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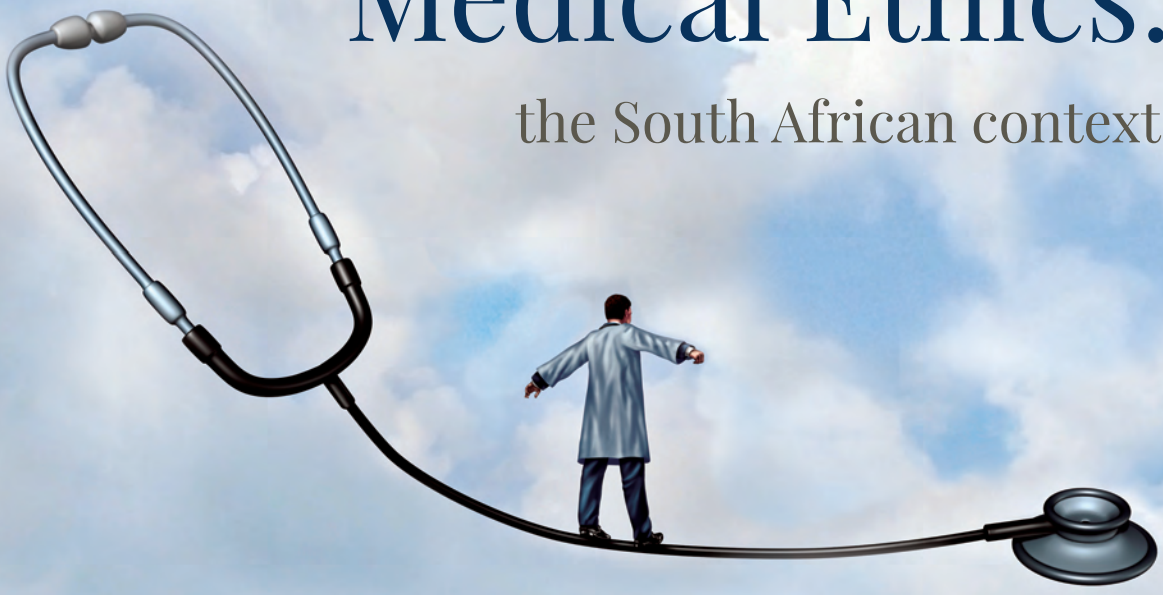
# Challenges in Medical Ethics:

## the South African context



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# Preface

This is a book about a number of serious challenges that bioethicists have to deal with in our time, particularly in the South African context. The term 'bioethics' will, in what follows, be used interchangeably with the term 'medical ethics'. By bioethics/medical ethics we mean the outcome of systematic reflection on moral problems that arise in health care and the life sciences generally, as well as the institutional practices that provoke or are influenced by such reflection (e.g., the institutionalised generation of abortion laws in Parliament).

Bioethics ironically represents both the oldest and one of the newest 'sciences' widely practiced at the current-day university. As an instance of intellectual endeavour, it originally draws on the work (particularly the oath) of the ancient Greek physician, Hippocrates. The Hippocratic tradition, however, never developed into a systematic body of scholarship. The latter only occurred in the course of the 20th century, mainly as a result of the rapid development in current-day medical science and technology. At the same time, the 20th century brought, in a very notable manner, the realisation that, in spite of the unprecedented strides made by medical sciences in our times (e.g., the successful treatment of ischemic heart disease, various cancers, transplantation technologies and the like), health care professionals are not only prone to do good, but can indeed sometimes indulge in ethically questionable practices. In this respect, one hardly needs to be reminded of more than the abominable 'medical experiments' on (particularly disabled) human subjects by Nationalist Socialist 'doctors' (like Joseph Mengele) during World War II, or, alternatively, the infamous Tuskegee medical 'research trials' in the USA in the early part of the 20th century.

These (and many other) events launched bioethics as not only a prevailing, but indeed an extremely necessary intellectual endeavour. From an almost non-existent 'science' at the beginning of the 20th century, bioethics has since been growing with unprecedented strides and established itself as a major field of study across the world.

This book is an acknowledgement of the relevance and actuality of this development of bioethics, not only internationally, but particularly in South Africa. The saga surrounding the death of Steve Biko in the late 1970s amply testifies how bioethical issues also permeate the South African socio-political context.



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This book is not only an inter- and multidisciplinary composition of contributors, but also a very good reflection of the interdisciplinary approach that is, in our time, universally required for bioethical work. The contributions also testify to diversity in background.

**In chapter one, Anita Kleinsmidt** looks at the relationship between law and bioethics. She considers how societies came to adopt laws as their governing systems and specifically describes sources of law and how laws are made in South Africa. There is a brief description of the increasing use of the criminal law in medical negligence matters and also the current pressing problem of unaffordable insurance for obstetricians due to massive civil claims in their discipline. South Africa has a culture of human rights necessitating a discussion on the nature of rights and opposition to rights as a concept. Finally, at the intersection of medical ethics and law, there is a selection of cases from the South African courts summarising judgments involving ethical concepts such as confidentiality, medical professionalism, the doctor-patient relationship, abortion, surrogate pregnancies, and physician-assisted suicide.

**Mariana Kruger, in chapter two**, reasons that everybody has the right to health. According to the World Health Organization (WHO), this is achievable through universal access to health coverage (UHC). Countries should provide access to quality health services which addresses the need of the population with priority setting regarding health care interventions for the improvement of general health. Usually these decisions focus on safety, efficacy, and cost-effectiveness, but health care decision-makers should also address issues such as equity, fairness, financial protection, and impact on the national budget. South Africa is in the process of implementing UHC through the establishment of National Health Insurance, which is crucial to address the inequity of health care provision during the apartheid era. There are four key interventions planned, namely the transformation of the health care service provision with a sustainable health care workforce, a complete overhaul of the health care system, administration and management changes, and provision of a comprehensive health care package for all South Africans.

**In chapter three, Carike Noeth** provides a brief overview of recent historical legislation regarding the termination of pregnancy in South Africa, focusing on the Abortion and Sterilization Act of 1975 and the Choice on Termination of Pregnancy Act 92 of 1996. This is followed by a discussion of the reasons why the termination of pregnancy is regarded as an ethical dilemma in the 21st century, such as politics, technology, paternal rights, and religious conviction. The complexities and challenges of the termination of pregnancy are then discussed



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to determine where the shortfalls are regarding the Choice on Termination of Pregnancy Act 92 of 1996. By determining the challenges, it is argued that different role-players are key to accepting ethical responsibility when it comes to reproductive health in South Africa to ensure that policies, laws, and regulations are implemented practically. This includes the acceptance of the ethical responsibility to ensure the implementation of rights as set out by South African laws to promote the furtherance of gender equality, women's rights, and the right to reproductive health care.

**In chapter four, Juri van den Heever and Chris Jones** point out how sex and gender have been contentious issues, historically and up to the present time, in various walks of life, none perhaps more so than in international athletics. They examine the origins and historical development of sex and gender discrimination from the perspective of hunter-gatherer societies to the present, referring to the influences of agricultural practices, religion, and legal systems. Advances in biological disciplines such as neurobiology, embryology, and genetics have revealed, and made public, a wide range of detailed insights about the physical realities of human sexuality and gender choices that can no longer be ignored. It is suggested that administrative bodies, such as the International Association of Athletics Federations, now World Athletics, and indeed the public in general, avail themselves of this information, thereby fostering a more balanced view of issues pertaining to sex and gender. Finally, they suggest a tentative option which may allow World Athletics an escape route from the impasse they currently find themselves in regarding sex and gender discrimination.

**Willie Koen, in chapter five,** writes about the ethics of transplantation and refers to the different factors that must be considered regarding cadaver organ transplantation. He also focuses on living donor organ transplantation, where the organs are harvested from a live donor opposed to cadaver organs. The author further writes about the allocation of cadaver organs in transplantation, the transplant waiting list, artificial mechanical circulation, stem cell transplantation, Xeno transplantation, and non-lifesaving organ transplantation such as penile, facial, and uterus transplantations. He concludes that the field of transplantation is fraught with ethical challenges. However, these challenges can be addressed by the fundamental question of 'risk versus benefit' by following the first part of the Hippocratic oath of the medical profession namely "do no harm", and by adhering to the four main principles of medical ethics: respect for autonomy, beneficence, non-maleficence, and justice.

**Elmi Muller, in chapter six**, describes the decision-making process around the use of HIV-positive donors for HIV-positive patients with renal failure for the



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purpose of kidney transplantation. It highlights the very specific South African health care environment in which this decision was made when the programme was started in 2008. It also discusses some of the ethical considerations surrounding these transplants. It is important to note the landscape for HIV-positive patients in South Africa at the time – there were no treatment options available for HIV-positive patients with renal failure. The author writes the chapter from a personal perspective: both as the transplant surgeon who planned and executed the procedures, as well as the person who followed up with these patients over the long term. The chapter uses Alain Badiou's essay on the understanding of evil as a starting point to think about some of the decisions that had to be made. It also reports on the clinical risks that had to be considered for a medical procedure where there was no evidence-based treatment guidelines available. In clinical medicine, evidence-based practice is considered best medical practice. This chapter considers how difficult decisions can be if there is no evidence available in a context where patients and their health care providers are faced with their own mortality.

**In chapter seven, Rosaan Krüger** outlines the South African legal framework in response to organ trafficking and transplant tourism with reference to the international legal standard set out in binding and non-binding instruments. It does so by comparing the legal framework in place at the time of the organ trafficking scandal in South Africa in the early 2000s, which involved the Netcare group, with the framework currently in place in terms of the National Health Act and its regulations and the Prevention and Combating of Trafficking in Persons Act. The current legal framework adheres to the international standard by reflecting the principles of non-commercialism and altruism in donation but fails to address the issue of organs supply for transplantation adequately.

**In chapter eight, Hanru Niemand** investigates to what extent the political dilemmas of multiculturalism translate to obligations, particularly in mental health service delivery. He discusses some of these obligations, all of which can be summarised under the heading of cultural competence. He also discusses different types of cultural competence in terms of (1) the obligations on larger structures, including policymakers, educators and selectors to create structures for cultural equality; and (2) the obligations of practitioners and theorists to practice an approach characterised by (a) an awareness of the cultural conditioning involved in their existing models and (b) a willingness to understand models with different cultural origins as if from the inside, and not as so-called neutral observers. In this regard, he pays special attention to criticisms aimed at the scientific method as practiced by mainstream psychology. He also introduces the distinction between simple and complex multicultural problems. He concludes that the progressive



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equality to be striven for, particularly by larger structures, represents a solution to simple (but practically difficult to achieve) multicultural problems. In contrast, the freedom from bias that is to be achieved, particularly by practitioners and theorists, is a logical impossibility. For this, he suggests a process model of justification, whereby the obligation that rests with practitioners and theorists lies in their attitude, that is, in the process in which they approach these matters.

**Andrea Palk, in chapter nine**, engages with neuroethics as an interdisciplinary field, encompassing the full array of ethical, legal, and social implications of our study, understanding and deepening knowledge of the human brain, including our ability to increasingly alter or enhance our brains. While the field is broad in scope, it has largely been shaped by the input of researchers situated in high-income countries, with less participation from low-resourced contexts. Participation of African scientists and ethicists, in particular, has been lacking in the field. In light of these observations, she takes as her point of departure a need to critically engage with neuroethics, with the aim of working towards a field that is more globally informed and inclusive of a range of concerns and perspectives. Given that neuroethics is not well established in Africa, in the first half of the chapter, she provides an overview of the traditional conceptualisation of the field as concerned with the 'ethics of neuroscience' and the 'neuroscience of ethics', with examples of typical areas of discussion. She then considers four suggestions for developing the field in African contexts, thus working towards increasing its global relevance. Her suggestions include: building neuroethics capacity through the growth of neuroscience research collaborations across the African continent; exploring congruence with the global mental health movement to engage in neuroethics activism to address brain and mental health research and treatment priorities in Africa; drawing on the strong tradition of empirical ethics research on the continent to establish an evidence-base comprising the perspectives of underrepresented populations on established neuroethics concerns; and finally, engaging with the underlying moral framework of neuroethics by drawing on African moral frameworks. While developing neuroethics in Africa will benefit those who are impacted by its reach in African contexts, the field itself also stands to benefit insofar as it is recognised that any field or area of focus is improved by including a plurality of perspectives, concerns, and input.

**In chapter ten, Anton van Niekerk** investigates (bio-)ethical issues related to indefinite life expectations and significantly prolonged longevity. It is shown that Yuval Noah Harari regards increased longevity and life expectation as the central scientific, medical, and technological agenda of the 21st century. The contribution of Aubrey de Grey, who advocates the indefinite prolonging of life, is submitted to critical scrutiny. Attention is paid to the causes of death,



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and particularly to the question as to whether old age ought to be interpreted as a disease. A key argument in the chapter is the prudence of preferring better health than a longer life as one matures. The danger of immeasurable boredom associated with indefinitely prolonged life is argued. The chapter is concluded with arguments about the organic nature of human life and the fact that human life is essentially a narrative quest. These concerns do not support the idea of significantly prolonged human life.

**In chapter eleven, Willem Landman** reasons that for some, dying is peaceful and dignified. For others, it is suffused with fear, suffering, and loss of autonomy and dignity. We need not die while suffering physically and mentally, with loss of control over one's body. Morally and legally, we have choices that can mitigate what would otherwise be an even worse death. There are four categories of end-of-life choices: end-of-life pain management that hastens death; refusal of and refraining from life-sustaining treatment; advance directives; and assisted dying – referring to assisted suicide and voluntary euthanasia. The first three are, and should be fully recognised as, standard medical practices, but they present several problems relating to their exact legal status and unanswered questions about how they should function in practice. This calls for legislative clarity.

The fourth is more controversial. Rendering assistance with dying – in the forms of assisting with suicide and practising voluntary euthanasia – constitutes the common-law crime of murder. Significantly, though, assisted dying presents a formidable and untenable tension between our common law and rights recognised and protected by the Bill of Rights in our Constitution such as the rights to autonomy, dignity, and bodily integrity, including control over one's body. The crucial public-policy question is how to get the embedded right to assisted dying recognised. In a 2016 ruling, the Supreme Court of Appeal (SCA) made it clear that our common law will "no doubt evolve" when the court is presented with a "full argument and time to reflect". The court would then declare an "incompatibility" between the common law and the Constitution "to enable parliament to remedy the deficiency". In the final analysis, moral responsibility for decriminalising assisted dying rests with our dysfunctional Parliament. The prior challenge is for a dying person, with access to the necessary monetary means, to bring an application to our courts, and remaining alive while the case proceeds through successive court processes.

**Himla Soodyall and Jerome Singh, in chapter twelve,** write that public trust and confidence in researchers and medical professionals are essential when engaging with research subjects and patients. Coupled with this, there have been a range of ethical challenges related to consent; privacy; ownership of samples; data



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sharing; re-identification of previously de-identified participant information; access to electronic health records; the collection, storage, and secondary use of biospecimens; and issues related to incidental findings that have been raised in the context of sensitivities to medical and genetic data. While research subjects and patients are mostly happy to consent as participants for research, they still have many concerns about confidentiality of data, particularly in the era of data-sharing and electronic access to information. Patients are also part of families and sometimes their medical information impacts on other family members. Disclosure of such information often poses challenges around privacy and confidentiality, while in other instances family members have shown gratitude for such engagement. Advances in genomic and other diagnostic technologies have vastly improved on diagnosis, treatment, and delivery of health care. Such capabilities have raised concerns about how to deal with incidental findings and whether to disclose this information to patients or not. In this chapter, they address some of the ethical issues outlined above when dealing with sensitive medical and genetic data.

**Basie von Solms, in chapter thirteen,** argues that new developments in technology have, over the ages, always been core drivers in the dramatic improvement in all areas of health care. Such developments include the availability of newer and more effective drugs as well as the possibility to implant a stent and a pace-maker in the body to address a problem which, only a few years earlier, may have needed a massive invasive operation. Technology developments, operating in what we today experience as 'cyberspace', have already become massive new drivers in improving health care, and will continue to do so at a dizzying pace in coming years. Such technological developments have, among others, led to the implementation of the internet of medical things (IoMT) where numerous sensors and devices are used in the medical ecosystem. However, as has always been the case with any new technology, there are always risks which must be managed as comprehensively as possible to prevent the new technology from causing negative consequences. The IoMT is specifically prone to such risks, which can even threaten the lives of patients. Medical ethics has an essential role in the IoMT as well as in the whole medical ecosystem. This relationship between cyberspace, cybersecurity, and medical ethics in the medical ecosystem is also addressed. This chapter gives an overview of how cyberspace has already impacted the medical ecosystem, and what are some of the important risks which must be identified and managed.

**In chapter fourteen, Susan Hall** argues that technological advancement often gives rise to novel ethical problems. This is as true with respect to the development and application of biotechnology in the context of health care as elsewhere. The



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best known and probably most contentious possible application of biotechnology in the context of health care is genetic engineering. While genetic engineering holds great potential for the treatment of disease and disability, to many the prospect of the development and use of interventions which aim to manipulate our genetic makeup evokes discomfort or repugnance, particularly when such interventions aim not only to treat but also to enhance. In this chapter, the author outlines the bioethical debate surrounding genetic engineering. She considers two groups of arguments against the development and use of gene editing technologies which focus on (1) the inherent nature of genetic modification itself and its relationship to human nature, and (2) the likely consequences of gene editing, and she explores possible lines of defence against these challenges. Finally, she briefly puts forward the case that both genetic therapy and some forms of genetic enhancement hold great potential for the transformation of human health, and, in the case of enhancement, human well-being more generally. We should therefore be cautious of rejecting these technologies out of hand.

*The Editors*



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