to be available. As observed in chapter 3, countries such as Canada with the most advanced shared consent programs in place, have adequate funds channelled into their healthcare system. It is suggested that South Africa should develop a model of funding that prioritize patient rights through participation in their medical treatments and participation.

"In the long-term, shared decision-making might lead to changes in resource utilization, perhaps to reductions in cost, and to modification of workforce composition."[88] It is therefore submitted that investment of adequate resources in the health sector with respect to the development of shared consent is likely to lead to affordable quality services.

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[86] Agency for Healthcare Research and Quality (AHRA), Shared Decision-Making to Improve Patient Safety, Education, and Empowerment, *James Madison University*, (2016), p 1 – 2. Available on: https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/shareddec-1.pdf. Accessed on: 10 October 2018

[87] AHRA, (2016), p 1 – 2.

[88] Glyn Elwyn *et al*, Implementing Shared Decision-Making: consider all the Consequences, *Implementation Science*, 2016. Available on: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4977650/. Accessed on: 11 October 2018.

## 3. Conclusion

In this work, it was argued in chapter 1 that obtaining the consent of a patient is at the centre of medical practice and as such medical practitioners need to ensure proper patient's approval in the administration of medical services or prescription of medical products. Informing a patient about the medical implications involved in the procedure they are about to undergo is not sufficient as patient needs to be fully engaged. The transcendence beyond informed consent delineates shared or dynamic consent in which patient autonomy is entirely prioritised. It also delineates the amplification of an enhanced doctor-patient partnership that is centred on the patient's rights, and automatically total eradication of medical paternalism. Shared decision-making requires that medical practitioner and patients discuss the diagnoses as well as treatment options available for the patient. In such a discussion, the final decisions lies with the patient, and the doctor has a duty to take all the steps to ensure the availability of the necessary information to the client and to inform the patient of his or her right to make further consultation.

In South Africa, there are some issues of contention in which consent can flow from court orders. With respect to those issues, for example termination of pregnancy, it is extremely difficult for medical professionals to ensure shared consent in that the instructions for doctors to treat an individual flow from the court. With regard to matters that involve termination of pregnancy, the courts are of the feeling that the fact that the rights of women under the age of 18 years should be protected where such women would not like to involve their own families. Medical practitioners are also compelled in some instances to operate suspects with items lodged inside their bodies where such items would serve as evidence. In such instances, the interests of the community to punish crime are said to be more important than the suspect's right to bodily and psychological integrity.

It is suggested in this work that South African needs to develop legislation that regulate consent across a full spectrum of clinical treatments and provision of healthcare products. Such legislation, similar to the Canadian Health Care Consent Act of 1996, would ensure an effective development of shared consent.  It was noted that a proper development of shared decision-making requires effective funding models similar to those of Canada, USA and UK.

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