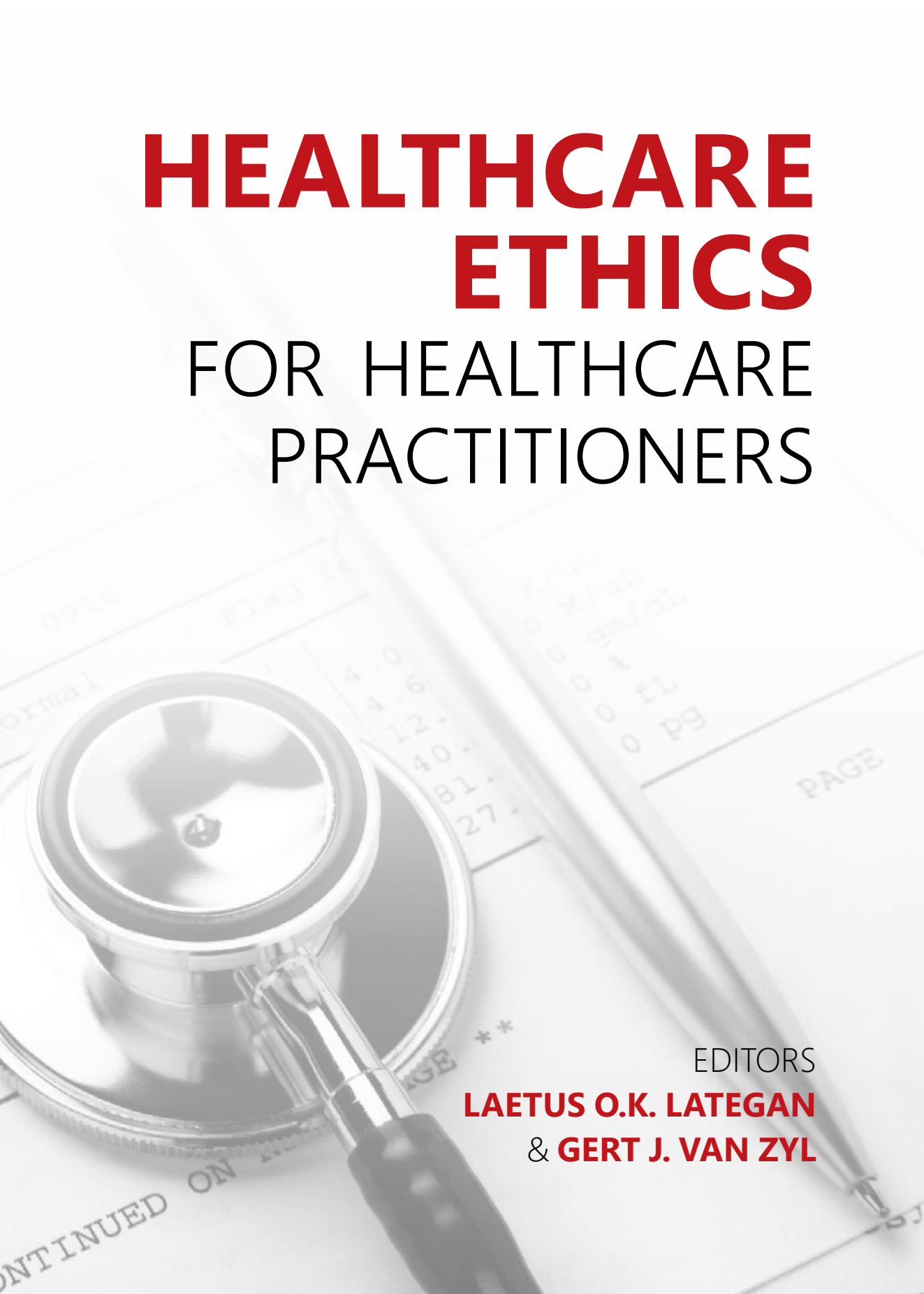


HEALTHCARE ETHICS

FOR HEALTHCARE
PRACTITIONERS



EDITORS

LAETUS O.K. LATEGAN

& GERT J. VAN ZYL

sb

Healthcare ethics for healthcare practitioners

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HEALTHCARE ETHICS

for healthcare practitioners

Laetus O.K. Lategan & Gert J. van Zyl

EDITORS

sb **SUNBONANI
SCHOLAR**

“Science and technology are not embedded in machines, they are embedded in people, and minds are usually connected to bodies”

M. Castells

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*“To understand medicine better, therefore,
we need to explore the way in which
science functions, and to confront the
technologically-based world”*

D.G. Jones



ORIENTATION

The need for healthcare ethics

Laetus O.K. Lategan and Gert J. van Zyl

1. BACKGROUND TO THE BOOK PROJECT

The debate on and interest in ethical challenges in healthcare is not new. Evidence for this comment can be found in (the earliest) recorded medical-ethical codes such as the Hippocratic, Helsinki and Geneva Codes. These codes are further supplemented by reports from the World Healthcare Organisation (WHO) and a continuous debate on how best to provide healthcare in a global environment. The challenge is well described by Ten Have (2011) who identifies the different meanings attached to bioethics in different countries and different health systems because of technological developments, socio-economic needs and developments stimulated through business and industry partnerships (especially pharmacology).

A common observation deriving from these codes, reports and debates is the *ethical vulnerability* from which healthcare practitioners are currently suffering. As a result of ethical vulnerability, healthcare practitioners often find it hard to deliver quality-based healthcare.

Ethical vulnerability is closely associated with four dominant influences on healthcare. These influences are:

- *Healthcare is unthinkable without modern technology.* Thanks to technology, the so-called “*machbarkeit aller dinge*” influences healthcare practices. Three different opinions portray the impact technology has on healthcare: Consider the following opinions: We should not do everything that we are able to do (Jan-Hendrik van den Berg, 1969); we should do everything we can do (R. du Jardin) and technology is in service of life (Echbert Schuurman, 1995).
- *Medical economy (medical industry):* The pharmaceutical industry sparks questions with regard to medical insurance and business ethics. The question is correctly asked: *What is at stake: health improvement or profit margins?* This is closely related to consumerism in healthcare. Typical debates are around *needs* versus *wants* in healthcare, substitution, replacement and make-over.
- *The democratising of healthcare systems:* Equality and access to basic health and healthcare systems open challenges such as *affordability, necessity* and *quality*. At the same time a debate on e-medicine, e-health and tele-medicine is opened.
- *Slow living as a contra culture:* Slow living is a post-materialistic culture advocating a return to a holistic lifestyle, and looking at how we live and what we consume. It advocates sustainability of communities, happiness (“the real good life”) and harmony between people and their habitat (as collective for work, home and social networks, interaction and support).

Ethical vulnerability necessitates a new understanding of *healthcare ethics*; its meaning(s) and application(s). In addition, a post-religious and post-structural world together with a technological-driven society, require a new understanding of the healthcare environment.

Healthcare ethics is trans-disciplinary of nature and transcends the common dictums of *do no harm, do to others as to yourself* and *be your brother/sister's keeper*. Healthcare ethics calls on stewardship ethics where you care for something as if you own it. In addition, healthcare ethics is challenged through questions such as: are we caring for patients because of a social contract between healthcare worker and patient? human and constitutional rights? humanitarian or religious conviction and/or professional calling?

It should be obvious that (healthcare) ethics is more than moral *behaviour* (expected reactions and behaviour) or the *application* of norms and standards. Healthcare ethics depends on a *cosmological understanding of ethics* [Kobus (J.H.) Smit, 1985], *informed decisions* (Joseph Badaracco, 1998), *responsible acts* (Joachim Douma, 1999), *ethical relations* (Paul Schotmans, 2012) and *ethical growth* (Roger Burggraeve, 1997).

2. OBJECTIVE OF THIS BOOK

This book promotes the argument that modern day healthcare ethics cannot be limited in scope to apply only to the patient but needs to apply to the healthcare practitioner as well. Healthcare practitioners include doctors, professional nurses and therapists. The relationship between the patient and the healthcare practitioner has shifted from a *power relationship* (the healthcare practitioner has the knowledge and skill to cure, care, heal, support and comfort) to a *complementary relationship* (mutual respect, acknowledgement of individual interests). Leadership, mentorship and coaching play an important role in facilitating this shift.

In the debate on healthcare ethics we need to consider questions relating to: the preservation of life; the uniqueness of people, their personal values, faith and traditions; the protection of dignity, welfare, personal security or safety; freedom of choice and informed consent; the enhancement of basic medical care; affordability, economies of scale and consumerism; professional attitude and patient privacy, shared information on therapies; potential risk and value of therapies and treatment, coaching, leadership and mentorship.

3. OUTLINE OF THE BOOK

Several themes informed this book on healthcare ethics. The themes are:

- Vulnerability in healthcare ethics
- Decisions between right and wrong
- Quality of care
- Life-ending decisions

THE NEED FOR HEALTHCARE ETHICS

- Research involving the community
- Making ethical choices
- Spirituality in healthcare

The focus of the book is to contribute towards a new understanding of healthcare ethics and how to deal with healthcare practitioners' ethical vulnerability in a post-religious, post-structural, technology-informed and human rights-driven society.

This book suggests guidelines to the patient and healthcare practitioner and invites an engaged dialogue between patients, healthcare practitioners, healthcare managers and administrators, and habitats supporting the people working in healthcare and the people who benefit from healthcare.

REFERENCES

- Badaracco, J.L. 1998. Business ethics: roles and responsibilities. St Louis: McGraw-Hill.*
- Burggraave, R. 1997. Een christelijke ethiek van het haalbare. In Wuyts, B. (red.). De geest rust nooit: Gelovigen in beweging. Kapellen: Patmos. 143-152.*
- Douma, J. 1999. Grondslagen christelijke ethiek. Kampen: Uitgeverij Kok.*
- Schotsmans, P. 2012. In goede handelen. Tiel: Lannoo.*
- Schuurman, E. 1995. Perspectives on technology and culture. Potchefstroom: IRS.*
- Smit, J.H. 1985. Etos en Etiek. Bloemfontein: Patmos.*
- Ten Have, H. 2011. Bioethiek zonder grenzen. Mondialisering van gezondheid, ethiek en wetenschap. Nijmegen: Valkhof Pers.*
- Van den Berg, J-H. 1969. Medische macht en medische ethiek. Nijkerk: Callenbach.*



CHAPTER 1

An introduction to healthcare ethics

Laetus O.K. Lategan and Gert J. van Zyl

1. CONCEPTUALISATION

The concept “ethics” finds its origin in the Greek *èthos* and/or *êthos*. These words refer to custom, practice, attitude and motive and relate to universal principles for moral human behaviour and the subsequent identification and application of norms or values derived from these principles. Essentially ethics refers to people’s moral behaviour following on a particular value system. Behaviour is informed by their deepest motivation, also known as *ethos*. The application of a principle is commonly referred to as *norms* or *values*.

In view of these concepts can healthcare ethics be defined as the identified principles informing the moral practices and behaviour of healthcare practitioners towards patients and the application of the values and norms in the performance and execution of healthcare. Ethics influence both healthcare practitioner and patient. In addition, ethics is also extended to healthcare management and administration, and to the habitat supporting healthcare practitioner and patient. This view corresponds with Glouberman and Mintzberg’s (2001) identification of the “four worlds” in healthcare: *cure, care, control* and *community*. [See Chapter 2.2 for a description of these four worlds.]

The working definition of healthcare ethics in this book is the *identification of principles and the application of values and norms informing the practice of healthcare*. The scope of this definition will cover the four worlds associated with healthcare, namely cure, care, control and community.

2. ADDRESSING THE MAJOR THEMES IN HEALTHCARE ETHICS

A central theme in this book (see Introduction and Chapter 2) is that healthcare ethics *cannot be limited in scope to apply only to the healthcare practitioner or only to the patient*. In addition, healthcare is not restricted to the *conventional settings* of hospital, clinic or hospice only.

A “site” that cannot be overlooked is the practice of healthcare within a *community* – as part of basic healthcare or a context for research. Healthcare ethics deals with vulnerable people (healthcare practitioners, patients, communities), situations and institutions (healthcare management and administration). It is for this reason that Lategan (Chapter 2) and Vanlaere and Burggrave (Chapter 4) deal with vulnerability and ethical relationships at length. Lategan’s arguments informed the three positions taken in this book (the scope of healthcare ethics, the context for healthcare ethics and the encompassing influence of vulnerability on healthcare ethic). In addition a cosmological understanding of healthcare ethics is presented. In this presentation it is evident that ethics is always defined within a particular context and that regardless of religion and/or cultural orientation, there are universally accepted principles, values and norms that inform healthcare ethics.

It is therefore expected that (healthcare) ethics entertain the difference between right and wrong. Van Zyl and Van Zyl (Chapter 3) argue that this differentiation is not that simple, and for the health

professional, may be more complex than what is sometimes envisaged. Ethics is particularly applicable to the professional practice of medicine in guiding decision making within the doctor-patient relationship, and protecting self-directedness for the patient in an essentially unequal power relationship. The maintenance of the reputation of the individual practitioner and the medical profession as a whole are important. The links with freedom, ethics, morality and professionalism are explained and some solutions are suggested. One of these solutions is the “*patient charter*”. Ethics is the formal expression of values and norms that a profession or business or other societal structure selects and prioritises to ensure a particular standard of moral decision making and to protect their reputation. It is ethics that transforms the subjective nature of right and wrong to an objective measure of moral behaviour.

Vanlaere and Burggraeve (Chapter 4) add a specific understanding to healthcare ethics. They approach healthcare from a quality-of-care perspective. It is evident that today, more attention is given to the quality of care than ever before. These authors link this interest to the greater emphasis that is placed on service delivery because of safety requirements and to the impact that good or poor healthcare delivery can have on healthcare systems. This raises the question as to what *quality* is when it comes to healthcare. For them quality demands an increase in carefulness, with its objective means and methods, and an increase in caring, with its subjective attitudes and virtues. This has a direct impact on professionalism and responsibility. As a result healthcare must be seen as a relationship and not a product. Hence an ethical framework has to inform healthcare regardless of the context and situation.

This relationship is based on an ethical obligation for healthcare practitioners to provide culturally competent, patient-centred care. MacKinnon and Comer (Chapter 5) claim that in order to do so, healthcare practitioners need to be aware of patient and family culture, values, and faith-based beliefs as they will impact end-of-life decisions, to mention but one scenario. Additionally, the culture, values and faith beliefs of the healthcare practitioner will also affect end-of-life decision making, and sometimes these two entities collide. In this chapter the authors provide some guidelines to consider in working together to make culturally sensitive end-of-life decisions. It is also evident that healthcare cannot be removed from a human rights point of view. Moore’s contribution (Chapter 6) supports the notion that medical issues belong within a human rights culture. It is this culture, with its universal principles, that contributes towards the care of patients and the security of their well-being. To illustrate this point, Viljoen (Chapter 7) deals with euthanasia in a South African context. She points out that although a case can be brought before court and assisted life-end euthanasia can be granted, it still leaves the healthcare practitioner and patient in a vulnerable position. This proves the point that although an act may be legal, it does not safeguard the individual or enable the individual to be at ease with such an act.

AN INTRODUCTION TO HEALTHCARE ETHICS

In healthcare the focus is very often on the healthcare practitioner and the patient only. A neglected topic in healthcare ethics is how do we deal with communities? Lewitt, Campbell and Cross (Chapter 8) address this issue by focusing on community-based participatory research (CBPR). In CBPR community participants are actively engaged with, and influenced by, all aspects of the research process, from design to dissemination. There is a commitment to practical change in this strength-based approach, which builds trust, enhances community capacity and may lead to solutions to complex health questions that were unforeseen by the academic researchers. As healthcare research moves from working 'on' communities to working 'with' communities, a concomitant shift in the ethical orientation of healthcare practitioners is required. CBPR requires an awareness of power relationships between healthcare practitioners and the community members or service users. In CBPR the whole community should be considered the subject of research and ethical considerations should encompass respect for community as well as individual autonomy. When working with children there is a further need to work sensitively with power dynamics.

Kruger (Chapter 9) is right when he remarks that healthcare is not a new concept and several modules are available to assist the healthcare worker with the decision making process. However healthcare is a very dynamic field, causing the ethical decision making competency of healthcare workers to become more and more important but also more challenging. The healthcare worker should be aware of how changes within healthcare could influence the ethical decision making process. Healthcare workers should be aware of the multifactorial approach that is needed within the decision making process. It is recommended that an integrated approach be followed in which the healthcare worker should consider following a systematic analysis of the ethical issue at hand. The purpose of such an integrated approach is to ensure that the ethical decision making process is conducted by means of a simplified step-by-step approach. Healthcare workers must remember that they do function within a multidisciplinary team. However, the final ethical decision is essentially an individual process and the healthcare worker will take responsibility for the entire ethical decision making process no matter what approach is followed. The outcome of their ethical decisions might have a much more far-reaching effect than expected.

Another neglected theme in healthcare ethics is spirituality. This should not be confused with religion or faith. Swart (Chapter 10) unpacks this important theme and explains how spirituality can assist with the healing of a patient but also how religion and faith can open existential issues in healthcare that should be part of the holistic treatment of a patient. As healthcare practitioner, patient, healthcare management and administration and habitat may not share the same spirituality, religion and/or faith, all of those involved in healthcare should guard against making spirituality, religion or faith the condition for treatment rather than a consideration in healthcare.

3. AN OUTLINE OF HEALTHCARE ETHICS

Based on the discussion of what healthcare ethics is, the following outline for healthcare ethics can be presented:

- Healthcare ethics is the identification of principles and the application of values and norms informing the practice of healthcare. It aims to transform a situation and to bring about a change in attitude, behaviour and practice.
- Healthcare ethics cannot be limited to the patient only but covers four worlds associated with healthcare, namely cure, care, control and community.
- Vulnerability includes human experiences such as ethical decision making, physical suffering, psychological disorders, economic challenges and cultural orientation. It goes without saying that every person is dependent upon other people's understanding of his/her vulnerability and therefore his/her care. In a medical context it is about caring for life, health, state of mind and general well-being.
- Quality healthcare is important due to safety associated with the healthcare value chain. The core of this value chain is not healthcare as a product but healthcare as a relationship.
- Healthcare ethics is informed by family, culture and religious values. Although a healthcare practitioner may not share those same values, people's values should be respected and accommodated in the practice of care and decision making. The healthcare practitioner deserves the same respect for his/her values as does the patient.
- Healthcare ethics can never be removed from professional practice. Healthcare ethics should form part of healthcare education for professionals and healthcare ethics orientation for patients and their habitat.
- Part of extending our understanding of healthcare is to do research within communities. This often presupposes a power relationship between those who know and those from whom the information is gathered. This situation opens the possibilities of power play and vulnerability. In dealing with communities the primary objective should remain, namely the preservation of the dignity of all involved in a project. This can be facilitated by shifting the emphasis from research *on* to research *with*.
- Legality can never be removed from healthcare. It does not, however, remove ethical responsibility from healthcare. The law dictates what can be done, while ethics informs how it should be done.

AN INTRODUCTION TO HEALTHCARE ETHICS

- Ethical decision making cannot be avoided. Although informed decision making is the cornerstone of ethical behaviour, proper guidance is needed to make the 'best interest' decision to address the ethical challenges of a particular situation.
- Spiritual needs and religious orientation should be integrated in healthcare but cannot form the basis for effective healthcare.
- Healthcare practitioners, managers and administrators should be trained, mentored and coached in dealing with healthcare ethics. Patients and their habitat should be sensitised regarding the ethical rights and responsibilities of healthcare practitioners, managers and administrators.

REFERENCES

Glouberman, S. & Mintzberg, H. 2001. Managing the care of health and the cure of disease. Part 1: Differentiation. Health Care Management Review. Winter 56-69.



CHAPTER 2

Unpacking vulnerability in healthcare ethics

Laetus O.K. Lategan

1. VULNERABILITY – A MULTI-PERSPECTIVE REALITY

In a case study entitled, “*The Serphent was here*” an account is given of an encounter in a repository of medicine which resulted in the patient’s blindness. A bottle was wrongly labelled.

The case study reported by Badaracco (1998) illustrates four challenges: a patient believes that the Serphent has visited her (the Serphent, being associated with the “devil”, symbolises punishment because of the wrongful personal life (personal ethics, religion) of the patient); a medical practitioner blames himself for his negligence and oversight; the hospital’s superintendent realises that this may be the end of this American support programme in his country because of a mistrust that existed even before this incident; and the community’s distrust has been confirmed by the misfortune.

The ethical dilemma is on truth telling because of vulnerability. If this event were to be made public it could bring an end to the work of this non-profit organisation which has been providing modern treatment for surgical disorders. The dilemmas are whether the patient should believe that the blindness was caused by the Serphent, in which case there is at least a chance to continue with this programme, or should the risk be taken and the beans be spilled, even though this might bring an end to a programme from which many people have already benefitted. Depending on the angle from which one is looking, different answers may be given (see Lategan, 2002).

In reading this case study it is evident that people (regardless of their position) are vulnerable. Vulnerability can be caused by a real life incident (an incident in a repository of medicine, for instance), inability to help (the doctor’s dilemma) or mistrust from/in/of people, a programme or a situation (foreign medical assistance, for example). The case study confirms that it is not only health challenges that contribute to people’s vulnerability but the way in which the treatment is experienced. In addition it is evident that neither medical staff, medical organisation nor the community in general can escape the vulnerability of ethical dilemmas in healthcare.

In looking more deeply into these ethical dilemmas, one cannot escape the fact that vulnerability is part of human existence. When people are faced by a situation (read illness) in which they are no longer in command (for example, people cannot heal themselves), this is when they realise their own vulnerability. When we observe people with their physical, emotional and human needs, then we note their vulnerability. It is therefore no surprise that ethics has as its “first” dictum not to do any harm and, by implication, to care for other people. *Do no harm* is coupled with *do to others as they should do to you*.

The implication is that vulnerability is a *multi-perspective* occurrence. Hence, vulnerability should be viewed from different perspectives. The intention is to promote the argument that vulnerability

is not limited to patients only and that a multi-perspective view on vulnerability in healthcare ethics can contribute towards constructive guidance for everyone dealing with vulnerability in healthcare.

2. VULNERABILITY IN HEALTHCARE ETHICS – A PERSONAL ACCOUNTABILITY

As a student of medical ethics I was interested in three major issues: questions around *the beginning and ending of life*; questions around *ethical decision making where there is an ethical conflict of interest* and *how societal developments impact on our understanding of illness and consequently how patients are treated* – especially the vulnerable because of poverty, war and life experience.

These questions remain valid due to the ongoing ethical challenges associated with them.

To begin with, the abortion and euthanasia debates are good examples of ongoing ethical dilemmas. Legislation in South Africa moved from no abortion on demand (Act 2 of 1975 – *Abortion and Sterilisation Act*) to abortion on demand (Act 92 of 1996 - *Choice on Termination of Pregnancy Act*). Following a lengthy debate on active and passive euthanasia, the question of *ending life on request* has also now emerged in South Africa (in Chapter 7).

My interest in medical ethics was initially stimulated by four powerful events which influenced my research, doctoral studies and own knowledge of healthcare ethics. I will not be giving a detailed account of these events in this publication, it being sufficient to mention that the events themselves contributed to shaping my own comprehension of healthcare ethics. The mentioned events led to a shift in my own original orientation and to my quest for an in-depth understanding of healthcare ethics. To unpack these comments, the following highlights from these events can be reported:

- For some length of time I was exposed directly to vulnerable people. Their vulnerability was caused by illness, poverty, the South African border war and political unrest. I observed how life events caused people to lose trust in themselves, other people and political systems. The lack of money increased the mistrust the vulnerable people had because sometimes they could not afford basic food and livelihoods, let alone access to medicine and medical treatment. In anecdotal fashion, elderly people commented that their children, family and friends disregarded them and very often they were treated as if they no longer had the ability to make any decisions for themselves. Their lives had in effect been taken over (for geriatric references see Holtzer, 2015 and Vanlaere and Gastmans, 2010). Soldiers in the border wars and police in public unrest situations very often questioned the cause but had limited choices as the ideology of the day was informing/legitimising what they were doing. Victims, including the military and police, of global terrorism since 9/11 have opened this debate

again. A relevant example is the increase in hand surgery needed as a result of explosions and fire because of combating international terrorism. As people age, there is a decline in ability and impetus. In the book of Ecclesiastics in the Bible, the Teacher describes aging and vulnerability in a poetic manner: the weaknesses of old age are described in terms of weakness in human, spiritual and sexual abilities, and life's end is compared to a broken bowl – it cannot be used for anything anymore. It was Alexander Strachan's book, "Verste Grens", that established the concept that war is not limited to a physical place, but rather that it is something that is within ourselves: he describes events that culminate in the realisation that people are vulnerable, especially in situations where events (read medical challenges) beyond their control have taken charge of their lives. These are the influences that have contributed to my desire to understand healthcare ethics and to know how to deal with vulnerable people.

- The seeming contradiction between power and care presents two sides of a single theme. Power represents strength, domination, authority and dominance whilst care embodies maintenance, attention, repair and concern. It was this seeming contradiction that appealed to me and sparked the question of whether care can be provided outside the basis of power. Typical examples are the sophistication of medical technology (see for example Schuurman) and the fear of technology especially where there has been limited exposure to technology by, for instance, a patient, in a situation of communication between patient and doctor, nurse and healthcare worker; there may be little or no basis for common understanding because of the lack of exposure to technology on the part of the patient. The situation may be exacerbated in situations where gender inequality exists: not everyone is prepared to be treated by a female doctor, and an elderly person may not be comfortable taking advice from a much younger doctor. In a South African context, Phalime (2014) gives a good account of such dilemmas in her book: *Post-mortem: the doctor who walked away*. She notes how language inability adds to people's vulnerability. This occurs when there is limited communication between doctor and patient in situations where, for example, they cannot speak each other's language. How do you explain your challenge, or how do you respond to questions if you don't understand what is being asked? Furthermore, people fear technology if it is unfamiliar to them. If a patient lives in a remote area and has never been exposed to technology, he/she may not be able to comprehend its benefits, and may well be afraid of it. Differences in culture, life orientation and experience can leave people in extremely vulnerable positions. Jan-Hendrik van den Berg's (1969) question as to whether we should do everything that we are able to do, lends a further dimension to the situation. The essence of this question hints at the fact that ability (read power) is not without ethical challenges. A good example may be genetic engineering (power): is it ethical to create the proverbial Frankenstein monster? Another example is the question of whether a person has the right to make decisions about his/her own death, and whether he/she may or may not decide to end his/her own life with

medical assistance. Considering the contradiction between power and care sensitised me to the fact that without power (for example in the form of money, or well-trained officials) government cannot deliver basic healthcare. Poor service delivery (either through misuse of service, position and situation) can derail care and contribute towards increasing people's vulnerability. Well-known examples are hospitals that cannot optimise performance due to mismanagement or no management at all, and patients being, ill-treated, injured or even raped, for example.

- Due to an emerging healthcare economy (see Remans, 2005) and the rise of managerialism in healthcare (see for example Glouberman and Mintzberg, 2001 and Creplet, 2013), a gradual shift has taken place from care for the patient to care for the organisation. Healthcare has become a commodity of significant value for medical research, pharmaceutical companies and private service providers (see Ten Have, 2011 and Creplet, 2013). It is therefore no surprise that healthcare management has become a profession in its own right. From my observations, the traditional nurse's cloak has been replaced by a more modern, corporate image. At the same time, record keeping and control have been growing phenomena. As with any other major company, corporate governance and accountability have become the order of the day. Glouberman and Mintzberg (2001) have assisted tremendously by identifying four different "worlds" or "activities" in healthcare: *cure*, *care*, *control* and *community*. Although their analysis is given from a management perspective, it is most helpful in understanding the complexity of the healthcare system, its interrelatedness and interdependence and the impact of each of the "worlds" on each other. Glouberman and Mintzberg (2011) correctly advocated a closer link between these worlds. From a healthcare perspective, the same sentiment is echoed by Creplet's (2013) suggestion that there should be more homogeneity between cure, care, control and community. In the context of this study the cure is associated with doctors, care with nurses, therapists and carers, control with the healthcare management, and community with relatives and different stakeholders in healthcare. The case in point is simply that whether one is referring to the performing or managing of healthcare, or benefiting from healthcare, none of these should exist without the others. Linked to these different "worlds", the claim can be made that *healthcare workers* (as collective term for doctors, nurses, therapists and auxiliary workers), *patients* (regardless of the state of their health), *administrators* (as collective term for healthcare management) and the *community* (as collective term for family, friends, associates, beneficiaries of healthcare, auxiliary services) should all benefit from healthcare ethics. The shift in emphasis is also evident in what Creplet (2013) refers to as the "third revolution" in healthcare. Here technology and commercialisation impact on how healthcare is delivered. (Also see the discussion in the next paragraph on the interrelatedness of these different parties in healthcare.) This shift has also benefitted healthcare workers by acknowledging that they too, have needs. The legal and ethical debate as to whether a

nurse, for example, may go on strike, is a fair indication that healthcare workers have needs too – they too are occasionally vulnerable. Vanlaere and Burggraeve (2013) correctly refer to a situation where the healthcare worker sometimes has no other option but to behave in an unethical manner because this may be his/her last resort to raise concerns about unethical practices. The conclusion that I arrived at was that healthcare ethics can no longer be limited to the needs of the patients only but must be extended beyond this. Cure, care, control and community are all in need of healthcare ethics.

- Studies in medical ethics, sociology of medicine, philosophy and pastoral care, as well as studies of healthcare providers and systems, have created an awareness that healthcare ethics is more than merely a concept – it should be the backbone of the cure, care, control and community support provided by doctors, nurses, healthcare practitioners, managers and administrators. New developments in medicine and healthcare have revealed new challenges with regard to medical costs, treatment and legislation. Three dominant influences on healthcare are evident from these studies. The first of these is that personal life has become extremely individualistic. Because of this development, the focus is more on the individual's needs and rights, and healthcare has become more of a private matter than it was previously. Secondly, healthcare is a commodity, with profit making becoming as important as access to sophisticated healthcare and therapies. This is in sharp contrast to government's drive to promote access to basic healthcare, to regulate private healthcare providers and to steer clinical research towards addressing major health challenges such as HIV/Aids, diabetes, tuberculosis, substance abuse and malnutrition. Thirdly, there is the realisation that healthcare ethics does not only affect only the patient but all healthcare service providers, the community and stakeholders as well. Just as patients have rights, so do the people in the healthcare profession; just as patients should be treated with respect and dignity, so too should the healthcare providers; just as ethics is informing personal care, so should organisational behaviour and activities also be steered by ethical behaviour.

Subsequently in my own studies and according to my understanding of these developments and phenomena, I wrote a thesis in philosophy on the compromise in medical ethical dilemmas. Although many findings can be reported, the one I want to single out is that the compromise highlights that occasionally we need to make ethical decisions despite the fact that one has only one choice between two conflicting commitments. A typical example would be the choice to terminate pregnancy if the continuation thereof threatens both the mother and the unborn child's life. The conflict arises where the ethical imperative is to protect both the life of the mother and that of the unborn child but in this situation it is only possible to protect the life of one of the two. The compromise functions typically in a borderline situation and is associated with terminology such as the choice between the lesser of two evils. Such terminology and the fact that a person has a very limited choice in a borderline situation, emphasises the vulnerability of people.

It was Schotsmans (2012:17-22) who reminded me that healthcare is essentially based on relations. Within this relationship, accountability, responsiveness and responsibility are very important. Although general guidelines for healthcare may exist, one is always looking for guidelines informing a specific situation, the primary reasons being the uniqueness of personalities and that people are extremely vulnerable. In this context, Schotsmans (2012: 136-138) adds the importance of ethical growth since there are both limitations and opportunities. In conclusion, Schotsmans (2012: 141) states that healthcare ethics should inform, guide and provide a futuristic perspective on how to deal with human vulnerability.

The emerging question remains: who is the vulnerable?

3. WHO IS THE VULNERABLE?

The World Health Organisation (2013) defines vulnerability as an essential feature of human nature. In addition, special vulnerabilities are addressed as a consequence of personal disability, environmental burdens, social injustice or the application of emerging technologies in the biomedical sciences.

Although the common practice is to understand vulnerability in the context of patient care, it can never be limited to patient care only. In medical ethics and bioethics patients are vulnerable by default. But it would be a limitation to regard only the patient as vulnerable. The medical practitioner and healthcare workers are equally vulnerable. For many years the perception has existed that healthcare ethics focuses exclusively on what the doctor and the nurse should do/should not do (as a basic understanding of ethics), and suggests that the patient is the only one with (ethical) rights. *The patient (customer – sic!) is always right!* This perspective outlines an outdated service model (what about the auxiliary professions?) and a consumer-driven model – as if being a patient is similar to being a customer (with implications of supply and demand, quality of service, customer satisfaction, value for money, and so forth). Care however embodies vulnerability; hence you need to protect and watch over the vulnerable. Vulnerability signals weakness and calls for protection. You have to extend support to those in need of the support. But those who can care for others are very often also in need of care themselves. It would therefore be a limitation to reserve healthcare ethics only for the patient.

This is no new insight but something that we keep on overlooking. This behaviour is contradictory to the spirit of so many medical ethical codes. For example, the Hippocratic Oath, the Helsinki Declaration and American Medical Association all advocate respect for life, respect for people and respect for humanity. Although not necessarily explicitly stated, it is not only the patient that is vulnerable. Doctors, nurses, therapists, carers, family and friends are also vulnerable in the context of healthcare and cannot be excluded from consideration in the promotion of a sustainable

healthcare ethic. The fact that their ethical needs should also be treated as a priority often takes a back seat, however, when medical ethics and bioethics are discussed.

In line with this observation, one cannot but agree with Holtzer (2015), who argues that no one can claim that he/she is not involved in healthcare. This observation is imbedded in the question: *what care would you like to receive and what care would you like to extend?* Healthcare cannot be limited to medical practitioners, auxiliary healthcare professions or patients only but should involve all healthcare providers and the community.

Several scientific disciplines and professions can assist in framing our understanding of healthcare ethics. In dealing with healthcare, Holtzer (2015) discusses diversity, technology, autonomy, engagement and self-realisation. The conclusion is clear: healthcare should be understood in juxtaposition to a variety of scientific disciplines (healthcare as science), professions (healthcare worker as profession) and humanity (active engagement to improve the life of the vulnerable).

The perspective that this chapter confirms is that healthcare ethics should be extended beyond the typical doctor-patient relationship. The argument that is currently leading this perspective favours an approach that will include the patient, doctor, nurse, therapist, carers, family and friends, as well as the medical industry as a whole, with the latter referring to the commercialisation and corporation of healthcare.

In the next section, vulnerability will be further highlighted by means of a medical narrative. A medical narrative embodies the concept of using a story to help people to understand the complexity of healthcare ethics and challenges. The value of a narrative is that through storytelling an account is given of a real life example, for example the Tale of the Surgeon's Knife.

4. NARRATIVE

Life is not fictitious. Neither is illness or suffering.

One morning someone who is very close to me called me and informed me that “old age” had arrived. She felt very sick. She was not able to care for herself anymore.

Since I was out of town I was not able to assist. The best solution I had for this challenge was to suggest that an ambulance be requested, via the doctor's rooms that could take her to hospital for tests and possible treatment.

This advice had a history. The week before she had also been feeling very sick due to a set-back and I had taken her to the doctor's room. It was no easy task since she could hardly walk and getting in and out of the car was quite a challenge.

She was also living on her own.

The doctor was most helpful. The Emergency Medical Care (EMC) technician was very professional and reacted immediately to her need. The hospital staff at the closest hospital was supportive but no bed was available. When transferred to another hospital, a number of forms had to be completed. The impression was that admission is the key to treatment.

One can imagine the fear and the anxiety for the new and the unknown – a ward and not your own bedroom, nurses making observations and recording them, tests and more tests to inform the best treatment, communication in different languages, visits by different specialities to care holistically, family members raising concerns as to the condition of the relative. “*What will happen to me?*” was a spontaneous reaction. *Will I ever be discharged? Is this the end ... of what?*

In the meantime, at the proverbial “*back at the ranch*”, there was a household that required to be managed, decisions that had to be taken on another person’s behalf. Was this still the best space for her to return to? She could not stay in hospital forever. Would she be able to care for herself or had the time arrived to consider moving to a caring facility? Dignity should prevail, decisions should be passed. Who should be in command of these decisions?

The post box was growing in size as the medical bills were arriving. Not everything was covered by the medical fund. As a “private” patient she was responsible for some of the costs.

The debit card was also marching on towards the red ...

5. UNPACKING VULNERABILITY

The narrative suggests a number of themes associated with healthcare ethics and vulnerability.

The *first* observation is the fear instilled because of the unknown. The unknown is informed by the new space, the newness of treatment, the rising cost of medical treatment and the well-known question: *What next?*

A *second* interpretation is the observation that the organisation has become just as, or perhaps even more, important than the patient. One cannot but observe a business-centred model in healthcare – client and service provider. From a business perspective each party wants its rightful share. The patient’s primary need is to be cured and cared for. The healthcare practitioner has rights and needs too. He/she needs to be professional and to provide the best service that is possible but this cannot be performed outside the context of the hospital, clinic or care facility. Pharmaceutical companies want to make a profit (see for example Ten Have, 2011). A more progressive way of dealing with these issues would be discussions on personal ethics, professional ethics (and codes), legislation and what constitutes “good” healthcare. The observation is often made that

a fairly abstract view of healthcare ethics has emerged, and that this view should be promoted and implanted without a discussion on what is really the basis for good healthcare. Verbruggen (2013) promotes the view that healthcare practitioners should take charge of their profession and should assist in framing a healthcare ethics guideline. The voice of especially the elderly should be recognised in this debate. (See Vanlaere and Burggraeve's contribution in Chapter 4 for a detailed discussion on the quality of healthcare).

A *third* observation is that related to role play and responsibility. Who is in charge, and when? Spanish philosopher Fernando Savater (2013) addressed the complexity of ethical decision making and understanding. His book challenges the "good life" that everyone wants to live and still be ethical. Ethics denotes our responsibility (commitment) towards other people. Following from this, is the importance of appreciating people in their own right for who they are and not simply as a means to meet one's own goals. Of particular importance is the question of one's personal/individual rights versus those of the group. This takes us back to Plato's *The Republic*, in which the question concerning how we should treat other people is also posed. The answer is no different from the evangelical answer: *Do unto others as you would have them do unto you*. This response implies that man should be respectful of, and of service to, other people. This dictum (also known as *the Golden Rule*) needs to be extended to a person's interaction with culture, nature and structure. A second problem is that aging of nature may demand medical and social intervention.

Medical intervention is necessary since the elderly may no longer be in a position to take care of their own health. Social intervention may also be required to manage their broader interaction with society and communities. These interventions create the impression that the elderly constitute a "problem" group (Vens, 2013). The ethical challenge that emerges is the behaviour and/or perception that elderly people need to be treated differently from other people. It is this relativism of capability and dignity that leads to confrontation between the elderly and the community (collective for other people). The elderly very often experience that their lives appear to have been taken over by other people, or that other people are now deciding what is good for them and what not. This leads to feelings of disempowerment and loss of autonomy. As if this is not enough, elderly people very often also experience this disempowerment and loss of autonomy in the very way that people treat them, communicate with them and involve them in decisions pertaining their own life. The common assumption is that elderly people are now comparable to infants – they cannot make any decisions.

A *fourth* comment relates to life view and orientation. Robert and Edmund Shidelsky (2013) rightly indicate that each person longs for a good life, but how is a good life to be measured? Although there is a tendency to equate a good life to a life in which one can afford what one needs and wants, people are generally in agreement that this cannot be measured in financial terms alone. A good life is nonetheless often the expression of a lifestyle associated with progress and prosperity.

In the postmodern world especially elderly (geriatric) people find it difficult to make peace with the life that was and the life that they are now experiencing. The remembrance of the past often contributes towards a growing vulnerability since many people, especially geriatric patients, find it hard to accept that things are no longer the way they used to be. The most difficult aspect of the vulnerability is the loss of competency and identity. One's life has been taken over by others and is now almost lived by others as if one has no say over one's own life any more. It is for this reason that the World Health Organisation pays special attention to the vulnerable – especially those who cannot make decisions on their own behalf any longer. The emerging philosophy of *slow living* is a development according to which food play an important role in challenging and changing a materialistic lifestyle (see Honore, 2004). The concept of slow living questions materialism, wellness, pleasure, values – in essence the ethics of how we live (see Parkins and Craig, 2006).

A *fifth* issue is the experience of a power relationship. The need for healthcare ethics is deepened with science and technology that creates endless new opportunities for cure and care but at the same time subjects healthcare workers and patients to control and power. A history of philosophy reminds one that knowledge is power (R. Descartes), power destructs relationships (M. Foucault), power is an ideology ruling human life (J. Thompson) and medical technology dominates healthcare (J-H van den Berg, E. Schuurman). More recently, Ten Have (2011) has argued that it is thanks to technological developments that healthcare practice has changed positively, while at the same time it has generated new ethical challenges, most notably captured in bio-ethics. The conclusion is simply that the power issue cannot be avoided in healthcare. The challenge is rather how best the power can be balanced in order not to contribute to power distortion but to utilise power as an enabler to address vulnerability.

The analysis of this narrative was intended to point out that care is not limited to the patient only but that those who are involved in the areas of cure, care, control and community should benefit mutually from each other's care. The comment suggests that care is not one-way traffic, neither is it reserved for one group only. Care should manifest itself in all aspects of healthcare. It is not always health challenges that demand a deeper sense of healthcare ethics. Activities in relation to healthcare also call for the practise of healthcare ethics. Most notably are the roles of science, technology, pharmaceutical companies, health insurance, legislation, general healthcare delivery and diversity of personal beliefs, convictions, culture and personal circumstances. Typical examples are the ability (knowledge and skill) to identify illnesses for which medicine may not be available or if available, not affordable; the fear of technology if one has never been exposed to even basic technologies; the collapse of public medical services which leaves many patients helpless; the inability to communicate if there is not a common language and the socio-cultural interpretation and understanding of illness (see Creplet (2013)). The question remains as to whether the medical staff, hospital management and community are focusing enough on vulnerability.

However, care alone is insufficient if it is not directed by a value system. Creplet (2013) and Schotsmans (2012) rightly argue that it is time for all of these developments to be aligned with values. If healthcare is more than patient cure and care only, and if healthcare ethics goes beyond the needs of patients only, then we need to define healthcare ethics that can deal with the different worlds in healthcare as well as with those developments and structures that have an influence on healthcare.

Healthcare ethics is no abstract function but a deep human activity informed by life experiences, expectations, view and current circumstances. It is for this reason that care must be imbedded in a value system. To achieve this, one has to understand what the ethos of healthcare ethics is.

6. THE ETHOS OF HEALTHCARE ETHICS

Schotsmans (2008) claims that ethics has three tasks. Firstly it deals with human behaviour. How do we behave towards others and towards societal institutions? Secondly it investigates the application of norms and values and their challenges. Thirdly it assesses human behaviour in the context of humanity.

From these tasks, three important markers can be identified:

- Regardless of the space or time frame, no person can live as if there are no ethical guidelines. Ethics is no *bourgeois concept* applicable only to certain groupings in society.
- Ethics should not be limited to our engagement with people only, but should also have meaning for human behaviour towards culture, nature and structure.
- Ethics should address injustice in society and it should contribute towards a responsible lifestyle.

These markers can be further extended through the following comments. Emmanuel Levinas' *evoking of the other* serves as a basis for interpersonal relations – no person can live as if he or she is the only person alive (see Burggraeve 2008a for a provocative dialogue with Levinas' ideas). Further, people discover themselves through engagement with others. The ethical pointer is that the individual cannot be isolated from the group and the group or the other cannot isolate themselves from the individual. What people do may impact on the group and/or the other and *vice versa*. Burggraeve (2008b) pointed out in his analysis of Levinas' ethics, that ethics is a matter of recognising the "other" for who the "other" is. This recognition implies acceptance of the "other" for who he/she is. The identity of the "other" is important to understand the person and to meet the person on that basis.

Following from these comments as well as arguments presented in this chapter, the following ethos for healthcare ethics can be provided:

- Ethics is more than the identification of an appropriate value and norm for a situation. Ethics includes value-informed decision making, lifestyle and treatment. At the same time it necessitates the support of change, transformation and growth in a person, support networks and institutions. Ethics is primarily about the bringing of righteousness to a person and the institution and the specific situation in hand.
- Although universally acceptable criteria exist for determining the beginning and end of life, the mystery of what constitutes life can never be subjected to evidence-based criteria only. Life is much more than merely a set of quantitative or qualitative physical criteria. Life is an experience in the richness of human experience and existence.
- Regardless of religious, spiritual or cultural orientation and/or conviction, the universally acceptable Human Rights Bill and approved global medical codes should be regarded as baseline for healthcare – both for the providers and recipients of cure and care.
- Ethical care is firstly directed at the human, before it is directed at the condition. It happens too often that the condition is addressed without recognising the person with the condition. The human being can never take the second position when care is required.
- Medical practice can never waive the basic principle of the “Golden Rule” – do no harm and do to other as you expect others to do to you. This will demand dignity for all – immaterial of the fact that one provides cure or care or receives cure or care.
- Regardless of the status of the patient or of who the cure- or caregiver is, no discrimination can be permitted. Although special interest for vulnerability and people in vulnerable circumstances are demanded at all times, this does not mean that there are circumstances that allow inequality towards other people in different circumstances.
- Vulnerability is a human experience and condition, whether ethical, physical, psychological, economic, environmental or cultural. As a result every person depends on other people’s understanding of his/her vulnerability and hence care. In a medical context it is about caring for life, health, state of mind and general well-being.
- When dealing with ethical judgement, it should be remembered that no two cases are the same. An ethical baseline is that each case is unique and should be treated on the basis of the situation informing the case.
- Change is always aimed at improvement but never at the makeover of a person. Whether health cure and –care provider and/or recipient, the purpose of ethical guidelines is to guide the person to get as close as possible to the “ideal” situation. The objective of ethics is to

show the ethical way out of a dilemma and to further guide a person to understand and experience what ethical alternative could be available.

- Vulnerability is a human experience – hence it depends largely on the ethical frameworks of other people which in turn inform their mercy, gratitude and respect towards another human beings and social institutions.
- The delivery of quality, respectful and supportive care can never be removed from the care that the vulnerable are in need of. It would be hard to justify care without quality service delivery.
- Care can never be limited to humans only – part of ethical care is also to respect social institutions. As institutions are very often the basis for service delivery these institutions are subject to sound ethical behaviour too.

The comments offered in this section of this chapter may form the basis for some of the discussions in the chapters to follow.

7. SUMMARY

This chapter has highlighted the complexity and multi-perspective approach associated with vulnerability in healthcare ethics. From the many perspectives provided it was evident that vulnerability can be experienced in different aspects of human existence.

This chapter looked into what constitutes vulnerability and confirmed that vulnerability is not an experience of the patient only, but that the health care and -care practitioners also experience vulnerability. It was also stated that vulnerability can be extended to social institutions (such as the hospital and clinic) or the community (family, friends and support) networks too.

This chapter concludes by identifying the ethos of healthcare ethics. The ethos was identified on the basis of what ethics is, the meaning thereof for human behaviour in a medical context, the application of ethics to care and service, and the argument that healthcare ethics has application for humans and social institutions.

8. LITERATURE

Badaracco, J.L. 1998. Business ethics: roles and responsibilities. St Louis: McGraw-Hill.

Burggraeve, R. 2008a. (Ed.). The awakening to the other: A provocative dialogue with Emmanuel Levinas. Leuven: Peeters.

Burggraeve, R. 2008b. Als ik de ander erken, ken ik de ander. In Guwy, F. (Samenstelling en redactie). De ander in ons. Emmanuel Levinas in gesprek. Een inleiding in zijn denken. Amsterdam: Sun.

- Creplet, J. 2013. *De derde revolutie in de geneeskunde*. Brussel: Pharma.be.
- Holtzer, L. 2015. *De 7 privileges van de zorg*. Leuven: Acco.
- Honore, C. 2004. *Slow: Een wereldwijde revolutie*. Rotterdam: Lemniscaat.
- Gastmans, C. & Dierick, K. 2004. *Ethiek in witte jas. Zorgzaam omgaan met de leven*. Leuven: Davidsfonds.
- Glouberman, S. & Mintzberg, H. 2001. *Managing the care of health and the cure of disease. Part 1: Differentiation*. *Health Care Management Review*. Winter 56-69.
- Lategan, L.O.K. 2002. *Teaching business ethics: how effective are case studies? An illustration from Badaracco's business ethics: role and responsibilities*. In Lategan, L.O.K. and Le Roux, P.G. (Eds). *Business Ethics*. Bloemfontein: Tekskor. 102-120.
- Parkins, W. & Craig, G. 2006. *Slow living*. Oxford/New York: Berg.
- Phalime, M. 2014. *Postmortem: The doctor who walked away. A true story*. Cape Town: Tafelberg.
- Remans, J. 2005. *De boom van goed en kwaad: Over bio-ethiek, biotechniek, biopolitiek*. Leuven: Acco.
- Republiek van Suid-Afrika. 1975. *Aborsie en sterilisatiewet. Wet 2 van 1975*. Pretoria: Staatsdrukker.
- Savater, F. 2013. *Ethiek Nu! Een filosofie voor het moderne leven*. Utrecht: Bijleveld.
- Schotsmans, P. 2008. *Handboek medische ethiek*. Tiel: Lannoo.
- Schotsmans, P. 2012. *In goede handelen*. Tiel: Lannoo.
- Shidelsky, R. & Shidelsky, E. 2013. *Hoeveel is genoeg? Verlang na een goed leven*. Antwerpen: De bezige bij.
- Ten Have, H. 2011. *Bioethiek zonder grenzen. Mondialisering van gezondheid, ethiek en wetenschap*. Nijmegen: Valkhof Pers.
- Van den Berg, J-H. 1969. *Medische macht en medische ethiek*. Nijkerk: Callenbach.
- Vanlaere, L. & Gastmans, C. 2010. *Zorg aan zet. Ethisch omgaan met ouderen*. Leuven: Davidsfonds.
- Vanlaere, L. & Burggraave, R. 2013. *Gekkenwerk: Kleine ondeugden voor zorgdraggers*. Tiel: Uitgeverij LannooCampus.
- Vens, E. 2013. *Ouderen en zorg. Een verkennend antropologisch perspectief*. In Van Kerckhove, C., De Kock, C. and Vens, E. (Eds). *Ethiek en zorg in de hulpverlening. Over taboes gesproken*. Gent: Academia Press. 31-41.
- Verbruggen, A. 2013. *Over de verhouding tussen beroepsethiek, deontologische codes, wetten en een 'goede' beroepsuitoefening*. In Van Kerckhove, C., De Kock, C. and Vens, E. (Eds). *Ethiek en zorg in de hulpverlening. Over taboes gesproken*. Gent: Academia Press. 159-168.
- World Health Organization, 2007. *New health threats in the 21st century (Chapter 3, pp. 34-43)*. Geneva: WHO.



CHAPTER 3

The difference between right and wrong

Gert J. van Zyl and Paulina van Zyl

1. INTRODUCTION

There is a universal expectation for everyone to know what is right and what is wrong. Such expectation when related to moral decision making is embedded in the value systems of rational and functional individuals and communities. Society at large plays an important role in defining what the right or wrong thing to do is. Yet, we all believe that we have an intuitive sense of what the difference between right and wrong is.

2. PHILOSOPHICAL ASPECTS OF MORALITY

Moral intuition implies that we have a sense of what is right and what is wrong that is independent of other senses. But is this really the origin of our moral judgment? The question as to whether the concepts of right and wrong emanate from an individual's objective intuition or subjective feeling or attitude has been debated by many scholars of philosophy (Foot, 2002a:3-5).

Another subject of contention among philosophers regarding right and wrong is whether you can or cannot define the two terms. Stevenson concluded that the terms *right* and *wrong* have several interpretations, based on the context of the argument (Stevenson, 2002:29). Also, it differs among individual perspectives and even across time in the same person. In the context of judging between right and wrong, the person in question uses multiple *beliefs* to settle on a specific *personal attitude* that may also influence the attitudes of others. Moore (2002:34) argues that it is not possible to define goodness, which is not a natural entity, in terms of natural attributes.

The Concise Oxford Dictionary (Sykes, 1982:897) has no problem with defining right and wrong and defines "right" as "just"; "morally good"; "required by equity or duty"; "proper"; "the opposite of wrong" – "adding natural inclination to face what is right"; "correct"; "true"; "the preferable"; or "most suitable" – "this less wrong are often not wrong". "Wrong" is defined as "bad or abnormal condition"; "contrary to the law or morality"; "treat unjustly"; "bad motives"; "injustice, contrary to the law", "not entitled to position" (Sykes, 1982:1246).

3. DEVELOPMENTAL ASPECTS OF MORALITY

From a developmental psychology viewpoint, morality develops in an individual through well-defined stages linked to physical development, graded in six discrete phases according to Kohlberg's theory of moral development (Kohlberg, 1971:online). In young children, direct consequences for the individual concerned drives decision making. This phase is called the pre-conventional phase and consists of two levels: decision making in individuals in level 1 is driven by obedience and punishment, while level 2 individuals seek to satisfy self-interest. During adolescence and young adulthood (conventional phase), decisions are driven by social norms (level 3) and law and order

(level 4). In the post-conventional phase (principled conscience) decision making is led by social contract (level 5) and universal ethics (level 6) (Kohlberg, 1971: online).

4. THE MORAL IMPRINT OF SOCIETY

Moral judgment does not develop in isolation; it develops in an individual through the interaction of innate empathy and the influence of formative societal values.

- “Don’t do that!”
- “Don’t touch that!”
- “Yes, you may take some of those.”
- “Share that with somebody.”

We all were exposed to this kind of instruction as children. Some of these phrases might have been the very first instructions that we can remember being exposed to. This early guidance created a unique internal environment for us as well as the framework for deciding what is right and what is wrong. The foundations of this cultural imprint are laid by our parents, whose ideas of right and wrong were in turn shaped by the ideas of their parents and those of the community in which they lived. As we are increasingly exposed to the social network of our parents, religious environments and school environment, our sense of right and wrong is moulded to match the expectations of the larger community. Finally, operating within a work environment and as an adult member of a society, it is expected of individuals to be able to know instinctively what is right and what is wrong in both familiar situations and on issues that may have no precedent.

In essence, then, morality is the imprint of societal values on the individual, expressed through behaviour. The imprint may be weak or strong, an individual may have more or less empathy, and different societies leave different imprints.

The coming together of individuals from multiple backgrounds in the workplace challenges the limits of the imprint of morality developed in the first classrooms of life, complicating decisions concerned with the issues of right or wrong. The strong influence of cultural and religious background often dictates the status of individuals and thus the range of interactions that is allowed or prescribed between individuals of different groups.

5. REASONING ABOUT RIGHT AND WRONG

In order to transcend the restraints of cultural diversity in determining right and wrong, we need to understand how we reason in order to decide between issues of right and wrong. At the same time

we need to be able to apply such judgement to everyday problems, and also beyond the mundane in uncharted territories.

5.1 Frameworks of moral judgment

Morality is expressed through value judgments, selecting between options. The primary elements to consider in seeking the greater good are the value judgments between truth and falsity; good and bad and ultimately, right and wrong. Good and right are generally seen as related and overlapping concepts; the same applies to the counter weights, bad and wrong. Telling the truth, for instance, is generally considered good and right, yet measured by the consequences might in fact turn out to harm someone. Telling the truth might in some instances be bad. Gossiping or leaking confidential information may be true, but harmful and therefore bad. It is therefore possible that these forms of judgment might be in opposition to each other. An important aspect of these value judgments is that they each form a continuum. It is easy to distinguish between absolutely right and absolutely wrong, but increasingly difficult as alternatives move towards a midpoint where the issues become mingled and less clear. For the sake of clarity, let us view the sets of value judgements as separate “scales” of judgement.

As for “truth” and “falsity”, the deciding factor on which the continuum is balanced, is the presence of evidence (Foot, 2002b:83). Facts determine the outcome of judgment between these poles.

“Good” and “bad” can be seen as “emotives”: terms of commendation or rejection based on personal preference, aimed at promoting a certain behaviour (Foot, 2002b:84). Geach (2002:65) argues against this notion, and proposes that good or bad should be seen as descriptors, but not necessarily in the frame of commendation. The characteristics of “good” depend on the nature of what is described. If a “good” book fulfils the reader’s criteria for good books, it is lacking in being a “bad” book. In the absence of the requirement of evidence, good and bad remain highly subjective judgments. “Good” however differs substantially from “red” or “sweet” and is consequently classified as a “non-natural” descriptive term by some philosophers, although rejected by Geach. The difference in the nature of these descriptive terms is however undeniable. “Good” and “bad” are abstractions, imaginary labels that are attached to an entity after completion of a process of value judgment.

“Good” can also be placed opposite “evil”. Geach (2002:64) does not distinguish between bad and evil. If we consider these terms as opposites on a judgment scale though, good-evil represents a different scale of judgment from good-bad. The good-evil scale imposes a different moral belief system to the judging framework. Evil infers intent to harm and good on the same scale the intent to confer beneficence.

Let us consider “right-wrong” as a scale for moral judgment. “Right” and “wrong” are concerned with the foreseen outcome of actions, according to J.S. Mill (Urmson, 1953:34). The test for the “right” option is whether it promotes the ultimate objective, but also how effectively it does so. In his dissection of Mill’s moral philosophy, Urmson (1953:34) points out that Mill did not simply try to give definitions for right and wrong, but rather aimed at determining how to distinguish between these two moral poles. Such distinction is based on the guideline that an action is “right” if it complies with a “moral rule”. The moral rule in turn is right if it leads to the intended goal, the *summum bonum* or “greater good” which Mill defines as “happiness”. However, such “moral rules” are not the sole scale of judgment and their application is only appropriate in issues with substantial consequences (Urmson, 1953:35).

But whose happiness should be declared the ultimate goal? Mill’s test for right and wrong does not get rid of the subjectivity of the right-wrong scale and judgment remains prone to highly diverse interpretation, influenced by demographics, traditions, cultures, social status and religion.

5.2 The challenge of multi-cultural settings and universal values

In multi-cultural settings, diverse backgrounds create a challenge for making moral decisions. The subjective nature of value judgments and the major cultural component thereof of course pose a special challenge to multi-cultural settings or fields. Hence, the need arises to create a common code of conduct that incorporates or supersedes this diversity.

It is here that the concepts of values and ethics enter the discussion. Values are prioritized criteria or principles guiding choices, aimed at arriving at reaching a particular goal (Schwartz, 2012:3-4). Values are similar to norms in that both designate a set of societal rules guiding behaviour. Norms are the unwritten codes of conduct of societies, through which the society moulds the behaviour of individuals to convention. Values are the expression of the belief system of an individual regarding how to behave in order to reach a desirable goal or fulfil the needs of society. Schwartz (2012:4) reasoned that individual values represents the cognitive expression of the needs of societal groups: biological and survival needs, social interaction, and welfare needs. Defining these values aims at transforming abstract cognitive processes with unconscious execution into concrete entities with conscious execution. Ten universal values salient to all cultures were identified and integrated into the Schwartz theory of values (Schwartz, 2012:5). Schwartz defined these values in terms of the broad goals that they represent as: power (social ranking and dominance, based on the inherent hierarchical structure of societies), achievement; hedonism (enjoyment of life); stimulation; self-direction; universalism; benevolence; tradition; conformity; and security. This theory identifies the underlying motivations for these universal values as self-enhancement vs. self-transcendence; and openness to change vs. conservation (Schwartz, 2012:5).

THE DIFFERENCE BETWEEN RIGHT AND WRONG

Schwartz (2012:3-4) describes the characteristics that all values share, including that they represent beliefs linked to emotion, that they are directed at outcomes and that they apply to a multitude of situations. The latter characteristic distinguishes them from attitudes which have a narrow application tied to specific situations. The opposing nature of some values, necessitates prioritisation.

Gillon (1985:1118) defines ethics as a critical and analytical activity that judges the assumptions, underlying concepts, attitudes, reasons, arguments and approaches to the moral decision making process. Healthcare ethics is already defined as the identification of principles and the application of values and norms informing the practice of healthcare. It aims to transform a situation and to bring about a change in attitude, behaviour and practice (*cf* Chapter 1, paragraph 3). Ethics then can be said to study values, the building blocks of morality, the innate sense of right and wrong of individuals, and to formalise common codes of conduct. It implies a disciplined behaviour aimed at harmonising and streamlining interaction between humans, but also guiding human conduct towards the environment, animals and future generations. It can be seen as the formal expression of the morality of a societal structure that frames the decision making process.

Landman (2010) explains that healthcare delivery is in essence an ethical issue where ethics is about our (my) living according to core values in relationship with others. He continues by asking the question of whether universal values do actually exist, and explains that these must be seen in the context of the fact of cultural relativity of values (descriptive). He continues by saying that universal values originated in history and that these values show us how we ought to live in a good and just society (prescriptive) (Landman, 2010).

The need for negotiated codes of conduct arises within societal structures, when people from different backgrounds need to interact. The purpose is to guide individual behaviour in the interest of the collective. In the workplace, ethics encompasses issues of resisting exploitation of power in relationships, such as bullying or sexual harassment; of maintaining trust and good faith by being honest and open, balanced with appropriate discretion; of being committed to the greater good in protecting discipline and good order and protecting the company's interests. Such a code of conduct is made up of values. Values are the cumulative beliefs that direct the choices humans make. Moral values specifically guide moral decision making. Landman (2015) indicates that there are certain parameters that need to be taken into account in the debate on assisted dying within a constitutional democracy. The public policy should, in his view, reflect the spirit, values and rights of the Constitution.

6. RIGHT AND WRONG AND THE MEDICAL PROFESSIONAL

Ethics are particularly applicable to the professional practice of medicine to guide decision making in the doctor-patient relationship, protecting self-directedness for the patient in an essentially unequal power relationship. The maintenance of the reputation of the individual practitioner and the medical profession as a whole are important considerations.

The Hippocratic Oath represents one of the oldest known attempts to voice universal goals for the medical profession. Pope John Paul II remarked to the World Medical Association in 1984 (Pope John Paul: 1984): “It is more than ever necessary to overcome the separation between science and ethics, to rediscover the profound unity. It is man that you treat, man whose dignity is protected by ethics.” It is the specific references to treatment and patient that makes this statement more important for doctors. Yet, it is the reference to human dignity and the imperative to protect human dignity that reiterates a universal goal stated in the Hippocratic Oath.

Since the time of Hippocrates, however, fundamental changes have occurred in societal values and even in the understanding of concepts like “the common good”. Unprecedented change has occurred in healthcare service delivery that could not have been foreseen by the ancient philosopher. These changes have profoundly and irreversibly affected the dynamics of the relationship between medical professionals and their patients. Society no longer accepts treatment without questions asked. It also does not regard medical professionals as having the authoritarian status that they had in former times.

Historically important as the original source of ethical codes and guidance for conduct of medical professionals and a common commitment, the Oath is however a subjective expression of values and entrenched in a particular historical setting.

The past two decades have seen a renewed interest in the search for common ethical standards in healthcare delivery. The changing world of medicine requires a novel appreciation of the needs of society and a new contract with society. The World Health Organisation (2002:19) declared that one of the main issues that need to be addressed to meet societal needs and expectations is the provision of leadership in ethical aspects of health. Van Zyl (2004: 141) quotes Leaming who admonishes us to remember that a faculty member is not necessarily wrong just because he/she sees things differently and behaves differently from the way somebody else will do. It is therefore not just about the ethics but also about the action.

PriceWaterhouseCoopers (1999) emphasises an increasing need for healthcare organisations to take into consideration the needs of the populations they serve in the face of changes in the healthcare environment, such as increased competition between providers for patients and capital, the emergence of e-businesses, a shift towards preventative medicine, globalisation and the need

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for cost-effective health services. Medical professionals therefore need to work towards global standards of medical treatment.

The principles of beneficence, avoidance of harm, respect for autonomy and justice are the formal principles of bio-ethics as formulated by Childress and Beauchamp in 2001 (Lawrence, 2007:34). These became the guiding principles for ethics in medical research and bio-ethics in general.

Beneficence refers to the duty of a medical professional to provide help. This principle is however subject to the principle of autonomy: the physician needs the patient's permission to intervene. The principle of non-maleficence indicates the duty of the physician to avoid harm. Justice refers to the fair distribution of limited resources and respect for personal rights and laws (Lawrence, 2007:35-36).

Strauss (1991:5) comments that it is a universal and primary duty of doctors to take care during the treatment of a patient – performing operations and procedures – to execute these activities with such professional skill/s as to avoid injuring the patient. If the doctor fails in this, a civil wrong has been committed, making the doctor liable and potentially leading to prosecution. Although there is no legal duty in general upon a doctor to take in a patient, the counter argument is also applicable where doctors do not get the automatic right to treat any patient.

Another interesting apparent contradiction arises between the universal values of “power”, which includes “respect for authority”, and “self-direction”, which includes a goal like “freedom”. Also, the latter term may be simplistically interpreted as meaning that you can do as you wish without consideration of right and wrong, in which case it becomes contradictory to the notion of following ethical rules in the first place.

Freedom, however, within a framework of values and ethics, remains subject to the ultimate goal of the greater good. In the context of bio-ethics, it is expressed in the exercise of choice and allowing choice in the first place.

These examples demonstrate the potential conflict that may arise within a value framework and underlie the importance of prioritising principles.

7. PROFESSIONALISM AND THE HEALTHCARE DELIVERY SYSTEMS

The Physician Charter on Professionalism was published simultaneously in *Annals of Internal Medicine*, *The Lancet* and the *European Journal of Internal Medicine* in 2004 (ABIM Foundation, American College of Physicians Foundation and the European Federation of Internal Medicine). The charter represents the efforts of major role players in the medical community and Sox (2002) remarked that it was a watershed event (Sox, 2002). It was started in order to revive sensitivity

for medical ethics in response to a sense that Healthcare Delivery Systems in the United States and elsewhere increasingly threaten medical ethical values. The charter is based on the premise of professionalism as the common platform through which the expectations of societies and reciprocal needs of the medical profession can be formalised.

Professionalism is expressed in occupations whose core element is the performance of work that is based on the mastery of a complex body of knowledge and skills. Such professions, seen as vocations, are practised in the service of others, by practitioners who are accountable to society for their actions. Its members profess a commitment to competence, integrity, morality and altruism and the promotion of the public good within their domain. In exchange for these commitments to society, the profession gains the right to self-regulate and make their own decisions in practice (Van Zyl, 2002:11).

Physicians serve two simultaneous roles in society: that of healer and that of professional. A code of ethics is central to both of these roles and the medical profession derives values from the healer as well as from the professional. Attributes gained from the professional include issues like self-regulation and team work, while attributes from the healer involve patient care and the caring ethos (Van Zyl, 2002:11).

The contract between the medical profession and society thus hinges on professionalism. The charter is based on three fundamental principles, namely: the primacy of patient welfare; patient autonomy; and social justice.

Contemporary characteristics of the medical profession and the obligations required to sustain professionalism include the complexity of the knowledge base, service, altruism, autonomy, professional associations, accountability, morality, integrity and codes of ethics.

The charter further defined a set of commitments that are essential to health ethics and professionalism (ABIM Foundation, American College of Physicians Foundation and the European Federation of Internal Medicine, 2004) These commitments are honesty; confidentiality; maintaining appropriate relationships with patients; to uphold scientific knowledge and professional responsibilities; improving care and access to care; fair distribution of resources and maintenance of trust. The main areas of the Charter are shown in Table 1.

TABLE 1: THE PHYSICIAN CHARTER ON PROFESSIONALISM IN SUMMARY

<ol style="list-style-type: none">1. Commitment to honesty with patients which includes:<ul style="list-style-type: none">• informing patients completely and honestly before and after treatment;• empowering patients to participate in decisions affecting their health;• disclosing fully and promptly all medical errors.2. Commitment to patient confidentiality:<ul style="list-style-type: none">• Adhere to all safeguards governing this disclosure of patient information.• Disclose confidential information only when consideration of public interest overrides the interest of privacy.3. Commitment to maintaining appropriate relations with patients including:<ul style="list-style-type: none">• recognising inherent vulnerability and dependency of patients; and• never exploiting patients for sexual advantage, personal financial gain or any other private purposes.4. Commitment to scientific knowledge which includes:<ul style="list-style-type: none">• upholding scientific standards;• promoting research to create new knowledge;• ensuring appropriate use of scientific information.5. Commitment to professional responsibilities:<ul style="list-style-type: none">• Participate in the processes of self-regulation.• Assist in establishing educational and standard-setting activities.• Accept external scrutiny of professional performance.6. Commitment to improving quality care which includes:<ul style="list-style-type: none">• working collaboratively to reduce medical errors, increase patient safety and minimise overuse and optimise outcomes of care;• helping to develop and implement better measures of quality healthcare.7. Commitment to improving access to care:<ul style="list-style-type: none">• Strive to reduce variations to equitable healthcare.• Promote health of the public without concern for self-interest.8. Commitment to adjust distribution of resources:<ul style="list-style-type: none">• Base individual patient care decisions on cost-effective management of limited resources.• Work collaboratively to develop clinical guidelines.• Scrupulously avoid superfluous tests and procedures.9. Maintain trust by managing conflict of interest:<ul style="list-style-type: none">• Recognise the existence of many opportunities to pursue private gain.• Prepare to resist temptation and disclose all conflict of interest involving professional activities.

Adapted from: Medical Professionalism in the New Millennium: A Physician Charter (ABIM Foundation, American College of Physicians Foundation and the European Federation of Internal Medicine: 2004).

1. PROFESSIONALISM IN MEDICAL EDUCATION

The World Federation for Medical Education (WFME) represents all medical teachers and medical teaching institutions and it undertakes to promote high scientific and ethical standards in medical education, initiating new learning methods, new instructional tools and innovative management of medical education. It sets the purpose to provide a mechanism for quality improvement in medical education in a global context to be applied by institutions responsible for medical education (World Federation for Medical Education, 2003:3). Ethics and the teaching of ethics in a medical curriculum play an important role. Therefore the position of the WFME is important when one talks about ethics, because it is these positions of ethics that are taught. This organisation acts as an umbrella organisation, with partnerships with regional organisations such as AMEE (Association for Medical Education in Europe), AMSA (Association of Medical Schools in Africa) and PAFAMS (Pan American Federation of Associations of Medical Schools), among others.

AMEE presents a bi-annual conference, called the Ottawa Conference. The Ottawa Conference of 2002 presented the Physician Charter on Professionalism as an important guideline for application within medical education. The objective of the conference was to have a curriculum which includes the teaching of professionalism to ensure that students and residents know the meaning of profession; have adequate background on the historical development and present status of the profession; and know the attitudes and behavioural patterns characteristic of professionalism.

The conference identified life-long professional development and the maintenance of competence as critical to the application and teaching of ethics in medical education.

In practical terms: faculty development is essential prior to the introduction of expanded programmes or teaching professional evaluation. Faculty workshops provide effective strategy, and they should have as objectives increasing core knowledge of professionalism and producing more effective role models. The basis of all teaching must be a knowledge of the definitions of profession and the attitude and behavioural patterns characteristic of professionals. These issues are still relevant today.

Role models are still the most effective means of promoting professional values. Individuals serving as role models should demonstrate the following:

- Commitment to personal and professional excellence
- Enthusiasm
- Effective communication with patients, peers, students, residents and staff

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- Integrity
- Clinical competence
- Altruism
- Respect for the dignity of colleagues, patients and members of allied health professions
- A balanced lifestyle (Van Zyl, 2002:12).

Professionalism should be an integral part of the orientation sessions of all new faculty members. The professionalism of faculties should be evaluated as part of their ongoing performance assessment. Core knowledge about the profession and professionalism should be presented in a structured way early in the curriculum. It should include a definition of profession and professionalism that is in turn linked to the value systems of medicine. It should be presented in a historical context so that the student knows how the profession arrived at its present state. The charter of medical professionalism can serve as a resource representing a set of universally acceptable principles and values (Van Zyl, 2002:13).

Professionalism should be integrated into bedside teaching, emphasising both professional and unprofessional attitudes. Under some circumstances, professionalism can be combined with ethics teaching while recognising that it is a subject linked to but separate from ethics. Community-based clinical projects can reinforce this emphasis.

For internship, community-based rotation and postgraduate training, the core material relating to the nature of professionalism should be part of structured residence education as a formal part of training and assessment. A good example is in the M Med programme at the University of the Free State where this is part of the formal curriculum. Issues related to professionalism should be incorporated on a regular basis into bedside teaching, and can be combined with ethics teaching where feasible. The participation of residents should be mandatory and some self-regulatory activities such as reflections on ethics and communication are cornerstones to the training. As part of professional responsibility, residents should be required to participate in clinical teaching including the teaching of ethics to junior colleagues.

The charter also can serve as an organisational framework for professional portfolios and a blueprint for the designing of certification and re-certification. This is potentially a very useful tool for medical schools (Van Zyl, 2002:16). In the table below, Rice and Upson (2003) refer to the role of respect and integrity that needs to be demonstrated by the actions of individuals, groups and organisational leaders.

Table 2: Actions reflecting on respect and integrity

Principle action demonstrating respect and integrity	Actions contributing through individual effort	Actions contributing through groups	Actions contributing through organisational leaders
<ul style="list-style-type: none"> • Demonstrates respect for all individuals • Adheres to ethics, shared values, business practices of the organisation • Demonstrates courage of conviction 	<ul style="list-style-type: none"> • Builds trusting relationships with others • Values people's differences in background, culture, pursuit of work and personal life balance and perspective • Acts in accordance with organisation's ethical principles • Takes a stand for what he/she believes in 	<ul style="list-style-type: none"> • Recognises the value and contribution of all team members through words and actions • Takes responsibility for the behaviour of his/her department or team • Enforces high standards of ethical conduct • Acknowledges the ideals and convictions of others at all levels 	<ul style="list-style-type: none"> • Holds managers accountable to high standards of treating others with respect and valuing differences throughout the organisation • Makes broad-based business and organisational decisions that support our shared values • Demonstrates respect for neighbours and local communities

Adapted from: Table on actions reflecting on respect and integrity (Rice and Upson, 2003)

2. CONCLUSION

We have described how differences in upbringing, culture and religion could lead to different moral judgments in different communities and even between individuals in the same community. While an inherent conflict about decisions on right and wrong may drive individuals to refine the expression of moral behaviour in their personal lives, the diversity of the modern workplace complicates decisions concerned with the issues of right or wrong. Hence the need to change from decision making based on individual concepts of right and wrong to a distinguishable set of values and practices that we call ethics.

Ethics is the formal expression of values that a profession or business or other societal structure selects and prioritises to ensure a particular standard of moral decision making and to protect

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their reputation. It is ethics that transforms the subjective nature of right and wrong to an objective measure of moral behaviour.

As society becomes increasingly complex, ethics develops and its application expands. Wilson and McLaughlin (1984:333) quote Gardner as saying the following about moral order:

“The moral order is not something static...it is an attribute of a functioning social system. As such it is a living, changing thing, liable to decay and disintegration as well as to revitalization and reinforcement, and never any better than the generation that holds it in trust. Men and women who understand this truth and accept its implications will be well-fitted to renew the moral order – and to renew their society as well. They will understand that the task of renewal is endless. They will understand that their society is not like a machine that is created at some point in time and maintained with a minimum of effort; a society is being continuously recreated, for good or ill, by its members. ...but it will summon other to greatness.”

REFERENCES

ABIM Foundation, American College of Physicians Foundation and the European Federation of Internal Medicine. 2004. *Medical Professionalism in the New Millennium: A Physician Charter*. Retrieved on 6 November 2015 from: <http://www.abimfoundation.org/Professionalism/Physician-Charter.aspx> and <http://www.abimfoundation.org/~media/Foundation/Professionalism/Physician%20Charter.ashx?la=en>.

Foot, P. 2002a. 1967. “Introduction” in *Theories of Ethics*, P. Foot (ed.). London: Oxford University Press. pp 1-15.

Foot, P. 2002b. 1967. “Moral beliefs” in *Theories of Ethics*, P. Foot (ed.). London: Oxford University Press. pp 83-100.

Geach, P.T. 2002 (1967). “Good and evil” in *Theories of Ethics*, P. Foot (ed.). London: Oxford University Press. pp 64-73.

Gallon, R. 1985. *An Introduction to philosophical medical ethics: the Arthur case*. *British Medical Journal*, 290:1118.

Kohlberg, L. 1971. *Stages of Moral Development*. Retrieved on 8 November 2015 from: <http://info.psu.edu.sa/psu/math/Stages%20of%20Moral%20Development%20According%20to%20Kohlberg.pdf>.

Landman, W. 2010. *Practising an ethics of human rights in health care*. Lecture at University of the Free State to academic members. 14 September 2010, Bloemfontein.

Landman, W. 2015. *Assisted dying: The debate in South Africa following the Fabricius ruling*. Lecture to the South African Association for Health Educationalists (SAAHE), University of the Free State. 5 August 2015, Bloemfontein.

HEALTHCARE ETHICS FOR HEALTHCARE PRACTITIONERS

- Lawrence, D.J. 2007. *The Four Principles of Biomedical Ethics: A Foundation for Current Bioethical Debate*. *Journal of Chiropractic Humanities*, 14:34-40.
- Leaming, D.R. 1998. *Academic Leadership: A practical guide to chairing the Department*. Bolton Massachusetts: Anker Publishing Company, Inc. (Chapters 11 & 12.).
- Moore, G.E. 2002 (1967). "A reply to my critics" in *Theories of Ethics*, P. Foot (ed.). London: Oxford University Press. pp 33-63.
- Pope John Paul II. 1984. *The physician and the rights of mankind*. *JAMA*; 1984; 251: 1305-1309.
- PriceWaterhouseCoopers. 1999. *HealthCast 2010: Smaller World, Bigger Expectations. Executive Summary*. PriceWaterhouseCoopers, Pretoria.
- Rice, J.A. & Upson, R. 2003. *Managing Strategy. Workshop for heads of department in the Health Sector, Free State, South Africa. Executive Roundtable Discussions*. Bloemfontein.
- Schwartz, S.H. 2012. *An Overview of the Schwartz Theory of Basic Values*. *Online Readings in Psychology and Culture*, 2(1). Retrieved on 8 November 2015 from: <http://dx.doi.org/10.9707/2307-0919.1116>.
- Sox, H.C. 2002. *Editor of Annals of Internal Medicine*. Retrieved on 6 November 2015 from: <http://www.abimfoundation.org/Professionalism/Physician-Charter.aspx> and <http://www.abimfoundation.org/~media/Foundation/Professionalism/Physician%20Charter.ashx?la=en>
- Stevenson, C.L. 2002 (1967). "Moore's arguments against certain forms of naturalism" in *Theories of Ethics*, P. Foot (ed.). London: Oxford University Press. pp 16-32.
- Strauss, S.A. 1991. *Doctor, patient and the law. A selection of practical issues*. J.L. van Schaik, 3rd edition, 1991.
- Sykes, J.B. 1982. *The Concise Oxford Dictionary*. 7th edition. Oxford University Press. pp 897 and 1246.
- Urmson, J. 1953. *The interpretation of the Moral Philosophy of J. S. Mill*, *The Philosophical Quarterly* 3 (1953): 33–39. Reprinted in *Theories of Ethics* (ed. Philippa Foot) Oxford University Press, 2002 (1967).
- Van Zyl, G.J. 2002. *A Management Report of the 10th Ottawa Conference: Day 3 - 15 July 2002: A Charter on Medical Professionalism for the New Millennium: Project of the ABIM Foundation, ACP–ASIM Foundation, and European Federation of Internal Medicine, Session 14. Ottawa, Monday 15 July 2002. (Unpublished)*. pp 1-41.
- Van Zyl, G.J. 2004. *A Management Model for Heads of Department in the Medical School, University of the Free State. Unpublished PhD Thesis. University of the Free State*. p 141.
- Wilson, M.P. & McLaughlin, C.P. 1984. *Leadership and Management in Academic Medicine*. New York: The Association of American Medical Colleges. p 333.
- World Federation for Medical Education. 2003. *Postgraduate Medical Education: Global Standards for Quality Improvement*. Published standards of WFME Office. (In-house publication.) University of Copenhagen, Denmark.
- World Health Organisation. 2002. *Ethical Choices in Long-term Care: What does Justice require?* Retrieved on 6 November 2015 from: www.who.int/mediacentre/news/notes/ethical_choices.pdf

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CHAPTER 4

The quality of healthcare: A care ethics approach

Linus Vanlaere & Roger Burggraeve

1. THE ATTENTION TO QUALITY OF CARE

In healthcare today, more emphasis is given to the quality of care than ever before. Hospitals and other care institutions want to guarantee the safety of patients, so they focus on quality systems that are intended to achieve this safety. There is a great increase in practices that are intended to improve the quality of healthcare.

The question that arises however is: what is quality when it comes to healthcare? Is it merely a question of the safety of patients, or does it involve more than this? We will reflect on this question in this contribution. We take a specific framework, namely that of care ethics, inspired by the 'dialogical anthropology' of Buber, and particularly Levinas¹, as our point of departure. On the basis of this approach, it becomes clear that quality not only demands an increase in carefulness, with its objective means and methods, but also an increase in caring, with its subjective attitudes and virtues. What does this approach to quality mean in a healthcare system that is in every respect characterised by shortage, namely by lack of time, people and means? It is important for care ethics that the healthcare organisation make it possible for the professional to be more and more in a position to implement the available "means" – to be understood here as services and goods – for what is most important for the patient.

2. NO MANAGEMENT, NO CARE ETHICS

Let us first look at what characterises care ethics. This fairly recent trend in ethics is more than the sort of ethics that is concerned about care issues. Care ethics offers its own perspective on care issues by taking the position that care itself is a practice that is ethically charged in every respect. To put it in Carlo Leget's (2009:110) words: care ethics "... seeks to understand how healthcare works by looking at it from a particular perspective".

Considering care from the perspective of care ethics means in the first place looking at the relationships and at the way in which people give shape to their responsibility for each other (or how they withdraw from it) (Van der Hoven, Kanne & Mol, 2003). Care ethics focuses on the extent to which people are involved with each other. Secondly, care ethics always considers the way in which the provision of care is influenced by the context (Van der Hoven *et al.*, 2003), in other words, the specific patient who entrusts him/herself to the professional caregiving in the here and now, and what is at stake for the person from the point of view of care provision. Thirdly, care ethics pays special attention to the vulnerability of the person. Care is only good care when

1 For an in-depth discussion of this 'dialogical anthropology', see: E. Levinas, 1998. *Dialogue* in: ID., *Of God Who Comes to Mind*, Stanford, CA: Stanford University Press, pp. 137-151. Cf. also: R. Burggraeve, 2009. *Proximity with the Other: A Multidimensional Ethic of Responsibility in Levinas*, Bangalore (India), Dharmaram Publications; P. Atterton, M. Calarco, & M. Friedman (eds.), 2004. *Levinas and Buber. Dialogue and Difference*, Pittsburgh, PE, Duquesne University Press.

the care provision is tailored to what is most important for the patient (Baart & Grypdonck, 2003). This is usually not discernible through, for example, a questionnaire or check-list. Tuning in to the patient's priorities demands an attentive attitude on the part of the professional (Grypdonck, 2013). At the same time, it also demands a continuous weighing up of the situation. Professionals may then be sensitive to the vulnerability of the care receiver, and should notice what is at stake for the person, even though they may be limited in the time and space available to actually respond to this adequately.

Grypdonck (2013:13) remarks that “[t]he scarcer the means, the more attuned to the needs one needs to be”. She indicates by this that care can only be good care if the scarce means are used as efficiently and as usefully as possible. At the same time, the good that can be present in care is always more than “useful” or “efficient” (Legget, 2009:110). From a care ethics perspective, these two latter categories do not have a value in themselves. They do however form part of the care ethical assessment that professionals have to make because, unless the best way to implement the available means is sought for, in a way that is tuned to what the patient needs, one cannot speak of being attuned to what is needed (and therefore one cannot speak of good care). Good care means seeking what is the best and most humanly attainable care in a particular situation (Burggraave, 1994:73-94).

Care ethics is, from this perspective, not possible without management. As Grypdonck (2013:13-14) rightly observes, much of the failure in healthcare is not the result of wrong decisions on the part of the management. It seems to be the practice today to point a finger at the management of care organisations as the creators of such failure of which professionals and consequently the patients are the victims.

This polemic of “perpetrator” and “victim” often does not tally with reality and may have as a consequence that people can wallow in the role of victim by using the management as an excuse for not doing what should and could be done. Both the professional as an individual, and the management are called upon to take up their responsibility. For the professional this means *“doing their best to use the available means in such a way that they contribute as much as possible to doing justice to their patients’ and resident’s needs”* (Grypdonck, 2013:14). For the management this means organising the care in such a way that the professionals are in a position to take their responsibility as seriously as possible and to carry out their responsibility as well as possible.

When care ethics only represents the responsibility of the professionals for their patients and not the responsibility of the management for the organisation of the care as well, then it fails to achieve its objective. It is not possible to offer care independent of the system. The care organisation is in itself a sort of ethical correction in healthcare. It is not only a question of any particular patient who requires care: there is always another one, and yet another one, and so on, in the here and now

and at the same time. This multiplicity of simultaneous care seekers demands both ethical and practical organisation. This has to take place in a reasonable and just way that allows care seekers to be similarly and equally treated. The exclusiveness of one-to-one care must be moderated and brought into balance with what the “other others” need. In the simultaneous plurality of care everything needs to be weighed up, urgencies and priorities need to be identified and formulated in such a way that people are treated “as every other”. This demands organisation, structure, consultation and agreements, or to put it succinctly, it requires proper management. Caring has to become carefulness. If caregivers, on the basis of their caring, only listen and respond to the needs of the one unique other, then they are being unjust, not from ill-will but from a good-will point of view, to the real, present others. In this way, what is good is converted to its opposite...unless caring is transformed into a well-thought-through and reasonable approach and direction. The care organisation itself, the management and by extension the care policy at the level of society is confronted with the challenge of providing a just distribution of means, goods and services, to stand as far as possible for a correct assessment of the real care needs and, last but not least, to meet these needs as practically and as adequately as is possible, in a context of comparative and distributive justice searching for fair and equal treatment (Levinas, 2006:198-199).

3. PARADOX 1: CARE ETHICS DOES NOT AIM IN THE FIRST PLACE AT PROVIDING A BETTER SERVICE

The first paradox that comes to light here is that care ethics continually approaches care as a relationship and not as a product that has to be improved in order to be sought after or to be of greater value. A practical example to illustrate this: In a unit of competent care-dependent elderly people in a residential home, the professional staff finds that the twenty minutes available to them in working practice to provide the necessary morning hygienic care is much too short. They feel as though they are washing-robots who perform routine work without regard for the person for whom they are providing the care. Consideration is given to the organisation of hygienic care from the position of care ethics. A new view is explored that results ultimately in a new approach. From now on, every morning anew, each resident will be asked what he/she would like to see happen in the twenty minutes that the professional has at his/her disposal. In due course, residents begin to react enthusiastically to this question. The professional gains a greater sense of contentment through being released from a routine approach and experiences that in many areas a much more efficient approach to time has developed. The residents themselves also experience a greater sense of contentment, as they feel more valued because they receive much more attention.

We wish to illustrate by means of this example that care ethics seeks in the first place to create space in the care relationship for attuning the needs to the available time. Care should not be considered in the first place as a product that must be performed according to certain specific

standards, but rather as a relationship in which the relationship itself takes precedence over the content or over what is subsequently specifically done. However important the result is, it is not a value in and of itself, but only gains significance in and through the nature and the quality of the care relationship, in which relationship both the well-being of the care-seeker and the sense of satisfaction in and through the care relationship have priority. First comes the question: “*What can I do for you?*” Professionals need to listen and look very carefully in order to get an answer to this question. Only when they fully recognise what is important for the patient does the service, and with it the organisation of care, come into the picture.

4. PARADOX 2: FROM THE PERSPECTIVE OF CARE ETHICS, IT IS NOT POSSIBLE TO COMPLETELY ORGANISE GOOD CARE

Good care can never be completely organised. This is a second paradox. Care ethics makes it clear that care is not only about carefulness but also about caring. Carefulness has to do with the expertise of professionals through which they seek for technically achievable, safe, efficient, accurate, attainable solutions in answering to the needs of the care-receiver. Caring relates to the attentiveness with which professionals pick up on the needs, but also to the ethical sensitivity for the care-seeker’s person, which they take into account throughout the whole care process. Frans Montaine (2000:130) puts it this way:

“[For] what a person who has been ill will remember is not the speed with which the doctor managed to correct his dehydration, but rather the way in which the doctor did so. The difference namely between the cup of water offered to him, or the one that was shoved between his teeth. The difference between that fresh glass of water and the one that has been there since yesterday. The difference between being given the time to drink or just time enough not to choke. The difference between being forced to drink and being able to say: May I wait a little?” (Montaine, 2000:130).

This kind of caring now only has to be cultivated. When it comes to caring, however, what is it that needs to be cultivated? Friendliness, basic courtesy? However important these qualities are in relation to caring, they constitute the bottom line, the bare minimum.

Caring can perhaps best be described by what the French philosopher Emmanuel Levinas (1995:117-119 *passim*) called “small goodness”. He meant by this a sort of everyday, human goodness, a personal goodness of the one person toward the other.¹ It is precisely this small goodness that makes a big difference in care. It is however so fleeting and small, and, in the light of the ideal of good care, so seemingly banal, that Levinas has rightly qualified it as “small”, partial and provisional. It is thus nothing more than a little bit of goodness, a moment in which good lights up, so much so that it briefly alleviates, postpones momentarily, a patient’s suffering. The small goodness is essentially a gift, both for the patient and the professional, because it is made possible

in spite of the latter. What is characteristic of this small goodness is that it cannot be willed, let alone programmed or planned. It cannot be summarised in procedures and regulations. It can only come about in the relationship between two people, in which one just does something for the other, without deep reflection on what it will lead to, without the intention even of bringing about some good, and particularly without concocting great plans and strategies to achieve the very best. What the professional does is much too small for this, much too fleeting, much too fragile. The small goodness is to be found in very ordinary things that characterise day to day relationships without attracting much attention. It is even a little difficult to call these things “small goodness”. At the same time, the human aspect of care disappears if such “small goodness” is no longer possible. Or, one could even say, without “small goodness”, one cannot speak of caring. And one cannot then even speak of carefulness, for without “small goodness”, carefulness has no soul.

What is paradoxical about “small goodness” is that it cannot be organised. To put it even more strongly, every attempt to organise it is doomed to failure. The only thing that can be organised is the averting of the danger that threatens every care organisation, namely that small goodness is smothered or drowned out by an excess of organisation and is restrained by the emphasis on systems, goals and efficiency. The care organisation as a system reflects an objective, distant and anonymous character that approaches care seekers collectively, as all being the same consumers of care. The system’s generalised objectivity has as a result that those who fall under it – the care seeker in the first place, but also the caregivers – no longer feel they are treated as unique individuals, but rather as parts in a much greater whole. We can, with Levinas, call this a form of structural violence that is inherent to every system, even the most ethically valid systems. The worst thing that can happen to a care system is that it elevates itself into the ultimate, smug truth about the quality of care. This is why an open system is necessary that allows for a permanent evaluation. A care system must in other words be prepared to weigh up the achieved forms of justice and fairness, the agreed options, priorities and achieved equilibrium on the basis of the ethical dissatisfaction that arises in the workplace among the caregivers as a result of the shortcomings of the established care practices. An open care system seeks in other words for an increasingly improved fairness, on the grounds of institutional disillusionment expressed by – whether emotional and possibly imbalanced or not – care seekers and care receivers. Only an open care system that is concerned about providing increasingly better care also makes room for the creativity of the small goodness of singular caregivers, skilled through their experience during the provision of care in their routine work as caregiver. At the very least, it does not obstruct this room for creativity. It is also precisely this small goodness that can lead to critical alertness within the care system in relation to the care system itself, so that the improvement of the system can also be sought after.

5. PARADOX 3: CARE ETHICAL IMPROVEMENT DEMANDS THAT PROFESSIONALS DARE TO DEVIATE FROM THE RULES AND THE PRINCIPLES THAT ARE MAINTAINED BY THE CARE SYSTEM

Once again it becomes apparent how important it is for care ethics to find a balance between the environment of the system and the living environment, between an effective care organisation and the small goodness of the one person to the other. The small goodness on the part of the professional then forms an important and indispensable counterweight to the depersonalisation that is characteristic of every organisation and therefore also of the care organisation. Care ethics often challenges the policy and the care organisation because it is concerned that the organisation of care becomes a goal in itself. This is to say that the system is improved for the sake of improvement, that innovation is stimulated for the sake of innovation, that efficiency is pursued for the sake of efficiency as the highest good, and so on. Every care organisation is exposed to the risk that it is no longer focused on the vulnerable individual, but on the organisation itself as a successful professional and financial whole. When all attention is focused on the organisation itself, there is always the danger that there will be no more room to tune the individual professional to the individual care receiver. In this case the suffering of the care-receiver is no longer noticed and this moreover also has the effect that “suffering is added to suffering” (Levinas, 1994:80-81 *passim*; Vanlaere & Burggraeve, 2013:67).² Levinas makes it clear that the balance between the environment of the system and the living environment can only be achieved when individuals in the organisation allow their conscience to speak. It is thus only the “responsible I” of the caregiver that is in a position to allow him- or herself to be touched by the individual care-receiver. It is namely in and through the small goodness that the suffering of the vulnerable care-receiver is picked up. And only in (and through) the small goodness is a response to suffering possible and can people have justice done to them. Levinas calls this the “noble casuistry”: only through the small goodness do caregivers allow their judgement to be based on the individual person that they have before them and do they take the specific situation of every “case” into consideration (Levinas, 1982:121). Or better put, it does not reduce the other to a number or the specification of a generally held rule. The other is more than one of dozens who cannot be reduced to a category or general term. The other facing me is unique, an exception to the rule, with an inalienable own name by which he or she needs to be addressed.

In this way the organisation also makes it possible to truly offer care that is fair. In the equal treatment of every person in need of care as whomever, the small goodness is able to give attention to the unicity of the other. Without destroying the fair approach, it still rises above it. It raises the care organisation to a higher level, to a level of human excellence, without destroying agreements that have been made or established as procedure or approach, and without making this excellence into another generalised procedure, method and tool. It remains stubborn in its

small scale, coincidental character, spontaneous nature and casualness. It stubbornly refuses to rise to embrace a great, but at the same time threatening, idea of good. However it remains in this way alert to what no one system can achieve as system, however fair it may be, namely the recognition and the assistance of the other, so that the other is no longer an object but a subject and the bearer of care and the care relationship.

6. PARADOX 4: THE IMPROVEMENT OF CARE ETHICS IS ONLY POSSIBLE IF THERE IS ROOM FOR MEDIOCRITY

Once again it becomes apparent how important it is that the care organisation make room – or leave sufficient room – for small goodness, that is for the *face-to-face*, the encounter between the care-seeker and the caregiver. Even if this *face-to-face* takes place in the institutional context of a service or care organisation, this *face-to-face* also always transcends this system. It cannot be organised, or rather, it must not be organised, but it is possible to cultivate it. Possibly, the cultivation of this small goodness of the *face-to-face* approach greatly resembles the development of plants: it requires light, air, space and water. Just as plants do not thrive on too many pesticides, the small goodness suffers from too many “ethicides” or from too great a pressure to do what is good and to continually improve on this. The paradox is that care professionals lose their ethical inspiration – as passion for what is good – if they have to continually strive for an improvement of the given care and no allowance is made for the experience of mediocrity.

Professionals personally experience that they can never be careful enough: attentiveness is never attentive enough; closeness is never close enough to truly do patients justice. This is the mediocrity that these professionals experience when they are fully involved in healthcare: whatever they do, their caregiving always falls short of the mark. This does not necessarily involve a shortcoming in expertise or want of means. Sometimes the suffering of the care-receiver is of such a nature that, whatever they do, they can never do it well enough. This experience of mediocrity demonstrates that professionals are completely taken up in giving care. It demonstrates that they can still be affected, are vulnerable to the suffering of the other and that this can even affect them physically. For the experience of mediocrity is accompanied by what Levinas calls discomfort, which may even be understood quite literally: it disturbs you; you can't sleep as a result; you suffer through the suffering of the other. This discomfort demonstrates, according to Levinas, that we are already connected to the other even before we have turned towards the other.

Professionals must have room for this mediocrity. It puts the (at times) excessive expectations of a continual improvement into perspective and introduces a sort of down-to-earth approach that takes reality into account to the extent that it helps the professional to find the right measure of care, namely the one to be found between the unattainable ideal and not realising anything. More

than anything else, mediocrity introduces modesty into the care system: the *best care* is not of this world, and we need to be prepared to accept this. This modesty, not only of the caregivers but also of the care system, is necessary in order not to abandon the pursuit of what is good, or rather good enough. Only when professionals *and* systems – through their ‘representatives’, the managers and caregivers – are aware of the limitations of their own capacities do they find room for what is possible. Thanks to the mediocrity, room is created for the small goodness. Not as a sort of self-comfort, for once again, small goodness is not something that can be sought after, it just happens. And yet it is this small goodness that ensures that professionals can retain their passion for what is good. As Levinas says: *“It defines people’s humanity, in spite of its powerlessness. It is beautiful in its powerlessness, like morning dew. It never wins, but it is never conquered”* (Levinas, 2013:67).

It thus becomes the source of modest hope, without eschatological nor apocalyptic claims of a ‘definitive and perfect care regime’ – the evil as the downside of the good, the final and most horrible disaster.

7. CONCLUSION

We conclude that caregiving of a high quality does not only have an object-side but likewise a subject-side. With the object-side we mean the quality of the care-treatment that must comply completely with the norms of meticulousness, namely that of the safety of the patient, of evidence-based work, and so on. With the subject-side we mean the quality of the care-relationship and the caring that should be tangibly present in this relationship. The subject-side has to do with the openness to being touched emotionally, with concern, with responsibility. Investing as well in the quality of this subject-side of care does not go hand in hand with ‘loudly-spoken norms’. It will best be coupled with the acknowledgement that our care from the perspective of caring will always remain mediocre and thus ‘be found wanting’. Acknowledging this mediocrity – inherent to the ‘being-human’ of the caregiver and to the ‘human’ care-organisation – creates space for improvement because it makes one reflect on the humanity of caregiving. Moreover, it creates space for ‘silent values’, namely a whole gamut of non-sensational, non-heroic ways of acting, attitudes, gestures, but also the ambitions and motives of people (of which they often are only partially aware) that make the essential difference between good care and bad care. The ‘silent values’ of people thrive on two elements: space and trust. Caregivers must obtain space within frameworks that are not too strongly disturbed by peremptory policy regulations and procedures. ‘Silent values’ witness to the ‘small goodness’ and only thrive when people receive the space *and* the trust that they are actually doing all right, or perhaps will even do better, without all those rules. They flourish only when people have regulative space, can take up responsibility for that which they deem is at stake for their care-receivers, and can open themselves up to be touched

emotionally. They flourish only when people can be – as moderate radicals – gently ‘counter current’ or even ‘disobedient’ – and when they can dare to flout the rules once in a while and deviate from the beaten path. The care-ethical quality of caregiving does not flourish when it is kept within the handgrip of thinking in systems, targets, efficiency and output. Indeed ‘being-caring’ has everything to do with a subtle process of involvement and meaning that gradually unfolds between people.

REFERENCES

Baart, A. & Grypdonck, M. 2008. *Verpleegkunde en presentie. Een zoektocht naar de betekenis van presentie voor verpleegkundige zorg.* Den Haag: Uitgeverij Lemma.

Burggraeve, R. 1994. *Tussen Rome en leven. Essay over een ethiek van het haalbare* (red. Ilse Van Halst), Lannoo: Tielt. 73-94.

Grypdonck, M. 2013. *Verpleegkundige zorg bij schaarste*, In Pijnenburg, M. & Leget, C. (reds). *De tijd, het geld en de wijsheid. Een bezinning op het tijdsprobleem in de gezondheidszorg.* Den Haag: Boom Lemma Uitgevers. 13-24.

Leget, C. 2009. *Alledaagse dilemma's.* Tijdschrift voor verpleeghuisgeneeskunde 34:110-112.

Levinas, E. 1982. “L’au-delà du verset.” *Un entretien avec Emmanuel Levinas.* In Balbont, L. *Mère Thérèse en notre âme et conscience.* Paris: Seuil.

Levinas, E. 1994. “Transcendance et hauteur” In ID., *Liberté et commandement*, Montpellier: Fata Morgana. 80-81 passim.

Levinas, E. 1995. *Altérité et transcendance.* Montpellier: Fata Morgana. 117-119 passim.

Levinas, E. 2006. *Entre Nous. Thinking-of-the-Other*, London: New York. Continuum. 198-199.

Montaine, F. 2000. *Verpleegkunde. Een persoonlijke bewogenheid.* In Dierckx de Casterle & Gastmans, C. (reds). *Verpleegkundige excellentie. Verpleegkunde tussen praktijk en ethiek.* Maarssen. Elsevier Gezondheidszorg:121-139.

Van den Hoven, M., Kanne, M. & Mol, L. 2003. *Zorgethische gespreksmodellen voor de gezondheidszorg. Denken over zorgverantwoordelijkheid en ‘goede zorg.’* In Manschot, H. & Van Dartel, H. (reds), *In gesprek over goede zorg. Overlegmethoden voor ethiek in de praktijk.* Amsterdam: Boom. 134-152.

Vanlaere, L. & Burggraeve, R. 2013. *Gekkenwerk. Kleine ondeugden voor zorgdraggers.* Lannoo: Tielt.



CHAPTER 5

**The Influence of culture, values
and faith on end-of-life decisions**

Joyce MacKinnon and Amber Comer

1. INTRODUCTION

The culture, personal values, and faith of the patient, the family, and the healthcare practitioner are not always in alignment and, indeed, may commonly clash during a situation of end-of-life decision making. In order to understand how each of these viewpoints can affect end-of-life decision making, it is important to understand their ethology. Faith is usually synonymous with a set of religious beliefs, and denotes a set of shared beliefs that are divine in nature, while culture is a set of collective beliefs among a group of persons. Personal or individual values are the beliefs held within the individual. Religion is important in shaping culture and values; however, persons of the same religion, but raised in different cultures, may not share the same individual beliefs. For instance, a Roman Catholic raised in the American culture of autonomous decision making, may have a very different viewpoint on end-of-life care from that of a Roman Catholic raised in Brazil, which subscribes to a more paternalistic form of medicine. The following hypothetical offers some insight into the importance of understanding how culture, religion, and individual values can come into conflict during end-of-life decision making situations.

2. HYPOTHETICAL: A CLASH OF CULTURE, INDIVIDUAL VALUES, AND RELIGION

A 40-year-old woman named Ashlee is involved in a car accident which leaves her a quadriplegic and in need of long-term mechanical ventilation. She does not, however, have substantial brain damage. Although Ashlee was born in America, her parents are Iranian and have only lived in America since shortly before Ashlee was born. With mechanical ventilation, Ashlee will survive and live a relatively normal life span; however, she will be confined to a bed and unable to do anything for herself. Without mechanical ventilation, Ashlee will probably die within hours. As Ashlee is a Muslim raised with Iranian cultural views, her parents inform her doctor that they would like Ashlee to have permanent ventilation because life and death are controlled by God and as such, all measures should be taken to preserve Ashlee's life. Ashlee's parents believe that not doing everything possible, including indefinite mechanical ventilation, would in effect be playing God by taking Ashlee's life, and would therefore be a sin.

Ashlee was raised in the US, and twenty years ago she married an American named Brian, who was raised with a Mormon religious affiliation. Brian believes that Ashlee would not want to be kept alive as a quadriplegic, confined to a bed, in need of mechanical ventilation to survive. Brian exhibits the American cultural belief that there is no obligation to keep someone alive with artificial life support when there is no hope of recovery and that people have the right to choose how they die. Brian asserts that he does not intend to take Ashlee's life, but rather that she should be allowed to die a natural death free of man-made medical intervention. Furthermore, Brian exhibits

the Mormon religious view that it is not a sin to allow a person to die from natural causes, which would be the case if mechanical ventilation were removed from Ashlee.

Further conflating the issue is that although Ashlee was raised as a Muslim and was very engaged in Iranian culture, she was also raised in America and has been married to Brian for twenty years. She seems to be an American who exhibits the American cultural belief of patient autonomy. It is determined that Ashlee holds a mixed viewpoint on end-of-life care and decision making where she believes that you should do everything possible to help save a patient, but that there are some situations that leave a patient in a state worse than death and therefore, it is not a sin to remove life support. It is unclear to everyone what those situations are, and as such Ashlee's parents and husband are left to sort through this clash of religious, cultural, and individual values.

One of the most crucial health-related decisions to be made occurs at end-of-life. This is a profound decision making point: while it ultimately affects the patient most, it also affects family and significant others as well as healthcare practitioners. All of those involved may be influenced by personal culture, values and faith, as reflected in the hypothetical situation presented above. Therefore, in this chapter we propose to examine the influence of culture, values and faith on end-of-life decisions.

Let's first put this discussion in a conceptual framework. In 1995 Wilson and Cleary (Wilson & Cleary, 1995:60) presented a conceptual model that proposed that social, economic and psychological supports, patient values and preferences, and the patient's environment were all influential in a patient's perception of quality of life, and that these factors would influence health outcomes and healthcare decisions. A patient's environment includes the culture in which he/she is situated or raised, as well as aspects of faith or religious background.

Reinforcing this conceptual framework, the Picker/Commonwealth Program for Patient Centered Care developed a model of care in 1998 that focused on the patient and family and acknowledged the role that factors other than biological or physiological components have in healthcare decision making (Gertsis, Edgman-Levitan, Daley & Delbanco, 1993) Echoing the importance of integrating patient values and preferences into the healthcare decision was the report from the United States Institute of Medicine in 2001, which highlighted the importance of these concepts as fundamental in patient care and decision making (National Research Council, 2001).

In 2010, 58 people from 18 countries attended the Salzburg Global Seminar where a statement on shared decision making in healthcare was crafted and then released (Salzburg Global Seminar, 2010:12). This statement encouraged healthcare practitioners to involve their patients in healthcare decisions and to ask about personal preferences. Particularly in an age of increased electronic access to health information, patients are becoming equipped with knowledge and questions and should be encouraged to express their values and preferences with regard to interventions and treatments.

Research into the influence of culture in end-of-life decisions has been identified as a priority by a European based research collaboration (PRISMA-Positive Diversities of European Priorities for Research and Measurement in End of Life Care) (Gysels, Menaca, Bausewein, Gomez-Batiste, Husebo, Higginson & Harding, 2012) The term culture encompasses multiple constructs to include societal norms, values, race, ethnicity, religion, language, role of self and family, national origin, customs, and traditions (Bullock, 2011:85; Braun, Pietsch & Blanchette, 2000). In May of 2010 an international workshop was organised to explore this issue. A group of experts came together and, through discussion, several themes emerged (Gysels *et al.*, 2012).

The first theme was that of cultural competence. With the growing realisation and willingness to acknowledge that there were racial and ethnic disparities in healthcare access and treatment (Smedley, Stith & Nelson, 2003) “the concept of cultural competence was developed to enable healthcare practitioners to respond to cultural diversity in practice” (Gysels *et al.*, 2012:289). This is particularly important in end-of-life decisions. As stated by the participants in the workshop, healthcare practitioners need a greater “understanding how the cumulative problems of illness; economic, social and linguistic marginalization; and racism affect palliative care experiences and needs.” (Gysels *et al.*, 2012:289). There was recognition that more research is needed in this area, to include creating useable data bases.

The second theme was that of diversity in an environment of change. There are countries with more homogeneous populations that are somewhat isolated, but in most of the world there is migration of people from different countries or regions into others, resulting in either a clash or a blending of culture. There are also inter-generational differences in approaches to end-of-life decisions, and with an aging population these differences will need to be acknowledged (Gysels *et al.*, 2012:289).

A third theme to emerge from this workshop was the need to recognise the role of religious identity in end-of-life decision making. A study conducted by Sprung, Maia, Bulow, Ricou, Armaganidis, Baras, Weenberg, Reinhart, Cohen, Fries, Nakos and Thijs (2007) and published in 2007 found that the religious affiliation of physicians influenced end-of-life decisions. Physicians who identified as Muslim, Jewish or Greek Orthodox were more likely to withhold end-of-life prolonging interventions as compared with those who were Protestant, Catholic or had no religious identity. However, the latter were more likely to withdraw treatment when compared with the former (Sprung *et al.*, 2007:1732). In some cultures and religions, there is a belief that what happens is the will of God or Allah and that interventions are therefore not appropriate. Even within religions there are differing views in different sects.

A fourth theme was the importance of recognising cultural differences as they relate to how autonomy is perceived and valued (Gysel *et al.*, 2012:289). In Western cultures, individual autonomy is valued, but in three-quarters of the world’s population it is not (Blank, 2011). This will

have an effect on end-of-life decision making. For example, a study by Croasdale (2005) found that, in contrast to United States resident physicians, Japanese resident physicians were more likely to include the patient's family in end-of-life decisions.

In summary, the workshop experts identified areas of culture that should be recognised and acknowledged as affecting end-of-life decisions, with the understanding that more research needed to be done to develop a greater appreciation for the role of culture in healthcare decision making. As stated by Blank, "Even more so than in other areas of medicine, issues at the end of life elucidate the importance of religion and culture, as well as the role the (sic) family and social structure" (Blank, 2011:213)

In 2011 Robert Blank, a professor of political science at the University of Canterbury in Christchurch, New Zealand, published an article titled "End-of-life Decision Making Across Cultures" (Blank 2011). In this article he explored cultural differences in Western and Eastern countries that affect end-of-life decisions. For example, how is death defined? In some countries, the legal definition is a cessation of brain function. However, in other countries death is defined by cardiorespiratory cessation. These definitions are influenced by advances in technology, where it is now possible to prolong cardiorespiratory function even in the absence of brain function (Blank, 2011: 203). Another area where culture impacts end-of-life decisions is that of artificial feeding at the end stage of life. In the United States, this intervention is not uncommon. In other countries, cause of death is not attributed to failure to eat, which rather is considered one of the signs that a person is near death (Dunn, 2009). Advanced directives and euthanasia, whether active or passive, are also subject to cultural influences. Active euthanasia occurs when the patient is provided or given a lethal injection; passive euthanasia occurs when measures to prolong life, such as mechanical ventilation, are either not provided or are withdrawn (Blank, 2011: 210).

An article written by Jill Klessig, MD, highlights the influence of values and cultures on end-of-life decisions; in this case, to withdraw life support. Klessig used case examples to illustrate the influence of culture, particularly with regard to religion, in making these decisions. One example was that of a young Iranian girl who was admitted to hospital on full ventilation support, but upon evaluation was found to be brain dead. The family did not want the ventilator removed, and also requested other medical procedures, making what the healthcare team characterised as unreasonable demands. On the second day of admission, after the family had left the ICU, the attending physician removed the ventilator. Upon return, the family was extremely upset and accused the medical staff of murdering their daughter. Not only did this example highlight the influence of religion and culture (Islamic, Arabic) but also the clash between the values of the family and those of the healthcare practitioners (Klessig, 1992: 317).

In looking at aspects of this case, Klessig points out the influence of culture and religion on end-of-life decisions, and some of the nuances of both. For example, in Islam, the belief is that both life and death occur according to the will of God (Hathout, 1990:25). Interestingly, initiating treatments and interventions is acceptable because one is using the 'gift' of technology but stopping life support, once initiated, is not (Al-Mutawa, 1989:S11). This case also illustrates the conflict that may arise between the western view of autonomy and a more family centred patriarchal view when making healthcare decisions. The case also points out the influence of culture on a definition of death. To the family, their daughter was not dead since she still had a heartbeat. To the physician, the patient was dead due to a lack of brain function. One pivotal cultural clash is that in the Iranian culture, the family is expected to be demanding with regard to healthcare; not doing so would indicate a lack of concern for their daughter (Al-Mutawa, 1989:S11).

One of the few books to compare and contrast end-of-life decisions in multiple countries was edited by Blank and Merrick (Blank & Merrick, 2005). In this book, differences of culture, religion, values, and economics were highlighted as influencers on end-of-life decisions in countries as diverse as the United States, Kenya, Israel and China. For example, in countries where there is a strong familial interdependence coupled with a scarcity of affordable healthcare facilities, most people die at home. In contrast, particularly in western societies, the majority of deaths occur in hospital.

An example of cultural differences was reported by Chattopaddhyay and Simon (2008) as they contrasted the cultures of India and Germany and their effects on end-of-life decisions. They found, for example, that in India illness is more of a family affair rather than an individual experience and therefore a physician is more likely to respect the family's wishes with regard to what information to share with the patient and decisions regarding end-of-life. In contrast, in Germany a physician is legally required to inform the patient regarding his/her illness or disease. However, in many Asian cultures, it is not considered appropriate to inform a patient of a cancer diagnosis (Searight & Gafford, 2005; Hu, Chiu, Chuang & Chen, 2002). Finally, advance directives are extremely rare in India while mandatory in Germany (Chattopaddhyay & Simon, 2008). In Kenya, Turkey and India euthanasia in any form is illegal while in other countries what is termed "passive euthanasia" – withholding food and water or active medical treatment – is more acceptable (Blank & Merrick, 2005). In the United States, five states have legalised physician-assisted suicide, often referred to as "death with dignity".

Even within a single country, there are cultural differences. For example, in a study conducted in the United States, it was found that hospice use was low among Latinos due to a culture that is family-centred, tending not to want information about illness prognosis, and making decisions collectively as a family (Kreling, Selsky, Perret-Gentil & Mandelblatt, 2010). In another United States study, African Americans wanted life-saving interventions to a greater degree than did Caucasian

Americans (Shrank, Kutner, Richardson, Mularski, Fischer & Kagawa-Singer, 2005:703). Family support is particularly influential in ethnic minorities. For example, African Americans and Latinos tend to rely more on family members than healthcare practitioners when making end-of-life decisions (Bullock, 2011:91). In some cultures, particularly those that are patriarchal, end-of-life decisions may be made by the dominant male in the family rather than by the patient him\herself.

In 2011 Frost, Cook, Heyland, and Fowler (2011) published a systematic review focused on factors influencing end-of-life decisions. They identified 6259 publications with possible relevance, and then narrowed inclusion to 102 relevant articles. They concluded that patients and clinicians did indeed differ in preferences and expectations regarding end-of-life decisions. In general, culture, religion, race and geography appeared to be important factors in influencing end-of-life discussions and decisions. Of particular note was that there seemed to be consensus among patients and healthcare practitioners that age, co-morbidities and functional status would affect end-of-life decisions. North American and Northern European patients of Caucasian background were less likely to want intensive interventions at end-of-life when compared to other cultures and ethnic groups. When healthcare practitioners and patients were of similar ethnicity or came from the same geographic region, intensive interventions were also less likely to be prescribed. Finally, it was noted that increased availability of technology makes these conversations even more critical and complex now and will do so in the future.

It is important to remember that while the patient is the person most affected by end-of-life decisions, the family and significant others are also affected and influence such decisions. The other group involved in the decision making process and final choice are the healthcare practitioners. Practitioners' culture, religious beliefs and personal values can affect end-of-life decisions, both consciously and unconsciously. In studies conducted by Obermeyer, Powers, Maker, Keating and Cutler (2015) and Seale (2010) it was found that the way in which end-of-life decisions were framed by the healthcare practitioner influenced patient and family choice. One of the hardest aspects for healthcare practitioners in providing patient care is accepting the values and preferences of the patient, even when they are not aligned with one's own beliefs.

It must be recognised that patient values may change over time and this change should be respected. For example, let's say we have a husband and wife who have been married for over 50 years. They are devoted to each other and have expressed on multiple occasions the fact that they will do everything in their power to stay together. Then the husband suffers a stroke, and must live with the physical and mental changes that accompany such a condition. His values slowly change, and he tells his wife that if he were to experience another stroke he would not want intensive interventions to prolong his life. The wife listens, but still values their intention of staying together for as long as they can. Then the husband has a second stroke. His values have changed, as we have seen, and he does not want heroic measures to prolong his life. His wife, on the other

hand, says that they have always wanted to stay together, no matter what, and asks the healthcare team to institute whatever measures are necessary to prolong his life. Clearly, an ethical dilemma is presented here as to whose values and desires ought to be paramount.

3. CONCLUSION

In this chapter, we have emphasised how complicated resolving ethical dilemmas can be for healthcare providers and patients' families. Even with information about the patient's values and preferences, identifying what the patient would truly want and aligning the patient's desires with the wishes of the patient's family members can still present challenges and create conflict. Although it may seem daunting to resolve ethical dilemmas, such as those presented in the examples provided in this chapter, there are resources available to clinicians and the healthcare team to help resolve these dilemmas and provide quality care to the patient.

When faced with an ethical dilemma, clinicians and healthcare providers are encouraged to consult their organisation's medical ethics committee. Ethics committees are trained to support healthcare teams in resolving complicated ethical dilemmas in order to optimise patient care (Ethics Committee Judicial Council, 1994). In the event that an ethics committee is not available, clinicians and healthcare providers should consult ethical resources to assist them in resolving the ethical dilemma. For instance, the American Medical Association's Code of Medical Ethics is available to all persons, free of charge via the internet (AMA, 2015).

In summary, this chapter was written to highlight the influence of culture, values and faith on end-of-life decisions. Healthcare practitioners must be mindful of these influences if they are to provide culturally sensitive care. Practitioners also need to accept that their own beliefs may be in conflict with a patient's beliefs: one of the most difficult situations to manage. When confronted with end-of-life decisions, the practitioner needs to recognise that the patient comes with a set of cultural mores, personal values and faith and all must be recognised to create a dialogue in which these factors are acknowledged and an informed decision can be made.

Healthcare practitioners must first recognise the influence of their own culture, values and faith on their practice. This should be a reflection done prior to confronting patient end-of-life decisions. This is not a one-time exercise, but should be performed periodically since we have seen that influences may wax and wane over time and be affected by life experiences and changing environments. For example, a healthcare practitioner who has experienced the death of a loved one may be influenced by that experience and may perhaps think differently about end-of-life choices and decisions than he/she has previously done. Furthermore, a practitioner who becomes immersed in a culture that differs from his or her birth culture may assume some of the values of the new environment.

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Once the healthcare practitioner has identified his or her own values and beliefs, and has acknowledged the impact of faith and culture on these beliefs, he or she needs to explore the culture, faith and values of each patient. It is important not to make assumptions based on what we might think we know about a particular belief system or a particular geographically located community. Also, as we have seen, it is important to understand the family dynamics in any end-of-life decision. As has been presented in this chapter, sometimes the family is more influential than the practitioner in the decision making process. Finally, while it is the duty of a healthcare practitioner to explain options, it is also the obligation of the practitioner to respect the decision of the patient/family even when that decision may not be the one the practitioner would recommend. However, if the patient's decision is one that is in severe conflict with practitioner values or beliefs, the practitioner should, ethically speaking, refer the patient elsewhere to ensure culturally competent care.

REFERENCES

- Al-Mutawa, M. 1989. Healthcare ethics in Kuwait. Hastings Cent Rep. 19: S11-12.*
- American Medical Association. 2014-2015. Code of Medical Ethics: Current Opinions with Annotation, Chicago, Ill, AMA Press. Available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics>.*
- Blank, R.H. 2011. End-of-life decision making across cultures. Journal of Law, Medicine and Ethics. Special Issue: Cost and End of Life Care. 201-214.*
- Blank, R.H. & Merrick, J. (Eds). 2005. End-of-Life Decisions Making: A Cross National Study. MIT Press: Cambridge.*
- Braun, K.L., Pietsch, J.H. & Blanchette, P.L. 2000. An introduction to culture and its influence on end-of-life decision making. In Braun, K.L., Pietsch, J.H. & Blanchette, P.L. (Eds). Cultural Issues and End-of-Life Decision Making. Thousand Oaks, CA.: Sage Publications. pp 1-11.*
- Bullock, K. 2011. The influence of culture on end-of-life decision making, Journal of Social Work in End-of-Life & Palliative Care. 7:83-98.*
- Chattopadhyay, S. & Simon, A. 2008. East meets west: Cross-cultural perspective in end of life decision making from India and German viewpoints. Medicine, Healthcare and Philosophy. 11:165-174.*
- Croasdale, M. 2005. Study examines death across cultures. American Medical News. 48(31):13.*
- Dunn, H. 2009. Hard Choices for Loving People, 5th edition., Lansdowne, VA.: A&A Publishers.*
- Ethics Committee Judicial Council. 1994. Guidelines for Ethics Committees in Health Care Institutions. Journal of the American Medical Association, 253(18):2698-2699.*

THE INFLUENCE OF CULTURE, VALUES AND FAITH ON END-OF-LIFE DECISIONS

- Frost, D.W., Cook, D.J., Heyland, D.K. & Fowler, R.A. 2011. *Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: A systematic review. Critical Care Medicine.* 39 (5):1174-1189.
- Gertesis, M., Edgman-Levitan, S., Daley, J. & Delbanco, T. 1993. *Through the patient's eyes.* Jossey Bass: San Francisco.
- Gysels, M., Menaca, A., Bausewein, C., Gomez-Batiste, X., Husebo, S., Higginson, I. & Harding, R. 2012. *Culture is a priority for research in end-of-life care in Europe: a research agenda. Journal of Pain and Symptom Management.* 22(2):285-294.
- Hathout, H. 1990. *Islamic basis for biomedical ethics. In Transcultural Dimensions of Medical Ethics, Symposium Proceedings. Washington, DC.: Fida Research Foundation. pp 25-26.*
- Hu, W.Y., Chiu, T.Y., Chuang, R.B. & Chen, C.Y. 2002. *Solving family-related barriers to truthfulness in cases of terminal cancer in Taiwan: A professional perspective. Cancer Nursing,* 25(6):486-492
- Klessig, J. 1992. *The effect of values and culture on life-support decisions. Cross-cultural Medicine – A Decade Later (special issue). Western Journal of Medicine,* 157:316-322.
- Kreling, B., Selsky, M., Perret-Gentil, E.E. & Mandelblatt, J.S. 2010. *The worst thing about hospice is that they talk about death: contrasting hospice decisions and experiences among immigrant Central and South American Latinos with US-born white, non-Latino cancer caregivers. Palliative Medicine,* 24 (4):427-434.
- National Research Council. 2001. *Crossing the quality chasm: a new health system for the 21st century.* Washington, DC: National Academic Press.
- Obermeyer, Z., Powers, B.W., Maker, M., Keating, N.L. & Cutler, D.M. 2015. *Physician characteristics strongly predict patient enrolment in hospice. Health Affairs.* 34(6):993-1000.
- Salzburg Global Seminar. 2010. *The greatest untapped resource in healthcare? Informing and involving patients in decisions about their medical care. December 2010. pp 12-17. www.salzburgglobal.org.*
- Seale, C. 2010. *The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care. Journal for Medical Ethics.* 36:677-682.
- Searight, H.R. & Gafford, J. 2005. *Cultural diversity at the end of life: Issues and guidelines for family physicians. American Family Physician,* 71(3): 515-522.
- Shrank, W.H., Kutner, J.S., Richardson, T., Mularski, R.A., Fischer, S. & Kagawa-Singer, M. 2005. *Focus group findings about the influence of communication preferences in end-of-life care, Journal of General Internal Medicine,* 20(8):703-709.
- Smedley, B.D., Stith, A.Y. & Nelson, A.R.E. 2003. *Unequal treatment: Confronting racial and ethnic disparities in health care. Committee on understanding and eliminating racial and ethnic disparities in health care. Board on Health Sciences Policy, Institute of Medicine. Washington, DC: National Academy Press.*

HEALTHCARE ETHICS FOR HEALTHCARE PRACTITIONERS

Sprung, C.L., Maia, P., Bulow, H-H., Ricou, B., Armaganidis, A., Baras, M., Weenberg, E., Reinhart, K., Cohen, S. Fries, D., Nakos, G. & Thijs, L. 2007. The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. Intensive Care Medicine, 33 (10):1732-1739.

Steinbrook, R. 2008. Physician-assisted death: From Oregon to Washington State. New England Journal of Medicine, 359:2513-2515.

Wilson, I.B. & Cleary, P.D. 1995. Linking clinical variables with health-related quality of life. Journal of the American Medical Association, 273 (1):59-65.



CHAPTER 6

ETHICS AND HUMAN RIGHTS IN HEALTHCARE

Andrè Moore

1. INTRODUCTION

Everybody has a right to healthcare.

This *fundamental* and *inclusive* right is undeniably the basis on which health programmes and policies should be built. This right to health is a fundamental part of our human rights and of our understanding of a life of dignity (Constitution WHO.1946). The 1946 Constitution of the World Health Organisation (WHO) defines health as “a State of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (The Right to Health, June 2008). In 1948 the Universal Declaration of Human Rights also confirmed health as part of the right to an adequate standard of living (Declaration of Human Rights, 1948). The 1966 International Covenant on Economic, Social and Cultural rights also recognised health as a basic human right (ICESCR, 1966).

The general consensus is that one’s own health and the health of those we care about is a matter of daily concern (Declaration of Human Rights, 1948). To all of us, our health is regarded as our most basic and essential life asset.

The tragedy is that vulnerable and disadvantaged groups are more susceptible to health problems and do not always have access to quality healthcare. In many countries, such as South Africa, a large majority of the population is dependent on the state to provide adequate and quality healthcare.

There are certain basic and important observations that should be borne in mind when it comes to human health: health is more than simply the absence of disease; human well-being is a human right; and circumstances such as poverty contribute to health challenges and vulnerability.

In this chapter the focus will be on how a human rights culture can contribute towards addressing people’s vulnerability in public healthcare.

2. THE STATE’S RESPONSIBILITY TOWARDS PROVIDING HEALTHCARE

In South Africa, the right to healthcare is provided for in three sections of the Constitution (Republic of South Africa, 1996):

- Section 27(1) (a) states that “Everyone has the right to have access to healthcare services”.
- Section 27(1) (b) places an obligation on the State to “take reasonable legislative and all measures, within its available resources, to achieve the progressive realisation of the right.”
- Section 27(3) states that no one can be denied emergency medical treatment.

In addition to these obligations to the provision of healthcare, Section 7(2) of the Constitution confirms the obligation on the State – “the State is obliged to respect, protect, promote and fulfil all the rights in the Bill of Rights (Constitution of South Africa, 1996).

It is not only the South African Constitution that emphasises the State’s responsibilities. Article 12 of the International Covenant on Economic, Social and Cultural Rights, provides the framework for the State to realise the right to “the enjoyment of the highest attainable standard of physical and mental health conditions to living a life of dignity” (United Nations resolution 2200A(XXI) 16 Des 1966) Interventions to reach this objective include: the provision of healthcare facilities, goods and services in sufficient quantity; these must be physically and economically accessible to everyone; they must be ethically and culturally acceptable; and must be of medically appropriate quality.

Furthermore, the progressive realisation of the right in regard to, and the provision of the healthcare services cannot be deferred indefinitely. According to the Limburg Principles, state parties must move as expediently as possible towards the full realisation of the right. (Right to Health April 2000-March 2002).

In April 2009 the South African Human Rights Commission (SAHRC) found the public health system in a lamentable state (IRIN News, 2009). Between 80 and 90% of the population are dependent on the public health system. There is an obligation on the state to provide healthcare based on human rights and ethical principles.

*“The mandate to ensure and protect the health of the public is an inherently moral one”
(Thomas, Sage, Dillenberg and Guillory, 2002).*

The obligation of care for the well-being of communities implies the possession of an element of power to carry out the mandate (Thomas, Sage, Dillenberg & Guillory, 2002). Thus the authorities must use the power vested in them to create a public health system ensuring healthcare services to everybody. A public health system can be defined as: “The Science and Art of preventing disease, prolonging life and promoting health through organized efforts of society” (Blacksher, 2014).

The role of a public health system is well described by a Graduation Class in 2002 of the Public Health Leadership Institute that drafted a code of ethics for public health. Although it was written with the American public health system in mind, it can be useful to all people, throughout the world, working in a public health environment or public health system. The principles of the ethical procedure of public health are (Thomas, Sage, Dillenberg & Guillory, 2002):

- Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes.

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- Public health should achieve community health in a way that respects the rights of individuals in the community.
- Public health policies, programmes, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.
- Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.
- Public health should seek the information needed to implement effective policies and programmes that protect and promote health.
- Public health institutions should provide communities with the information they have that is needed for decisions on policies or programmes and should obtain the community's consent for their implementation.
- Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public.
- Public health programmes and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs and cultures in the community.
- Public health programmes and policies should be implemented in a manner that most enhances the physical and social environment.
- Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others.
- Public health institutions should ensure the professional competence of their employees.
- Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

The state's responsibility towards public health is imperative for quality service delivery in (public) health. This responsibility should therefore be evident in patient care.

Dorland's Medical Dictionary (1994) defines "patient care" as "the services rendered by members of the health profession and non-professionals under their supervision for the benefit of the patient. In this case patients are the beneficiaries of the services. The focus on patient care is to treat people in need of medical care without any discrimination on any grounds, or any exclusion due to social group, ethnic, race, gender, religion or political affiliation. This approach constitutes equity in healthcare. Equity means social justice or fairness, and can be defined as the absence of socially

unjust or unfair health disparities (Braveman & Gruskin, 2002). Braveman and Gruskin regards equity as an ethical principle and is closely related to human rights principles.

To achieve ultimate patient care, a fine balance between patient and providers' rights is critical. Providers can only provide high quality care if their rights are respected and if they can work in decent conditions with professional independence.

The concept of human rights in patient care widens from the individual patient-provider relationship to system factors and state responsibility in the provision of healthcare. Human rights can therefore not be limited to the individual treatment of a patient but are part of the broader ecology of healthcare.

This orientation is evident when the close relationship between medical ethics and human rights is examined.

3. MEDICAL ETHICS AND HUMAN RIGHTS

It is evident that medicine, public health, ethics and human rights are all interrelated (Mann, 1997)

Medical ethics are based on four principles, also known as the *Georgetown Mantra*. These principles are:

- Respect for autonomy
- Beneficence
- Non-maleficence
- Justice

Beauchamp and Childress (2001:88) give context to these principles:

- **Respect for autonomy:** respecting the decision making capacities of autonomous persons; enabling individuals to make reasoned informed choices.
- **Beneficence:** this considers the balancing of benefits of treatment against the risks and costs; the healthcare professional should act in a way that benefits the patient.
- **Non maleficence:** avoiding the causation of harm; the healthcare professional should not harm the patient. All treatment involves some harm, even if minimal, but the harm should not be disproportionate to the benefits of treatment.
- **Justice:** distributing benefits, risks and costs fairly; the notion that patients in similar positions should be treated in a similar manner (Beauchamp & Childress, 2001:12,13).

Human rights and medical ethics work together to provide the maximum benefit to each individual. Human rights are concerned with socio-political aspects and place a duty on the state to provide services and facilities to realise these rights and to comply with minimum standards. Medical ethics are more personal and focus more on the doctor-patient relationship. The implication is that medical ethics place a duty on doctors to comply with a parallel standard (Beauchamp & Childress, 2001). Doctors must treat their patients within ethical guidelines whilst adhering to their employers' specifications and rules, without violating patient's rights.

Human rights and medical ethics complement each other and create maximum protection and care for the patient. Medical ethics and human rights are also closely related and dependent on each other, for example, the right to life and physical integrity as a basic human prerogative. Thus a human rights framework can be used to protect people from harm in the biomedical speciality (Adorno, 2007).

It can be said that human rights actively function as a global ethical foundation.

4. APPLICATION

It is possible that a healthcare provider could be forced to provide a standard of care that violates ethical principles due to lack of resources or poor working conditions. This may not only offend basic human dignity, but also violates the patient's right to the highest standard of care.

Jonathan Cohen and Tamar Ezer (2013:7) refer to dual loyalty as another possible risk of human rights violations. Dual loyalty refers to a healthcare provider's simultaneous obligation to a patient and to a third party, for instance the state. The risk of human rights violations becomes a reality when governments and other third parties demand that healthcare professionals follow instructions and guidelines that often violate the rights of patients.

A classic example is the Steve Biko case. Steve Biko was an anti-apartheid activist in South Africa in the 1960s and 1970s. He was a student leader and founder of the Black Consciousness movement. He was arrested and was brutally assaulted by the security police. Dr Ivor Lang, a district surgeon, examined Steve Biko who was brought to hospital by the security police after interrogation. Although Biko had bruises, slurred speech and unstable gait, Dr Lang issued a medical certificate stating "I have found no evidence of any abnormality or pathology on the patient". Biko was examined a second time by Dr Lang and his superior, Dr Benjamin Tucker. Dr Lang found clinical signs indicating a possible brain injury. A neurologist also examined Biko and recommended Biko to be transferred to another hospital for admission and close observations. Biko, however, was transferred to Pretoria Central Prison where he died unattended after having been denied correct medical treatment. This gross violation of the right to healthcare constitutes

gross negligence and unethical conduct. A medical practitioner's primary concern is the well-being of the patient: the best interests of the patient should always bear more weight than any other consideration.

The right to healthcare places an ethical obligation on the state to provide health services and facilities that are accessible and acceptable – this include goods and services to be respectful of medical ethics. Healthcare professionals must meet appropriate ethical codes of conduct. Access to healthcare facilities and services must be without discrimination, more especially in regard to vulnerable and marginalised groups. Public health ethics should therefore focus on creating professional codes to regulate the profession in relation to the public, human rights, target governments and/or the policies they enforce (Cohen & Ezer, 2013:7)

In addition, human rights and patients' rights should provide "a method for arriving at concrete decisions" and should provide a framework within which to judge complex and ethically challenging clinical interventions, as well as a set of procedures for enforcing those decisions (Marks, 2001). (See Chapter 9 for a framework for decision making in healthcare.)

5. CONCLUSION

Ethics traditionally encompasses controlling, guiding and directing relationships and actions of healthcare workers. Ethical standards have been drafted and developed over many years for the protection of patients and healthcare workers. They are nevertheless adaptable and can and should be adjusted to meet evolving new challenges in healthcare and science.

Human rights are drafted, negotiated and incorporated in international law. These rights are more rigid and less adjustable than ethics. There is, however, a close link between ethics and human rights, both conceptually and operationally (Guskin, Mia & Dickens, 2006:1903-1905).

This relationship not only provides maximum protection to patients, providers and vulnerable groups, but also the means to examine relevant issues. One example of protection is to be found in the requirement of state responsibility. This confers upon the public health system an obligation to provide services of the highest attainable standard, and also to protect patients from any inhumane treatment.

REFERENCES

Adorno R. 2007. Global Ethics at UNESCO: In defence of the Universal Declaration on Bioethics and Human Rights Journal of Medical Ethics, 33 (3): 150-154.

ETHICS AND HUMAN RIGHTS IN HEALTHCARE

Beauchamp TL and Childress JF, 2001. *Ethical frameworks - The four principles of biomedical ethics. Principles Biomedical Ethics, OUP, 5th edition.*

Blacksher, E. 2014. *Public Health Ethics, Ethics in Medicine University of Washington, School of Medicine. Available at <https://depts.washington.edu/bioethx/topics/public.html>.*

Braveman, P. and Gruskin, S. 2002. *Defining equity in health. Journal of Epidemiology & Community Health. 57: 254-258*

Dorland's Medical Dictionary. 1994. 28th edition. Philadelphia PA: Publisher: Elsevier Health Sciences

Committee of ESCR. 2000. General Comment no.14, para 12. The Right to the Highest Attainable Standard of Health Office of the High Commissioner for Human Rights adopted at the second session (E/C.12/2000/4)

Economic, Social and Cultural Rights Handbook for National Human Rights Institutions United Nations New York and Geneva UN publication salesno.E.04.xiv.8

Guskin, S., Mia, J.D. & Dickens, B. 2006. *Human Rights and Ethics in Public Health. American Medical Journal of Public Health. November: 96 (11):1903-1905.*

Jonathan Cohen and Tamar Ezer 2013, *Human Rights in Patient Care: A Theoretical and Practical Framework. Health & Human Rights, Vol. 15 Issue 2. p 7.*

IRIN News. 2009. *South Africa: Public healthcare "lamentable", 20 April 2009. Available from <http://www.IRINnews.org>.*

International Covenant on Economic, Social and Cultural rights adopted UN general assembly 16 December 1966 (www.ohchr.org).

Mann, J.M. *Medicine and public health, ethics and human rights Pubmed Hastings cent rep.1997 May-June,27(3) 6-13Pmid 9219018.*

Marks, S.P. 2001. *The New Partnership of Health and Human Rights. , Carnegie: Council for Ethics in International Affairs.*

Republic of South Africa. 1996. Constitution of South Africa, 1996. Pretoria: Government Printer.

United Nations office of the High Commissioner for Human Rights June 2008 Factsheet No 31. The Right to Health.

Thomas, J.C., Sage, M., Dillenberg, J., Guillory, J., Do, V. A.M.J. 2002. *A Code of Ethics for Public Health. Public Health, 92(7).*

The Universal declaration of Human Rights adopted. UN: General Assembly 10 December 1948 Palais de Chailiot Paris (www.un.org.en/universal-declaration-hum-rights/)



CHAPTER 7

Euthanasia, do we dare?

Charnè Viljoen

1. INTRODUCTION

With the advances in medicine and technology, life can be prolonged for some, but for others it can mean a prolonged suffering which moves us to ask whether or not we should do everything that we are able to do for a patient (The End of Life Decisions Bill, 1998:x).

On 4 May the South African High Court made a ruling allowing euthanasia in *Stransham-Ford v The Minister of Justice And Correctional Services and Others* (27401/15) [2015] ZAGPPHC 230. This ruling opened up, a whole new field of possible ethical challenges. Stransham-Ford was allowed by the High Court to end his life through medical intervention.

The High Court also ruled that the practitioner who acceded to the request of the applicant, Adv. Stransham-Ford, would not be acting unlawfully and would not be subject to prosecution by the National Director of Public Prosecution or subject to disciplinary proceedings by the Health Professions Council of South Africa for assisting the applicant (*Stransham-Ford v Minister of Justice and Correctional Services and Others*, 2015 4 SA 50 GP:35(26)).

With this controversial order the High Court established a cause of action where no cause of action had existed in South African law before (Van Der Merwe, 2015:8). This was changed however by the ruling made on the 6 December 2016 by the South African Supreme Court of Appeal in *Minister of Justice and Correctional Services v Estate Stransham-Ford* (531/2015) 2016 ZASCA 197 (6 December 2016). The Court upheld the appeal of the applicant and found that it is still illegal to allow euthanasia, whether assisted or administered by a physician. This can only possibly be changed once contested in the Constitutional Court of South Africa. As a human rights driven society we should all support the preservation of human life. However, an equally important human right is the right to dignity.

By allowing a decision on the choice of termination of pregnancy, for example, we already allow the choice to terminate a human life, yet it somehow seems easier to end a life that is still in development rather than a life that is nearing an end.

If people are granted the right to make such end-of-life decisions, both dignity and freedom of choice will be protected and promoted; but there is also the possibility for abuse, which was one of the South African Supreme Court of Appeal's main concern in its ruling. It is also important to keep in mind that this is not a death penalty: when a person chooses euthanasia as an option, the decision can be changed at any time, if the patient so wishes.

This chapter is not an argument for or against euthanasia, but rather an acknowledgement of the fact that it can be made legal by the South African Constitutional Court. There need to be strong and clear guidelines for healthcare ethics established, should we dare to brave this new development.

2. DEFINITIONS

Firstly it is important to understand the concept of euthanasia as well as the different forms of euthanasia (Verschoor, 2013:87-89). Euthanasia was derived originally from the Greek words meaning simply “good death” (Beauchamp & Walters, 1989).

Voluntary euthanasia

Voluntary euthanasia occurs when the patient requests someone to give him/her a lethal drug to bring about death.

Involuntary euthanasia

Involuntary euthanasia occurs when the patient has not given consent or requested anyone to give him/her a lethal drug. Rather, the person initiating the euthanasia believes it to be the wish of the patient to be euthanised, and takes matters into his/her own hands.

Direct euthanasia

Direct euthanasia occurs when the occurrence of death is directly established.

Indirect euthanasia

Indirect euthanasia occurs when death is hastened in some way, either by withholding treatment or by giving an overdose of medicine.

Active euthanasia

Active euthanasia is to act in a positive way (*comissio*) in order to end a person's life with the aim to spare them, the patient, pain and suffering as well as an undignified death.

Passive euthanasia

Passive euthanasia is the act of *omissio* (not acting) where the person does not do anything to save the patient's life.

3. RULE OF LAW

Life – *Everyone has the right to life* (Constitution of the Republic of South Africa).

EUTHANASIA, DO WE DARE

The right to life, as set out in section 11 of the South African Constitution, is a right with high value in our society and everything in our power should be done to support this right. What happens, though, when a person is diagnosed as terminally ill, with no prospect of recovery, and in fact a slow painful death is unavoidable?

The only thing that can be done, currently, for such a patient is to provide them with palliative care, but this could prove to be very expensive. The patient has no other choice but to pay for this care, since euthanasia is not a legal option.

This brings us to another, equally highly valued, right. According to the right to human dignity as set out in section 10 of the South African Constitution, everyone has inherent dignity and the right to have their dignity respected and protected. A person's dignity is lost the moment he/she cannot do anything for him-/herself anymore when he/she has to be fed and bathed like an infant.

Furthermore section 12(2) of the South African Constitution states that everyone has the right to bodily and psychological integrity, which includes the right to security and control over their body.

Should euthanasia be legalized and become an option, clear guidelines should be set as to when it could be authorised. This process must be regulated by law.

In 1998 the Law Commission (now known as the Law Reform Commission) wrote a report on proposed legislation regulating euthanasia. This was called the "End-of-life decisions Bill". Firstly the Bill sets out the different circumstances under which a patient may request a practitioner to provide a lethal drug which will cause the patient to die; then it also mentions the situation in which the patient is clinically dead and kept alive by life-sustaining machines and these are then switched off; and furthermore it deals with the case where the patient is both mentally and legally capable of making a decision to end his/her own life, by way of euthanasia. The Bill furthermore sets out the circumstances in which a patient may be seen as not mentally or legally capable of making a decision regarding his/her own life, and also has no chance on recovery.

The End-of-life decisions Bill goes further and distinguishes between the circumstances in which the patient only requests the practitioner to provide the lethal drug, but not to administer it, and those circumstances in which the patient requests the practitioner to both provide and administer the lethal drug.

This Bill sets out clear guidelines as to how the medical practitioner should conduct him- or herself in the event of clinical death and also how the medical practitioner should conduct him-/herself in relieving distress.

Using the guidelines set out in the End of Life Decisions Bill as well as new, more modern guidelines, an attempt may be made to address the ethical challenges which professionals will be facing with regard to euthanasia.

It is also good to have a look at countries where euthanasia is already legalized and in practice. The Netherlands for example requires that the physician terminates a life with due care. Furthermore, a patient may qualify for euthanasia or assisted suicide if the doctor holds the conviction that the patient's suffering is lasting and unbearable. There is no requirement that the suffering be physical or that the patient be terminally ill (Patients' Rights Council. <http://www.patientsrightscouncil.org/site/hollands-euthanasia-law/>).

4. ETHICAL CHALLENGES

The Health Professions Council of South Africa (HPCSA) sets out thirteen core ethical values and standards required of healthcare practitioners (HPCSA Booklet 1, 2008:2). Out of these thirteen core ethical values and standards, four can be identified to have the greatest impact on decisions related to euthanasia. These four core values are collectively known as the "Georgetown Mantra" and consist of *autonomy*, *non-maleficence* and *beneficence* and *justice* (Hadjistavropoulos, 1996:169).

According to the HPCSA concerning *patient autonomy*, healthcare practitioners should honour the right of patients to self-determination, to make their own informed choices and to live their lives by their own beliefs, values and preferences (HPCSA, 2008:2). This can be emphasised by section 12(2) of the Constitution granting the right to bodily and psychological integrity.

Refusing a competent person's request for cessation of therapy or cessation of life implies a disrespect of that person's deliberate choices and infringes the value of *autonomy* (Albright & Hazler, 1995). Granting autonomy to a patient can lead to the compromise of another ethical value, however, that of *non-maleficence* (Albright & Hazler, 1995), that is, to do no harm.

Healthcare practitioners should not harm or act against the best interests of patients, even when the interest of the latter conflict with their own self-interest (HPCSA, 2008:2). However, providing a patient with active euthanasia proves to be committing physical harm, because it results in the death of the patient. In such a situation it will be the ethical value which has the most precedent that should provide an indicator as to what the healthcare practitioner is to do.

Beneficence implies that healthcare practitioners should act in the best interest of patients even when the interests of the latter conflict with their own personal self-interest (HPCSA, 2008:2). To expect a healthcare practitioner to make a decision entirely by himself or herself with regard to the best interest of the patient when it comes to euthanasia is hardly fair. Therefore clear guidelines

should be set out in legislation as to how healthcare practitioners should go about making such a decision and what support should be sought in order for them to make the decision, for example, consulting with an independent practitioner.

With regard to directives of a terminally ill person, the Law Commission also recommended that a terminally ill person who is over 18 years of age and of sound mind shall be competent to issue a written directive (End of Life Decisions Bill, 1998:190).

In the absence of a directive however, the practitioner is advised to compare his/her opinion, in writing, with the findings of at least one other medical practitioner who has not treated the patient, but who has examined him/her and if the findings are the same the first medical practitioner can grant authorisation for the cessation of all further life-sustaining medical treatment.

The practitioner may however not act as such when it is against the wishes of the interested family members of the patient, unless authorised thereto by a court order (End of Life Decisions Bill, 1998:209).

Furthermore the court may grant an order for the cessation of medical treatment if it has given the family members the opportunity to be heard or if at least two medical practitioners who have expert knowledge of the patient's condition have convinced the court that the patient.

The Law Commission also recommended that a medical practitioner who gives effect to an order of the court shall not incur any civil, criminal or other liability (End of Life Decisions Bill, 1998: 211).

Justice, the last component of the *Georgetown Mantra* (1996:170), suggests that healthcare practitioners should treat all individuals and groups in an impartial, fair and just manner (2008:2). The concept of justice as one of the values can also be used to set limits to autonomy in order to preserve the greater good. When a healthcare practitioner respects the rights of patients, colleagues and other healthcare professionals, and also safeguards the patient's confidences within the constraints of the law, the value of justice is adhered to (1996:179).

However in our current situation, where a precedent has been set as determined by the South African High Court decision of Judge Fabricius, active voluntary euthanasia can only be granted by the court if it accedes to such a request. This option is therefore only really available to persons with enough money and resources to access the court and to carry the costs. This means that the value of justice will not be properly adhered to since not all patients will be treated in the same fair and just manner.

By identifying these four values it becomes clear that we aim to move towards a goal of virtue, which brings us to virtue ethics.

5. VIRTUE ETHICS

The values of the *Georgetown mantra* (see paragraph 4) also imply virtue ethics.

Virtues are neither passions nor capacities but states of character (Ross & Brown, 2009:29). Virtue ethics are all about making the 'right' decision, but how does one, as a healthcare practitioner, bring about the 'right' decision?

Ethical decisions are made daily by healthcare practitioners. Virtue ethics, however, suggest that the healthcare practitioner does not merely observe in the ethical process of deliberation, but that they are the living body of ethical practice (Koch and Menezes, 2015).

As previously stated, virtues are states of character and virtue ethics consist of making the 'right' decision, thus bringing about a good state of character together with making the 'right' decision, which will lead to a 'good life' – an integral part of Aristotle's philosophy. By living a 'good life' we can reach a state of *eudaimonia* which is a deep, lasting happiness and a state worth having (Ross & Brown, 2009:205). For a healthcare practitioner, living in a state of *eudaimonia* will basically mean being able to sleep at night (Koch and Menezes, 2015:49).

Pursuing virtue ethics will lead one to make the 'right' decision because one is in a state of good character: this will then lead to living a 'good life'.

Furthermore it may be argued that the core function of medicine is to improve the well-being of the patient. If one applies virtue ethics, also known as the *Georgetown mantra*, when treating a patient who is terminally ill and who has a wish for active euthanasia, it may be argued that the outcome will be an improvement for the patient, since nothing else can be done for him/her and a drawn-out and painful death is the alternative.

Without virtue, ethics is simply an obligation (Koch & Menezes, 2015:49).

6. CONCLUSION

The topic of euthanasia is still uncertain ground upon which we must tread cautiously. To have clear guidelines one has to resort to basic ethical values and to refine these values until they constitute virtue ethics, at which point the healthcare practitioner should be the best healthcare practitioner that he/she can be for the patient; he/she will then respect the autonomy of the patient and will also be able to sleep at night because he/she will have made decisions guided by ethical values, even if the decision concerns an ethical dilemma such as euthanasia. From the discussion above, it is also clear that arguments based on ethical values can also cause new dilemmas to arise.

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When facing an ethical dilemma, ethical values need to be part of the decision making: as soon as one implements the decision, new ethical dilemmas may arise, and a cycle of continuous ethical reasoning with no obvious conclusion ensues.

To solve this problem, legislation should be implemented to govern decisions that have to be made: yet the very implementation can create further ethical dilemmas. At this point, however, legislation is the only recourse we have to try and prevent further ethical dilemmas arising from the implementation of an ethical decision.

Thus it is clear that for ethical values to be properly incorporated into decision making, ethics and law need to be applied in concert to create a safe environment for both the healthcare practitioner and the patient.

REFERENCES

Albright, D.E. & Hazler, R.J. 1995. A Right to Die?: Ethical Dilemmas of Euthanasia. Counseling and Values 39(3):177-189.

Beauchamp, T. & Walters, L. 1989. Contemporary Issues in Bioethics. 3rd edition. Belmont: Wadsworth.

Davison S. 2016. Statement by Professor Sean Davison. <<http://www.dignitysa.org/blog/>>. (Visited on 10 November 2016)

Hadjistavropoulos, T. 1996. The Systematic Application of Ethical Codes in the Counselling of Persons Who Are Considering Euthanasia. Journal of Social Issues 52(2).

Koch, K. & Menezes C.N. 2015. Virtue ethics: Beyond moral theory. South African Journal of Bioethics and Law 8(2).

Patients' Rights Council. 2013. Holland's Euthanasia Law. <<http://www.patientsrightscouncil.org/site/hollands-euthanasia-laww/>>. (Visited on 10 November 2016).

Ross, D. & Brown, L. 2009. Aristotle's Nicomachean Ethics. Great Britain: Oxford University Press.

Van der Merwe, S. 2015. Is doctor-assisted suicide now legal in South Africa? Casebook, 23(2).

Verschoor, T. 2013. Etiese en regsaspekte van geneeskunde. Bloemfontein: Universiteit van die Vrystaat.



CHAPTER 8

Community-based participatory research in healthcare: ethical issues and impact on healthcare practitioners

Moira S. Lewitt, Pamela Campbell and Beth Cross

1. INTRODUCTION

Community-based participatory research (CBPR) draws on constructivist and critical theory paradigms, and uses a range of research methods that are both qualitative and quantitative. Culturally appropriate engagement is important to the methodology; for instance when working with children, elements of storytelling and play are incorporated. The distinctive feature of CBPR is *active engagement and influence of community members in all aspects of the research process* (Israel, Schulz, Parker & Becker, 1998). Furthermore there is an explicit commitment to generating practical change, so that this approach can be regarded as sitting within, or overlapping with, the field of participatory action research. Indeed CBPR is seen as arising from the action research school of Kurt Lewin (1946) and the dialogic methods based on critical reflection of Paulo Freire (1970). In addition to these roots, the self-determination movements of indigenous peoples have contributed significantly to the development of community participatory research (Cargo & Mercer, 2008). It also meets the definition of “co-creation” research that involves researchers and stakeholders from the onset (Goodyear-Smith, Jackson & Greenhalgh, 2015). A strong benefit to CBPR is that it builds trust, enhances social networks and improves cultural competency, in addition to enhancing the rigour of the research. These are important to ethical healthcare practice because in these ways the process of CBPR can deepen understanding of healthcare practices by both practitioners and communities members.

This chapter will explore the range of ethical issues that arise in community-based participatory research (CBPR) in healthcare, with a particular focus on supporting the role of children as participants in that research. It will explore the literature, and a case study from the authors’ research setting will be used to highlight particular ethical considerations.

2. IMPORTANCE OF COMMUNITY-BASED PARTICIPATORY APPROACHES IN HEALTHCARE RESEARCH

Healthcare is in a state of transition from a traditionally regulated system centred around institutions and highly trained healthcare professionals, to one that is more personalised and integrated, and acknowledges the role of healthcare service users in decisions about the design of services and information provision. Personalised health relies on a dynamic network of interconnected systems in different contexts, some of which are outside healthcare-specific legal frameworks (Ruotsalainen & Blobel, 2015). The relationship of healthcare user to healthcare practitioners and services is also context-dependent and is sometimes complicated by technological change. Individuals may use sensors and online software applications, for example, in patient-entity relationships (Ruotsalainen & Blobel, 2015).

Community-based participatory research (CBPR) in health is defined as

“a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities” (W. K. Kellogg Foundation, Community Health Scholars Programme, 2001:2).

A key feature of CBPR is that it is collaborative and reciprocal: academic and non-academic researchers work together in a way that is mutually beneficial (Cargo & Mercer, 2008). There is a focus on improving local practice and quality of life but, from a research perspective, there is also an obligation to discover generalisable knowledge that is of social value (Buchanan & Wallerstein, 2007). Therefore it is important to strive for a balance between research that yields generalisable results, and action that has positive local impact (Israel *et al.*, 1998). It is considered a research orientation rather than a method, with location of power as key. It has been used to place the less powerful at the centre of the knowledge creation process in order to empower:

“... participatory research fundamentally is about who has the right to speak, to analyse and to act” (Hall, 1992:22).

As an approach, CBPR strives to be equitable and therefore requires awareness of power relationships between the researchers and community members or service users (Wallerstein & Duran, 2006). It seeks to share power between academic and community partners at every stage of the research process (Cornwall & Jewkes, 1995; Boser, 2006, 2007). Indeed the degree of success of CBPR may be dependent on group dynamics with the ability of the partnership to manage conflicts, communicate tasks, negotiate in a participatory manner, bridge culture differences and share power and resources ranking highly important (Wallerstein, Oetzel, Duran, Tafoya, Belone & Rae, 2008). It is also a strength-based approach which encourages community members to be aware of their own assets and build upon these (Morgan & Ziglio, 2007), with social capital being described as an ‘asset’ for communities and as being positive for health and well-being (James, Schulz & Van Olphen, 2001; McPherson, Kerr, McGee, Cheater & Morgan, 2013).

There has also been an increase in public involvement in the design and development of public health services, with co-production of services becoming more prominent (Bovaird, 2007). In CBPR, since community members are involved throughout the research process, issues are identified which are important to the local context and the public within a particular community. Furthermore involvement of the community in interpreting research outcomes will lead to solutions and interpretations around complex health questions that were unforeseen by the researchers (Macaulay & Nutting, 2006). In this way community members can have a greater influence on healthcare policy and practice (Batalden, Betalden, Margolis, Seid, Armstrong, Opipari-Arrigan & Hartung, 2015).

CBPR has an importance for children as well as adults (Cross, 2012). In the past decade a great body of work has focused on children's rights and participation, which has stemmed from attempts to implement article 12 of the United Nations Convention on the Rights of the Child (United Nations, 1989). In doing CBPR with children, there is a key focus on developing relationships of trust, using spaces and activities which children value and are comfortable with for research. It is crucial that all children be perceived as competent and participating as active contributors in the research, and that time is taken for relationship building in order for the working towards common goals to become meaningful (Chawla, 2001; Malone & Hartung, 2010).

While some may perceive that CBPR may have "reduced value", there are advantages to collaboration of healthcare practitioners with community participants that may lead to improvement in the quality of research. Increased response rates because of insider knowledge and the breaking down of barriers of distrust (Thompson, 2000; Farquahar & Wing, 2008) may contribute directly to internal validity of the research. There is also a positive impact on external validity, the relevance and sustainability of the research, and being grounded in the lived experience of community members (Altman, 1995; Israel *et al.*, 1998; O'Fallon & Dearry, 2002; Gair, 2012).

3. ETHICAL ISSUES IN COMMUNITY-BASED PARTICIPATORY RESEARCH IN HEALTHCARE

The cardinal ethical principle guiding research with human participants is respect for human dignity. CBPR clearly aligns well with this, and particularly with the key moral principles of autonomy and equity; in many contexts CBPR might be regarded as an ethical mandate:

"The more powerful the intervention and the greater the possibility of exploitation, the more extensive the level of community participation, both in outreach to the community and in their involvement in all phases of the research" (Buchanan & Wallerstein, 2007:6).

There are implications for the researchers' ethical approach, since CBPR is regarded as a research *orientation* (Minkler & Wallerstein, 2007). Partnership-working of researchers and communities may lead to unconventional research designs that reflect involvement of the community at all stages of the research, from design through to dissemination. The varying degrees of power and control over the research that are held by the community partners impact on the range of ethical issues that arise. Sources of 'insider-outsider' tensions in CBPR are well discussed (e.g. Minkler, 2004; Gair, 2012). Ethical guidelines need to accommodate this and traditional ethical review processes may not be well suited to these research collaborations (Buchanan, Miller & Wallerstein, 2007; Flicker, Travers, Guta, McDonald & Meagher, 2007). The situated nature of ethics is paramount and requires responsiveness, for example, to the dynamics of power relationships between various stakeholders. Therefore, in addition to the principle-based approaches to ethics

'regulation' of conduct, CBPR projects require awareness of *virtue ethics* and *ethics of care* (Banks, Armstrong, Carter, Graham, Hayward, Henry, Holland, Holmes, Lee, McNulty, Moor, Nayling, Stokoe & Strachan, 2013). This means that attention should be paid, not only to how the partnership between researcher and community is established, but also how it is reviewed as relationships change and power is negotiated. There is also a challenge in ensuring that ethics review accommodates emergent designs, where defining research questions, methodology and dissemination strategy are part of the research project (Goodyear-Smith *et al.*, 2015).

In CBPR the whole community should be considered a subject of research and ethical considerations should encompass respect for community as well as for individual autonomy. Indeed, it can be argued that self-determination *requires* that an individual is situated in, and derives their values from, a community. Indeed, it can be argued that the protection of the community is in the individual's interests (Weijer, 1999). Research may have an impact on the beliefs and values of a community. Community beliefs around traditional healing, for example, may be challenged by healthcare interventions. Seeking informed consent from individuals may be problematic in a community that makes decisions collectively (Weijer, 1999) and dilemmas arise when the consent of individuals within communities and the community as a whole do not align with the need for higher level social change (Hall, 1992). In some communities signed consent can serve to heighten distrust (Johnson, Ali & Shipp, 2009), and verbal consent may be perceived as having higher value. Considerations of the community as a unit of identity encompass the socio-cultural norms and values that influence the research; this is of particular importance in indigenous communities with traditional health beliefs (Johnson *et al.*, 2009; Stordahl, Tørres, Møllersen & Aira-Åhren, 2015). Development of CBPR has been influenced by the increasing recognition of the rights of indigenous peoples and other vulnerable communities to self-determination of interest and identity. This is reflected in the guidance from a number of national and international organisations; for example:

"... there should be a fair balance of risks and benefits amongst all role-players involved in research, including participants, participating communities and the broader South African society" (Department of Health, 2015:14).

"The research proposal should demonstrate evidence of respectful engagement ... this might require letters of support from Aboriginal and/or Torres Strait Islander community Councils..." (National Health and Medical Research Council, 2007).

"... a study of sensitive topics or behaviour (illicit drug use; domestic violence; etc.) may merit review because of its potential effects on a community or group even if the data were to be recorded anonymously" (Council of International Organisations of Medical Sciences, 2008: 8).

Alternative approaches to ethical review have been recommended and these include guidelines to facilitate reflection on ethical issues by researchers before, and also during the research process.

Flicker and colleagues (2007) suggest mandating that CBPR projects seeking ethical review should provide memorandums of understanding that outline the goals, partnership principles and partners roles, decision making processes and guidelines for handling and disseminating data. There should also be a requirement to document the processes through which key research design processes were made and the communities most affected consulted.

A further recommendation is that partners develop a set of codes for the research that includes an ethical framework that protects the community as well as individuals (Macaulay & Nutting, 2006). Indeed the process of drawing up such guidelines is likely to strengthen the partnership and therefore the research. An innovative Code of Research Ethics was developed for a participatory research project with a native community in Canada that included a clause in covering the community's right to dissent (Macaulay, Delormier, McComber, Cross, Potvin, Paradis, Kirby, Saad-Haddad & Desrosiers, 1998). It has been recommended that communities and populations have the right to a voice in more powerful community interventions through a Community Advisory Board (Buchanan *et al.*, 2007), including in work that affects their identity (Gostin, 1991).

CBPR recognises the rights of children to be heard and their opinions sought. Some of the ethical issues arising in CBPR with children are highlighted by the following case study.

Case Study: Hearing children's voices in a community weight management programme

Families completing a community-based lifestyle weight management intervention for overweight children aged 3 to 16 years decided to establish their own programme with the aim of supporting each other to continue their health improvement. Older young people (aged 16 to 22 years) provided leadership for the group, primarily by facilitating physical activity through sport and games. The local council and researchers at the University of the West of Scotland were invited by the group to facilitate further development of the initiative one year after the group was established. Risks to the group were minimised through relationship building to ensure that adults and children felt comfortable to express their attitudes and ideas for the research, and what they felt was useful for their own group.

The primary researcher used a long-term ethnographic approach, attending a variety of group events over an 18-month period, sometimes weekly. Participatory approaches were incorporated for children, families and leaders to actively contribute to ideas for development of the group, including research questions and methodologies. The children were presented with opportunities to select the methodologies that they wanted to use for the research, as well as for evaluation. They explored the positive and negatives of using photography, drawing, interviews, mapping and video diaries. The activity also included a 'something else' option to share ideas for approaches that were not offered by the researcher. The children selected photography, drawing and mapping. Further negotiation was done over the period of research to hone each method to mutually

agreed on benefit, for instance photography could be used to explore how community weight management programmes can help families in their daily lifestyle changes and how families engage with opportunities in the community to facilitate this, whereas mapping could be used to map the community in which they live or to document the process of research. In negotiating the use of methods it became clear that different members of the group had different views, with parents being much more reluctant to photograph children's activities outside the meetings than the children were. As a compromise, photographs of activities in the sessions were used to document choices and activities. These photographs helped to provide a basis for discussing unequal decision making and its consequences for younger children.

Group leaders across a range of levels of experience had explained to the researchers that they wanted to use children's ideas in the sessions. Leadership training had been provided to the younger leaders, and it was believed that this helped them to appreciate young children's views. Children's ideas communicated through participatory activities were communicated by the researcher to the young leaders. There was however a hesitancy for these leaders to use these ideas in practice. This highlighted an area to be further evaluated by the researcher, and one in which the group themselves could develop to increase the likelihood that children's voices were being heard and incorporated.

Consent was obtained at the start of the research from all participants, children, families, group leaders and facilitators from the local council, and at regular intervals throughout the project, to ensure that members of the group were happy both for the researcher to be present and with their own involvement as active contributors. However the researcher was aware that throughout the life of the project other individuals might be present, such as families considering joining the group in the future, from whom consent had not been obtained.

The researcher is a young, white, Scottish female, only slightly older than some of the leaders within the group. Dressing casually and speaking in 'child friendly' language, she was aware not to present herself as a leader figure. At the start of the project the researcher would be asked questions by the children as if she had a leadership role, and she would refer them immediately to a leader. In this way boundaries were soon clarified and this dynamic was no longer evident. The researcher adopted a reflexive approach throughout, being continually aware of the dynamics within the group and how her attendance has affected these dynamics. Field notes and reflections on data collection provided the researcher with an important opportunity to reflect and consider her impact on the group. Initially the researcher documented field notes during the group sessions, however since the children regularly expected her to participate actively in games and activities, it was decided that field notes would be recorded after the session.

Group members observed positive benefits of the research and perceived children as having a voice through the research. They have gone on to further develop the research in their own group setting, independent of the lead researcher, with similar activities and methods, and use the results to develop their programme.

In this case study, the researcher's involvement with a community group highlighted ethical and methodological challenges in CBPR, particularly in relation to children. Guidelines for research involving human subjects stipulate that standard practice is to obtain consent from the parent(s) or guardians(s) of children. When the research or healthcare intervention is situated in a community setting, information, protocols and consent should be designed to meet the needs of all age groups and contexts, and consideration should be given to formally reviewing each of these throughout the research process. Obtaining informed consent from children is also important. In the case study, consent was obtained at the start of the research and at regular intervals throughout so there was a constant negotiation of ideas and interests (Dockett & Perry, 2011; Fine *et al.*, 2000; Renold *et al.*, 2008; Warin, 2011). In CBPR there are challenges to issues of anonymity and confidentiality, as well as to consent, since most ethical guidelines and procedures appear to draw a line between researchers and individual subjects of research. In this collaboration the group was not static and other individuals, such as families considering joining the group in the future, were sometimes present. This posed an ethical challenge around defining the boundary of the community and therefore the project and ethical consent were not as neatly defined as the ethical protocols were constructed.

The approach of involving children from the outset of the research is often overlooked and it is usually the researchers and other adults involved who choose and select which methods they want children to use. Morrow and Richards (1996: 98) have stated that the "*biggest ethical challenge for researchers working with children...is the disparities in power and status between adults and children*". In this case study we used an approach that involved children from the start as active contributors in research that helped reduce the level of power held by the researcher. The case study also highlights the disparities in power between younger children and older children (the group leaders), and how this can impact on children's voices being heard. It is important to look at the factors that contribute to this as they hold lessons for research that empowers communities more generally.

Lessons from the UNESCO World Symposium on children's participation in community projects are important to consider. In tackling the thorny issue of young people's differing developmental experiences and processes, the developmental psychologists taking part in the symposium summarised the best approach to take as:

“... to assume competence in some degree, and to ask at every age: what support can be provided to enable children to participate to the best of their ability?” (Chawla, 2001: 12).

What would this mean for the case study under consideration? Social contextualisation is important to consider to begin to understand the dynamics at play. One of the crucial pre-conditions for empowering those with less power in a group is to recognise this power imbalance (Gair, 2012). Asking people whose own increased power is relatively recent, and in many respects fragile, to put themselves back in a position of having less power in order to understand how those they are leading might want to be led is not an easy ask, regardless of the ages of those involved. If one's previous experience of social settings is that those with less power are bullied, opting to re-experience a position of less power may make even less sense. To begin to understand if this kind of leadership is something the older young people wanted and felt comfortable doing would take very sensitive facilitation. A cursory discussion of broad principles of respect are unlikely to be enough of a foundation. Visual methods and embodied methods such as forum theatre techniques can open up people's lived experience and give them the tools to express embodied knowledge of what respect looks and feels like as well as what it feels like when it is lacking. It is this level of sharing experience which can open up to change embedded patterns of disempowerment that otherwise may simply be reinforced. These tools can then be a resource for looking at tensions throughout the life of the group. Kesby (2007) cautions that even these techniques have their limits, particularly if sensitive health issues are being explored. There will always remain a difference between what can be made public and what remains a matter of private or internal negotiation.

It has to be stressed that the skills of facilitating discussions on power and leadership as such are not skills taught as a rule in post graduate research courses in health or social sciences faculties. These are craft skills, i.e. skills learned and refined through experience, learning from more skilled facilitators as well as through one's own work. Time is required to encounter a range of responses and group dynamics in order to have a robust understanding of them and of one's own capacity to work productively with them. This is not to say that health researchers should shy away from attempting to use these methods. It does mean they should not underestimate the importance of making those who have these skills, be they community members, community workers, or experienced researchers, part of a research team. It does require a high level of teamwork and a willingness on the part of researchers to take part reflexively themselves in forum theatre group processes. Over time these skills can become part of the wider research culture as their importance becomes recognised. This in itself is an ethical goal worth achieving.

Within this case study the visual methods did allow younger children's views to be recorded and referred to in discussions. The group leaders and the children perceived these methods as useful and beneficial; if this had not been the case it could have had a negative impact on the group itself and how they moved forward after the research was finished.

Another ethical consideration was the researcher's positionality. Although the researcher did not position herself in the same way as adult leaders (Mandell, 1988), the children still recognised her as an adult. Therefore the researcher intentionally engaged in different ways with the children compared to other adult or leader figures in the group (Christensen, 2004).

4. IMPACT OF COMMUNITY-BASED PARTICIPATORY RESEARCH ON HEALTHCARE PRACTITIONERS

When community members are active partners, raising research questions, approving and owning projects and disseminating results, there is likely to be a greater impact on healthcare in communities. However it requires that healthcare practitioners relinquish control in a number of areas from the start, negotiating the research partnership and adapting the research methodology to maximise community benefit. Even the naming of the project becomes a matter of collaboration (Thompson, 2000). This constant balancing of priorities for two usually separate communities, the participants and researchers, is challenging. In CBPR the researcher is by necessity also a participant and this challenges requirements for objectivity of research, since all researchers, professional and community, are focused together on promoting health and healthcare. This requires that healthcare practitioners shift away from positivist research paradigms (Hall, 1992) and an agenda driven by professional interests, institutional agendas and funding priorities, to one that is owned by the local community, and where the methodologies chosen aim to empower local people (Cornwall & Jewkes, 1995). There are inevitably tensions that arise from the fact that researchers are rewarded more for their individual creativity and expertise, and publication in peer-reviewed journals.

Power differentials will have an influence on how research questions are framed and what decisions are made (Israel *et al.*, 1998). Since the academic researcher may be the dominant voice, it is important that explicit efforts be made to reshape this to establish "equitable power relationships" (Schulz *et al.*, 1998). Indeed it is possible that building power in the community will itself have a direct impact on health, including cases where feelings of powerless lead to poor health (Wallerstein, 1992). CBPR requires that healthcare workers relinquish some of their power and strive to acknowledge the expertise, resources and perspectives of all participants. This may involve "letting go" of primary leadership of a project and allowing a shift to a balanced partnership model or even one where the main authority rests with the community (Macaulay *et al.*, 1998). A relinquishing of sole ownership of the research outcomes, to shared ownership, is also necessary in CBPR (Cornwall & Jewkes, 1995). Since the outcomes are of value to the community, local knowledge should inform use of the work, including dissemination strategies. This level of collaboration involves flexible research designs and the removing of the distinction between academic and non-academic participants that could lead to tensions. Academic researchers

may express concerns about data being used prior to peer-reviewed publication, for example (Israel *et al.*, 1998; Minkler, 2004).

The treatment of research as 'lived experience' by CBPR requires a strong reflexivity by healthcare practitioners.

“Cultural humility and critical self-reflection, especially from high status... may be critical to high emotional and social capacity, trust and empathy, and a successful partnership”
(Wallerstein *et al.*, 2008: 382).

The context of healthcare is usually complex, often involving multiple organisations and discipline/professional groups. Healthcare practitioners should be aware of these complexities and of the fact that evaluation healthcare research in communities usually involves the assessment of multiple interventions simultaneously, in an open, dynamic system (Buchanan *et al.*, 2007).

5. CONCLUDING COMMENTS

As healthcare research moves from working 'on' communities to working 'with' communities, a concomitant shift in the ethical orientation of healthcare practitioners is required. In CBPR tensions may arise between the community and researchers because of competing expectations and values. Nevertheless researchers should not lose sight of their academic goal to produce generalisable knowledge alongside the objective to improve healthcare and empower the community partner. Efforts should be made to create *active* community partnerships and ensure alignment of expectations amongst all partners. This requires developing relational practice skills and incorporating negotiation and discussion skills. When working with children there is a further need to work sensitively with power dynamics. An important way of levelling the playing field is to incorporate playful and creative means of facilitating each phase of research from deciding the focus and design to implementing, analysing and reporting. There is a need for researchers to be reflexive in CBPR, especially in relation to ethical practice and review, due to shifts in power, changes in dynamics and the possibility of unexpected issues arising during research.

REFERENCES

- Altman, D.G. 1995. *Sustaining interventions in community systems: On the relationships between researchers and communities. Health Psychology, 14: 526-536.*
- Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opipari-Arrigan, L. & Hartung, H. 2015. *Co-production of health services. BMJ Quality and Safety, Sep 16. Pii: bmjqs-2015-004315. Doi: 10.1136/bmjqs-2015-004315. [Epub ahead of print].*

COMMUNITY-BASED PARTICIPATORY RESEARCH IN HEALTHCARE

Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., McNulty, A., Moore, N., Nayling, N., Stokoe, A. & Strachan, A. 2013. *Everyday ethics in community-based participatory research*. *Contemporary Social Science*, 8: 263-277.

Boser, S. 2006. *Ethics and power in community-campus partnerships for research*. *Action Research*, 4(1):9-21.

Boser, S. 2007. *Power, ethics and the IRB: Dissonance over human participant review of participatory research*. *Qualitative Inquiry*, 13(8):1060-1074.

Bovaird, T. 2007. *Beyond engagement and participation: user and community coproduction of public services*. *Public Administration Review*, 67(5):846-860.

Buchanan, D.R., Miller, F.G. & Wallerstein, N. 2007. *Ethical issues in community-based participatory research: Balancing rigorous research with community participation in community intervention studies*. *Progress in Community Health Partnerships: Research, Education, and Action*, 1(2):153-160.

Cargo, M. & Mercer, S.L. 2008. *The value and challenges of participatory research: Strengthening in practice*. *Annual Review of Public Health*, 29:325-350.

Chawla, L. 2001. *Evaluating children's participation: seeking areas of consensus*. *PLA Notes*, 42:9-13.

Christensen, P.H. 2004. *Children's participation in ethnographic research: issues of power and representation*. *Children & Society*, 18:165-176.

Cocks, A.J. 2006. *The Ethical Maze: Finding an inclusive path towards gaining children's agreement to research participation*. *Childhood*, 13(2):247-266.

Cornwall, A. & Jewkes, R. 1995. *What is participatory research?* *Social Science & Medicine*, 41:1667-1676.

Cross, B. 2012. *How does community matter? Misrecognition and the participation agenda for children in social disadvantaged communities*. *Ethnography and Education*, 7:311-326.

Council of International Organizations of Medical Sciences. (2008) *International Ethical Guidelines for Epidemiological Studies*. Geneva: CIOMS. ISBN: 92-9036-081-X, WHO Press, Geneva, Switzerland.

Republic of South Africa, Department of Health. 2015. *Ethics in health research: principles, processes and structures*. 2nd edition. http://www0.sun.ac.za/research/assets/files/Integrity_and_Ethics/DoH%202015%20Ethics%20in%20Health%20Research%20-%20Principles,%20Processes%20and%20Structures%202nd%20Ed.pdf Accessed 18 March 2016.

Dockett, S., Einarsdottir, J. & Perry, B. 2009. *Researching with children: Ethical tensions*. *Journal of Early Childhood Research*, 7(3):283-298.

Dockett, S. & Perry, B. 2011. *Researching with young children: Seeking assent*. *Child Indicators Research*, 4(2):231-247.

Farquhar, S.A. & Wing, S. 2008. *Methodological and ethical considerations in community-driven environmental justice research: Two case studies from rural North Carolina*. In M. Minkler and N. Wallerstein

(eds.) *Community-based participatory research for health: From process to outcomes* (pp 263-283). San Francisco: Jossey-Bass.

Fine, M., Weis, L., Weseen, S. and Wong, L. 2000. For whom? Qualitative research representations and social responsibilities. In N. Denzin., & Y. S. Lincoln (eds.) *Handbook of Qualitative Research* (2nd edition.) (pp107-132). Thousand Oaks, California: Sage.

Flicker, S., Travers, R., Guta, A., McDonald, S. & Meagher, A. 2007. Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*, 84(4):478-493.

Freire, P. 1970. *Pedagogy of the Oppressed*. New York: Seabury.

Gair, S. 2012. Feeling their stories: Contemplating empathy, insider/outsider positionings, and enriching qualitative research. *Qualitative Health Research*, 22:134-143.

Goodyear-Smith, F., Jackson, C. & Greenhalgh, T. 2015. Co-design and implementation research: challenges and solutions for ethics committees. *BMC Medical Ethics*, 16:78 DOI 10.1186/s12910-015-0072-2.

Gostin, L. 1991. Ethical principles for the conduct of human subject research: population-based research and ethics. *Law, Medicine & Health Care*, 19(3-4):191-201.

Hall, B. L. 1992. From margins to center: The development and purpose of participatory action research. *American Sociologist*, 23(4):15-28.

Israel, B.A., Schulz, A.J., Parker, E.A. & Becker, A.B. 1998. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19:173-202.

James, S.A., Schulz, A.J., & Van Olphen, J. 2001. Social capital, poverty and community health: An exploration of linkages. In S. Saegert, J.P. Thompson and M.R. Warren (eds.), *Social capital and poor communities* (pp 165-188). New York: Russell Sage Foundation.

Johnson, C.E. Ali, S.A. & Shipp, M.P.-L. 2009. Building community-based participatory research partnerships with a Somali refugee community. *American Journal of Preventive Medicine*, 37:S230-S236.

Kesby, M. 2007. Spatialising participatory approaches: The contribution of geography to a mature debate. *Environmental Planning A*, 39(12):2813-2831.

Lewin, K. 1946. Action research and minority problems. *Journal of Social Issues*, 2:34-46.

Macaulay, A.C., Delormier, T., McComber, A.M., Cross, E.J., Potvin, L.P., Paradis, G., Kirby, R.L., Saad-Haddad, C. & Desrosiers, S. 1998. Participatory research with native community of Kahnawake creates innovative code of research ethics. *Canadian Journal of Public Health*, 89(2):105-108.

Macaulay, A.C. & Nutting, P.A. 2006. Moving the frontiers forward: Incorporating community-based participatory research into practice-based research networks. *Annals of Family Medicine*, 4:4-7.

- Malone, K. & Hartung, C. 2010. *Challenges of participatory practice with children*. In B. Perry-Smith & N. Thomas (Eds). *A Handbook of Children and Young People's Participation: Perspectives of Theory and Practice* (pp 24-38). London: Routledge.
- Mandell, N. 1988. *The least-adult role in studying children*. *Journal of Contemporary Ethnography*, 16(4):433-467.
- McPherson, K., Kerr, S., McGee, E., Cheater, F. & Morgan, A. 2013. *The role and impact of social capital on the health and wellbeing of children and adolescents: a systematic review*. Glasgow Centre for Population Health, Glasgow. http://www.gcph.co.uk/assets/0000/3647/Social_capital_final_2013.pdf. Accessed 18 March 2016.
- Minkler, M. 2004. *Ethical challenges for the "outside" researcher in community-based participatory research*. *Health Education & Behaviour*, 31(6):684-697.
- Minkler, M. & Wallerstein, N. 2008. *Introduction to community-based participatory research: New issues and emphasis*. In M. Minkler & N. Wallerstein (eds.) *Community-based participatory research for health: From process to outcomes* (pp 5-23). San Francisco: Jossey-Bass.
- Morgan, A. & Ziglio, E. 2007. *Revitalising the evidence base for public health: an assets model*. *Promotion & Education*, 14(S2):17-22.
- Morrow, V. & Richards, M. 1996. *The ethics of social research with children: An overview*. *Children & Society*, 10(2):90-105.
- National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee, Commonwealth of Australia. 2007 (updated May 2015). *National Statement on Ethical Conduct in Human Research*. National Health and Medical Research Council. www.nhmrc.gov.au/guidelines/publications/e72. Accessed 11 May 2016.
- O'Fallon, L.R. & Dearry, A. 2002. *Community-based participatory research as a tool to advance environmental health sciences*. *Environmental Health Perspectives*. 110(Suppl 2): 155-159.
- Renold, E., Holland, S., Ross, N.J. & Hillman, A. 2008. *Becoming participant: problematizing informed consent in participatory research with young people in care*. *Qualitative Social Work*, 7(4):427-447.
- Ruotsalainen, P. & Blobel, B. *The new role of patients in future health settings*. In: *pHealth 2015*, B. Blobel et al. (eds.) IOS Press, 2015. Doi:10.3233/978-1-61499-516-6-71.
- Schultz, A.J., Parker, E.A., Israel, B.A., Becker, A.B., Maciak, B.J. & Hollis, R. 1998. *Conducting a participatory community-based survey for a community health intervention in Detroit's East Side*. *Journal of Public Health Management and Practice*, 4(2):10-24.
- Stordahl, V., Tørres, G., Møllersen, S. & Eira-Åhren, I.-M. 2015. *Ethical guidelines for Sami research: the issue that disappeared from the Norwegian Sami Parliament's agenda?* *International Journal of Circumpolar Health*, 74: 10.3402/ijch.v74.27024 /ijch.v74.27024.

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Thompson, S.J. 2000. *Participatory epidemiology: Methods of the Living with Diabetes Project*. *International Quarterly of Community Health Education*, 19(1):3-18.

United Nations. 1989. *The United Nations Convention on the Rights of the Child*. Office of the United Nations High Commissioner for Human Rights, London.

<http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>. Accessed 18 March 2016.

Wallerstein, N. 1992. *Powerlessness, empowerment, and health: implications for health promotion programs*. *American Journal of Health Promotion*, 6(3),197-205.

Wallerstein, N. & Duran, B. 2006. *Using community-based participatory research to address health disparities*. *Health Promotion Practice*, 7(3):312-323.

Wallerstein, N., Oetzel, J., Duran, B., Tafoya, G., Belone, L. & Rae, R. 2008. *What predicts outcomes in CBPR? In M. Minkler and N. Wallerstein (eds.) Community-based participatory research for health: From process to outcomes (pp 263-283)*. San Francisco: Jossey-Bass.

Warin, J. 2011. *Ethical mindfulness and reflexivity managing a research relationship with children and young people in a 14-year qualitative longitudinal research (QLR) Study*. *Qualitative Inquiry*, 17 (9):805-814.

Weijer, C. 1999. *Protecting communities in research: philosophical and pragmatic challenges*. *Cambridge Quarterly of Healthcare Ethics*, 8:501-513.



CHAPTER 9

Ethical decision making processes

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1. INTRODUCTION

Healthcare workers deal with people in a state of vulnerability who trust that their needs are put first. Such a relationship is what makes ethics particularly important in healthcare.

Ethics in healthcare is not all that different from ethics in everyday life, although some unique situations may arise. Healthcare workers tend to focus on what is right or what is in the best interest of the patient. However, ethics is not that simple and cannot be explained in terms of what healthcare workers think is good or right. It is not just all about the actual decision making process but rather about putting everything into context. Therefore, the issue is all about constructing ethics with other people. Ethics is the intricate matrix of comprehension and communication we as human beings co-construct. Ethical practice is not just a function of rational thoughts but is an embodied process. Because ethics is an inherent part of being human, it is important to have a more human understanding and practice of ethics. Therefore, it is essential to understand the fundamentals of ethics, including normative ethics. In normative ethics, the focus is the determination of a set of acceptable standards for right or wrong behaviour.

The purpose of this chapter is to provide healthcare workers with essential information to understand and to shorten the process of ethical decision-making. It is not the purpose of this chapter to provide healthcare workers with a quick solution to the ethical dilemmas although it is often necessary for healthcare workers to make quick ethical decisions. Healthcare workers must remember that each and every situation is different and therefore several frameworks are provided in this chapter that could be used to simplify the decision-making process although it may not be the ideal.

2. LOOKING MORE CLOSELY AT ETHICS

There are two theories of ethics applicable in healthcare namely *utilitarian* and *deontological ethics*. Although there are other applicable theories discussed in the literature, these two theories are well known and used within healthcare.

Utilitarian ethics is based on the premise that an action or practice is right if it leads to the greatest possible balance of good consequences or to the least possible balance of bad consequences.

Deontological ethics focuses on binding obligations or duties in which there is a justification of principles and actions irrespective of the consequences. In other words, an act is right if and only if it conforms to an overriding moral obligation, and wrong if it violates the overriding moral duty or principle. In this perspective, persons are valued for their inherent worth and are to be treated as ends in themselves and never solely as a means to the ends of others.

Although normative decision making models may assist the healthcare worker to know what they should do in certain circumstances, it is not yet clear whether this knowledge actually translates into ethical behaviour in healthcare.

3. HEALTHCARE ETHICS

Bringing ethics into healthcare, patients' safety and well-being, amongst other things, are dependent on the ethical decisions made by healthcare workers. In order for healthcare workers to provide responsible healthcare, the healthcare workers have to be competent in ethical decision making. The healthcare worker should not rely solely on his or her excellence in clinical knowledge, experience, expertise and skills to provide healthcare of a high standard.

It is therefore not surprising that the opinion exists that a healthcare worker who has low or non-existent ethical standards should be considered unfit to practice. Therefore also, there could be a concern about the ethical competency of healthcare workers because they often adopt inconsistent decision making processes or reach inconsistent ethical conclusions in attempts to resolve identical ethical problems.

One of the main reasons for this concern is the fact that ethical dilemmas experienced in the clinical setting may not be the same as those that the healthcare worker will be confronted with in their daily lives. The implication is that the ethical norms learned in their earlier years, including those as a child, are not sufficient to resolve these sometimes complicated clinical ethical dilemmas.

To some extent the healthcare worker considers the applicable ethical principles in the attempt to identify the best possible and morally-justifiable resolution while prioritising the interests of the patient. However, the concept of "to some extent" is not sufficient to make consistently high-quality ethical decisions.

Ethics is not all that straight forward, as mentioned earlier in this chapter. It is entirely possible for conflicts in ethics to arise when the actions of a healthcare worker have an impact on the beliefs of a patient, or *vice versa*. Sometimes, in such a scenario, it is not possible to decide who is right or who is wrong; it is however the healthcare worker's ethical responsibility to resolve the dilemmas to the best of his or her ability. It is evident that several role players are involved in the ethical decision making process and therefore ethical practice is not only a personal process but also a professional as well as a socially mediated process.

Ethical decision making in healthcare can be described as a process where a healthcare worker is required to make an appropriate decision about a morally toned dilemma with the consideration of the presence of the ethicality surrounding the situation. It is based on four components: ethical awareness, ethical intention, ethical judgment and ethical behaviour. Hence, it is a central aspect of

ethical decision making to define and support the “best” solution. Practitioner-patient relationship is one of the cornerstones of quality healthcare delivery and these four components could contribute towards an ethically sound practitioner-patient relationship (see also Chapter 4). It is embedded within ethical norms, mutual trust and respect, where the patient has an abundance of confidence in the healthcare worker. Medical ethics is used to guide healthcare workers in choosing the correct option when dealing with philosophical problems encountered routinely in the practice of medicine.

It can be concluded that ethical issues, including the ethical decision making processes, are characterised by complex, dynamic interactions with multiple, often competing goals and guidelines where resolutions are not readily apparent. The approach to the decision making process can further be complicated when decisions involve complex situations, conflicting ideals, vague or non-existent guidelines, and strong emotions. Therefore, the ethical decision making process cannot be done by using only a set of standards or guidelines or even simple rationales within a model.

Ethical decision making is considered to be an abstract exercise with an exploration of both problem evasion and problem solving. Therefore, it is important to revisit a few definitions before the actual ethical decision making processes are discussed.

4. DEFINITIONS AND CONCEPTS

Ethics can be viewed as a systematic reflection on and analysis of morality and it is considered to be a fundamental part of the life of all the people in a community. Therefore, it is possible that ethics is a requirement for human life because it is way that society organises its goals so that it can demonstrate the core values; this means that a society cannot be without its core values. As an additional explanation, morality is a systematic sustainability of relations between human beings and how they can live in peace and harmony. Morality also refers to the value dimensions of human behaviour and decision making. It is agreed that it is possible for people to recognise some common ethical norms within societies. However, communities consist of individuals with their own unique moral principles and values. Therefore it is possible that individuals might interpret, apply, and balance these norms in different ways, taking into consideration their own values and life experiences. Despite having their own unique moral principles and values, it is important that individuals should not seek to impose such unique principles and values on others.

Another definition of ethics considers the principles, norms, and standards of conduct governing an individual or group (see Chapter 1). This approach to ethics suggests that there are guidelines related to ethical conduct within societies. Therefore, ethics refers to those rules of conduct that direct people to act in a manner consistent with the values they profess. These rules are referred to as codes of ethics, with the intent to serve as a guide to everyday professional conduct. All

healthcare workers are required to adhere to the specific code of ethics relevant to their line of work. At the same time, it is important for healthcare workers to note that being ethical by adhering to the relevant code of ethics is not necessarily the same as following the law (see Chapter 1). It is stated that ethics and the law are not the same. Some professionals are of the opinion that legislation often serves as the starting point for ethics, or serves as the minimum standard for ethical behaviour. Communities might argue that ethics has higher standards than legislation therefore it is possible that ethics might challenge unjust laws. other hand, legislation should not just be considered as the only guideline to set the

A last concept to understand is the term *sense making*. The term describes how the healthcare worker deals with unique situations in his/her field of practice that are characterised by equivocality and uncertainty, and how he/she makes sense of competing streams of information by composing them into a useful framework to facilitate decision making and action.

In order to understand the various concepts as well as the definition of ethics, it is important to review the key ethical principles of autonomy, beneficence, justice, non-maleficence, and the duty to protect, as well as the practical implications in healthcare (see the concepts informing the *Georgetown mantra*).

Autonomy

Autonomy refers to the right of an individual to self-determination. People should be able to make their own free choices. The concept of autonomy involves liberty, the responsibility for personal behaviour, freedom of action and freedom of choice. In the healthcare arena, the principle of autonomy grants the patient the right to make informed choices about interventions without coercion or undue influence. Essential to autonomy is the need for full information so that the choice is informed. Healthcare workers should not presume to make decisions for others, especially relating to acceptability of risk, and should not withhold information necessary for others to make choices.

Beneficence

The concept of beneficence entails doing good for others by contributing to and promoting overall human health and welfare.

Justice

Related to beneficence, the principle of justice can broadly be defined as striving for fairness. Ethical practices and decision making strive for fairness and justice. Issues of justice include

ensuring equal access to psychological services, respect for human rights, client dignity, and limiting unreasonable and unfair treatment.

Non-maleficence

Very relevant to healthcare and related to justice and beneficence, the concept of non-maleficence comes from the Hippocratic Oath to 'above all do no harm'. The concept of 'to do no harm' is not a stand-alone concept and some authors such as De Vries and Verhagen (2008) regard it as a meaningless slogan except when it is placed in context. For example the ultimate goal of medicine can be twofold, namely to promote quality of life, as well as to increase the length of life. In order to apply the 'do not harm', healthcare workers need to put it into perspective by adding a third dimension to the ultimate goal and that is the fact that healthcare workers should also consider whether the life in question is a life that is, or will be, worth living. Only when all three aspects are put into context, can 'do not harm' have a meaningful impact.

Duty to protect

The duty to protect refers to the clinician's responsibility to protect the client's (or an identified third party's) welfare when the healthcare worker knows that a patient poses an imminent risk of danger towards him or herself or an identified third party.

Despite the clear key ethical principles as mentioned above, healthcare workers should acknowledge that providing healthcare is not without ethical conflict. It is important to identify possible sources of conflict that could arise. Such causes could lead to negative conflict which can complicate the ethical decision making process. The healthcare worker should take note of the possible sources of conflict especially when dealing with ethical issues. The following paragraphs provide a short explanation of some of the sources of conflict:

Pluralism – meaning not all people are the same.

Value – a concept considered to be very important and is usually named in a single word (freedom, courage).

Principle – an expression of values, duties, rights, etc. A principle is usually expressed in the form of a sentence.

Uncertainty – about the future, facts, outcomes and circumstances. Examples are new issues and development in healthcare such as termination of pregnancy, patient rights, and confidentiality. There could be also uncertainty about ongoing issues such as euthanasia and corruption.

In conclusion to this section on definitions and concepts, it is evident that ethics cannot be explained in one simple definition. Furthermore, researchers such as Cusveller Ivanhoe and Postow (1998) suggest ethical pluralism, or applying diverse ethical theories and perspectives in decision making, as one ethical theory or perspective is unlikely to be a universal remedy for each and every ethical problem. In addition it is recommended that diverse guides for ethical decision making to be used in collaboration in the decision making process. Such diverted guides include the ethical principles as discussed, ethical professional rules, code of ethics, comparable case studies, as well as healthcare workers' conscience.

5. ETHICAL DECISION MAKING MODELS

Structured models for ethical decision making is not a new phenomenon and several such models have been developed over the years. The main aim of a number of these models is to assist with the actual decision making process by breaking down the decision making process into steps that the decision maker can follow. The result is that the decision maker is guided through a prescribed rational route in order to make an eventual decision with the relevant responsibility. However, many of these models do not take into account the full complexity of ethical thought and practical dilemmas. Healthcare workers need to acknowledge the complex and multiple influences on the ethical decision making process. In the process of acknowledging the mentioned influences, the healthcare worker will be better prepared to address the unique ethical dilemmas to be found in the healthcare environment while taking more informed and responsible ethical decisions. It is not the purpose of this chapter to discuss individual models but it is the opinion of researchers that such systematic decision making models could assist people to have a better understanding of an ethical issue that might occur. However, with such a variety of models available, it is not always an easy task to promote certain models based on their strengths or weaknesses. Also nobody can predict which model is more widely accepted by healthcare workers. Nevertheless, during the process of ethical decision making it is important to accumulate as much information as necessary. By making use of such an acceptable model it should allow for the accumulation of valuable information, making the ethical decisions easier and more appropriate.

The value of ethical decision making models should not be underestimated, as illustrated by the following discussion on a few of these types of models. It is not the purpose of this section to recommend a specific model but rather to look at the implications of using models in the decision making process.

Theory-based models of ethical decision making

Several models have been developed that rest on a theoretical or philosophical basis. These models offer an important contribution as they defend against the accusation that ethical models often fail to take into account the complexity of meta-ethical perspectives, and as a result fail to respond to the complexity involved in making ethical decisions. A specific philosophical model includes two levels of thinking – a level that is concerned with rights and duties, and a second level that is concerned with attending to the interests of patients and based on utilitarianism.

Practice-based models of ethical decision making

In addition to the theory- and philosophy-based models, practice-based models for ethical decision making may be used. The difference with practice-based models is that such models offer a distinct line of inquiry by focusing on the *how* of the decision making process. When using a practice-based model, the healthcare worker will be able to follow a sequence of practical steps in order to come to a final ethical decision. Such an approach will probably ensure that an outcome of the ethical decision process can be considered as ethical sound.

It must be emphasised that it is possible that practice-based models may not give sufficient consideration to explanatory frameworks for the decision making process itself. However, the strength of these models lies in their attempt to apply and translate theory into practical steps. Healthcare workers must take into account that the result of the implementation of practice-based models may be only to evaluate a situation, rather than ending up with a final decision. On the other hand, practice-based models cannot be dismissed merely for the reasons discussed in this section. It has been stated that professional ethical codes can be considered as examples of practice-based models for decision making. It must be noted that good decisions are usually taken if they are based on acceptable practice theory. When combining such an approach with the values of the any healthcare worker, such healthcare worker should be able to make sound ethical decisions within their professional capacity.

Process-based models of ethical decision making

The main focus of the process-based models is actually on the processes to be followed in the ethical decision making. Such models however, often don't offer a comprehensive theoretical or practical framework. At the same time, process-based models may be considered prescriptive or normative with their focus only on strategies to be followed. Therefore, ethical principles are interpreted and applied within our relationship between knowledge and the actual decision making.

Integrated approach

Not all the ethical decision making models are as effective as they appear to be. The reason for this is that these models do not explain how each step or process should be accomplished or which other factors should be considered. The main focus of such models is on the processes itself, while the context in which decisions are to be taken tends to be ignored. The result is that applying a single model in practice is often not very useful. Therefore, it is recommended that the healthcare worker rather consider a more systematic analysis of the ethical issue at hand. Such an approach attempts to move the ethical decision making process more towards a simplified step-by-step approach. Below is an example of a simplified step-by-step approach.

- Step 1. Any ethical decision making process starts with perceiving the problem. It is important to state the actual ethical problem clearly.
- Step 2. Additional information collection and analysis of the problem. It is important to decide what kind of information is needed from each role player.
- Step 3. Develop alternatives and analyse and compare them. This is one of the important steps in the decision making process because all individuals affected by the decision share the necessary information. The problems and/or reasons for conflict should be clearly described.
- Step 4. Select the best alternatives and justify the decision. The main objective of the ethical decision making is not just to identify the best solution for the problem but to make the best decision with which most parties (if not everybody) will be satisfied.
- Step 5. Strategies to implement the chosen alternative and take action must be developed and implemented. Once a decision is taken, everybody must take responsibility. Therefore, all of the healthcare workers involved have to be actively involved in the development of the best strategies and action plans to implement the chosen ethical decision regardless of whether the final decision is the one he or she originally intended.
- Step 6. Evaluation. The development and implementation of the strategy in an action plan (Step 5 above) is not final last step in the decision making process. It must be remember that healthcare workers need to evaluate not only the effects of any chosen ethical decision but also the actual decision making process itself.

In summary, Williams (2000) proposes the following ethical decision making framework that could be applicable and used effectively within the healthcare industry. It is called the RESPECT framework:

- R** Recognise moral dimension of problem
- E** Enumerate guiding and evaluative principles and policies

ETHICAL DECISION MAKING PROCESSES

- S** Specify stakeholders and their practices
- P** Plot various action alternatives
- E** Evaluate alternatives
- C** Consult or involve stakeholders as appropriate
- T** Take decision that, all things considered, is the best

6. ETHICAL DECISION MAKING CHECKLISTS

In addition to the models as discussed above, healthcare workers can also use the following checklists to assist them with the ethical decision making process. In order to guide healthcare workers in an industry often confronted with ethical dilemmas, healthcare workers should continuously ask themselves the following questions:

Ethical checklist 1:

The main focus of this first checklist is on the patient.

- Am I respecting the patient's autonomy and not restricting choices?
- Am I respecting the patient's self-image?
- Am I honest with the patient?
- And if I am not honest, at this time, can I justify it?

Ethical checklist 2:

The second checklist is a combination of three questions involving legislation, the patient and the healthcare workers.

- Is it legal?
- Is there any legislation or are there policies and procedures to guide me in the decision making process?
- Is it balanced?
- Are we looking at a win-win situation for both sides if a specific decision is made?
- Would I be proud?
- After making the decision, would I be proud of what I decided?

Ethical checklist 3:

The dominant ethical consequences to consider should ultimately be:

- utility
- cost-effectiveness
- quality of patient care
- quality of life

Ethical checklist 4:

This checklist is based on the key ethical principles as discussed previously in this chapter.

- Beneficial:
 - All decisions should be aimed at improving the patient's condition and ensuring quality patient care.
- Non-maleficence:
 - The healthcare worker should ensure that all decisions avoid any harm to the patient.
- Justice:
 - Equal to all people. One needs to be careful because justice for the one could mean an injustice for another.
- Autonomy:
 - Before making the decision, the healthcare worker should consider the issue of autonomy because of the possibility of provoking disagreement within the medical profession.

7. PROFESSIONAL ETHICAL GUIDELINES

Professional ethical guidelines (codes of ethics) are sets of rules and principles to be used to guide healthcare workers when confronted with ethical dilemmas within their professional practice. These are preferences that are systematically presented as a list of principles that “prescribes and explains the obligations for good, right conduct on the part of professional members.” Each country’s relevant professional associations should have such a set of principles, or code of ethics, and these codes are designed to articulate the standards of practice for a specific group of people. Therefore, codes can be viewed as a manner to express the collective values of a specific profession.

For a very long time, healthcare ethics has been guided and dominated by using these specific codes of ethics along with ethical principles in order to assist healthcare workers with the ethical decision making process. However, it has become increasingly evident that ethical decision making and subsequent actions involve more than just applying the mentioned codes, principles and models. Furthermore, authors are of the opinion that these guidelines are often presented as linear, progressive models of decision making, facilitating first order change which traditionally focuses on changing the problem as defined by the system. It is suggested that these guidelines should rather facilitate recursive or systemic ones that bring about second order change. Second order change processes traditionally focus on changing the system and should have a bearing on therapy, research, as well as on the actual ethical decision making processes. The American College Health Association (ACHA) (2010) is also of the opinion that no code of ethics can encompass every potential ethical dilemma faced by a healthcare worker, but the specific code of ethics for a session should be considered and used as a blueprint for laying the foundation for ethical decision making within a specific healthcare profession.

8. ADDITIONAL FACTORS TO CONSIDER

As mentioned earlier, the models and steps as discussed above do not always take into consideration all the necessary factors in order to come to a final decision. When the healthcare worker is considering an integrated approach, there are several factors that needs to be considered. Such other variable factors could include cultural context, the law, specific circumstances, and likely outcomes, to mention but a few. These factors will impact on the final decision and ethical practice of the healthcare workers. Some of these factors are described in the following paragraphs.

Morality

Ethical decision making cannot be done without considering morality. Five values are important in assessing the moral discourse: (i) caring and compassion, (ii) self-determination, (iii) human diversity, (iv) collaboration and democratic participation, and (v) distributive justice. It should be mentioned that moral reasoning involves logical rather than chronological thinking. Four major psychological processes were introduced to enable people to behave in a moral fashion even with different starting viewpoints, namely awareness, judgment, intention and behaviour. Moral awareness means the healthcare worker acknowledges the existence of an ethical dilemma. Moral judgement is the next process, meaning that the healthcare workers must decide what is right. This process is viewed as critical because it is all about moral reasoning. The healthcare worker must take into account that moral reasoning is informed by the set of knowledge, beliefs and assumptions that healthcare workers carry with them. Lastly, moral intent or ethical behaviour is actually all about doing the right thing. In summary, moral principles and codes can only be

guidelines for ethical decision making purposes. It is suggested that healthcare workers should constantly be refining their ethical behaviour to achieve ethical maturity. In order to achieve this maturity, active participation is a key activity. With active participation comes personal experience which will result in case-based, experiential knowledge. The question may be posed as to whether the same quality of knowledge regarding ethics can be gained without having the necessary personal experience in ethical decision making.

Communication

The core business of healthcare workers is to take care of patients and therefore it often happens that healthcare workers consider communication as a given. However, communication plays a strategic role when it comes to the ethical decision making process. It is stipulated that communicative ethical theory puts dialogue at the centre of decision making processes. The following question is often asked and should be considered by the healthcare worker when dealing with an ethical decision making process: *How does this view influence the understanding of moral development as a manifestation of dialogue/communication?*

Social context

Ethical decisions are not made without any personal contact and should be placed within a specific social context. There is an agreement that ethical decisions should involve a process of acting according to consensual reality (consensualising). Ethical conceptualisation should also take place within context while considering the political, philosophical and social reality surrounding the ethical decision making process.

Personal factors

Personal factors cannot be ignored as these could play an important role in ethical decision making. The complexity of personal characteristics is the key to ethical decision making as it involves choosing from alternatives in responding to ethical dilemmas. Some of these characteristics include personal value systems, perspectives of the health professional-patient relationship (paternalistic mode vs participatory mode vs advocate, for example), role responsibility, decision making styles, level of cognitive moral development, ethical orientation, and demographic profile. Taking into consideration all of these personal factors, healthcare workers bring to the ethical decision making process “a proclivity toward selecting choices of action that are in line with their personal preferences, professional roles, commitment to laws and policies, practice experience, motivations, attitudes, and other individualized perspectives” (Mattison 2000). The healthcare worker must remember that apart from these personal factors, other factors such as organisational

characteristics including organisational culture, policy, line of authority, and communication system are also important. These organisational factors should not be regarded as less important or even ignorable because of their possible influences on the ethical decision making process. It is not the purpose of this section to go into the detail of the organisational characteristics but rather look at three personal factors namely age, gender and experience.

Age and gender are additional factors to consider in determining the ability to reason ethically. Older healthcare workers are considered to be more mature and it is said that the age factor does affect the healthcare worker's wisdom and ability within the ethical decision making process. Apart from age, gender difference is a further factor that could influence the ethical decision making process because of the possibility that people of different genders may have different approaches to the same ethical dilemma. It is stated that the initial attitudes of men and women tend to differ when it comes to questionable behaviour, with females having a more negative attitude than men towards such behaviour. Furthermore, social interaction may shift women's judgements of questionable behaviour while men tend to rely on prevailing social norms.

A third personal factor and linked to age, is experience. It is accepted that ethical decision making progression evolves with the healthcare worker's level of experience. The older the healthcare worker is, the more experienced he or she ought to be. It must be noted that as healthcare workers gain more experience, their ethical decision making becomes more intense and purposeful – or so it is believed. A question that could be asked is, if the healthcare worker is getting older and gaining more experience, does this mean that the healthcare worker can reach a state of ethical maturity? Before the question can be answered, however, ethical maturity must be defined. Ethical maturity is “the increasing capacity to embrace ethical complexity and deal with appropriate respect to all parties involved in a situation” (Vivian-Byrne & Hunt, 2014). As the healthcare worker is gaining more experience, there could be a heightened recognition of contextual complexity. Therefore, the healthcare worker develops the potential to have a more ethically aware practice. There could be a relationship between experience and ethical maturity but being mature in the ethical decision making process is not equal to the increase in age or being experienced, as the maturity can vary due to other factors as mentioned earlier this section. Professional behaviour of healthcare workers is often linked with experience but this is considered to be a matter of etiquette rather than ethics. The distinction between a moral code of behaviour and good manners is not always clear.

In this section a few personal factors that could influence the decision making process have been discussed. In summary it can be concluded that an ethical dilemma cannot be solved effectively simply by using a model or following a formula. The ethical dilemma should be put into context, and should be approached taking into consideration of a variety of factors as well as particular circumstances. It is important to acknowledge and evaluate the mentioned contextual factors that directly or indirectly influence the quality of ethical decision making.

9. SUMMARY – ETHICS IN HEALTHCARE

Healthcare is not practised in a vacuum and there are a number of regularly emerging themes that challenge the healthcare worker. One of the main objectives in healthcare is patient care and one such theme challenging the healthcare worker is the vulnerability of patients and their family while the healthcare workers do in fact have the perception of power of authority in this relationship. This theme becomes even more complicated when healthcare workers are required to maintain a trusting relationship with the patients while respecting their patients' subjectivity and not objectifying or reducing it. Ethical decision making competency becomes more and more challenging in clinical practice for a variety of reasons, including the increasing diversity of individual value systems, rapidly changing healthcare environments, and the complexity of healthcare systems.

Healthcare workers need to work in partnerships and teams to elevate the perceptions by the community at large with respect to ethics related to science, technology and healthcare. Such perceptions will only be achieved if all the efforts are consolidated and principles of ethical decision making and the system operate in a synchronised as well as in a structured manner. Despite the recommendation that healthcare workers need to work in partnership, the final ethical decision is essentially an individual process set within a modernist perspective, resting largely on the internal world of the healthcare worker who finds himself at the centre of the decision making process.

The exposition in this chapter is discursive due to the complexity of the ethical decision-making process. It is not always possible to have a quick solution for the decision-making process because various factors - as discussed in this chapter and book - must be considered. However, ultimately the healthcare worker will take responsibility for the entire ethical decision making process no matter what approach is followed.

REFERENCES

American College Health Association. 2010. General Statement of Ethical Principles and Guidelines. Journal of American College Health, Jul/Aug 2010, Vol. 59 Issue 1, pp 61-64.

Cusveller, B. 1998. Cut from the right wood: spiritual and ethical pluralism in professional nursing practice. Journal of Advanced Nursing, Aug 98, Vol. 28 Issue 2, pp 266-273.

De Vries, M., Verhagen, C. & Eduard, A. 2008. A case against something that is not the case: The Groningen Protocol and the moral principle of non-maleficence. American Journal of Bioethics, Nov 2008, Vol. 8 Issue 11, pp 29-31.

Doane, G., Pauly, B., Brown, H. & McPherson, G. 2004. Exploring the heart of ethical nursing practice: implications for ethics education. Nursing Ethics, May 2004, Vol. 11 Issue 3, pp 240-253.

ETHICAL DECISION MAKING PROCESSES

Du Preez, E. & Goedeke, S. 2013 *Second order ethical decision-making in counselling psychology: Theory, practice and process*. *New Zealand Journal of Psychology*, 2013, Vol. 42 Issue 3, pp 44-49.

Gibson, C.H. 1993. Underpinnings of ethical reasoning in nursing. *Journal of Advanced Nursing*, Dec 93, Vol. 18 Issue 12, pp 2003-2007.

Hlongwane, M.J. 2000. *The need for a national ethics committee in South Africa*. In *Medical Ethics 2000 Conference. Abstract from a presentation given at a Medical Ethics Conference, VW Conference Centre, Midrand August 21-23, 2000*. Midrand.

Ivanhoe, P.J. *Pluralism, toleration, and ethical promiscuity*. *Journal of Religious Ethics*, Jun 2009, Vol. 37 Issue 2, pp 311-329.

Khalid, K., Syed, A., Syed, O. & Khalid, K. 2012. *The synthesis of ethical decision making*. *International Journal of Academic Research*, May 2012, Vol. 4 Issue 3, pp 47-50.

Khalid, K., Omar, M.W., Syed, A., Syed, O. & Khalid, K. 2013. *The effects of individual characteristics on ethical decision making in SMEs*. *International Journal of Academic Research*, Jan 2013, Vol. 5 Issue 1, pp 23-27.

Kocet, M.M. 2006. *Ethical challenges in a complex world: Highlights of the 2005 ACA Code of Ethics*. *Journal of Counseling & Development*, Spring 2006, Vol. 84 Issue 2, pp 228-234.

Chan, L.M., Jamilah, O. & Rusinah, J. 2012. *Gender differences of human resources practitioners in their ethical decision making*. *International Journal of Academic Research*, Jul 2012, Vol. 4 Issue 4, pp 38-44.

Mattison, M. 2000. *Ethical decision making: The person in the process*. *Social Work*, May 2000, Vol. 45 Issue 3, pp 201-212.

Matusek, J.A., Wright, M.O. 2010. *Ethical dilemmas in treating clients with eating disorders: A review and application of an integrative ethical decision-making model*. *European Eating Disorders Review*, Nov/Dec 2010, Vol. 18 Issue 6, pp 434-452.

Mosalakae, K. 2000. *Ethics, the doctor and managed care*. In *Medical Ethics 2000 Conference. Presentation given at a Medical Ethics Conference, VW Conference Centre, Midrand August 21-23, 2000*. Midrand.

Nel, T.J. 2000. *Ethics in relation to blood transfusion*. In *Medical Ethics 2000 Conference. Presentation given at a Medical Ethics Conference, VW Conference Center, Midrand August 21-23, 2000*. Midrand.

Nelson, J., Smith, L.B. & Hunt, C.S. 2014. *The migration toward ethical decision making as a core course into the B-School: Instructional strategies and approaches for consideration*. *Journal of Education for Business*, 2014, Vol. 89 Issue 1, pp 49-56.

Park, E. 2012. *An integrated ethical decision-making model for nurses*. *Nursing Ethics*, Jan 2012, Vol. 19 Issue 1, pp 139-159.

Postow, B. 2007. *Toward Honest Ethical Pluralism*. *Philosophical Studies*, Jan 2007, Vol. 132 Issue 2, pp 191-210.

HEALTHCARE ETHICS FOR HEALTHCARE PRACTITIONERS

Rogerson, M.D., Gottlieb, M.C., Handeisman, M.M., Knapp, S. & Younggren, J. 2011. Nonrational Processes in Ethical Decision Making. American Psychologist, Oct 2011, Vol. 66 Issue 7, pp 614-623.

Robson, M., Cook, P., Hunt, K., Alred, G. & Robson, D. 2000. Towards ethical decision-making in counselling research. British Journal of Guidance & Counselling, Nov 2000, Vol. 28 Issue 4, pp 533-547.

The Royal Australasian College of Physicians. 1998. Guidelines on ethics and professional conduct for occupational physicians. <http://www.racp.edu.au.htm> Accessed on October 15, 2015.

Vivian-Byrne, K. & Hunt, J. 2014. Ethical decision making: social metaphors towards ethical action. Journal of Systemic Therapies, Spring 2014, Vol. 33 Issue 1, pp 1-15.

Williams, J.R. 2000. Ethics in Health Care: A practical guide. In Medical Ethics 2000 Conference. Presentation given at a Medical Ethics Conference, VW Conference Centre, Midrand August 21-23, 2000. Midrand.



CHAPTER 10

Spirituality and healthcare

Marius Swart

1. INTRODUCTION

Depending on the severity of the disease, a patient also has, apart from the physical discomfort, psychological and social challenges to deal with. In the holistic approach to patient care, the healthcare practitioner should be sensitive to the spiritual needs of the patient – and this sensitivity should involve taking the religious and faith needs of the sick person into consideration.

To treat only the body is to deny the person as a whole. In the Judeo-Christian faith the heart is the place where the body, soul and spirit connect as one (Nouwen, 2011:95). The Latin word for heart is indeed *cor*, which is the etymological origin of the more familiar word core or centre. However, these concepts of body, soul, spirit, and even mind, can be confusing. Waaijman (2002:132) attempts to clarify this by stating that the soul is the place where the soul chooses to be spirit (*pneuma*) or flesh (*sarx*). One should not see this trichotomy of body, soul and spirit in an anatomical context, but should rather understand a human being as an embodiment of soul, or an ensoulment of body (Louw, 2005:16). Soul does not represent a part, but rather soul represents wholeness (Louw, 2012:2). Spirituality could thus be the religious dynamic of this ensoulment or embodiment. Spirituality, in a broad sense, means to find significance and direction in life, because spirituality is the point of interaction between the spirit of the human and the spirit of God (Schneiders, 2005:51). In particular spirituality refers to the meaning or even lack of meaning the patient may experience during illness (Truter & Kotze, 2005:974). However, this does not necessarily mean that spirituality is a pathway to “strange” religious experiences.

Spirituality is the way of life. The rabbinical word *halacha* refers to the way of the Torah. The follower of Buddhism sees spirituality as the way to Enlightenment. Even the root of the word Taoism (a Chinese philosophy) refers to “the way”. The Christian is familiar with Jesus’ claim of being the way (New Testament John 14:6). For the believer of Islam *shari’ah* is the road to travel (Waaijman, 2002:123-125). All of these religions have an eschatological emphasis that is important to the patient who, in his or her vulnerable state, may be thinking about what will happen after this life.

The term “spirituality” has its equivalents in many other languages: the French have *spiritualité*, derived from the Latin *spiritualis*, the Hebrew use the term *ruach* and the Greek *pneuma*. The term spirituality is also not bound to a specific religion; the Jewish *kaballa*, for example, means mysticism and inner life (Waaijman, 2002:360).

Spirituality is also not necessarily even associated with a religion. People may well be spiritual, but not religious. All people are spiritual to some degree, even though they may deny this (Hinshaw, 2005:271). To be human is to be spiritual (Pesut, Fowler, Taylor, Reimer-Kirkham & Sawatzky, 2008:2804). To accept the idea that all people are spiritual though not necessarily religious, one has to acknowledge a secular spirituality, or reverence. Such a spirituality can be defined as, for

example, the amazement one can experience when spending time in nature; the enjoyment provided by a piece of art or music; the feeling of being loved; or the warm feeling engendered by altruistic deeds (Ai, Wink & Shearer, 2011:535). To Waaijman (2002:427) a secular spirituality is inclusive. Secular spirituality may include a sense of awe associated with, for example, environmental matters, feminism and other non-theistic forms of spirituality. However, there should always be something sacred to spirituality, even if it is not in a religious context.

2. SPIRITUALITY IN HEALTHCARE

When it comes to healthcare matters, and in particular the investigation of spirituality as it relates to healthcare, it is important to distinguish between the concepts of religion and spirituality. Patients often do not realise this difference and even authors use these terms interchangeably, although they could mean or refer to the same human experience (Koenig, 2008:5).

Religion concerns the service and worship of (a) God. Religion is considered to be institutionalised and related to tradition. The members of a religious group are often accountable to some kind of authority. Certain aspects of religion can be measured and this is important in studies related to health. These aspects may be, for example, the regularity of attendance of religious meetings or the frequency of prayer, or of reading the Holy Scriptures. As a concrete example, the close association between religion and tradition or customs was strongly highlighted by the positive interreligious collaboration in West Africa during the Ebola crisis of 2014 (Marshall & Smit, 2015:5).

Spirituality is more personal, more inclusive and less formal than religion. Koenig (2007:S45) acknowledges that spirituality could also refer to psychological characteristics of people. This may well complicate the possibility of research which tries to find links between spirituality and (mental) health. When spirituality is investigated, the sacred or transcendent should be seen as part of spirituality (Koenig, 2007:S46; Lucchese & Koenig, 2013:105). The transcendent is that which lies outside the physical and perceptible reality. In that sense spirituality is very close to religion and to measure religion is to measure spirituality. In a practical sense spirituality in healthcare refers to everything about the patient that is not body (anatomy or physiology), but which belongs rather to the vulnerable inner space (Waaijman, 2002:436), and which is concerned about why me, why this, what if, what then. These are the typical existential questions people ask when confronted with disease.

For centuries, perhaps millennia, medicine and religion have gone hand in hand. The same person often performed religious and medical rituals. During and after the Enlightenment an epistemology of reason, objectivity and empirical data forced religion into the private lives of individuals (Pesut, Fowler, Taylor, Reimer-Kirkham & Sawatzky, 2008:2805). Science and religion separated and developed in different directions. However, today this is changing again, and a new era has

dawned, or perhaps returned. The science-faith debate is very topical. The fields of science and theology do not need to be in conflict with one another. Theology should take note of the findings of the hard sciences, re-interpret them and apply them in a religious tradition (Buitendag, 2004:65). Since the 2000s an explosion of research articles on spirituality and medicine has been observed (Lucchese & Koenig, 2013:105; Neely & Minford 2008:176; Van Erp, 2006:66). *Where Science and Spirituality Meet* becomes an appropriate subtitle for the book on health and religion by Harold Koenig (2008). The argument by Willis (2000:355) that healthcare should make some serious paradigm shifts, is thus relevant. These paradigm shifts can be summarised as a change in the way healthcare workers see patients; the way patients see themselves; and how God is perceived in suffering and healing.

3. WHAT IS THE EVIDENCE?

Religious people would rejoice if evidence could be produced to prove that spirituality, and in particular faith, contributes to curing. Of course, true believers don't need proof, and sceptics won't be persuaded by facts (Tarpley & Tarpley, 2002:644). There is, in fact, no lack of evidence for a positive link between spirituality on the one hand, and health and curing on the other. When the evidence is evaluated one should be attentive to the outcome of the investigation and the way that spirituality has been applied. One should also be aware of underlying factors that may assist in explaining the association. Obviously, in such a debate one should be open to alternative standpoints.

Unfortunately, faith-linked controversies in healthcare are often closely related to culture, social factors and politics (Tomkins, Duff, Fitzgibbon, Karam, Mills, Munnings, Smith, Seshadri, Steinberg, Vitillo & Yugi, 2015:19). Family planning, child marriage, female genital mutilation, sexuality and end-of-life issues (suicide, euthanasia), to mention but a few, could all be faith/tradition related and have a decisive effect on health and well-being. Surgeons are familiar with the stance of the Jehovah's Witness religion pertaining the transfusion of homologous blood.

The positive relation between health and religion in general has been established. A meta-analysis of 42 articles and 126 000 patients who were followed up for a fixed period reveals a lower mortality rate among patients with active religious involvement – the odds ratio was 1:29 (McCullough, Hoyt, Larson, Koenig & Thoresen, 2000:211). People with religious affiliations were shown to have a better chance of being alive at follow-up. This finding was however criticised as a weak association, and it was pointed out that other psychosocial factors are or could be more important to health (Sloan & Bagiella, 2001:228). Sloan and Bagiella's (2002:19) own review of the literature a year later concluded that religion has no beneficial effects on health. However, the claim that religious attendance could have the same benefit in terms of additional life-years as

using a statin or exercising regularly, is almost provocative (Hall, 2006:106) – yet no one will doubt the importance of a statin and exercise in managing coronary artery disease. In a review article, physicians at the Mayo Clinic expressed the opinion that spirituality and religious activities have a direct positive relationship with health outcomes (Mueller, Plevak & Rummans, 2001:1232).

In the positivistic sciences it would make perfect sense to test faith by comparing a study group and a control group. This was done by Byrd (1988:826) in the late eighties and repeated ten years later by Harris, Gowda, Kolb, Strychacz, Vacek, Jones, Forker, O’Keefe, & McCallister (1999:2273), who tracked intercessory prayer, and concluded that intercession improves the outcome in the coronary care unit. In both of these studies, hard endpoints were used, such as antibiotic usage, ventilator dependence or coronary care scores. The consensus after a review of five randomised control studies was that intercessory prayer is useful. However, soon after this finding, the contrary was demonstrated by the Mayo Clinic, which presented findings of a methodologically very sound study (Aviles, Whelan, Hernke, Williams, Kenny, O’Fallon & Kopecky, 2001:1192). It was a randomised, double blind study to assess the effect of intercessory prayer on patients for 26 weeks after they had been discharged from the coronary care unit. The endpoints were also robust outcomes, but they found no difference between the two groups. In another study, intercessory prayer was applied to a surgical group (Benson, Dusek, Sherwood, Lam, Bethea, Carpenter, Levitsky, Hill, Clem, Jain, Drumel, Kopecky, Mueller, Marek, Rollins & Hibberd, 2006:934). Post-operative coronary artery bypass graft surgery patients were randomised into three groups. One group received prayers, though they were not aware of it. A second group received no prayers, but they did not realise it. The third group received prayers and they were conscious of it. Again, no difference was found between the first two groups, but surprisingly, the third group, which received prayers and were aware of it, had more postoperative complications. The measured outcome was the complications typically associated with major cardiac surgery. One possible explanation is that these patients experienced a religious struggle. The negative influence of religion has been investigated and confirmed (Ai, Pargament, Appel & Kronfel, 2010:1067; Ano & Vasconcelles, 2005:477). To add to this, links between the image of God, frequency of prayer and mental health have been established (Bradshaw, Ellison & Flannelly, 2008:654). Patients with a negative image of God (i.e. not-loving or remote) might experience more symptoms of psychopathology. This might even be in spite of a higher frequency of prayer, illustrating underlying stress. A good image of God shows an inverse association with mental health problems. To conclude on the possible correlation between intercessory prayer and curing, the authoritative Cochrane Library pronounced the futility of such “experiments” and concludes that such a positive correlation between intercessory prayer and no prayer as a way of curing patients does not exist (Roberts, Ahmed, Hall, Davison, 2009:2).

Prayer should be experienced as an end unto itself, and one should be careful of applying prayer as a means to reach some other endpoint, such as biomedical or physical curing (Pembroke, 2007:347).

A point of criticism against studies involving study groups and control groups that are defined by prayer or no prayer is the lack of a true control group, as patients themselves or their relatives may also pray. The dosage or duration of prayers cannot be defined. Someone who prays expects to experience change, especially after a petitionary prayer. This entails a change in the person who prays or in the outcome and thus a change in God and God's actions. Thomson (1996:534) asks whether it is possible that such experiments actually question the existence of God. When the patient relies on prayer for curing instead of believing in God, the emphasis is on prayer as a prescription, written on the treatment chart of the patient.

Ai, with several of her co-workers, investigated personal prayer extensively, together with its effect on alternative yet softer outcomes. After many years they confirmed the positive role of personal prayer in the post-operative recovery after, in particular, coronary artery bypass graft surgery (Ai, Ladd, Peterson, Cook, Shearer & Koenig, 2010:806). These investigators are of the opinion that patients' spiritual needs should be addressed by healthcare workers. They investigated, *inter alia*, the relationship between optimism and prayer and found that prayer predicted optimism, along with older age, better education and a healthier affect (Ai, Peterson, Boling & Koenig, 2002:77). Although the association is positive and in fact now generally accepted, the reason for the association is still unclear. Phrases such as, for example, a link, a relation or an association are often used to express the connection between spirituality and health. This does not necessarily imply a causal correlation. For the believer, however, such a connection is real and that should be respected. After all, how does one prove godly intervention, if that is what believers would like to believe? God does not need to be proven. God is supernatural. God is transcendent and experienced immanent. The only confirmation of God's existence is the fact that God is approached in confession, in glorification, in expressing gratitude or in petition.

Koenig (2008:2) lists six fields of medicine where this positive association is established, namely, mental health, the immune and endocrine systems, cardiovascular diseases, stress, death and physical disability. It is accepted that a spiritual or religious life is usually associated with healthier lifestyles, with positive support networks, with less sympathetic reactions and with strengthened immune systems (Koenig, 2001:1190; Mueller *et al.*, 2001:1229). Religious attendance could, for example, simply be a marker for active lifestyle, or a thriving social network (Bagiella, Hong & Sloan, 2005:451). It could perhaps even have been argued that religion is rather a demographic variable (Hall, 2006:107). This probably explains why Ai and her co-workers (2011:538) were able to find a positive correlation between secular reverence and healing after cardiac surgery. Does this mean there is no difference between a religious spirituality and a secular spirituality? Are they, in fact, the same experience? Certainly not. Both spiritualities could be acting through the same bio-physiological pathways (Ai *et al.*, 2011:539). The positive result of both might be the same, but faith implies a relationship that is important to the believer and, in particular, the believing patient.

4. INSTRUMENTS TO MEASURE SPIRITUALITY

When the literature on spirituality in health and medicine experienced a revival, a number of tools were developed to measure religious practice. The scientist can now measure spirituality and quantify it, and these instruments can be applied to many religions. Organised religion (OR) is often determined by the frequency of the attendance of faith assemblies. Religious encounters comprise a multitude of spiritual experiences that may be beneficial for physical health (Idler, Boulifard, Labouvie, Chen, Krause & Contrada 2009:1). Non-organised religion (NOR) is expressed as the frequency of the believer's prayers, private meditations or readings from a holy book. Intrinsic religiosity (IR) refers to an individual's beliefs and how the believer perceives the world and decisions that need to be made (Cheever, Jubilan, Dailey, Ehrhardt, Blumenstein, Morin & Lewis, 2005:71). A spiritual well-being scale can be used to assess an individual's connection to God (Saguil, Fitzpatrick & Clark, 2011:281).

Reverence is assessed by questions about the specific religious conditions (private prayer or meditation) or secular reverence (being in nature, enjoying music or art, being loved or serving others) that make a person feel reverent (Ai *et al.* 2011:535). A complete set of religious items is available, and they can be adjusted according to a researcher's needs (Idler, Boulifard, Labouvie, Chen, Krause & Contrada, 2009:5).

5. THE PHYSICIAN-PATIENT RELATIONSHIP AS IT RELATES TO SPIRITUALITY

It would appear that a significant number of patients expect their physician to have an interest in their spirituality, particularly in the case of more critical medical conditions (MacLean, Susi, Phifer, Schultz, Bynum, Franco, Klioze, Monroe, Garrett & Cykert, 2003:40). Yet patients do not use the allocated consultation time to address spiritual matters, but prefer to concentrate on the primary medical problem. Patients interviewed at a surgical specialist clinic had higher expectations that the treating surgeon would have an interest in their spirituality than patients at a general outpatient department had (Taylor, Mulekar, Luterman, Meyer, Richards & Rodning, 2011:41). Though the group of orthopaedic and surgical patients at a specialist clinic had a comparable degree of religiosity, the surgical group had a deeper need of spiritual enquiry. Some patients appreciate it if the surgeon is open about his/her own spirituality (Taylor *et al.*, 2011:40). However, this expression of spirituality by the surgeon may have ethical implications if the treating physician is too explicit. Certain medical situations are more relevant to the patient's need for spiritual care: these conditions are serious and life-threatening medical illnesses, or if loved ones have been lost (McCord, Gilchrist, Grossman, King, McCormick, Oprandi, Schrop, Selius, Smucker, Weldy, Amorn, Carter, Deak, Hefzy & Srivastava, 2004:358, 359). Spiritual care during less serious

situations is not that important. Patients should know that believers are not exempt from disease and that spirituality as a mode of treatment cannot be applied like antibiotics or surgery. The reality is that patients have a certain expectation regarding spirituality during medical treatment. This is particularly important where end-of-life decisions are involved.

If the physician is to address the spiritual needs of the patient, the physician should be in touch with his/her own spirituality (Fosarelli, 2008:838; Hinshaw, 2005:264). Doctors are not exempted from existential questions. Physicians could, in the case of a negative medical result, reflect on themselves, or focus on the comorbidities of the patient and the patient's contribution. The believing physician would like to seek God's involvement in whatever outcome. The extent to which individuals ascribe the outcome of an event to personal doing, for example, a decision, an intervention or ability, is determined by a locus of control (LOC). Physicians with high internal LOC will look at themselves to find reasons for complications. A high external LOC will lead the physician to find the reason for the negative outcome elsewhere. This nature of LOC does not necessarily correlate with religiosity (Cheever *et al.*, 2005:67). In other words, doctors may be religious, but in the hospital they want to be in control. One would expect surgeons to have a higher internal LOC. At surgical mortality and morbidity meetings surgeons often feel the need to explain the reason for a complication (Barnard, 2011:135). However, Cheever *et al.* (2005:73), whose study group consisted only of surgeons, found that surgeons have a surprisingly moderate internal LOC. They did find that younger surgeons battle with a higher internal LOC. It should be noted that, in this study, the question related to LOC was answered by only 16% of the surgeons in the study group.

The more religious a physician is, the better the chance that he/she will have a positive attitude towards the patient in terms of respect for autonomy, altruism, empathy and a holistic approach to care (Pawlikowski, Sak & Marczewski, 2012:506). This study was done to investigate the doctor's ethical approach to patient care. These authors also found that, as far as religiosity is concerned, there is no difference between male and female physicians, yet there is a small but statistically significant difference between surgeons and specialist physicians. The authors (Pawlikowski, Sak & Marczewski, 2012:505) conclude that the work in surgical disciplines requires more factual thinking, with a direct effect on the patient. The therapeutic influence of pharmacological intervention on patients by non-surgeons is more indirect. In general, religion can also have a positive effect on the well-being of the medical doctor (Ayele, Mulligan, Gheorghiu & Reyes-Ortiz 1999:453; Pawlikowski, Sak & Marczewski, 2012:505).

6. HOW TO ADDRESS SPIRITUALITY IN PRACTICE

Surgeons, in particular, are not only poorly prepared to deal with their patients' spiritual needs, they are often unaware of these needs (Woll, Hinshaw & Pawlik, 2008:3048). Oncology surgeons at Johns Hopkins are advised to consider patients' faith as rational and to respect it with the necessary sensitivity (Woll *et al.*, 2008:3056) – this advice is in accordance with the American College of Surgeons' Code of Professional Conduct. The College states that at the core of professionalism is the altruistic commitment to, *inter alia*, the spiritual needs of the patient (Gruen, Arya, Cosgrove, Cruess, Cruess, Eastman, Fabri, Friedman, Kirksey, Kodner, Lewis, Liscum, Organ, Rosenfeld, Russel, Sachdeva, Zook & Harken, 2003:606).

A basic spiritual enquiry permits the physician to establish the spiritual needs of the patient. The acronym FICA has been proposed for obtaining a spiritual history from the patient (Puchalski & Romer, 2000:131). A patient can be asked about his/her *faith* or spirituality. How *important* or what the influence of this faith is? Is the patient part of a faith *community* and does it contribute to support the patient? How should these issues be *addressed*? These questions respect privacy, but present an opportunity to involve professional spiritual caretakers. CSI-MEMO is another approach, and it refers to the possible *comfort* or *stress* and *influence* of beliefs. It enquires about *membership* of a faith community and whether the patient can be assisted in any *other* way (Taylor, Mulekar, Luterman, Meyer, Richards & Rodning, 2011:37). Such inquiries allow the doctor-patient relationship to be a source of kindness and optimism, especially in desperate situations.

Needless to say, training in spirituality for physicians should be as important as lectures in ethics and communication skills. Spirituality is indeed being taught more and more at medical schools in the USA and the UK (Neely & Minford, 2008:177), at both undergraduate and postgraduate levels (Saguil, Fitzpatrick & Clark, 2011:283).

7. A NEW PERSPECTIVE ON SPIRITUALITY IN HEALTH

In the past, medical doctors were taught to keep a distance between themselves and the patient. The familiar clerking of the patient, completing the clinical notes, and even the term registrar, all have the tone of an administrative connection which could create an emotional distance between patient and physician. It is therefore not surprising to find different interpretations of this relationship, which could, to a certain extent, also be considered a sacred relationship. It is also important to distinguish between disease and illness. Disease refers to the body, namely anatomy and physiology, whereas illness puts the accent on how the human being experiences this insult to the body (Frank, 1991:12). For instance, the doctor might see sickness as a purely biological phenomenon, while the patient might have serious existential questions. Hospitals should move away from a customer-driven attitude and rather see the patient as a guest (Willis, 2000:355).

Narrative medicine allows the healthcare worker to gain practical wisdom (Charon, 2006:vii) (see Chapter 2, paragraph 4). Within a specific surgical context and from a tradition of faith, interwoven narratives present the possibility of an interdisciplinary conversation between medical science and theology. Such practical wisdom was obtained from a narrative reflection on negative outcomes after coronary artery bypass graft surgery (Swart, 2015:376). Surgical outcomes the world over are similar. Mortality after surgery is related to co-morbidities as well as established risk factors. With a new hermeneutical approach to a personal surgical database it has become clear that patients have physiological limitations (Swart, Van Zyl & Van den Berg, 2015:128). Everybody has an innate power or energy to heal. In medieval times this was referred to as *vis medicatrix naturae*. The believer believes this “power” is from God and, as such, this is a dispensation of creation. The lifestyles of patients and the effects of other peoples’ lifestyles on the patient contribute to disease. Lifestyle involves free choice and this too is part of creation (Hicks, 2012:6). God acts without violating natural laws or the free will of human beings (Brümmer, 2011:83). Yet the patient, especially the critically ill patient and his/her relatives, would like to see an intervention by God. Miracles are uncommon (Collins, 2007:44; Lewis, 1985:171). God does not necessarily intervene in an *ad hoc* way and thereby disrupt natural laws and free human choice. If this was the case, science would be impossible, and so would social structures.

The believing patient should see and experience the “hand” of God with a fresh outlook. The average patient expects physical or biomedical curing each and every time after petition by prayer. However, with a new perspective, each curing from disease, whether spontaneous or by medication, and every recovery after surgery can be experienced as a miracle. One should be amazed by even the simplest curing of the body. The limitation is the physiological capability of the human body. God has allowed human beings to develop medical science and move the physiological frontiers. An answer in response to prayer could even involve the strength to manage the disease; a reduction of anxiety before the operation; personal growth after a serious illness; the ability to change a detrimental lifestyle or the experience of peace amidst terminal disease. The support of a social network or faith community should be perceived as God in action. The patient may not necessarily experience a miracle, but may instead feel the love and support of caring others. Illness should also be an eschatological reminder of perfect health. These positive outcomes are all more than merely plain biomedical curing, but are the healing of the total person.

8. ETHICS

The application of spirituality to healthcare is bound by the same ethical rules that govern medical care in general. The set of rules that protect the patient is referred to as principlism. These principles are respect for autonomy, non-maleficence, beneficence and justice (Van Niekerk, 2011:37). Although the association between spirituality and positive health outcomes has been

established, spirituality does not replace good medical care and treatment based on sound medical science. The physician has no right to proselytise the patient under care. The physician's inquiry into the spiritual needs of the patient should be important as far as it might influence diagnosis, treatment and well-being. The patient deserves respect for privacy regarding his/her religion, but not if, for example, spiritual struggle as a result of faith disappointments, or withholding treatment, stands to jeopardise the patient's recovery. The primary-health caretaker should be open to the spiritual needs of the patient and should know where and when to consult appropriately. It is also important to realise that spirituality is a personal matter, and that health workers do not necessarily have the know-how to deal with spirituality during health care. Few physicians are trained to guide patients spiritually – this guidance should be provided by people equipped to deal with the spiritual or religious needs of the patient.

9. FUTURE OF SPIRITUALITY IN HEALTHCARE

From a research point of view there are a number of limitations to the investigation of the role of spirituality in health. Mouch and Sonnega (2012:1051) point out a few:

- There is a need to measure spirituality more accurately.
- Though the concepts of spirituality and religion are defined separately, they are often applied randomly in studies.
- Studies in spirituality are likely to be qualitative studies, and that limits the study size. It is more convenient to interview fewer people.
- The association between spirituality, religion and health is strong, but causation is still not clear. Certain pathways have been suggested and were referred to in a previous paragraph. It has been suggested that in the future the accent should be on finding an explanation for this association (McCullough, Hoyt & Larson, 2001:229; Hummer, 2005:453). One should never forget that the field of faith and spirituality is, to a large extent, a mystery and research to unveil this might involve pitfalls and gaps.

The vast majority of related research has been conducted in the USA. The field of spirituality is still fallow land in other parts of the world. Other continents, countries and regions have their own versions of spirituality and the association with health should be confirmed under those circumstances. Faith leaders and health professionals all need to work together, perhaps by reinterpreting sacred texts and showing better understanding by moving out of their respective isolated disciplines, and starting to work together (Tomkins, *et al.*, 2015:24).

10. CONCLUSION

Spirituality is a way of life and underlines the completeness of the patient.

Spirituality and the medical sciences, more and more, are sharing the same domain, and should no longer be separated.

The positive association between spirituality and health is well established, though the causality is still unclear. In certain communities, however, religion and related customs can also be detrimental.

Patients cherish certain expectations of spirituality and physicians have varying levels of spirituality. Easy ways exist to address the patient's need for spiritual care by asking a few simple questions. The shift from a power relationship to a complementary relationship is enhanced by this holistic interest in the patient's well-being.

The sicker the patient, the more vulnerable the patient becomes. The healthcare worker should respect the patient's sources of strength and allow him/her to draw from those.

The application of spirituality in healthcare is also bound by ethical rules.

REFERENCES

Ai, A.L., Ladd, K.L., Peterson, C., Cook, C.A., Shearer, M. & Koenig, H.G. 2010. Long-term adjustment after surviving open heart surgery: The effect of using prayer for coping replicated in a prospective design. The Gerontologist, 50(6):798-809.

Ai, A.L., Pargament, K.I., Appel, H.B. & Kronfel, Z. 2010. Depression following open-heart surgery: A path model involving interleukin-6, spiritual struggle, and hope under preoperative distress. Journal of Clinical Psychology, 66(10):1057-1075.

Ai, A.L., Peterson, C., Bolling, S.F. & Koenig, H.G. 2002. Private prayer and optimism in middle-aged and older patients awaiting cardiac surgery. The Gerontologist, 42(1):70-81.

Ai, A.L., Wink, P. & Shearer, M. 2011. Secular reverence predicts shorter hospital length of stay among middle-aged and older patients following open-heart surgery. Journal of Medicine, 34:532-541.

Ano, G.G. & Vasconcelles, E.B. 2005. Religious coping and psychological adjustment to stress: A meta-analysis. Journal of Clinical Psychology, 61(4):461-480.

Aviles, J.M., Whelan, E., Hernke, D.A., Williams, B.A., Kenny, K.E., O'Fallon, W.M. & Kopecky, S.L. 2001. Intercessory prayer and cardiovascular disease progression in a coronary care unit population: A randomized controlled trial. Mayo Clinic Proceedings, 76(12):1192-1198.

Ayele, H., Mulligan, T., Gheorghiu, S. & Reyes-Ortiz, C. 1999. Religious activity improves life satisfaction for some physicians and older patients. Journal of the American Geriatrics Society, 47(4):453-456.

HEALTHCARE ETHICS FOR HEALTHCARE PRACTITIONERS

Bagiella, E., Hong, V. & Sloan, R.P. 2005. Religious attendance as a predictor of survival in the EPESSE cohorts. *International Journal of Epidemiology*, 34:443-451.

Barnard, M. 2011. *Defining moments*. Cape Town: Zebra Press.

Benson, H., Dusek, J.A., Sherwood, J.B., Lam, P., Bethea, C.F., Carpenter, W., Levitsky, S., Hill, P.C., Clem, D.W., Jain, M.K., Drumel, D., Kopecky, S.L., Mueller, P.S., Marek, D., Rollins, S. & Hibberd, P.L. 2006. Study of the therapeutic effects of intercessory prayer (STEP) in cardiac bypass patients: A multicentre randomized trial of uncertainty and certainty of receiving intercessory prayer. *American Heart Journal*, 151:934-942.

Bradshaw, M., Ellison, C.G. & Flannelly, K.J. 2008. Prayer, god imagery, and symptoms of psychology. *Journal for the Scientific Study of Religion*, 47(4):644-659.

Brümmer, V. 2011. *Wat doen ons wanneer ons bid? Oor die aard van gebed en geloof*. Wellington: Bybel-Media.

Buitendag, J. 2004. "Genes я us" – of juis nie? Oor determinisme en voluntarisme by die mens met verwysing na homoseksualiteit. *Hervormde Teologiese Studies*, 60(1-2):61-81.

Byrd, R.C. 1988. Positive therapeutic effects of intercessory prayer in a coronary care unit population. *Southern Medical Journal*, 81(7):826-829.

Charon, R. 2006. *Narrative Medicine. Honoring the Stories of Illness*. New York: Oxford University Press.

Cheever, K.H., Jubilan, B., Dailey, T., Ehrhardt, K., Blumenstein, R., Morin, C.J. & Lewis, C. 2005. Surgeons and the spirit: A study on the relationship of religiosity to clinical practice. *Journal of Religion and Health*, 44(1):67-80.

Collins, F.S. 2007. *The language of God. A scientist presents evidence for belief*. London: Pocket Books.

Curlin, F.A., Lantos, J.D., Roach, C.J., Sellergren, S.A. & Chin, M.H. 2005. Religious characteristics of U.S. physicians. *Journal of General Internal Medicine*, 20:629-634.

Fosarelli, P. 2008. Medicine, spirituality, and patient care. *Journal of the American Medical Association*, 300(7):836-838.

Frank, A.W., 1991. *At the will of the body: Reflection on illness*. Boston: Houghton Mifflin Company.

Gruen, R.L., Arya, J., Cosgrove, E.M., Cruess, R.L., Cruess, S.R., Eastman, A.B., Fabri, P.J., Friedman, P., Kirksey, T.D., Kodner, I.J., Lewis, F.R., Liscum, K.R., Organ, C.H., Rosenfeld, J.C., Russel, T.R., Sachdeva, A.K., Zook, E.G. & Harken, A.H. 2003. Professionalism in surgery. *The American College of Surgeons*, 197(4):605-608.

Hall, D.E. 2006. Religious attendance: More cost-effective than Lipitor? *Journal of the American Board of Family Medicine*, 19:103-109.

Harris, W.S., Gowda, M., Kolb, J.W., Strychacz, C.P., Vacek, J.L., Jones, P.G., Forker, A., O'Keefe, J.H. & McCallister, B.D. 1999. A randomized, controlled trial of the effects of remote, intercessory prayer on outcomes in patients admitted to the coronary care unit. *Archives of Internal Medicine*, 159(19):2273-2278.

- Hicks, J.M. 2012. *Classic arminianism and open theism: A substantial difference in their theologies of providence.* *Trinity Journal*, 33NS:3-18.
- Hinshaw, D.B. 2005. *Spiritual issues in surgical palliative care.* *Surgical Clinics of North America*, 85:257-272.
- Idler, E.L., Boulifard, D.A., Labouvie, E., Chen, Y.Y., Krause, T.J. & Contrada, R.J. 2009. *Looking inside the black box of "attendance at services": New measures for exploring an old dimension in religion and health research.* *The International Journal for the Psychology of Religion*, 19:1-20.
- Koenig, H.G. 2001. *Religion, spirituality, and medicine: How are they related and what does it mean?* *Mayo Clinical Proceedings*, 76(12):1189-1191.
- Koenig, H.G. 2007. *Religion, spirituality, and medicine in Australia. Research and clinical practice.* *Medical Journal of Australia*, 186(10 Supplement):S45-S46.
- Koenig, H.G. 2008. *Medicine, Religion, and Health.* West Conshohocken, Pennsylvania: Templeton Foundation Press.
- Lewis, C.S. 1985. *Miracles. 10th Impression.* Glasgow: William Collins Sons & Co.
- Louw, D.J. 2005. *Do I have a soul? Soulfulness in life.* In Louw, D.J. (Ed.) *Mechanics of the Soul.* Stellenbosch: Sun Press.
- Louw, D.J. 2012. *A theological model for pastoral anthropology within the dynamics of interculturality: Cura animarum and the quest for wholeness in a colo-spirituality.* In *die Skriflig /In Luce Verbi* 46(2), Art. #57, 9 pages. <http://dx.doi.org/10.4102/ids.v46i2.57>.
- Lucchese, F.A. & Koenig, H.G. 2013. *Religion, spirituality and cardiovascular disease: research, clinical implications, and opportunities in Brazil.* *Revista Brasileira de Cirurgia Cardiovascular*, 28(1):103-128.
- MacLean, C.D., Susi, B., Phifer, N., Schultz, L., Bynum, D., Franco, M., Klioze, A., Monroe, M., Garrett, J. & Cykert, S. 2003. *Patient preference for physician discussion and practice of spirituality.* *Journal of General Internal Medicine*, 18:38-43.
- Marshall, K. & Smith, S. 2015:5 *Religion and Ebola: learning from experience.* *The Lancet.* [http://dx.doi.org/10.1016/S0140-6736\(15\)61082-0](http://dx.doi.org/10.1016/S0140-6736(15)61082-0).
- McCord, G., Gilchrist, V.J., Grossman, S.D., King, B.D., McCormick, K.F., Oprandi, A.M., Schrop, S.S., Selius, B.A., Smucker, W.D., Weldy, D.L., Amorn, M., Carter, M.A., Deak, A.J., Hefzy, H. & Srivastava, M. 2004. *Discussing spirituality with patients: A rational and ethical approach.* *Annals of Family Medicine*, 2(4):356-361.
- McCullough, M.E., Hoyt, W.T., Larson, D.B., Koenig, H.G. & Thoresen, C. 2000. *Religious involvement and mortality: A meta-analytic review.* *Health Psychology*, 19(3):211-222.
- Mouch, C.A. & Sonnega, A.J. 2012. *Spirituality and recovery from cardiac surgery: A review.* *Journal of Religion and Health*, 51:1042-1060.

- Mueller, P.S., Plevak, D.J. & Rummans, T.A. 2001. *Religious involvement, spirituality, and medicine: Implications for clinical practice. Mayo Clinic Proceedings*, 76:1225-1235.
- Neely, D. & Minford, E.J. 2008. *Current status of teaching on spirituality in UK medical schools. Medical Education*, 42:176-182.
- Nouwen, H.J.M. 2011. *Spiritual formation. Following the Movements of the Spirit. Great Britain: Ashford Colour Press.*
- Pawlikowski, J., Sak, J.J. & Marczewski, K. 2012. *Physicians' religiosity and attitudes towards patients. Annals of Agricultural and Environmental Medicine*, 19(3):503-507.
- Pembroke, N. 2007. *Spiritual care by physicians: Maintaining the integrity of religion and finding an appropriate form. In Gräß, W. & Charbonnier, L. (Eds) Secularization theories, religious identity and practical theology. Berlin: Lit Verlag.*
- Pesut, B., Fowler, M., Taylor, E.J., Reimer-Kirkham, S. & Sawatzky, R. 2008. *Conceptualising spirituality and religion for healthcare. Journal of Clinical Nursing*, 17:2803-2810.
- Puchalski, C. & Romer, A.L. 2000. *Taking a spiritual history allows clinicians to understand patients more fully. Journal of Palliative Medicine*, 3(1):129-137.
- Roberts, L., Ahmed, I., Hall, S. & Davison, A. 2009. *Intercessory prayer for the alleviation of ill health. Cochrane Database of Systematic Reviews, Issue 2. Art. No.: CD000368. DOI: 10.1002/14651858.CD000368.pub3.*
- Saguil, A., Fitzpatrick, A.L. & Clark, G. 2011. *Are residents willing to discuss spirituality with patients? Journal of Religion and Health*, 50:279-288.
- Schneiders, S.M. 2005. *A hermeneutical approach to the study of Christian spirituality. In Dreyer, E.A. & Burrows, M.S. (Eds) Minding the Spirit. The Study of Christian Spirituality. Baltimore: The Johns Hopkins University Press.*
- Sloan, R.P. & Bagiella, E. 2001. *Religion and health. Health Psychology*, 20(3):228.
- Sloan, R.P. & Bagiella, E. 2002. *Claims about religious involvement and health outcomes. Annals of Behavioral Medicine*, 24(1):14-21.
- Swart, M.J. 2015. *The spiritual experience of a surgeon. Annals of Thoracic Surgery*, 1:376.
- Swart, M.J., Van Zyl, G.J. & Van den Berg, J.A. 2015. *'n Narratiewe teologiese verkenning van negatiewe koronêre vatomleidingsoperasie-uitkomst: 'n Chirurgiese hermeneutiek. Acta Theologica*, 35(2):120-141.
- Tarpley, J.L. & Tarpley, M.J. 2002. *Spirituality in surgical practice. Journal of the American College of Surgeons*, 194(5):642-647.
- Taylor, D., Mulekar, M.S., Luterman, A., Meyer, F.N., Richards, W.O. & Rodning, C.B. 2011. *Spirituality within the patient-surgeon relationship. Journal of Surgical Education*, 68(1):36-43.
- Thomson, K.S. 1996. *The revival of experiments on prayer. American Scientists*, 84:532-534.

SPIRITUALITY AND HEALTHCARE

Tomkins, A., Duff, J., Fitzgibbon, A., Karam, A., Mills, E.J., Munnings, K., Smith, S., Seshadri, S.R., Steinberg, A., Vitillo, R. & Yugi, P. 2015. *Controversies in faith and health care*. *The Lancet*. [http://dx.doi.org/10.1016/S0140-6736\(15\)60252-5](http://dx.doi.org/10.1016/S0140-6736(15)60252-5)

Truter, C.J. & Kotze, D.J. 2005. *Spirituality and health: A narrative-pastoral approach*. *HTS*, 61(3):973-984.

Van Erp, S.A.J. 2006. *Diagnosing hidden religion in medicine: Health, illness, and the politics of hope*. In Twohig, P & Kalitzkus, V. (Eds) *Making sense of health, illness and disease*. Amsterdam: Rodopi.

Van Niekerk, A.A. 2011. *Ethics theories and the principlist approach in bioethics*. In Moodley, K. (Ed.) *Medical Ethics, Law and Human Rights*. Pretoria: Van Schaik Publishers.

Waaijman, K. 2002. *Spirituality. Forms, Foundations, Methods*. Leuven: Peters.

Willis, R.W. 2000. *Positive paradigm shifts in health care*. *Journal of Religion and Health*, 39(4):355-365.

Woll, M.L., Hinshaw, D.B. & Pawlik, T.M. 2008. *Spirituality and religion in the care of surgical oncology patients with life-threatening or advanced illnesses*. *Annals of Surgical Oncology*, 15(11):3048-3057.



**HEALTHCARE
ETHICS CODE**

SPIRITUALITY AND HEALTHCARE

This book's major theme is healthcare ethics and how healthcare practitioners, patients, healthcare managers, administrators and the community in general can benefit from healthcare ethics. On the basis of the summative guidelines offered in Chapter 1 and the detailed explanations of these guidelines in Chapters 2-10, the following Healthcare Ethics Code for healthcare practitioners, patients, healthcare and managers and habitat are offered:

- Healthcare ethics reflects on respect, dignity, care and compassion for all involved in healthcare.
- Healthcare practitioners should at all times value life and treat patients with dignity, respect and care.
- Patients should acknowledge the ethical needs of healthcare practitioners and should behave towards them too with dignity and respect.
- The ethical responsibility of all stakeholders should be upheld at all times.
- Healthcare managers and administrators should ensure quality health service at all times.
- Communities should assist the healthcare profession to extend its knowledge on basic healthcare and should be supportive of quality service delivery.
- Healthcare is about a mutual relationship between the patient, the healthcare practitioners and the community.
- No healthcare can be value-free nor can it ignore the influence of religion, faith, spirituality and culture on decisions.
- Morality is expressed through value judgments, selecting between options.
- Ethical decision making implies understanding the situation and reacting appropriately.
- Healthcare practitioners should be mindful of the patient's culture, values and preferences when making medical decisions.
- Ethical decision making is a complex phenomenon which should be considered within the context of the situation.
- There are no standardised approaches or answers to address ethical issues in healthcare but checklists can be used to assist healthcare workers to make appropriate decisions.
- Healthcare should be promoted via training, mentorship and coaching.
- Ethical behaviour is the foundation for professionalism.
- Ethical behaviour is inherently part of all healthcare practitioners.

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- Ethics is particularly applicable to the professional practice of medicine to guide decision making in the doctor-patient relationship, and to protect self-directedness for the patient in an essentially unequal power relationship.
- When faced with a healthcare dilemma, the relevant organisation's medical ethics committee should be consulted. In the event that an ethics committee is not available, other resources as appropriate should be used.
- Healthcare practitioners shall respect the law and also recognise a responsibility to seek changes in those requirements which are contrary to the best interest of the patient.
- In community-based participatory research the whole community should be considered the subject of research and ethical considerations should encompass respect for community as well as individual autonomy.
- Note should be taken of the age and context of participants and these should be taken into consideration throughout the research project.
- Ethics is a process which should be continually reconsidered, with reflexivity by researchers encouraged.
- Healthcare workers should be sensitive to the spiritual needs of the patient, especially the seriously ill patient.



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Healthcare ethics cannot be limited in scope to apply only to the patient but needs to apply to the healthcare practitioner as well. The relationship between the patient and the healthcare practitioner has shifted from a power relationship to a complementary relationship. Leadership, mentorship and coaching play important roles in facilitating this shift. Several themes informed this book on healthcare ethics:

- Vulnerability in healthcare ethics
- Decisions between right and wrong
- Quality of healthcare
- Life-ending decisions
- Community-based research
- Ethical decision-making
- Spirituality in healthcare

Healthcare Ethics for Healthcare Practitioners was written by professionals from different spheres and, as such, it is ideal for group discussions and for teaching ethics. Special emphasis is placed on the vulnerability of patients, but also of healthcare workers, management and the community. Ethical norms, such as compassion, respect for personhood/autonomy, care and commitment, are fundamental in an ethical life attitude.

Kobus Smit (DPhil)

Emeritus Professor in Ethics

University of the Free State, South Africa

It is no secret that the South African health system is in a lamentable state. How do healthcare professionals working in this context, deal with the ethical dilemmas that arise? Now more than ever, it is essential that healthcare practitioners are competent in ethical decision-making. *Healthcare Ethics for Healthcare Practitioners* is a valuable resource to which healthcare practitioners can turn for ongoing information and guidance.

Maria Phalime (MD)

Author of Postmortem: The doctor who walked away

LAETUS O.K. LATEGAN (DIRECTOR FOR RESEARCH DEVELOPMENT AND POSTGRADUATE STUDIES, CENTRAL UNIVERSITY OF TECHNOLOGY, FREE STATE) and **GERT J. VAN ZYL (DEAN: HEALTH SCIENCES, UNIVERSITY OF THE FREE STATE)** have extensive research and management experience in healthcare ethics and have contributed to various research papers on this topic. This book forms part of a joint collaboration between the two universities, their international networks and the industry.

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