

THE TRAGEDY OF THE COMMONS: REFRAMING BIOETHICS IN A NEW MILLENNIUM

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BIOGRAPHY

Professor Keymanthri Moodley was born in Pietermaritzburg in the former Natal, now KwaZulu-Natal. She grew up in Durban during the height of apartheid. In accordance with the Group Areas Act of 1950, her family was compelled to live in an “Indian” area, she attended Indian schools and her medical undergraduate training was completed at a medical school for black students at the University of Natal, where she achieved distinctions in Paediatrics and Psychiatry. She worked as a medical registrar in Durban for three years. After the birth of her first son, Kehar, she relocated to the Western Cape in 1993 where she worked part time in general practice. She was subsequently a part-time registrar in Family Medicine at Stellenbosch University. Her second son, Nikhal, was born in 1997 and she worked at the Bishop Lavis Day Hospital as a family physician while studying Applied Ethics at Stellenbosch University part time. In 2001 she studied Bioethics and Epidemiology at Columbia University, New York. By 2004 she had completed her doctorate in Applied Ethics at Stellenbosch University.

Keymanthri is currently Director of the Centre for Medical Ethics and Law in the Department of Medicine at Stellenbosch University – a Centre she established 13 years ago to integrate the teaching of bioethics into undergraduate and postgraduate medical curricula. In 2015 the Centre was designated by the World Health Organization (WHO) as a Collaborating Centre in Bioethics – the first on the African continent and one of only seven in the world. The Centre has graduated 40 mid-career professionals from 10 African countries in Research Ethics with a NIH Fogarty Grant. Keymanthri holds two additional NIH grants exploring ethical, legal and social issues related to research on a cure for HIV and genomic bio-banking.

Professor Moodley has published 65 journal articles and book chapters and has edited two books. She is NRF rated as an established researcher, is a member of the Academy of Science of South Africa, and completed an Executive MBA in 2015.

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Inheriting both good genes and a strong work ethic from one's family is a privilege and is critical to success. My point of departure in this acknowledgment therefore starts with my parents. My late father, Kas Moodley, was probably the first person in his family to receive a university education. He was brilliant. At the age of 16 (after two double promotions at school) he was accepted to complete a BSc degree at the black University of Fort Hare in the Eastern Cape in the 1950s and graduated as one of the first black industrial chemists in South Africa. My brothers, Kuresh and Ravesh Moodley, both high achievers in commerce, have always supported my professional work. I also hail from a family of strong women: my maternal and paternal grandmothers collectively raised 10 children with minimal resources during extremely hard times. At the age of 75, my mother, Ursula Moodley, is still CEO of her own company.

I have spent most of my adult life balancing my career as a woman in medicine with family commitments. Achieving this work-life balance would not have been possible without a co-parent, Premesh Narismulu, and two wonderful, accommodating and supporting sons, Kehar and Nikhal.

There were specific people who believed in and supported my ideas and aspirations – however unconventional they were – Dr Dawie van Velden, Prof Pierre de Villiers, Prof Anton van Niekerk, Prof Wynand van der Merwe and the late Prof Barney de Villiers.

There are many supportive people in my life – medical school colleagues, friends and professional colleagues – in particular Prof Willie Pienaar, Prof Sharon Kling and Prof Rafique Moosa, who have steadfastly supported me on my journey.

I have learned valuable lessons from my sons, who are my greatest but most loving critics, as well as from my students and patients over the past 30 years. My super-efficient administrative assistants, Meagan Leukes, Kelsey February and Zainup Fanie, have contributed to running the Centre like a finely tuned machine.

Achieving respect and credibility nationally and internationally has been rewarding. I have been fortunate to have worked with the International AIDS Society (IAS), the International AIDS Vaccine Initiative (IAVI), the National Institutes of Health (NIH) and the World Health Organization (WHO). Prof Stuart Rennie at the Bioethics Center at the University of North Carolina-Chapel Hill has been a consistent and supportive collaborator for the past five years. I am grateful to these international bodies for the opportunities they have provided me to enhance my career in so many ways. I am also grateful to the Minister of Health, Dr Aaron Motaoleli, for appointing me to the National Health Research Ethics Council and the Board of the Medical Research Council over the past six years.

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THE TRAGEDY OF THE COMMONS: REFRAMING BIOETHICS IN A NEW MILLENNIUM

THE FIRST ETHICAL CHALLENGE

A career in health sciences is challenging, complex and exhilarating all at the same time. It is also emotionally exhausting and has the potential to impact negatively on the mental and physical health of professionals and their families. As a woman of colour in South Africa, my journey in medicine and academia has been both fascinating and soul destroying. The first ethical dilemma I faced was making a choice between a demanding, full-time career in internal medicine and raising a family. The long, inhumane hours and floor beds at the public hospitals in Natal made the possibility of raising a child under such circumstances untenable. In the late 1990s, most postgraduate training posts were full time and inflexible. An alternative, flexible training option was Family Medicine, which had a novel, holistic approach to health care that stimulated both right- and left-brain thinking. I was privileged to be immersed in a discipline that had moved away from pure reductionist medicine to holistic care; a discipline in which patients and families were managed as complex systems and in which treatment and prevention were practised concurrently. This was where I was first introduced to systems thinking – a theory that arose during the Second World War, when the first attempts were made to apply it to problem solving in management. At a broad, conceptual level, systems thinking is a reaction to the scientific approach of reductionism that seeks to solve complex problems by breaking them into discrete components. Systems thinking, on the other hand, embraces creativity and holism in an attempt to manage complexity, diversity and change. At a broad conceptual level, this way of thinking allows one to see death as an integral part of life and it embraces with equanimity the right to life and the right to death. It allows one to understand the inter-relatedness of pathology, psycho-social well-being, culture and behaviour. Holistic approaches seek to improve goal seeking and viability, explore purposes, ensure fairness and promote diversity (Jackson, 2004). In health care, a biopsychosocial approach to patients and families is critical.

Family Medicine also taught me the importance of being comfortable with uncertainty. William Osler described medicine as “a science of uncertainty and an art of probability” (Osler, 1932). Acknowledging uncertainty is critical to practising medicine with a mind fully open to possibilities.

Systems thinking, complexity and uncertainty are all captured in the work of Roy Bhaskar, the son of an Indian physician and a British nurse. He was a brilliant philosopher at Oxford. He proposed a version of realist philosophy called critical realism in 1975. Bhaskar (2008) proposed two versions of scientific realism: transcendental realism (for natural science) and critical realism (for social science). Critical realism “celebrates the existence of reality independent of human consciousness”, amongst other things (Yeung, 1997). It draws our attention to the difference between what we know and how the world really is. In order to build an understanding of the world in which we live, we make several assumptions about the nature of reality. In addition, during the research process we make both epistemological choices (based on what we know) and ontological choices (based in reality). Critical realism provides the philosophical basis for making these choices. In critical realism, ontology (the theory of being) is viewed as being distinctly different from epistemology (theory of knowledge). Critical realism involves a transition from epistemology to ontology and, within ontology, a transition from events to mechanisms. The epistemic fallacy refers to the belief that statements about being (ontology) can be reduced to statements about knowledge (epistemology) (Bhaskar, 2008). In other words, the fallacious belief that we can reduce the vast existence of mechanisms, events, and experiences in the real world to fit into our scientific knowledge base, theories and models. To a large extent this is the reductionist approach used in medical science – the Newtonian version of the scientific method. On the other hand, the point of departure in critical realism is a world that is “structured, differentiated, stratified and changing”, a world that exists with or without us (Danermark et al., 2006). Firstly, there are numerous events that occur in the world, we observe only some of them – yet these observed events are the sum total of empirical science. We are often not mindful of the events that are not observable by scientists or of the mechanisms that convert unobservable events to an observable state. Critical realism explores and assists in understanding mechanisms that generate unobservable events that we experience as observable events in the world. All these observable and unobservable events as well as the mechanisms that produce them exist in three inter-related domains of reality that are stratified ontologically as follows:

- (1) the empirical domain comprising our observations and experiences in the world (the scientific method is based on empiricism);
- (2) the actual domain where events and experiences occur whether we observe them or not; and
- (3) the real world that consists of structures, processes and the causal mechanisms that actually generate the events and experiences that occur.

Empiricism collapses these three domains (real, actual and empirical) into one, while critical realism sees them as separate entities. Empiricism reduces reality only to what is observable. The hallmark of the scientific method as we know it in health sciences is logical empiricism, which was made famous in the 1920s by the Vienna Circle philosophers (Schlick, Carnap and Neurath). They contended that scientific knowledge must be verified. In their worldview, anything that could not be directly or indirectly observed was to be regarded as non-scientific and meaningless (Mingers, 2000). Today we depend on evidence-based medicine in a similar manner. However, the art of medicine transcends empirical science alone. This has been very clearly illustrated over the past three decades of the HIV/AIDS pandemic where medical science has been necessary but not sufficient to end the disease.

Bhaskar describes transitive concepts as theories, facts, methods, paradigms and models used to describe intransitive objects such as the human immunodeficiency virus (HIV). In the real world, the HI virus exists independently of human activity (Bhaskar, 2008). It is complex, it exists with or without us and our knowledge of its capabilities and potential is limited. At this point in time, our ability to extract it and destroy it when it hides in reservoirs in the body is delaying the discovery of a cure for the disease.

THE JOURNEY FROM CLINICAL MEDICINE TO BIOETHICS

My life as a family physician was significantly enhanced and enriched by deviating into the world of philosophy. As I undertook my journey away from clinical medicine over the past 15 years, and as I unpacked the application of bioethics in health care, the words of Robert Frost have echoed constantly in my mind: “Two roads diverged in a wood and I took the one less travelled by and that has made all the difference.”

Travelling down the path of bioethics has enhanced my understanding of the doctor-patient relationship across all disciplines in medicine as well as my understanding of the biological sciences in general and the associated research in this field. Much of this

duality in understanding of two major disciplines, namely, philosophy and healthcare, has found expression in the ethics of prevention, treatment and cure research around HIV/AIDS (Moodley 2002, 2007a, Moodley et al. 2016). Likewise, the scientific world of biobanking brings with it great potential for medical research but also a host of ethical concerns. Consequently, I have spent the past 15 years inextricably embedding bioethics into the DNA of health sciences education and health research (Moodley, 2007b).

TEACHING BIOETHICS AT STELLENBOSCH UNIVERSITY

Establishing ethics as an integral and substantial part of the medical undergraduate curriculum was formally approved by the Faculty of Health Sciences at Stellenbosch University in 2002. This was a monumental victory for the emergent discipline of bioethics in South Africa. However, it posed a challenge, given the history of apartheid associated with this university, and the contention that apartheid is, in and of itself, unethical in every possible respect. I was constantly reminded of the words of Hendrik Verwoerd, a notable alumnus of Stellenbosch University, regarding education:

“There is no place for [the Bantu] in the European community above the level of certain forms of labour ... What is the use of teaching the Bantu child mathematics when it cannot use it in practice? That is quite absurd. Education must train people in accordance with their opportunities in life, according to the sphere in which they live.” (quoted in Lapping, 1987).

Given the context of education in South Africa as created by graduates of Stellenbosch University like Verwoerd, my second major ethical dilemma was whether I should teach bioethics at an institution that had become an icon of Apartheid in South Africa. On the one hand it would be the greatest paradox of my life and take enormous dialectical capability to work in such an environment. On the other hand, surviving and succeeding in establishing and growing this discipline was critical to change the beliefs so tenuously held about what people of colour were capable of. Proving Verwoerd wrong was a strong driving force in making a decision to become part of academia at Stellenbosch University. Others, like myself, have proven him wrong a thousand fold already, and continue to do so.

One of my earliest experiences while teaching bioethics confirmed my initial discomfort about the paradox inherent in the phrase “Bioethics at Stellenbosch

University". While discussing justice in a lecture almost 15 years ago, the famous quote by the Greek philosopher, Aristotle, was examined:

"Treat equals equally and unequals unequally".

Some students were extremely relieved to hear this and immediately accepted the quote as a justification for discrimination in apartheid South Africa. However, when the essence of this quote was explored in greater depth, it soon became obvious that the notion of disadvantage is central to the discourse around justice. Since all humans are equal, the circumstances of their lives may render them unequal due to no fault of their own. Such disadvantage requires more protection than normal, along with compensatory mechanisms to restore equality. Contrary to the initial interpretation of this quote by some students, Aristotle provided no justification for apartheid at all.

Much of the teaching in bioethics to date has a strong basis in Western philosophy. In the 4th century BC, Hippocrates, a philosopher and physician also known as the father of Western medicine, addressed important ethical questions in health care. The Hippocratic Oath, which is regarded as the first written document pertaining to the ethical practise of medicine, was written by him or one of his students. The basis of this oath is the concept of *primum non nocere*, or "above all, do no harm".

So, approximately 2 500 years ago, the ancient Greek philosophers – Socrates, Plato and Aristotle – debated questions about morality that still trouble us today:

"What does it mean to live a good life?"
"How does one find meaning in one's life?"
"What is right? How do we know it is right?"
"What is justice?"

Bioethics is the study of morality as it applies to the biological sciences, including health care and health research. As a discipline it seeks solutions to critical questions:

"What is the purpose of medicine as a discipline?"
"What does it mean to be a good doctor?"
"What is the meaning of a life worth living?"
"When are we playing God?"

Globally, different philosophical systems – some of them predating Western philosophy – have raised similar questions at various points in time. African philosophy, Confucian ethics, Buddhist and Hindu philosophy and Middle Eastern philosophies have all posed fundamental questions about the meaning of life.

Bioethics has grown in importance over the past several decades. Internationally, the invention of the Scribner shunt for renal dialysis in the 1960s and the

Seattle God Committee established to choose patients who would have access to this primitive but limited resource raised new ethical questions in health care relating to distributive justice. Locally, the first heart transplant by Professor Christiaan Barnard at Groote Schuur Hospital advanced debates on the definition of brain death. Since then, further technological advances in the health sciences have brought with them new and more complex ethical questions. Changing relationships between healthcare professionals, patients and the pharmaceutical industry have raised challenging new ethical questions. Complex relationships between the healthcare profession and medical funders raise ethical concerns around patient confidentiality and justice on a regular basis. Communication in health care using social media in the 21st century has ushered in a host of new ethical dilemmas.

The early days of teaching bioethics to medical undergraduates focused on the theory of liberal individualism and concepts of autonomy, such as informed consent, refusal of care and confidentiality. These notions of autonomy were brought into sharp focus over the past three decades of the HIV/AIDS epidemic in South Africa (Moodley, 2002; 2007a). The Centre has explored the ethical issues associated with HIV prevention and treatment, and we currently are grappling with the more complex ethical challenges related to HIV cure research (Moodley, 2015; Moodley et al. 2016).

Other complex issues have emerged over time, in particular resource constraints and the fair distribution of limited resources in public hospitals. In recent times we have been dealing not only with limited resources, but also with an ageing population, profound controversies about end-of-life care, physician-assisted death, finite healthcare funding and the threat of a healthcare system spiralling into unsustainability – a stark reminder of the well-known scenario of the tragedy of the commons.

THE TRAGEDY OF THE COMMONS

This seminal theory in economics (the tragedy of the commons) was first introduced by Garrett Hardin in 1968. The original theory described the situation of herders who made rational decisions on the basis of self-interest to exploit common grazing land by grazing as many cattle as possible, to the detriment of the common grazing fields and the common good (Hardin, 1968; Fadul, 2009). In several other contexts, individuals in society act out of self-interest and try to reap the greatest benefit from a limited resource. This behaviour is contrary to the common good, as limited resources are depleted and the common good is threatened. Environmentally, this

theory applies, inter alia, to land, water, food supplies and fishing. However, health care is a “commons” too. This is so because there are finite resources in health care in terms of hospital beds, ventilators, medical personnel, organs, medication, budgets for treatment and medical investigations, dialysis machines, medical insurance and theatre lists. HIV exceptionalism is a term that has been used often in recent times, as fears emerge about overuse of the health budget for one disease at the expense of many other conditions requiring treatment. Non-adherence to treatment and the consequent emergence of resistant organisms threaten to deplete finite resources. Clearly, the irresponsible use and overconsumption of health services will deplete resources to the detriment of all.

In recent times, private medical funders have increasingly been challenged when families demand chronic home-based care, including ventilation for elderly patients with poor prognostic factors and futile conditions. In the public sector it is also not uncommon to see patients with terminal diagnoses retained in high care and ICU beds because doctors refuse to step down care and allow natural death or, worse still, apply heroic measures to resuscitate patients who otherwise would not survive. In all these cases, limited resources in hospitals are consumed by patients with a poor prognosis at the expense of younger patients with reversible conditions. Private medical funders are threatened with unsustainability, and individual member contributions are subsequently increased, collectively disadvantaging all members of society. A recent article in the *New England Journal of Medicine* describes two patients being escorted by medical personnel on a flight back home. One patient was French, in his late 30s, diagnosed with acute myelogenous leukaemia. He had severe thrombocytopaenia, had been living in Los Angeles and wanted to return home to France to die. There was oxygen available on board and he was accompanied by a doctor and a nurse. Given his thrombocytopaenia, there were concerns about cabin pressure and an intracranial bleed. About 30 minutes into the flight the doctor was informed by flight attendants that insufficient oxygen had been boarded but they could pick up more by landing in Chicago. The attending doctor knew that an additional landing and take-off would be risky. It turned out that there was another patient on this flight, a woman in her early 20s who had sustained a sub-arachnoid haemorrhage. She was comatose. Her doctor was not keen that they land in Chicago to get more oxygen. He said: “Your patient is dying. My patient has a small but real chance of long-term survival. My patient’s needs should take precedence.” The doctor accompanying the French patient accepted that his patient was going to die anyway

and made the very difficult decision not to stop for more oxygen in Chicago (Shapiro, 2016). This was a decision taken in the interests of the common good. These are the types of difficult decisions healthcare professionals must be trained to make. Overconsumption of medical resources and self-interest or individual interest create a tragedy of the commons and compromise other patients.

EMERGING CHALLENGES IN BIOETHICS

Emerging biological and information technologies have created unparalleled opportunities to advance medical science. However, such advances have created complex ethical challenges, both in clinical medicine and medical research. Two research areas in which we have witnessed this phenomenon are in the fields of synthetic biology and the wide-scale storage of data, blood and human tissue. Some of these scientific advances result in the synthetic creation or modification of life as we know it via gene editing. The notion of the three-genome baby with three biological parents in the context of mitochondrial disease is a typical example. Other challenges that have arisen in the clinical setting in recent times occur when health professionals are required to withdraw care based on patient request or resource constraints, or when patients make requests for assistance with dying.

Creation of life forms in science laboratories

Synthetic biology is an innovative, transdisciplinary, emerging field of study in which new biological systems are being designed and built. This exciting new field has emerged at the intersection of biology, engineering and related disciplines to design chemically synthesised DNA that will give rise to organisms with unique or enhanced characteristics. Such advances have powerful implications for health care and the biological sciences in general. The potential for novel genomic research, enhanced drug development and managing diseases resistant to conventional therapy is enormous. In particular, the use of a new type of genetic scissors called CRISPR-Cas9 and gene editing as a strategy for HIV cure in Sub-Saharan Africa hold much promise (Tebas, 2014). However, research in a field with such enormous potential also carries with it weighty ethical and social challenges (Guttman, 2011).

While broad ethical issues such as scientists “playing God”, biosafety and biosecurity have dominated global discussions on the ethics of synthetic biology thus far, the African continent has concerns linked to social justice in the context of gross inequities in global health

and limited resources. The translation of science and community engagement are also critical in a context where basic science is poorly understood and where complex science poses a significant challenge to authentic consent processes. It is now almost universally accepted that respecting the autonomy of research participants and communities requires intense public engagement. The cultural nuances in Africa add a unique dimension to the ethical concerns around synthetic biology and create obligations to explore what the advances in this field will mean in various cultural contexts.

In this millennium, several emerging technologies are drastically changing the face of health care. In some respects, these technologies will improve the quality of life, in other respects they may prolong the quantity but not necessarily the quality of life. Most of all, they will bring with them complex ethical challenges. While we embrace the advances in medical science, we need to tread cautiously in terms of the extent to which medical professionals “play God” in creating new life forms or in manipulating DNA to eliminate disease. Although these technological advances are paved with good intentions, off-target effects are possible and unintended consequences may result in more harm than good. At this point it is important to re-iterate the foundational principle of medical ethics ... first do no harm.

“Blood narcissism” vs. human tissue as a public good

The collection, storage and future use of biological samples and data in medicine form an integral part of the clinical and research setting. Yet considerable cultural significance is attached to human biological material, especially blood, in health care. The availability of biological samples creates important opportunities for researchers to advance medical science and contribute to the collective good (Asslaber and Zatloukal, 2007; O’Doherty and Hawkins, 2010). However, several ethical, legal and social issues co-exist (Cambon-Thomas et al., 2007). Research Ethics Committees (RECs) globally have a mandate to protect research participant interests, such as confidentiality, ownership, export, storage and secondary use of samples (individual good), with specific consent, regulations and policies, but the implementation of these policies differs from one REC to another (Gibson et al., 2008). Researchers (unable to predict the future use of samples due to scientific advances) prefer a broad, general form of consent to advance scientific research and promote the collective good (Asslaber and Zatloukal, 2007; Hens et al., 2010; Hirtzlin et al., 2003; Ruiz-Canela et al., 2009; Stephenson, 1996; Zhang et al., 2010). This

divergence of perspectives creates tension between RECs that promote individual benefit and researchers who support collective benefit. Recently, the tension has been exacerbated by participant groups instituting litigation about the improper use of biospecimens, with the Havasupai Indian Tribe Case (Mello and Wolf, 2010) and other groups – the Yanamamo Tribe Case – requesting the return of specimens (Couzin-Frankel, 2010).

Debate should be bidirectional, however, with pathologists and researchers also actively engaged in the issue of consent for the use of biological specimens. This process is important for fostering mutual understanding and trust between researchers and participants and for informing research ethics guidelines. Pathologists have an important contribution to make, as they are generally the custodians of biobanks and other stores of biological samples (Stephenson, 1996). Pathologists and researchers share a common goal in terms of scientific research and the advancement of scientific knowledge (Asslaber and Zatloukal, 2007), but hold a variety of views relating to the use of biological specimens (Hens et al., 2010; Hirtzlin, 2003; Leiman, 2008; Moodley et al., 2014; Ruiz-Canela et al., 2009).

Issues relating to the storage of blood and data in biobanks have become topical in the bioethics discourse. Biobanks are located at the intersection of science, genetics, genomics, society, ethics, the law and politics. This multidisciplinary has given rise to a new discourse in health research involving diverse stakeholders.

African genetic diversity lies at the core of the controversy that surrounds data and sample mining. Samples from Africa are highly sought after internationally, and the unidirectional flow of samples out of Africa has raised huge concerns about the exploitation of vulnerable communities and countries. In an attempt to stem the tide of sample exportation, the Human Health and Heredity Africa (H3 Africa) project, funded jointly by the National Institutes of Health (NIH) and the Wellcome Trust, seeks to develop scientific capacity in Africa by encouraging African scientists to develop biorepositories in various African countries, including South Africa. If successful, this venture will present an incredible opportunity for research and health care in Africa.

Biobanking has become a core resource for medical researchers, as it has enormous transformative potential. However, researchers must also be mindful of the intricate web of ethical and social complexities inherent in collecting, storing and future use of biospecimens (Moodley and Singh., 2016).

The cultural, social and ethical complexity involved in the use of human tissue in health care and research has escalated, in part due to the perceived exploitation of indigenous communities around the world. South Africa is no exception, especially in respect of the San community. The response to this sense of exploitation and distrust has resulted in what currently is referred to as “blood narcissism” (Massar and Soifer, 2016). Individuals today claim ownership of their blood and wish to exercise control over the use of their blood. While this is a sign of evolution in community empowerment, it is not always in the best interests of science and society as a common good. This is an important challenge that bioethicists and researchers are grappling with globally – broad consent versus specific or tiered consent. New forms of consent, such as dynamic consent, are also being explored. The concern around these options to respect individual autonomy is the extent to which medical research for the common good will be obstructed.

Moving away from research to clinical medicine, several bioethical challenges have arisen in recent times, particularly in relation to the withdrawal of care and assistance with death.

From a right to life to a right to death

Autonomy, or a right to self-determination, has been extended from individual rights during life to individual rights prior to death.

To quote Isaiah Berlin (1969): “I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not of other men’s acts or will. I wish to be a subject, not an object: to be moved by reasons, by conscious purposes, which are my own” (Kuhse and Singer, 1998).

Conflicts over autonomy frequently reach the Clinical Ethics Committee that responds to queries of an ethical nature at Tygerberg Hospital. The most common ethical dilemma experienced by clinicians occurs when it becomes necessary to withdraw care and wean a patient with a poor prognosis off a ventilator. This is exacerbated when there are conflicting views expressed by family members. Doctors express significant discomfort withdrawing care, both in the public and private healthcare contexts. An advance directive such as a living will reflects the patient’s wishes and assists the process. However, where family members dispute the living will or if there is no advance directive, a substantial ethical dilemma must be resolved (Moodley, 2011).

In 2015, the debate on assisted dying in South Africa was re-ignited when Robert James Stransham-Ford, a 65-year-old advocate who had been diagnosed with

advanced cancer of the prostate in 2013, became terminal. His cancer (Gleason grade 9/10) had spread to his lymph nodes, kidneys and lower spine between 2013 and 2015. Robert was an intelligent, rational and well-informed advocate of the high court. He had three adult children and a 12-year-old daughter. He had been assessed by a psychologist, who found him fully competent to make a request for assisted dying via the legal system (Bateman, 2015).

According to the advocate, his request to end his life was justified as follows:

“I wish to end my life with dignity, surrounded by my loved ones, while I am able to breathe on my own, speak to my loved ones and see and hear them ... I am not scared of dying. I am scared of dying in this terrible way. It is not a dignified manner to end my life.” (Venter, 2015).

Reports indicate that Robert was in severe pain and was experiencing nausea, vomiting, abdominal cramps, loss of appetite, disorientation, weight loss and weakness. He was bed-ridden. Despite trying a wide range of Western allopathic treatments, Chinese and Ayurvedic treatments and cannabis, he was in excruciating pain. Judge H.J. Fabricius granted his request but, unfortunately, the decision was confirmed two hours after he died naturally (Bateman, 2015).

The Fabricius decision was strongly contested by the Minister of Health, the Minister of Justice, the South African Medical Association (SAMA) and the Health Professions Council of South Africa (HPCSA). One of the arguments against the legal ruling to allow assisted dying in this case was that death should not be seen as an individual affair as the death of a person affects the lives of others. Various appeals to Ubuntu have been advanced by those who argue that euthanasia is an issue where the interest of the individual cannot be separated from the interest of society as a whole (Larsen, 2015). Other arguments related to “playing God” when ending life and the duty of doctors to preserve life, not end life.

Extreme forms of autonomy or a step down the proverbial slippery slope?

In 2015, a 75-year-old healthy palliative care nurse from the United Kingdom, Gill Pharaoh, travelled to “Life Circle” in Basel, Switzerland to end her life. For years she had discussed her wish to end her life with family and friends. In her work in palliative care, she had seen many elderly patients suffer and, as a nurse herself, had experienced a sub-optimal public health system to care for the elderly. She said: “I have got so many friends with partners who, plainly, are a liability.” (Donnelly, 2015).

Gill made a voluntary decision to end her life while she was still healthy. In the 21st century, this is an unusual decision relating to the end of life.

However, historically, the ending of life of healthy elderly people was not uncommon when resources were scarce and had to be preserved for the younger members of society. Senicide is an ancient practice in which the elderly are sacrificed for the benefit of the specific group or community. The Inuit Eskimos were known to leave the elderly out to die on the ice. This was practised until around 1939. In south India, elderly people would be given coconut water to drink to precipitate renal failure – a practice referred to as thalaikoothal (Sellamuthu, 2016). Senicide was also allegedly practised amongst the Japanese, who took the elderly to the mountains (Obasute-yama or Granny Dump Mountain) and left them there to die (Fukazama, 1956).

In our current context of an ageing population and limited resources, how far are we from instituting measures to prevent the tragedy of the commons and to conserve finite resources for the common good?

REFRAMING BIOETHICS IN A NEW MILLENNIUM

Shifting paradigms: the tension between individual autonomy and the common good

The dominance of respect for individual autonomy as a principle in bioethics has emerged as a reaction to a long history of exploitation of civil liberties and individual rights. Although, for several decades, the focus in Western philosophy and Western societies has been on the celebration of individual rights, we need to seriously revisit this stance. Individual choice is important, but individuals rarely live in isolation in society. The notion of interdependence also must be revisited. In clinical medicine, when a patient makes treatment decisions alone, without consulting family, it is often the case that family members are left to pick up the pieces and involve themselves in damage control after surgery or other medical interventions, especially when complications set in. When one member of a family exhausts a medical fund, the health of other family members may be compromised. Systems thinking allows us to understand complexity in decision making and how the sum of the parts is bigger than the whole. The domino effect after the health profession intervenes in the lives of patients is important to consider in medical decision making. Intervening in creating and prolonging life is as questionable as intervening at the end of life. Making

decisions for the common good is often unavoidably necessary.

Similar considerations apply in health research. While traditional research ethics has advocated for individual, specific informed consent, privacy and confidentiality, in this millennium we have seen the emergence of big data, global data-sharing and the disruption of anonymisation and, contrary to the liberal individual approach, researchers are now accepting the notion of the “myth of confidentiality”. Genetic data can easily be traced back to individuals with Single Nucleotide Polymorphism (SNP) technology. The overlapping of large datasets can decode coded, anonymised information in health care and in the commercial world. Advances in information technology, hacking into databases, and scientists working outside of academia using “Do-it-yourself” (DIY) technology such as CRISPR-Cas9 have clearly fallen outside the net of academic research regulation. Preventing the tragedy of the commons requires a paradigm shift, from focusing on individual scientific ambition to thinking about the common good and the impact of science on society.

As pointed out by Weale (2001), “[w]hen enough of society participates in generalised reciprocity, the whole becomes greater than the sum of the parts due to the emergence of social capital”. The cohesive force that keeps societies together is referred to as social capital. This notion is consistent with systems thinking as discussed earlier. Advances in public health that result from medical research are to be regarded as a common good. In particular, the storage of blood and data in biobanks as an opportunity for future research is generally regarded as a common good for humanity. The trend in bioethics – to transition from individual good to approaches like solidarity and reciprocity that favour the common good – is critical, yet dependent on rebuilding trust between patients and doctors and between research participants and researchers. Moving the focus from self-interest to communal good is imperative, but will only occur when trust in medical science is restored. Reciprocity “extends the concept of self-interested co-operation” to “mutual advantage theories of social co-operation” (Prainsack and Buyx, 2013). Reciprocity contributes to “social cohesion through co-operation” (Prainsack and Buyx, 2013). They argue that reciprocity underpins social capital. Weale (2001) distinguishes between direct reciprocity and generalised reciprocity, as follows: Direct reciprocity is enough to sustain a system based on mutual advantage – “agents should do good only to those who have done good to them”. Generalised reciprocity results in a better outcome for all due to the effects of trust and other aspects of social capital. Weale (2001) asserts that

generalised reciprocity makes it possible to “move from mutual advantage” (selfish interests) to more “solidaristic forms of social union”.

Solidarity and reciprocity are overlapping concepts. With reciprocity, the expectation of a return is explicit or implicit. Solidarity goes beyond reciprocity, as it does not entail the obligation of giving back. The more generalised the reciprocity is, the more solidarity results, creating social capital (Soler, 2012). The economist Stefano Zamagni (2010) sees “reciprocity’s function as generating trust and social capital”.

It is time to “rethink the paramount position of the individual in ethics” (Knoppers and Chadwick, 2005). Reciprocity, mutuality and solidarity reflect the communitarian ethic of the common good. This is particularly relevant in Africa, where the concept of Ubuntu is embraced. Ubuntu is a Nguni word that “represents notions of universal human interdependence, solidarity and communalism which can be traced to small scale communities in pre-colonial Africa, and which underlie virtually every indigenous African culture” (Roederer and Moellendorf, 2004). There are similar words in African languages throughout Sub-Saharan Africa, and the idea of Ubuntu is shared by many different indigenous groups on the continent (Kamwangamalu, 1999). Augustine Shutte, a South African philosopher, is regarded as the first person to formulate a connection between Ubuntu and the proverb “umuntu ngumuntu ngabantu” (a person is a person through other persons) (Gade, 2011). Africans from South Africa define Ubuntu as a moral quality of a person that is positive, praiseworthy and refers to the capacity for “empathy with another person” and a capacity to “connect with another human being”. They also describe it as a phenomenon or a philosophy to assist in “rebuilding within and amongst different communities” (Gade, 2011). Michael Onyebuchi Eze argues that individuals and communities are not opposed, but co-exist in a “contemporaneous formation” (Eze, 2008). Given the consonance of the common good approach in bioethics and African philosophy, has the time not come to decolonise bioethics?

The imperative to “decolonise” bioethics in South Africa

The history of Western philosophy is increasingly being contested in the literature. It is interesting to note that Socrates was only 10 years old when Confucius died in 479 BC (Yu, 2005). It therefore would seem prudent to explore Confucian ethics and incorporate relevant principles and concepts into the teaching of bioethics. While the origins of Western philosophy are attributed

to ancient Greece, some argue that Western philosophy may also have its origins in the Kemetic civilisations of ancient Egypt in North Africa (Letseka, 2014). Philosophy thrived in Egypt from around 3400 BC to 343 BC and, in 390 BC Plato, visited Egypt to learn more about Kemetic culture and civilisation (Letseka, 2014). Recent student protests in tertiary education in South Africa have called for the “decolonisation” of academia. Student feedback in our Faculty is reflecting a thirst for other philosophical approaches to ethics:

“I feel that more other versions of ethics must be introduced and be able to be used in this module, not just Western ethics. Our country is a diverse nation and at minimum, African, Islamic and Chinese ethics theories should be taught or at least introduced into the syllabus.”

“Thank you. Fantastic module, well-co-ordinated. Include more African philosophy sessions.”

Clearly, it is no longer relevant in South African academic institutions to teach bioethics based on Western philosophy alone. Behrens (2013) argues that there is an obligation to decolonise bioethics to restore dignity, “as colonial and apartheid regimes systematically subjected the majority of our people to inhuman conditions and robbed them of their dignity”. A bioethics curriculum grounded in indigenous ideas is more likely to be accepted by African scholars. Furthermore, African philosophy can enhance the discourse in bioethics (Behrens, 2013).

Creating a “thinking environment” in health sciences

“It is the mark of an educated mind to be able to entertain a thought without accepting it” - Aristotle

Bioethics encourages thinking ... in particular, critical thinking. After more than a decade of teaching medical students, the shift to placing value on thinking as a skill has recently been acknowledged by our senior medical students. These are their voices:

From MBChBV student feedback, 2015:

“I want to start by saying thank you for the Ethics block, I really enjoyed it. It is one of the few blocks ... that makes us think and challenge”.

From MBChBV student feedback, 2016:

“The module was interesting and thought provoking. I am inspired to be the best health professional I can be.”

“This module encourages critical thinking within the profession and challenges paradigms.”

“Thank you for a very insightful block. One of the

best in the 5 years of my medical studies.”

“This module allowed for development of essential reasoning skills in a setting where optimal guidance was provided. During this short time, my competency developed far beyond what I had expected. I am a better medical student than I was 3 weeks ago.”

“Wat ’n fantastiese module. Dit het my geleer om krities te dink oor vele aspekte. Baie dankie.”

“Taught us to think, debate and come up with solutions and construct proper arguments. Really awesome rotation.”

And then, from MBChB students post-graduation, in 2016:

“Is it ethical to order a cardiac MRI costing R45 000 on a 70-year-old patient who would benefit from conservative treatment?”

“When a patient is brought to a private hospital for acute chest pain, is it the duty of the doctor to call the family telephonically to ask if the patient has medical aid cover or is it the duty of the doctor to treat the patient first – after all, it is an emergency? Training medical students in the private sector can sometimes expose them to poor role models from an ethics perspective.”

It has taken more than a decade for medical students to acknowledge the value of thinking as is encouraged in bioethics. Not only do they raise poignant questions during the ethics rotation, but they now continue to interact with the Centre after graduation when encountering ethical dilemmas in the real world. In particular, the current campaign by interns and young doctors for more humane working hours was initiated during their ethics rotation two years ago. Many recent graduates are also questioning the concept of “playing God” both in creating and ending life.

“The human mind, first freed by being paid the highest-quality attention, can also leap past debilitating assumptions, able to think of things inconceivable before” (Kline, 2014).

INTO THE FUTURE

Innovation in thinking will create novel solutions to mundane challenges in this millennium. New thought leaders have the power and potential to articulate strategic direction and avert the tragedy of the commons. As academics, we are those thought leaders. Traditional leadership is based on sound knowledge and a deep understanding of the world and human behaviour. However, another dimension of leadership is based on not knowing, not doing and not being in control of one’s own situation. Having the capacity to work creatively within this dimension is what John Keats referred to as negative capability in 1817 (Gitting, 2002). Negative capability is the “human capacity for containment” – the capacity to live with and tolerate ambiguity and paradox and to “be content with half knowledge” (Hoebek, 2000). Creative leadership is what is required on the edge between uncertainty and certainty.

As a university, we are a hub of knowledge production and consumption in which robust and fearless debate of ideas will lead to innovation, where connectivity to our students – past, present and future – and to civil society (via science translation) will ensure our relevance and sustainability.

Bioethics is not just an academic discipline or a career. Given the nature of our work, bioethicists play a strong advocacy role in all contexts where injustice is allowed to fester. We also play a critical role in conceptualising and articulating ethical dilemmas and advancing debates on controversial societal challenges. Failure to respond to ethical lapses in our work environment, in our personal lives, in the discipline of medicine, in academia and in society will not serve us well. Science and society will judge us for the action/s we fail to take when such obligations and opportunities arise. The opportunity for transformative leadership in academia, medical education and bioethics has never been greater.

“The longest journey
Is the journey inwards
Of him who has chosen his destiny,
Who has started upon his quest
For the source of his being.”

Dag Hammarskjöld Secretary General of the
United Nations (1953-1961)

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