AN EVALUATION OF ETHICAL PROBLEMS RELATED TO HYPOXIC ISCHEMIC BRAIN INJURY IN NEONATES BORN IN SOUTH AFRICAN STATE INSTITUTIONS

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DECLARATION

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

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This dissertation is dedicated to "BigBoy" Mdondo, who lives his life somewhere among the rolling hills of Kwazulu-Natal.

ABSTRACT

Thousands of South African children die or are physically and cognitively permanently impaired during birth due to a recurring pattern of professional negligence in state institutions. South African high courts persistently award large sums of money to plaintiffs for what is often described in judgements as gross or criminal professional negligence. This aberration in South Africa's health care delivery is in a downward spiral with no perceptible attempt from the health care bureaucracy to identify and address the root causes of what could be pronounced a national catastrophe.

The thesis evaluates the moral status of the term fetus in the intrauterine environment, concluding that it is equal to the moral status of the newborn infant in terms of a separation-survivability point, which is perceived as a morally significant milestone. At about 25 weeks gestational age, the gradual development of the prenatal human being reaches the stage where it can survive separation from its mother, should it be born alive at that point. This radically alters pre-personal moral significance: since there is no justifiable moral basis for differentiation between a specific (healthy) neonate and a specific (normal) viable fetus in the last weeks of pregnancy, these entities, the same human being in different phases of development, are entitled to equal treatment.

Once established that the moral status of the term fetus in the intrauterine environment is equal to the newborn infant, it follows that under Section 24 of the Bill of Rights of the Republic of South Africa, the term fetus has a right to an intrauterine environment that is not harmful to his or her health or well-being and the Constitution should protect them from the scourge of professional negligence during labour. The Constitutional Court of the land should uphold this right.

OPSOMMING

Duisende Suid Afrikaanse kinders sterf of word fisies en kognitief permanent beskadig gedurende geboorte as gevolg van ‘n herhalende patroon van professionele nalatigheid. Die Suid Afrikaanse hooggeregshowe ken op ’n deurlopende basis groot bedrae geld toe aan eisers vir wat gereeld in uitsprake as growwe of kriminele professionele nalatigheid beskryf word. Hierdie afwyking in Suid-Afrikaanse gesondheidsorg is in ’n afwaartse spiraal en kan beskou word as ’n nasionale ramp.

In die tesis word die morele status van die term fetus in die intrauteriene omgewing ondersoek met die gevolgtrekking dat dit op dieselfde vlak as die morele status van die pasgebore neonaat is in terme van ’n sogenaamde skeidings-oorlewingspunt wat as ’n belangrike morele mylpaal beskou word. Teen ongeveer 25 weke gestasie-ouderdom, bereik die geleidelike ontwikkeling van die prenatale mens ’n staat waarin hy of sy ’n skeidingsproses van die moeder kan oorleef as geboorte op daardie stadium sou plaasvind. Dit skep ’n drastiese verandering in voor-persoonlike morele belang: Aangesien daar geen regverdigbare morele basis is vir die onderskeiding tussen ’n bepaalde (gesonde) neonaat en ’n spesifieke (normale) lewensvatbare fetus in die laaste fase van swangerskap nie, moet hierdie twee entiteite, dieselfde mens in onderskeie fases van ontwikkeling, op gelyke vlak behandel word.

Nadat daar vasgestel is dat die morele status van die term fetus in die intrauteriene omgewing gelykstaande is aan die pasgebore neonaat, volg dit dat, onder Afdeling 24 van die Handves van Regte van die Republiek van Suid-Afrika, die term fetus die reg het tot ‘n omgewing wat nie skadelik is vir gesondheid en welstand nie, en moet deur die Grondwet beskerm word teen die gevolge van professionele nalatigheid tydens geboorte. Dit is die plig van die Konstitusionele Hof om hierdie reg te beskerm.

Contents

1 Introduction

Preamble

In this thesis, I investigate a devastating aberration in the field of health provision in the Republic of South Africa. Birth asphyxia is the term used to describe oxygen deprivation of the fetus during the first and second stages of labour when entirely dependent on placental supply. According to Buchman et al. (2002), South Africa's high rates of perinatal death from intrapartum-related birth asphyxia is characteristic of those in underdeveloped countries, and rural areas account for the most severe deficiencies. Most of these deaths are avoidable, and the reduction of these rates presents a fundamental challenge to providers of perinatal care. In addition to the deaths caused by birth asphyxia, it is difficult, if not impossible, to calculate or even estimate the number of children that survive with the debilitating consequences of cerebral palsy that can be directly linked to perinatal hypoxic ischemic injury (HII).

I performed the first magnetic resonance scan (MRI) in South Africa at the Medical Research Council in Parow, Western Cape, on Thursday, 17 October 1985. I specialised in neuroimaging, and from 2012 onward, I developed a particular interest in MRI features of hypoxic ischemic injury in preterm and term infants. In the period to date, I have conducted ongoing international correspondence with leading experts in the field of hypoxic ischemic injury in infants and compiled a database of more than five thousand (5000) cases of hypoxic ischemic injury in young children in a chronic stage of evolution. This academic effort embraces ongoing academic evaluation of the database and development of didactic teaching material in the field of hypoxic ischemic injury in children. The database also supports research in the field of hypoxic ischemic injury by affording prospective PhD candidates access to this unique collection (Misser & Lotz, 2020). Lately, I have become more active in addressing the unique concerns of hypoxic ischemic injury in children in the South African context.

Problem statement

In line with these concerns, this thesis aims to evaluate ethical problems related to the high incidence of hypoxic ischemic injury in neonates born in South African state institutions.

The objectives of the study include:

- Identifying the cause of the prolonged partial hypoxic ischemic injury.
- Linking the prolonged partial hypoxic ischemic injury to negligence of assisting obstetrical staff during the first stage of labour.
- Discussing negligence and the harm caused to individuals and lifelong caretakers.
- Delineating fetal moral status relative to intrauterine gestational maturity.
- Comparing the moral status of the term fetus during the first stage of labour with the moral status of the newborn infant.
- Assessing the implications of the moral status of the term fetus within the context of the Bill of Rights of the Constitution.
- Questioning the right of the term fetus to a healthy and non-toxic intrauterine environment during the first stage of labour.
- Advancing an argument for the protection of the mature fetus under the Bill of Rights of the Constitution of South Africa.

A limitation of this research will be that official statistics on the specific topic of hypoxic ischemic brain damage with resultant cerebral palsy are not readily available. The incidence of perinatal hypoxic ischemic injury resulting in death cannot be calculated from an index such as the infant death rate, as Statistics South Africa does not address cerebral palsy as an isolated entity. Therefore, no method exists to identify the incidence of this condition that directly links to perinatal hypoxic ischemic injury. However, the incidence of medical negligence cases against state health care institutions may indirectly shed some light on the extent of the problem. In this regard, the South African press has persistently

reported on High Court judgements and parliamentary debates. According to Ernest Mabuza (2019), The Gauteng Health Department faces claims of medical negligence totalling R29 billion. This amount, according to the Gauteng shadow health MEC Jack Bloom, could have been invested to clear outstanding maintenance in all hospitals in the province, purchased necessary equipment, covered salaries for all unfilled posts, and there would then remain sufficient funds to build the six new hospitals that the Gauteng province so desperately needs.

Rian van Jaarsveld (2017) compared the situation between different state institutions in the Gauteng province and stated that the Chris Hani Baragwanath Academic Hospital (CHBH) accounted for most of the negligence cases; a total of R514 million was paid to 44 claimants by the hospital. The five most substantial individual pay-outs were:

- R36 795 413 for cerebral palsy caused by brain damage at birth at CHBH.
- R33 469 290 for cerebral palsy caused by brain damage at CHBH.
- R29 989 117 for brain damage at the Natalspruit Hospital.
- R24 596 364 for brain damage at CHBH.
- R18 947 295 for cerebral palsy caused by brain damage at the CHBH (Van Jaarsveld, 2017).

According to treasury data reported in Medical Brief: Africa's Medical Media Digest (2019), the accumulated outstanding debt for medical negligence claims against the provincial health departments amounts to a staggering R80.4 billion. This amount represents more than 40% of total budgets for the 2020 financial year. The legal defence is in disarray, and experts from the private sector had to be recruited to assist in litigation defences of 14,000 outstanding cases. The extent of this accumulating financial disaster is expounded by the fact that in the 2017-18 financial year, the contingent liabilities for medical negligence tripled compared to that of the 2014-15 financial year and amounted to 41% of the provinces' annual budgets.

In an indirect method of data accumulation, I calculated that, over a period of five years, I compiled 2000 positive magnetic resonance imaging (MRI) reports of hypoxic ischemic brain injury for litigation purposes. If one accepts that four colleagues, active in the same subspecialty, hold the same number of positive reports over the same period, then it can be extrapolated that the incidence of surviving infants over five years is about 10,000. No parameter exists that indicates the number of infants that died during birth due to HII during this period. However, academic literature implies that only 40% of severely injured infants survive (Kurinczuk, White-Koning & Badawi, 2010:329-338).

South African obstetric practice is, however, not in question. The professional standards of South African gynecologists and obstetricians compare favourably with international practice. Unfortunately, they are bearing the consequences of this aberration of negligent fetal and maternal care during the first and second stages of labour. Medical protection insurance for practicing obstetrics in private practice in South Africa currently amounts to R1 million per annum, rendering this specialty less attractive. Obstetrical nursing staff are assumedly adequately trained and experienced. Professional boards tasked with upholding professional standards of practice are functional and efficient. Where then does the problem lie?

The argument in this thesis will be developed in seven chapters, starting with the contextualisation of the problem statement. This will be done by providing a brief overview of the South African health system and the South African Constitution, before further elaborating on the focus of this thesis.

The South African Health System

According to Statistics South Africa (2017), the population of South Africa is estimated at 54 956 900, with 80% of the population accessing health services

(e.g., public clinics and hospitals) that are run by the government. The health system comprises the public sector (run by the government) and a private free-market sector in which more than 60% of total health care spending occurs. Provincial departments of health manage various health facilities of the public health services, which are divided into primary, secondary, and tertiary levels. The provincial departments are thus the direct employers of the health workforce, while the National Ministry of Health is responsible for policy development and coordination.

The United Nations designates South Africa in the seventh position of relative wealth as a developing country on the African continent. Relics of the country's political past has burdened it with huge disparities between rich and poor, resulting in the country occupying only the 129th position out of 182 on the United Nations Human Development Index (2018:1). Since South Africa became a democratic government in 1994, a radical political and social transformation has taken place. However, medical services endure an intolerable inconsistency of an affluent private health care scheme providing for 20% of a privileged segment of the population, while the other 80% of the population has to depend on a public health system which is, by all accounts, overburdened and understaffed. As with many other government institutions, substantial resources allocated to social services and education for children are often squandered, leaving those most vulnerable individuals, mostly in remote rural districts, without much needed social security networks. The African Child Policy Forum (ACPF, 2011) investigated the realities of disabled children in South Africa. Similar to the findings of Statistics South Africa (SSA) published in 2005, they found that an estimated 5% of children between 0 and 19 years have a reported disability (approximately 496,000 children in total). Also, according to the SSA study, 80% of disabilities are attributed to cerebral palsy with a variety of clinical presentations.

The departments of health of the provinces provide and manage comprehensive health services via a district-based public health care model. Local hospital

management is responsible for operational issues, such as the budget and human resources, to facilitate quick responses to local needs. However, the allocation of these resources and the standard of health care delivery vary from province to province. A Health Charter has been put in place in an attempt to promote dialogue between different segments of the community in addressing equal access to quality health care services. The MEC for Health of the respective province is responsible for all nursing and administrative staff in state hospitals and institutions. Of the government's total budget, 11% is allocated to public health, which accounts for the second-highest part of the country's budget after education and amounts to 3.7% of GDP (more than R100 billion), mostly spent by the nine provinces.

Geddes (2010) sketches a paltry state of affairs in the public health care system. The gulf between private and public medical practice is underscored by statistical evidence; in 2007 one-third of public medical posts were vacant, and the vacancy rate for nurses was about 60%. Ever since, the situation has remained in steady decline to the extent that presently the public sector has one doctor for every 4,759 inhabitants while, in stark contrast, there is one practitioner for every 600 patients in private medicine. According to Geddes (2010) and supported by many who are familiar with the environment, the overall state of the public health care system is appalling. An unbiased assessment describes the hospitals as dirty and over-crowded, and patients are subjected to long waiting periods, lack of medicines, and a shortage of medical staff. A most disconcerting aspect of the circumstances of poor salaries and appalling work conditions is that thousands of public sector doctors, nurses, and other medical practitioners have emigrated.

The South African Constitution

The Constitution of the Republic of South Africa, instituted in 1996, is credited as one of the most liberal in the world. The second chapter, the Bill of Rights, defines the equal rights of all citizens and the state's commitment to promoting the equality

of all citizens, thus intending to prevent discrimination on any grounds, including characteristics that have historically served as justification for various forms of unfair treatment. The context of this study merits a specific focus on age and disability (Hall, 2008).

The Bill of Rights

The Bill of Rights is described as the “cornerstone of democracy in South Africa”. It protects “the rights of all people in our country and upholds the democratic values of human dignity, equality, and freedom” and stipulates that “the state must respect, protect, promote, and fulfil the rights” it sets out. Furthermore, the Bill of Rights binds “the legislature, the executive, the judiciary, and all organs of state” and defines a juristic person who is “entitled to the rights in the Bill of Rights to the extent required by the nature of the rights and the nature of that juristic person”. It also holds that “everyone is equal before the law and has the right to equal protection and benefit of the law” and that “[e]quality includes the full and fair enjoyment of all rights and freedoms” (South Africa History Online 2000).

Section 24 on the environment (South Africa, 1996) states:

> everyone has the right to an environment that is not harmful to their health or well-being, and to have the environment protected, for the benefit of present and future generations, through reasonable legislative and other measures

The stipulations in Section 24 embody the main thrust of this study.

The focus of this study

An individual passes through the birth canal in a relatively short time. The passage during childbirth entails exchanging the intrauterine environment for an extrauterine environment. While inside the uterus, the individual does not qualify as a natural juristic person. Once outside, the same individual, according to the Bill of Rights, becomes a natural, juristic person entitled to all the rights under the

constitution, including the right to a healthy environment. One may, therefore, question why the same individual at the same level of neurocognitive development when inside the uterus is not entitled to the natural right of a healthy environment. There appears to be an inconsistency inherent in the perception that moral status changes drastically in the process of passing through the birth canal.

If fetuses are deprived of oxygen during the first or second stages of labour, there is only a limited window of opportunity during which obstetricians can intervene to prevent hypoxic ischemic brain damage by performing a caesarean section. The timing of such a surgical intervention is critically dependent on maternal and fetal monitoring, especially during the first stage of labour. Oxygen deprivation during these stages leads to fetal distress, which is manifested initially by an increased heart rate due to a build-up of acid in the blood (metabolic acidosis).

This study focuses on the prolonged partial injury that occurs predominantly during an extended first stage of labour. A relative restriction of oxygen supply during this period triggers a compensatory process in which oxygenated blood is shunted from organs such as the liver and kidneys to avoid brain damage. If these measures do not correct the relative oxygen deprivation, there is a slow build-up of lactic acid in the fetal blood. This metabolic acidosis results in a downward spiral of higher demand for oxygen, which, if not met, leads to an acceleration of acid build-up. During this downward slide, the fetus becomes distressed, and the fetal heart rate increases. The role that obstetrical nursing staff play in detecting and monitoring fetal distress is of critical importance. Accurate and professional charting of uterine contraction, cervical dilatation, and fetal heart rate deceleration during contraction enable staff to detect abnormalities at an early stage and to define the point during the downward spiral at which a caesarean section becomes mandatory. If a caesarean section is, for some reason, not performed at this time, the fetus suffers a prolonged partial hypoxic ischemic injury or may die. The prolonged partial injury predominantly involves axonal white matter tracts that are conduits between the neurons (nerve cells) in the cortex and the effectors (muscles) of the upper or lower

limbs. Destruction of these fine fibres that relay electrical impulses to peripheral effectors (muscles of upper and lower extremities) results in paralysis with increased tone in both arms and legs (spastic quadriparesis). It manifests as the spastic form of cerebral palsy.

Chapter layout

This thesis aims to evaluate ethical problems related to the high incidence of hypoxic ischemic injury in neonates born in South African state institutions. Chapter One has provided an introduction and background to the study. In Chapter Two, I will explain the pathophysiology (mechanism) of the process of fetal distress and hypoxic ischemic injury in more detail. I will argue that failure to comply with professional standards of fetal and maternal monitoring results in a breakdown in the chain of accountability that eventually manifests in the devastating result of a prolonged partial hypoxic ischemic injury with its clinical sequelae of spastic quadriparesis or death. Imposing a risk on another may violate a standard of due care exists, which, if not adhered to, will result in consequences. On this point, interaction exists between law and morality, which both subscribe to a standard of due care. This standard determines whether the agent who is causally responsible for the risk is also morally or legally responsible, also inferring the principle of non-maleficence. A failure to achieve it is termed negligence. The concept of harm is intrinsic to the definition of negligence: the obligations of non-maleficence include not only a duty not to inflict harm but also obligations not to impose the risks of harm. In well-equipped institutions in which obstetricians routinely perform caesarean sections to avoid harm to the fetus, there is a natural expectation that professional responsibility and the chain of accountability shall hold. If a prolonged partial injury with its clinical sequelae occurs under these circumstances, I will argue that it can only be the result of a lack of due care and that this innately implies negligence in both the moral and legal sense.

In Chapter Three, I assess the influence of caring for a child with spastic cerebral palsy on the quality of life of parents in the South African township environment. A thesis submitted by Janet Modenyi Thoya to the University of the Western Cape (2017) provides a sobering rendition of this experience. An attempt to reconstruct the quality of life of affected children in the rural heartlands proved a more daunting endeavour as Statistics South Africa does not list cerebral palsy as a separate entity. The importance of defining the true extent of this devastating condition fades with entries such as "disability of hearing" and "disability of communication" (Census SA, 2017). There remains the need to reconstruct some perception of the quality of life that these individuals suffer against the background of poverty in rural South Africa (Statistics South Africa, 2017). As stated above, the provinces in which the living standards in rural areas often fail to meet even the lower poverty line are the same regions in which the incidence of litigation for negligence during childbirth is the highest.

In Chapter Four, I endeavour to define negligence in general terms but also to place the central issue of this study in a specific South African context. It seems that certain individuals are particularly vulnerable in the South African situation as areas in which the incidence of medical malpractice litigation is most prevalent coincides with the most deprived township and rural communities. I will argue that the major proportion of blame should be directed at an inefficient and corrupt bureaucratic hierarchy of the Department of Health. The Esidimeni disaster and the subsequent inquest by deputy chief justice Dikgang Moseneke (Green, 2018) unequivocally demonstrated the extent of these problems and their catastrophic results. There has up to now been only minor consequences, but nothing to begin to rectify the situation. People are demoralised by the actions of leaders in the bureaucratic hierarchies that they find themselves in; they are overworked and underpaid. The task of health professionals in the public sector is immensely difficult, but we must nonetheless recognise that every individual has a professional and moral responsibility to uphold. In this thesis, the following questions are therefore posed: Is it possible to secure basic human rights for the

fetus under the Constitution? Can the Constitutional Court ensure that these rights are respected, and will the individuals that violate these rights through negligence be held accountable?

Chapter Five encompasses a discussion on the different theories of moral status and how these apply to the fetus near term. Clarity is needed on individual rights under the South African Constitution and how these apply to environmental changes during the short period of normal childbirth. I will argue that separation-survivability is a significant developmental fetal milestone that can serve as a stage of development beyond which the moral status of the fetus and the newborn infant should be regarded as equal under the Bill of Rights of the Republic of South Africa.

Chapter Six focuses on three noticeable and related developments that have taken place around the world in the past decades. These include a wave of new and amended constitutions in both emerging and established democracies, the human rights revolution, and exponential growth in the awareness of the global environmental crisis. These three forces coalesce in this thesis. Their combination forms the basis of an argument to expand the right to a healthy intrauterine environment to beyond the separation-survivability stage.

Chapter Seven concludes the study, where I revisit the implication of extending the moral status of the newborn infant to a fetus that has developed beyond the milestone of separation-survivability. Herein, an argument is advanced that environmental health and well-being is imperative and should be protected under Section 24 of the Bill of Rights for everyone, and that the right to a healthy intrauterine environment beyond the separation-survivability point is a valid and logical position to hold.

2 Medical and Obstetrical Facts

Introduction

This study aims to evaluate ethical problems related to hypoxic ischemic injury in neonates born in South African state institutions. The moral status of the unborn fetus is contrasted with that of the newborn infant, and a question is posed whether there is a particular stage of development at which the fetus and newborn individual should share the same moral status. In this chapter, I discuss the pathogenesis (cause and mechanism) of a hypoxic ischemic injury that occurs during the first stage of labour in a compromised intrauterine environment. I also advance a suggestion that in a well-equipped and well-staffed obstetrical institution, this specific injury is innately related to professional negligence.

Oxygen deprivation, also known as birth asphyxia, occurs in approximately four of every one thousand nine-month term births worldwide. Shortly after delivery, infants start to breathe on their own. If they are deprived of oxygen during the first or second stages of labour, there is only a limited window of opportunity during which obstetricians can intervene by performing a caesarean section. The timing of surgical intervention is critically dependent on maternal and fetal monitoring during the first stage of labour. Oxygen deprivation during this stage leads to distress of the fetus, which is manifested initially by an increased heart rate, following a fall in heart rate during a uterine contraction that does not return to normal after relaxation of the contraction. A clinical condition of fetal distress is then identified.

Oxygen deprivation in the fetus, if not controlled, or as required in the majority of cases, not terminated by caesarean section, leads to hypoxic ischemic injury (HII) to the fetal brain or fetal death. HII is permanent and results in cerebral palsy, often with spastic quadriparesis (high tone paralysis in all four limbs). Other features could include autism, attention deficit hyperactivity disorder, impaired vision, or intrauterine death. Central to the prevention of the occurrence of HII is adequate

and professional monitoring of mother and fetus with the specific intention to identify the onset of fetal distress, to monitor fetal distress, and at a clearly defined juncture, to terminate the process by performing a caesarian section.

Measures of monitoring include applying a fetal cardiac electrode to the maternal abdomen (cardiotocograph) to directly monitor fetal heartbeat and document patterns of heartbeat variation during uterine contraction. The attending medical professional (midwife) records and plots acquired data on a graph known as a partogram. Analogous to the flight plan of an aircraft, the birth process and maternal and fetal well-being should then be under rigid control. The partogram pinpoints the juncture at which the progress of the birth process deteriorates to the level of an obstetrical emergency and identifies a specific point in time at which a caesarean section becomes mandatory. The obstetrical nursing staff are professionally trained to perform this task during the birth process, and the importance of reliability, precision, and empathy of the nursing staff in the execution of their tasks cannot be overestimated.

Pathophysiology of the prolonged partial hypoxic ischemic injury

According to Volpe et al. (2018:484-487), the neuropathological features (results of brain injury) of neonatal hypoxic ischemic encephalopathy (brain dysfunction as a result of lack of oxygen) vary considerably with the gestational age (intrauterine development) of the infant. Specific primary insults can be recognised that provide a useful framework for identifying clinical entities. Linda de Vries and Floris Groenendaal (2010:556) describe two patterns of hypoxic ischemic injury (HII) that manifest on magnetic resonance imaging (MRI) from around 36 weeks gestation onward in a fetus subjected to hypoxia (low oxygen content) and ischemia (low perfusion pressure). Acute profound or central injury follows on a sentinel event such as an abruptio placenta (separation of the placenta) or uterine rupture. The mother loses a litre or more of blood vaginally and is in a state of shock, constituting an obstetrical emergency with low blood pressure and an increased heart rate.

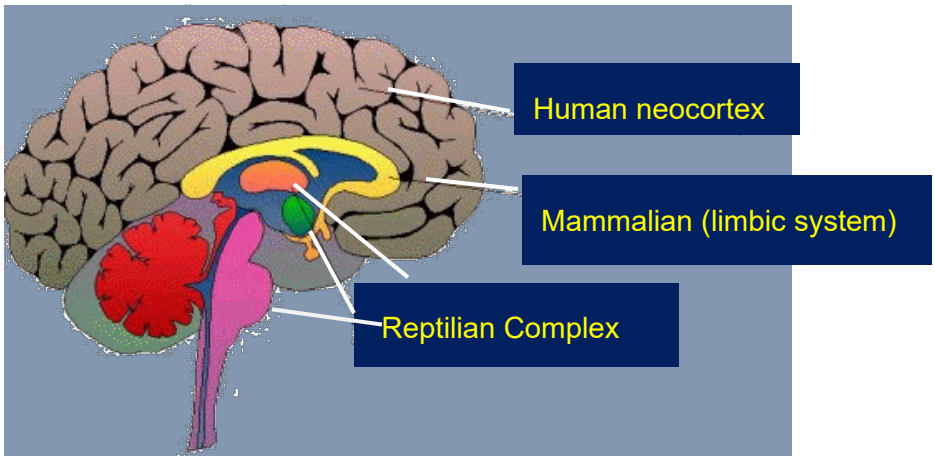
Most fetuses succumb, but if the mother is in a hospital, a short window of opportunity does exist to perform an emergency caesarean section. The infant seldom survives in a functional state. This study focuses on the prolonged partial hypoxic ischemic injury (PPHII) that occurs predominantly during the first stage of labour, and the acute, profound injury forms no further part of this discussion.

A short explication of the causes and presentation of the prolonged partial pattern is necessary to form the basis of an observation that this insult can be directly linked to inadequate or unprofessional maternal or fetal monitoring during the first stage of labour. The narrow delineation of a specific injury that occurs in state institutions under purported professional obstetrical care can only then be labelled as professional negligence.

The human brain (neocortex) evolved around a reptilian core over millions of years (Figure 1). The reptilian brain, being the first to sustain life, has all the vital centres of life imbedded in its substance. These centres autonomously control heartbeat, respiratory movement, and swallowing, which are all actions essential for the sustenance of life. Nature will protect the reptilian core at all costs and will sacrifice the rest of the brain, including the mammalian brain and the neocortex, to protect the reptilian core, the very centre of life itself. When labour commences, the reptilian brain is activated. An apt analogy would be a rocket on the launching pad, ready for take-off into outer space. The command "fire engines for lift-off" is equal to the activation of vital centres in the reptilian brain that would be needed for the fetus to pass through the birth canal and to arrive "on the other side", ready to suck and to swallow. As the nuclei in the reptilian core are activated, the larger and peripheral neocortex of the human brain is essentially asleep, as it plays no role in the birth process. The neocortex will become active once the individual starts making contextual sense of the world around him or her. It follows logically that during birth, vulnerability to oxygen deprivation would be centred on the vital centres within the deep central reptilian complex where all activity occurs.

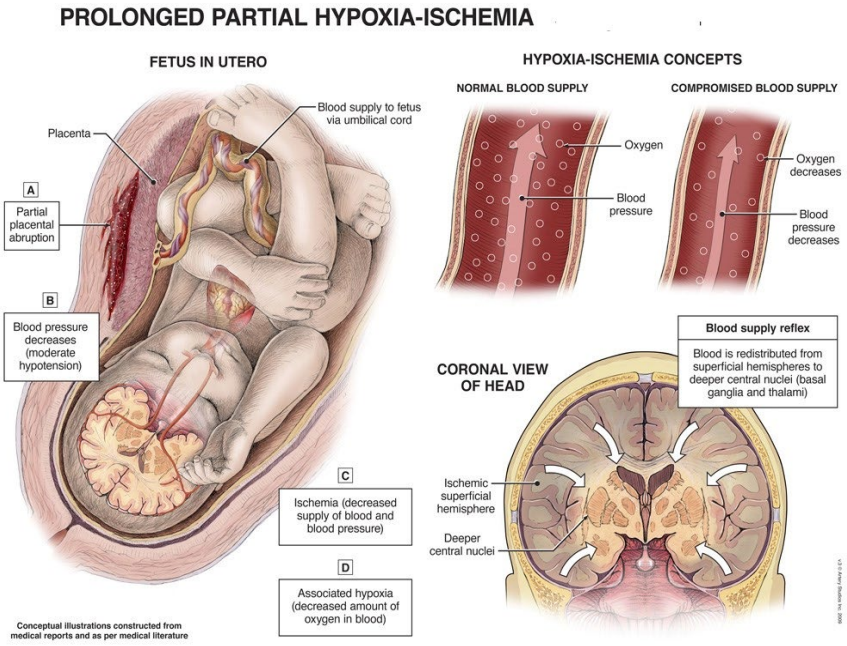
Figure 2 demonstrates a small, partial separation (abruption) of the placenta as an example of one of many causes of oxygen deprivation of the fetus in the in-utero environment during the first stage of labour. The result can be seen under "hypoxia-ischemia concepts" at the top right. The rings represent oxygen attached to haemoglobin in the red blood cells (erythrocytes) in a major supply vessel to the brain. The arrow represents a pressure wave induced by contraction of the left ventricle of the heart to provide the force to advance these erythrocytes and to perfuse the brain with oxygen-saturated blood. In contrast to the normal combination on the left, the compromised situation on the right identifies the reduction of oxygenated erythrocytes (hypoxia) and a diminished pressure wave (ischemia). The process thus incorporates both hypoxia and ischemia, and the injury that results is aptly called a hypoxic ischemic cerebral injury.

Figure 1



(Courtesy of Halpern, RC; Rogers, T)

Figure 2



(Courtesy of Halpern, RC; Rogers, T)

Oxygen deprivation is relative, and several compensatory mechanisms are activated. If the situation stabilises, the first stage may progress normally. If oxygen shortage persists, the fetus becomes distressed; excess lactic acid is produced, which increases the demand for oxygen, triggering a vicious cycle of heightened fetal distress. The process left uninterrupted will rapidly deteriorate, and the active, vital centres of the reptilian brain will become seriously at risk. Nature, tenaciously clinging to life, now intervenes and activates an autoregulatory process (“salvage team”), which induces certain blood vessels to contract, diminishing blood supply, and others to dilate, enhancing preferential shunting of blood to a specified area. In the bottom right diagram, it is shown how, at the time before and during birth when all activity occurs in the reptilian brain (in an abnormal situation of relative oxygen deprivation), blood is “stolen” or “parasitised” from the neocortex and diverted to the reptilian centres of life. The process of autoregulation does not happen instantly. It takes an hour or longer to become active, and it is helpful to

view it as a “salvage team” that needs to set up an infrastructure of pipes and pumps to relay oxygenated blood from the neocortex to the vital centres.

All fetuses that suffer oxygen deprivation become distressed at an early stage (in-utero, they are essentially fighting for their lives). The first sign is tachycardia (an increase in the fetal heart rate) that is easily detected by fetal auscultation (listening to the fetal heart and counting the beats per minute). Normal fetal heart rate is defined by Pildner von Steinburg et al. (2013) as between 110 and 160 beats per minute. Observers are obligated to identify any rate outside this range that constitutes fetal distress, which implies that the fetus is suffering in an abnormal environment of oxygen deprivation. Obstetrical staff must intensify the monitoring process by attaching a cardiotocograph to the mother's abdominal wall. Uterine contractions and fetal heart rates are recorded in a graphic format, and the results are plotted on a graph database, the partogram. Points of obstetrical emergency and mandatory caesarean sections are indicated by computerised compilation. The entire process is guided within rigid bounds that allow for the timely alert of the obstetrical team that a caesarean section has become mandatory. The apparent logic is that the child should be removed from an anoxic (low oxygen) intrauterine environment and placed in an incubator with adequate oxygen supply before the “salvage team” is forced to dismantle the neocortex to sustain life.

The partogram

The Department of Health of the Republic of South Africa published a manual entitled *Guidelines for maternity care in South Africa* (2007). It consists of eleven chapters and covers 170 pages. In the foreword, the Minister of Health states: *“*The purpose of the guidelines on maternity care is to give guidance to health care workers providing obstetrical care and services in clinics, community health centres, and district hospitals” (2007:2). The third edition of *Guidelines for Maternity Care in South Africa* is internationally recognised and a prescribed manual in most countries on the African continent, which serves to confirm that

theoretical training of midwives and nursing staff in South Africa is at an accepted international standard.

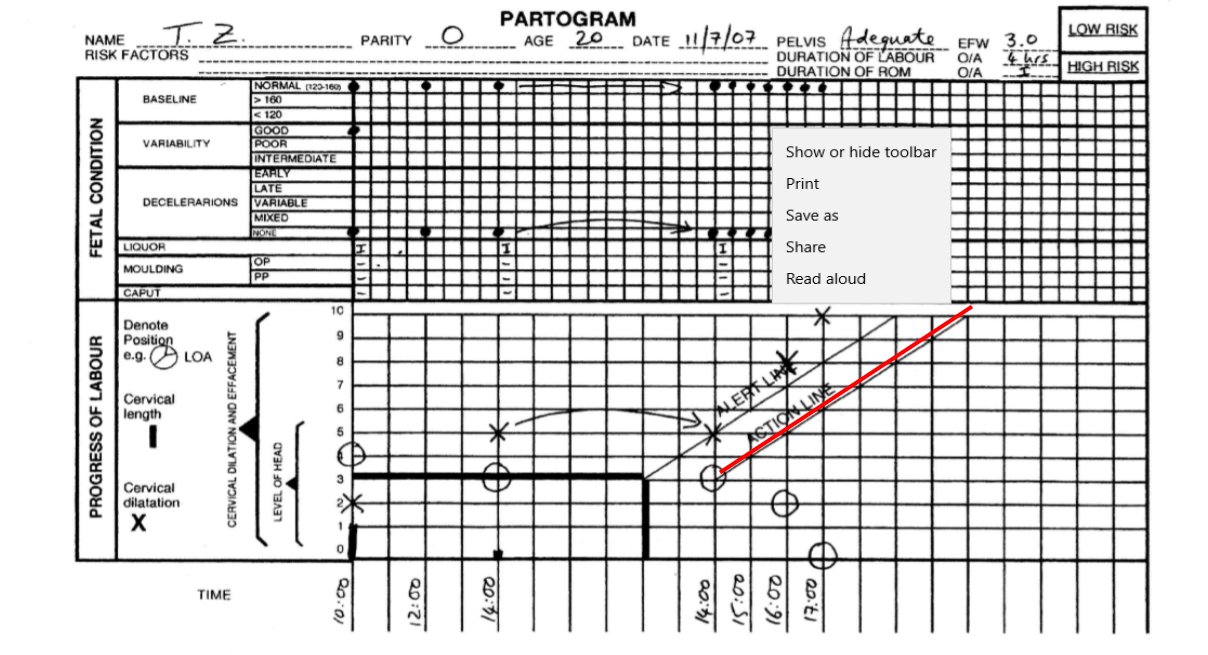
In this manual, the partogram is described as a chart to be completed by the attending midwife by populating defined spaces with information gained at specified intervals by the process of monitoring mother and fetus during the first stage of labour. A perfect comparison would be the rigid flight plan of a passenger aircraft and the fact that entries are made that specified beacons on its flightpath have been reached. The partogram defines "alert and "action" lines, which respectively dictate that a professional obstetrician should be alerted and the point of obstetrical emergency, which requires action to be taken to perform an emergency caesarean section for immediate removal of a severely compromised fetus from the womb. The entire exercise is constructed in such a way that prolonged partial hypoxic ischemic injury is averted as the obstetrical team would have beaten the “salvage team” to the post.

Magnetic Resonance Imaging (MRI)

In the case of a partogram adequately populated and correctly interpreted, it seems theoretically impossible for attending obstetrical staff not to alert a qualified obstetrician when the partogram indicates the action line for mandatory caesarean section. Nevertheless, consistently cases are encountered where prolonged labour extended over hours without a populated partogram being available for scrutiny. The standard excuse in court is often that all obstetrical records have "disappeared." In other cases, the partogram is populated so poorly and incompletely that no rational conclusions can be drawn. The worst scenario is a populated partogram showing perfectly normal progress of labour. The definitive proof of falsification is the arrival of a blue infant in a shocked state. These children

are born with Apgar scores[1] of 1 or 2 and are not breathing and are often convulsing. There is inevitably prolonged partial hypoxic ischemic brain damage.

Figure 3: Guidelines for maternity care in South Africa (2007)



Partogram. A graphic plot of the progress of labour with vital observations recorded. The ALERT and ACTION lines are identifiable. The dictate for mandatory surgical intervention is indicated (red line).

Magnetic Resonance Imaging (MRI) has a pivotal role to play in the diagnosis of hypoxic ischemic injury (HII), the identification of a specific pattern of the insult, and an estimation of the extent of cerebral destruction. The MRI report provides incontestable evidence of the injury pattern and the severity and extent of cerebral involvement. The radiologist has an ideal vantage platform of objectivity and scientific responsibility from which the substance of civil liability for compensation is formulated, and the attorney for the plaintiff requires this report to institute civil

[1] Apgar is a quick test performed on a baby at 1 and 5 minutes after birth. The 1-minute score determines how well the baby tolerated the birth process. The 5-minute score shows the health care provider how well the baby is doing outside the mother's womb. Normal 10.

litigation on behalf of a client (the mother) for damages suffered by a child during birth.

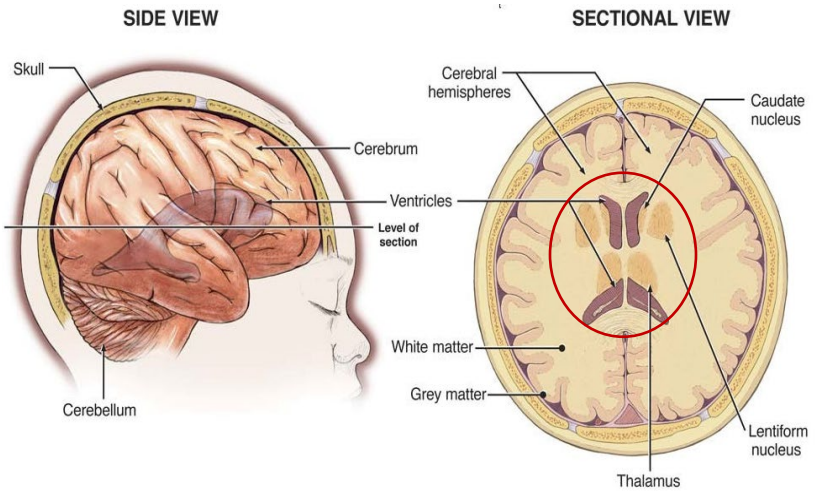
Hypothetically this MRI report is placed before the court in a larger frame of reference in which other medical experts are required to support or oppose arguments related to alleged negligence and whether this alleged negligence is the cause of the child's brain injury. The MRI report is the cornerstone of any litigation procedure, as, without it, there is no case. Several expert witnesses, such as obstetricians, neonatologists, paediatricians, and paediatric neurologists, are called on behalf of both the plaintiff and the defendant to testify regarding the timing of the injury, potential causative factors, and the clinical outcome. All this plays out against the background of an objective, scientific account of the type and pattern of injury as identified on the MRI study.

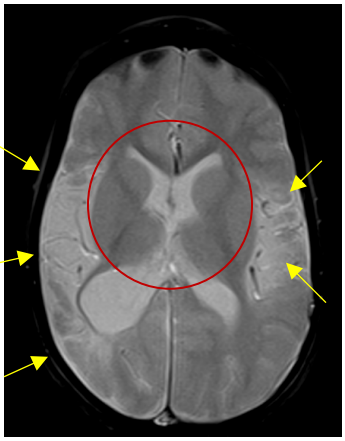
The identification of a prolonged partial pattern of hypoxic ischemic injury on MRI has wide-ranging implications. It implies that a situation of lack of oxygen supply (hypoxia; ischemia) existed in the intrauterine environment, which rendered the soon to be born fetus in a state of fetal distress. It can also be suggested that fetal distress was not detected due to inadequate monitoring and that the condition of the fetus deteriorated over time due to an ongoing metabolic acidosis (build-up of lactic acid in the blood). Oxygen deprivation of the neocortex leads to severe injury of white matter tracts (conduits for electrical nerve impulses) that ultimately manifests in paralysis with increased muscle tone, known as spastic cerebral palsy. Academic literature (Kurinczuk, White-Koning & Badawi, 2010:329-338) suggests that, alternatively, the majority of these infants die.

Figure 4a is a schematic representation of the acquisition of a 5mm axial section through the brain, and Figure 4b represents the actual MRI scan section. This is an MRI scan of the brain of a child that suffered a prolonged partial hypoxic ischemic injury. The image demonstrates that the reptilian core remained pristine (inside red circle). In contrast, the neocortex (yellow arrows) has been extensively

damaged on both sides because of a salvage process for sustaining life. It can be predicted that the child will pay the price in exchange for being alive. The outcome will be cerebral palsy with spastic quadriparesis (high tone paralysis of all four limbs) that will require lifelong care and support. There is an element of bitter irony in this image. The injury sustained in the neocortex was part of a process in which nature executed a desperate attempt to cling to life. The price paid for perpetuating this life is enormous, as residual functionality will only resemble reptilian capacity.

Figure 4a





(Courtesy of Halpern, RC; Rogers, T)

Figure 4b

Figure 4a*: Anatomical orientation of a 5mm thick axial section of the neonatal brain during MRI scamming, digitally extracted, and then projected axially on the screen. The observer sees the section from below. The red circle separates the central reptilian core from the peripheral neocortex.*

Figure 4b: *MRI scan: Normal reptilian core inside the red circle. Injury projects as a white signal, as these areas contain an excess of water. Injury to the neocortex is identifiable and indicated with yellow arrows.*

An MRI scan demonstrating a prolonged partial hypoxic ischemic injury of the brain conveys a clear and logical message. The partogram was never populated, or it was populated so poorly that the critical lines of “alert” and “action” were never recognised or identified. As I will argue in Chapter Four, this amounts to professional negligence. It also serves to demonstrate the persuasiveness of the argument, which I will develop further, that the identification of negligence is innate

in the diagnosis of a prolonged partial hypoxic injury on an MRI study of a compromised child's damaged brain.

Conclusion

In this chapter, I surveyed the pathogenesis and consequences of prolonged partial hypoxic injury. The critical role that obstetrical staff play in monitoring the progress of the first stage of labour with a specific focus on fetal well-being cannot be overestimated. Furthermore, the fact that the injury occurs due to a lack of oxygen places the emphasis on the need to intervene surgically to remove the fetus/infant from an oxygen-deprived intrauterine environment. The point of mandatory intervention by caesarean can be exactly defined, provided monitoring was professionally and responsibly executed and the partogram was diligently populated.

I intend demonstrating the very close association between the onset of the prolonged partial hypoxic injury and negligent failure to identify fetal distress during the first stage of labour. The injury causes spastic cerebral palsy which is a debilitating condition which significantly influences the quality of life of all concerned. In the next chapter I shall attempt to analyse the concept of harm and attempt to obtain a measure of understanding of the harm suffered by parents who care for children with spastic cerebral palsy, but more importantly, the quality of life that these children have to endure.

3 The Concept of Harm

Introduction

In Chapter Two, I explored the effect of relative anoxia on the fetus during the first stage of labour. An explanation of a compensatory process called autoregulation (associated with a "salvage team") was shown to prevent injury to the active, vital centres in the reptilian core of the human brain at the cost of causing extensive damage to the peripheral white matter of the neocortex. This white matter injury results in spastic cerebral palsy, with devastating consequences not only on the physical condition of the child but also on the quality of life of the individual and caregivers. I will discuss these consequences in this chapter.

The principle of non-maleficence refers to the prohibition against harming and is defined in terms of not causing injury or harm to another person. In this chapter, I intend to develop a definition of harm and examine the implication of the *counterfactual comparative account* of harm. Harm can be empirically quantified by measuring the quality of life (QoL) of individuals. QoL assessment allows for the identification of empirical-based evidence to guide and support therapeutic decision-making. The prevalence of harm caused by cerebral palsy in Africa is higher than anywhere in the world because of inadequate resources and a lack of research, which leads to immense suffering. Therefore, the central concern in this chapter will be on harm caused by cerebral palsy in the African context.

Defining harm

According to Beauchamp and Childress (2013:152), harm refers to the thwarting, defeating, or setting back of some party's interests. The term *harm* has normative and non-normative meanings. If one individual harms another, it may imply that the other person was wronged or treated unjustly. In some cases, however, it only means that the action set back another person's interests. Wronging implies violating another's rights, but harming need not imply such violation. People may be harmed without being wronged. For example, in the case of the state deciding

to quarantine individuals to control a dangerous communicable disease, sections of the community may suffer deprivation in the process, but the action is justified. Although they may be harmed in the process (i.e., their interests may be set back), in the context of a life-threatening disease, they are not wronged.

On the other hand, one may be wronged without being harmed. An example would be a private clinic refusing to admit a woman in early labour as she is unable to provide security for payment. If a bystander steps in and offers to act as a guarantor, it may be argued that the woman was wronged but not harmed by the hospital, as her interests are not set back, even if she is treated unfairly. Thus, harm may result in the setting back of a particular party's interest, but that harmful action is not necessarily wrong or unjustified, and one may be wronged without being harmed. The principle of non-maleficence, however, entails the obligation not to inflict harm.

Tanya de Villiers-Botha (2018:3-15) observes that despite the general disapproval of harming, which is not only prevalent in ethical theory but also encompasses common morality, the actual meaning of harm has not been sufficiently clarified. Recently, several attempts to rectify this oversight have appeared in the literature, and the adaptation of the definition of harm that is generally accepted is the *counterfactual comparative account* of harm.

The *counterfactual comparative account* of harm proposes a rational deduction that a harmful event, if it occurs, will leave another person (or thing) in an inferior or worse situation than had the event not occurred. For example, a caesarean section represents an invasive surgical procedure that carries a risk for both mother and child. In the context of post-operative morbidity, it leaves the mother worse off than had it not been performed. However, if performed professionally, the child is released from a potentially harmful intrauterine environment to prevent hypoxic ischemic brain damage. Thus, even if the mother experiences some post-operative pain or discomfort in this regard, overall harm is prevented. According to

Bradly (2012:392), the strength of the *counterfactual comparative account* concerns harm in general, as opposed to *pro tanto* harm, referring to an event potentially being *prima facie* harmful, with eventual beneficial consequences, outweighing its harmfulness. Before going on to discuss the harm inflicted by HII, I will firstly discuss quality of life, with specific reference to children with cerebal palsy and their caregivers.

Quality of life (QoL)

In an attempt to empirically quantify harm, Brown and Brown (2003:28) formulated a three-level framework[2] for quality of life. The practical value of this framework lies in its universal application, placing all aspects of the lives of all individuals everywhere into it. The first level relates to attaining the most basic requirements of life. The second level has to do with experiencing satisfaction with aspects of life that are important to the specific individual and the third concerns enjoying high levels of personal enjoyment and fulfilment. This framework mandates that the basic needs of individuals on level one should be met before moving to levels two and three. Jon Perry (2005:57) highlights the complexity and elusiveness of the concept of quality of life, admitting that although it is a sensible structure, one still has to resort to a multi-level constellation to explain QoL as simply as possible.

Gilson et al. (2014:1134-1140), in a wide-ranging article, emphasise that the capability to assess the quality of life of children with cerebral palsy allows for the evaluation of individual care plans, service provision, and intervention policies. The article is intended to serve as a guide to clinicians and researchers to use quality of life measures as a modus for influencing and providing for the specific needs of these children. Quality of life issues of children with cerebral palsy in a resource-

[2] A model of QoL (Brown & Brown 2003):
Being: Physical being; Psychological being. Spiritual being
Belonging: Physical belonging. Social belonging. Community belonging
Becoming : Practical becoming. Leisure becoming. Growth becoming.

limited environment mostly revolves around accessing the most basic requirements of human existence, such as running water and sanitation.

Establishing a person's quality of life requires weighing liabilities and impairments of whatever nature against the ability to find enjoyment at various levels of existence despite drawbacks and obstacles. In this way, it is possible to gauge the quality of the life of a specific individual. Various frameworks have been formulated of which the quality-adjusted life years (QALY) is the preferred method in the medical field. In the early 1990s, a desire for the advance of a method that identifies health outcome measures led to the disability-adjusted life year assessment (DALY). Assessment of disease burden is of primary importance in cerebral palsy where spasticity, resulting in loss of function and mobility, are dominant factors in the degradation of the quality of life. Actual DALY calculations may be relatively complicated, while the quality of life statistics for QALY calculations prove to be more flexible and detailed. This serves to adapt to improving or worsening health status changes over time (Sassi 2006:402).

Quality of life (QoL) considerations in cerebral palsy

Children with cerebral palsy suffer from two dominant forms of the condition, which will be discussed below.

Spastic cerebral palsy

As the dominant injury in the prolonged partial hypoxic ischemic injury involves white matter (neuronal axons), spastic hemi- or quadriparesis is the most often encountered form of the condition. Spasticity is the result of constant stimulation of the peripheral effector organ (muscle). Briefly, an electrical stimulus that is generated by a nerve cell in the motor cortex of the brain is carried by an upper motor neuron fibre (conduit) to a lower motor neuron in the spinal cord. From the lower motor neuron, a lower motor neuron fibre (conduit) runs in a peripheral nerve to the effector organ (muscle) to contract. In this circuit, the upper motor neuron

exerts inhibitory modulation on the lower motor neuron, preventing excess stimulation (spasm) of the effector organ. In spastic cerebral palsy, the upper motor neuron fibres (white matter fibres) are destroyed, and the inhibitory modulation on the lower motor neuron is lost. This leads to uninhibited stimulation of the effector organ by an “out of control” lower motor neuron. The result is a severe, consistent spasm of muscles. If it involves all four limbs of an affected child, it is termed spastic quadriparesis. If one side of the body only is involved, it is referred to as spastic hemiparesis.

Dyskinetic cerebral palsy

This type of cerebral palsy involves abnormal involuntary movements. It is divided into two types of movement problems, namely dystonia and athetosis. Dystonia refers to sustained muscle contractions that frequently cause twisting or repetitive movements, or abnormal postures. Athetosis is the additional uncontrolled movements that occur mainly in the arms, hands, and feet, as well as around the mouth. This type is closely associated with the acute, profound injury of the deep grey nuclei, which is not the subject of this discussion.

Impact of cerebral palsy

The severity of the condition determines the impact on the child and the carers. With near-complete destruction of the cerebral hemispheres, life may revert to the reptilian level of existence where the child essentially functions at impulse-reflex level. Under these conditions, cerebral palsy can have profound effects on every aspect of the lives of the parents or carers. Children with lesser degrees of cerebral palsy need to contend with a wide range of disability. Dominant is the issue of spasticity that results in muscle weakness and mobility impediments. These children often suffer different forms of epilepsy; they are emotionally unstable and often present with behavioural problems. This brief assessment underscores the fact that the establishment of quality of life in these children is essential in providing

a wide-ranging, subjective estimation of their well-being across several domains of life in order to plan and execute support and rehabilitation.

Data in a Statistics SA report on disabilities from the Census 2011 survey provide statistical information relating to the prevalence of disability in the broadest context. Unfortunately, cerebral palsy is not reported as an entity but concealed by profiling specific functional domains and the disability index. Statistics South Africa continues to disregard cerebral palsy as an entity, contrary to the international statistical practice in which the prevalence of the condition is adequately addressed. An example of the South African approach underscores the futility of the exercise in gaining a definitive picture of cerebral palsy as an entity:

> The national disability prevalence rate is 7,5% in South Africa. Disability is more prevalent among females compared to males (8,3% and 6,5%, respectively). Persons with disabilities increase with age; more than half (53,2%) of persons aged 85+ reported having a disability. The prevalence of a specific type of disability shows that 11% of persons aged five years and older had seeing difficulties, 4,2% had cognitive difficulties (remembering/concentrating), 3,6% had hearing difficulties, and about 2% had communication, self-care, and walking difficulties. Persons with severe disabilities experience difficulty in accessing education and employment opportunities. There were also disparities in terms of access to assistive devices across population groups and geography (Statistics South Africa, 2011).

In contrast to this approach, there has been a determined quest in international research to identify the applicable assessment of the quality of life in cerebral palsy to be able to comprehend the effect of the condition on a child's inclusive existence. In this process, scientific data acquired guides the entire remedial approach (Gilson et al., 2014). The need for children to self-report has been emphasised but is accepted that there will always be an element of subjective bias due to the inability of many children to communicate effectively.

A search for a similar integrated and holistic approach to cerebral palsy in the South African context confirms that in line with the inequality of health services alluded to the above, a relatively small percentage of the population has access to remedial and support services. Cerebral palsy associations are relatively well represented in regional and provincial centres. In major centres children are accommodated in excellent special public schools, offering a multi-disciplinary team approach to the holistic education of children that have specific barriers to learning which need to be overcome, with cerebral palsy being the dominant impairment. Nevertheless, an integrated national approach is lacking, and, as noted above, even reliable statistics of cerebral palsy as an entity are not available. Those that are not among the fortunate few disappear into obscurity in the rural heartland of South Africa. The only exercise that remains is to conceptually place a child who has cerebral palsy and spastic quadriparesis in the socio-economic environment in rural South Africa as reported by Statistics South Africa:

> Statistics South Africa has proposed three national poverty lines: an upper-bound poverty line, a lower-bound line, and a food poverty line. The food poverty line is the most severe, as people living below this level of income are unable to afford sufficient food to provide adequate nutrition. The lower poverty line is based on there being enough income for people to be adequately nourished, but only if they sacrifice other essential items. The upper poverty line is the minimum required to afford both the minimum adequate food and essential non-food items. This upper-bound poverty line should be used as the line of preference for reducing child poverty. The poverty lines were set at 2011 prices and increase each year in line with inflation. Using the headline consumer price index to inflate the poverty lines, the value of the food poverty line was equivalent to R415 per person per month in 2015, the lower line was R621 per person per month, and the upper poverty line was R965 per person per month. The child poverty rates are based on the upper poverty line, which allows for a minimum acceptable standard of living. Child poverty rates are compared for the years 2003 and 2015. The majority of young children (62%) live in

> households that fall below the upper poverty line. The highest rates of child poverty are in the Eastern Cape, Kwa-Zulu Natal, and Limpopo, where 79%, 75%, and 77% of young children respectively lived in poor households in 2015. The number and percentage of young children living in poverty had decreased since 2003 when 4.9 million (79%) young children lived in poor households (Statistics South Africa, 2019).

According to the Living Conditions Survey (2015), poverty rates are even higher than noted above. It is estimated that as much as 30% of children may suffer malnutrition as they exist below the food poverty line. Statistics South Africa (2015) also reported that young children, mostly under the age of six, live in circumstances where none of the adult caretakers (parents) can generate a basic income. While it seems impossible to establish the real quality of life conditions of children living with cerebral palsy in rural South Africa, it is essential to note that the areas mentioned in this report are those very provinces with the worst records of proven medical malpractice due to negligence during childbirth.

An interesting diversion on this theme relates to the phenomenon that in the spirit of Ubuntu, rural Black communities display collective responsibility for a disabled child. Ubuntu is an expression in the African ethical tradition. According to certain scholars, Africans view disability not as an impediment, but as part of common humanity. *Umuntu ngumuntu ngabantu* is the Zulu expression that translates into the sentiment “a person is a person through other persons” (Louw, 1998). Maria Berghs (2017) states:

> If what disablement and oppression mean in the African context ties into the ascription of a difference that is threatening common humanity, this entails that disability is also a more holistic concept than how it is understood in the Global North. If I *am* through the *otherness* and diversity of another, this does not deny feelings of ambivalence, pain, or disgust but locates them as part of the complexity and nuance of disability. It also calls into question the ascription of impairment as a disability instead of diversity. What is at issue is what individual

> moral actions or restorative politics we engage in against disablement and oppression. Examining disability history in the African context illustrates that disabled people have always been part of a visible fight for justice and rights, but that disability is still viewed as a specialised individual medical issue because of colonial and post-colonial influence.

Experiences of children with cerebral palsy in the African context

I have already alluded to the two-tier health care system in South Africa with a large subsidised public sector and a small, but very high quality, private sector. With significant funding and top specialists working in the private sector, there is a major gap between public and private health care facilities in much of the country. Cerebral palsy treatment and support in the private sector, as with most other aspects of health care, is purported to compare favourably with standards in developed countries. However, the medical and social support network for those children in the public health care system, more specifically those living in the rural districts of South Africa (remnants of the homeland policies of Apartheid South Africa), can only be assessed in an African context. In this respect, statistics indicate that the poorest rural districts in the Eastern Cape and Kwazulu-Natal, are also the same regions in which perinatal hypoxic ischemic brain injury is the highest.

In an article in The Lancet (2014:876-877), Adrian Burton provides a wide-ranging, informative survey about the fight against CP in Africa. He contrasts the causes of CP in resource-poor African settings - birth asphyxia, kernicterus, and neonatal infections of the central nervous system - with prematurity and low birth weight in the developed countries. From this statement, the logical deduction to arrive at is that many cases of CP could be prevented if the necessary resources would become available in Africa. Burton mentions, and I recall, that in February 2013, a working group of the African Child Neurology Association in Cape Town highlighted the vision of this conference as the attempt to extensively seek to gather information regarding CP throughout the continent. They endeavoured to

cultivate a holistic approach to the problem, but for this, they needed to ascertain how well-equipped different countries are to deal with CP. Delegates from 22 African nations reported that no surveillance system of at-risk babies was available in at least nine of these countries. On average, specialist services were absent, and in many instances, traditional healers were still the first point of contact for assistance. South Africa and Egypt were the only countries with guidelines for managing the condition, although, in some countries, physiotherapy was available. Despite a few being able to offer occupational, speech, or language therapy, most could not provide any orthopedic support. South Africa, the most developed of the nations represented in the working group, encountered similar obstacles and a huge burden in the rural areas of post-Apartheid South Africa. Supportive services outside the major cities are minimal, mainly as a result of inadequate staffing capacity and training for even the most basic services, let alone the multidisciplinary services envisaged. Delegates departed the meeting in agreement that further research and more information were needed to clarify etiologies and outcomes. Two years later, the results were as follows: In Botswana, basic research projects confirmed that the most common etiologies were as expected, perinatal hypoxia at 28% was dominant, followed by prematurity (21%), postnatal infections(15%), and prenatal TORCH [toxoplasmosis, rubella, cytomegalovirus, and herpes] infections (10%).

In *Perspectives on cerebral palsy in Africa,* Sandra Abdel Malik et al. (2020:175-186) stated that countries in Africa have a higher prevalence of cerebral palsy (CP) than in Western countries and emphasised the importance of environmental factors in the long-term support of individuals with CP. The information is distributed through the International Classification of Functioning, Disability, and Health (ICF); however, it was impossible to even ascertain whether this information ever reached the targeted regions. Malik (2020) set out to audit the literature pertaining to CP in African countries and how it aligns with the targets of the ICF. The results were predictably disappointing and confirmed that no support for this kind of research exists, as many other demands for limited resources overshadow

any such initiative. A telling statistic in this regard is that the WHO estimates that the African Region (excluding countries in the Eastern Mediterranean region such as Egypt and Morocco) suffers 24% of the world's disease burden while only being able to access 1% of the world's financial resources for health.

In a Master's thesis submitted in the Department of Physiotherapy at the University of the Western Cape, Janet Modenyi Thoya (2017:21-27) documents the experience of parents with children suffering from cerebral palsy residing in the Khayelitsha township outside Cape Town. It is a sobering rendition of what parents in this country experience as carers of children with spastic cerebral palsy (CP). Participants reported that health care professionals did not disclose their children's condition, and that they independently noticed their children's challenges and that they were not developing as other children would typically do. It is imperative to establish an early diagnosis of CP so that rehabilitation management can be timeously instituted as it can significantly impact the developmental progress of the child. Making a definitive diagnosis of cerebral palsy requires a systematic approach of a multidisciplinary team which is tasked with establishing features of delayed developmental milestones, the full range of neurological deficits, and a psychological assessment. Delays in effecting a definitive diagnosis increased the parent's mistrust and dissatisfaction with the medical service provided, as well as aggravated their "hopelessness and anger" (Ashwal et al., 2004:255).

Thoya (2017) outlines a range of emotional challenges experienced by caregivers. Symptoms of depression were accompanied by emotions such as regret, sorrow, self-pity, devastation, and loneliness. Emotional fluctuations ranged from blaming themselves for their children's disabilities to insecurity of what the future holds for them and their children. Parents were sensitive to other members of the community's responses and comments towards their children, and this caused them pain and embarrassment. In some instances, the perceptions were so strong that they refused to entrust other people with their children, fearing for their safety.

In a wide-ranging review of paediatric cerebral palsy in Africa, Donald et al. (2014:30-34) confirmed the limited reporting of information concerning the condition in the African context and ascribed this in part to the fact that the term cerebral palsy (CP) is employed as an all-embracing concept, which include many different etiologies and associated conditions such as epilepsy, intellectual compromise, sensory disorders, and behavioural problems. These authors also remark that very little has been reported on this condition in the African context. Confirmation of under-reporting of CP in many African communities raises the concern that the condition is presumed to be considerably higher than the projected 2-2.5 per 1000 births in Western-developed countries. These divergences are often attributed to methodological variations in the way these studies were conducted, but despite many explanations and justifications, the objective reader can come to no other conclusion that perinatal complications such as birth asphyxia are the main reasons why the numbers are substantially higher in Africa. Available statistics referred to in this thesis, confirm the notion that a lack of information conceals major discrepancies.

Poverty was singled out as the single most destructive influence that prevent caretakers from providing the most basic needs to disabled children. In an analysis conducted by the African Child Policy Forum (2011) on the lives of children with disabilities in Africa, caregivers acknowledged that the cost of providing medical care, remedial support, and transportation were the major prohibitive factors preventing them from seeking care. On the other hand, community-based initiatives, despite not being systematically implemented, were perceived to be effective, especially in affording access to education.

Individual initiatives sometimes come to attention, such as a South African study in which an 8-week randomised controlled trial of a strength training programme showed improved mobility and body image perception (Unger et al., 2006). Other efforts mainly focused on spasticity, which represents the most debilitating constituent of loss of functionality. The cause of spasticity refers to the loss of

modulation control of the upper motor neuron on the lower motor neuron. Botulinum toxin (Botox), one of the most potent biological toxins, is a substance obtained from cultures of the bacterium *clostridium botulinum.* The toxin acts at the level of the junction between the lower motor neuron conduit and the muscle where it prevents the release of the neurotransmitter acetylcholine. By blocking the transmission of an uninhibited electrical impulse, it converts spastic paralysis into flaccid paralysis, thus relieving the unbearable spasticity that these children suffer. A report from Egypt confirmed the effective application of botulinum toxin in a selected group of children, but there is no supporting information regarding the accessibility of this treatment option in the rest of the continent. Another method of alleviating spasticity relates to musculotendinous release for spastic hips and shoulders. In another report from South Africa, the results of selective dorsal rhizotomy were reported to have relieved spasticity and were interpreted as a safe and effective long-term treatment for spasticity in CP in a resource-limited setting in South Africa (Langerak et al., 2007).

The question of the acceptability of a disabled child by a rural African community is controversial and presumably varies between different regions and cultures on the continent. Donald et al. (2014) refer to the potential of stigmatisation of disabled children to the extent that children being "hidden" as not to draw attention when medical attention is not considered essential. The suggestion that families with children with disabilities are excluded from their communities because of stigmatisation is controversial and contrary to communication by other scholars (Louw, 1998). As previously noted, Maria Berghs (2017), for example, argues that in the spirit of Ubuntu, rural Black communities (especially amongst the Zulu in the heartland of KwaZulu-Natal) display a collective responsibility for a disabled child.

Similar to the views of Donald et al. (2014), I also assert that birth asphyxia due to recurring systemic professional negligence is the most prevalent root cause of CP. Other causes include central nervous system infections, kernicterus, prematurity, and low birthweight in descending order. Ironically, the reason for these conditions

apparently being smaller contributors to CP in Africa may lie in the relatively poor survival rate among these infants. Another issue that I criticised in the introduction of this thesis relates to the tendency of using CP terminology in the African context to describe all mobility dysfunction and even to equate it with birth asphyxia in general. These inapplicable interpretations of the condition render it impossible to acquire reliable data, which leads to the inability to formulate a structured, focused, and resilient screening programme for identifying developmental disabilities of CP amongst infants and preschool children on the continent.

In the private health care environment in South Africa, there is direct access to pediatricians and multidisciplinary support teams. The same does not necessarily hold for families that can afford privately funded health care in other countries. Despite having access to screening programmes, there is no standardised strategy that would ensure a holistic approach for referral or intervention. Isolated initiatives by a combination of non-governmental organisation-driven and government-subsidised community programmes have emerged in some countries. In this regard, there seems to be general agreement that at least some support can be forthcoming by the use of adaptable low-cost materials, extending the reach of community health care workers, and actively assisting the development of parent support groups. Finally, and not without a substantial measure of skepticism, one may suggest (and hope) that multi-disciplinary outreach programmes could aid in managing CP in Africa.

Are individuals with cerebral palsy worse off than they would have been, had they not suffered a brain injury?

No two cases of cerebral palsy are exactly alike. Disabilities may range from loss of almost all capability, reverting to a reptilian form of life where functionality centres on a primitive stimulus-reflex circuit, to relatively slight physical impairment with no significant impact on day to day existence.

Spasticity remains the single most debilitating physical impairment. Mobility depends on the smooth integration of the contraction of the primary muscles, with simultaneous relaxation of the opposing groups that centre on a particular joint. Flexing the forearm requires contraction of the biceps muscle (agonist) with simultaneous relaxation of the triceps muscle (antagonist), while extending the forearm necessitates the exact reverse where the triceps is now the agonist and biceps the antagonist. In cerebral palsy, both the agonist and the antagonist are suspended in perpetual spasm. This leaves the individual completely immobile as no movement around affected joints is possible. The worst form is spastic quadriparesis, where all four limbs are involved. In contrast, in spastic hemiparesis, only the arm and leg of one side of the body are in spasm.

Total immobility of this nature mandates physical care and support around the clock. These children need to be turned hourly to prevent bedsores. They are unable to reach for water or food, and in the majority of cases, they have no control over their bladder or bowel function. Many are looked after by parents who perform these endless tasks in dwellings with no electricity or running water. Regular cleaning and washing of soiled clothing and bedding often require carrying water in buckets over long distances. I find it difficult, if not impossible, to express my views on the magnitude of these difficulties.

One may ask whether affected individuals are worse off, even if they are not totally bedridden. Do they have a reduced range of opportunities available to them because of their functional impairments, even if, to a degree, they can fend for themselves? In this regard, the situation in developed countries, which provide a solid security net around these individuals, stands in stark contrast to the total lack of social security systems in rural Africa. I have often witnessed a regular bus service collecting small cerebral palsy children on their doorsteps to transfer them to excellent remedial environments where these children receive cognitive, emotional, and physical support of the highest quality (cf. Vista Nova in Rondebosch Cape Town). I have not witnessed the situation in a small village

somewhere among the rolling hills of rural KwaZulu-Natal, but I imagine that all is quiet. So, we may want to ask what infrastructure, if any, exists here to lend support.

Assessing larger centres in the African context, one could ask whether the harm suffered is compounded by having difficulty in accessing services that could mitigate these effects. Does any infrastructure exist? Is it constrained by a lack of cultural- and language-specific validated clinical assessment tools, low literacy rates, and limited facilities for rehabilitative services and equipment? The answer to these questions was partly provided by Malik (2020). I referred to his attempt to audit the literature relating to CP in African countries and how it aligns with the targets of the ICF. The results were predictably disappointing and confirmed that no support for this kind of research exists, as many other demands for limited resources overshadow any such initiative.

Do these children feel pain? Musculoskeletal pain, the most important cause of pain in this condition, is the result of muscle shortening resulting in joint deformities that manifest in the limited summary that I provided at the end of this chapter; conclusively establish degenerative joint disease. The situation deteriorates as the individual grows older, and adult CP patients consequently suffer the most pain. It is generally accepted that pain in CP is often overlooked and inadequately treated as the level of impairment prevents sufferers from expressing the extent of the pain that they feel.

The emotional pain of patients and carers is immeasurable. I documented several accounts of emotional pain and the range of emotional challenges experienced by caregivers. The question of acceptance of these children in their communities is central to their quality of life. Isolation is their worst enemy. Are these children accepted in the communities where they survive or is stigmatisation of disabled children creating such emotional despair that they are being "hidden" from the community? From these accounts, it is understandable that individuals with

cerebral palsy and their parents are at an increased risk for developing psychiatric conditions with clear indications of an increased incidence of depression, anxiety, and mood disorders.

In this section, the *counterfactual comparative account* of harm poses the essential central question that needs to be answered: Does an event that occurs leave another person (or thing) worse off than had the event not occurred? In the context of this thesis, the question can be rephrased by asking: Are children with cerebral palsy and their parents worse off than had they not suffered prolonged partial hypoxic ischemia that manifested in this condition?

I submit that the content of Chapter Three and the limited summary that I provided at the end of this chapter conclusively prove the immense harm that individuals that are cerebral palsied and their relatives suffer in the context of a drastic reduction in the quality of all lives concerned. The irony and tragedy that accompany this entity stem from the fact that in most cases, these atrocious consequences were easily preventable by timeously and diligently identifying an impending obstetrical emergency that can be terminated by removing a child at risk from an anoxic intrauterine environment by caesarean section.

Conclusion

This chapter included the formulation of a definition of harm, namely the setting back of the interests of persons. In the case of children with cerebral palsy, the obvious questions that arise include: What is the extent of the harm that they and their carers suffer? And, which factors, according to the counterfactual comparative account of harm, renders them worse off? Therefore, what is their situation now, compared to what they would have been, had the events that caused them to suffer brain damage with resultant cerebral palsy not occurred?

I believe that the content of Chapter Three leaves no reservations about the devastating effects that this readily preventable condition has on the individual and the nearest relatives. The attitude of different communities towards this form of disability was briefly touched on, but a wider discussion remains. What are the consequences on the loss of income, economic productivity, and in the widest sense, the burden on society as a whole and the South African taxpayer in particular?

I reiterate, most of these catastrophes are preventable, which implies that the consequences are directly linked to a failure of providing the required care and monitoring during the birth process. Appropriate recording of the features of a decline in the fetal well-being and an increase in fetal distress, defines the time at which surgical intervention becomes mandatory to release the fetus from a toxic environment. Timeously transferring the child to an incubator will prevent prolonged partial brain damage and a life of suffering. Failure to comply with these relatively simple aims and procedures is termed negligence. Negligence is defined, examined and discussed in the next chapter.

4 Negligence

Introduction

In the previous chapter, I discussed the concept of harm and ascertained that the fundamental description relates to thwarting, defeating, or setting back the interests of some party. This version defines harm in the context of its outcome but does not precisely clarify what it is. The *counterfactual comparative account* specifies that an event is harmful when it leaves someone (or something) in a less advantageous or in a less optimal situation than what she/he (or it) would have been had that event not occurred. This definition leads to the question: What would the position have been if the child did not suffer a prolonged partial hypoxic brain injury, manifesting in spastic cerebral palsy? Is the child worse off than she/he would have been had it not happened? The question on the condition of cerebral palsied children on the African continent is only partially answered in the previous chapter, as it is perceived impossible for any observer to remotely envisage the conditions under which the children and their carers survive.

During evolution over millions of years, nature has developed a propensity to cling to life at all costs, with the autoregulatory mechanism of redistribution of blood flow in the brain being a classic example of sacrificing less eloquent areas of the brain to sustain active, vital centres of life. I submit in this discussion that the prolonged partial injury does not occur without accompanying severe and deteriorating fetal distress. Hospitals and clinics that provide obstetrical services that are adequately equipped to perform caesarean sections are expected to identify fetal distress and to act upon it according to reasonable professional standards. In this chapter, I argue that failure to implement a defined strategy to release an infant from a toxic intrauterine environment by caesarean section before brain damage occurs is synonymous with negligence. I will discuss two forms of negligence, namely professional negligence and systemic negligence. Also, I will show how prolonged partial injuries are the result of both of these kinds of negligence in the South African context.

Negligence: an ethical appraisal

Annette Baier (2007:137) observed that “virtues are personal traits that contribute to a good climate of trust between people; when trust is taken to be an acceptance of being, to some degree and in some respects, in another’s power. The virtues applicable to health professionals include compassion, discernment, trustworthiness, integrity, and conscientiousness (Beauchamp & Childress, 2013:37). These virtues are central in caring, which is the dominant defining virtue in health care. These virtues also provide an ethical roadmap for health professionals. The ethical issue under discussion relates specifically to trustworthiness and conscientiousness. A failure on these two fronts is implicit in the concept of negligence.

As noted in the previous chapter, non-maleficence is a moral principle related to both harm and injury (Beauchamp & Childress, 2013:153), and obligates humans to abstain from causing harm to others. For Sharpe and Faden (1998), the literature on iatrogenic illness[3] is “replete with references to the Hippocratic injunction against harming patients”. The “cardinal tenet of medicine”, according to Kane (1980), is *primum non nocere*. Ferguson (1989) asserts that “the sense of non-maleficence dates back to the oath of Hippocrates, which is encapsulated in our quintessential maxim, namely, first to do no harm”. Beauchamp and Childress (2013:150) affirm that in medical ethics, “the principle of non-maleficence has been treated as effectively identical to the celebrated maxim *Primum non nocere*, or rather, above all, do no harm." Not inflicting harm is not the only obligation of non-maleficence, which also obligates one to avoid the imposition of the risks of harm.

Furthermore, intent takes a central position in law and ethics, which translates into the fact that a person can harm or place another at risk without malicious or harmful intent. Under these circumstances, the agent of harm may or may not be morally

[3] An iatrogenic disorder occurs when the harmful effects of the therapeutic or diagnostic regimen cause pathology independent of the condition for which the regimen is advised

or legally responsible for the harm. It is even possible for some agents to be causally liable for the harm that they did not intend or know about.

Negligence is the absence of due care (Beauchamp & Childress, 2013:145,155). Put differently, it constitutes a departure from the standard of due care in specific circumstances. According to the authors, the term “negligence” encompasses two types of situations:

i) Advertent negligence or recklessness: intentionally imposing risks of harm. An agent knowingly imposes an unwarranted risk.

ii) Inadvertent negligence: imposing risks without realising the consequence. This could be seen as unintentional but careless imposition of risks of harm. A harmful act is performed without the person involved realising that he or she should have known to have avoided it.

Morally speaking, both types of negligence are morally unacceptable, although under certain situations, mitigating circumstances may exist. Support for this statement emanates from an essay in the field of legal philosophy by Hart (2008:43-55), which focuses on the criminal law of most countries:

> The idea of intention is one of the principal determinants both of liability to punishment and its severity. All advanced penal systems make liability to punishment for serious crime dependent on what the person to be punished did in terms of the outward act of a crime, as well as a specific state or frame of mind or will in which he did it. These mental or intellectual elements are countless and vary and are collected together in the terminology of English jurists under the simple-sounding description of *mens rea*, a guilty mind. The most prominent, if not also the most important of these mental elements, is a person’s intention.

In appraising negligence, it is necessary to identify the action that is perceived to be below a standard of care that law or morality institutes to protect the public from

the careless and unnecessary imposition of risks. In the legal scenario, the plaintiff seeks compensation for impediments to interests or punishment for harm inflicted. Courts regulate the responsibility and liability for harm, and the legal example can be used at a significant advantage by adapting legal principles to express moral responsibility. This is of particular assistance in the assessment of evaluating the extent of harm inflicted by health care professionals.

In an article in the Legal Dictionary (2017), the term “due care” refers to a particular standard of responsibility that is expected from an individual in any particular circumstance. Responsibility, on the other hand, refers to a specific obligation. This defined obligation renders an individual accountable to remain an honourable member of a group or community. Due care and negligence are intertwined; negligence can be defined in terms of the failure or inability of a person to practice due care in a particular situation, and thus the failure to act as another reasonable person would have.

Professional malpractice is a prime example of negligent failure to adhere to professional standards of care. Qualifying as a medical doctor and swearing an oath to the profession, a person accepts the responsibility to uphold the standards and values unique to this profession. If their conduct falls below these standards, they are perceived to have acted negligently. If any therapeutic actions or interventions turn out to be ineffective or counterproductive, it does not necessarily amount to malpractice. Malpractice occurs only if health care workers do not meet professional standards of care (Beauchamp & Childress, 2015:158).

Systemic negligence

Thus far, the discussion has centred on negligence as a lapse of a specific professional duty by a health care worker or a medical facility. Negligence in the context of entire health care systems, known as systemic negligence, has also been highlighted and scrutinised by Chhanda Chakraborti (2015:208-213).

Systemic negligence is not only a miscellaneous collection of stray incidents of medical errors and system failures in a health system but a more pervasive kind of neglect. One of the hallmarks that is recognised is a lack of social and political will in certain countries that contributes to a form of systemic negligence in a national health system that immediately brings the analysis of the South African Health System in the introduction of this thesis into focus.

Ethical implications exist in both the concepts of patient safety and the improvement of health care delivery. Universal values guide our considerations about protecting patients from preventable harm in the practice of health care services, the overriding motivation being to provide them with safe and quality care. Chakraborti (2015) emphasises the importance of recognising and comprehending those issues or influences that create barriers to achieving these goals. The dominant drive is the need to recognise and address systemic negligence in the same way as individual professional negligence, as another compelling prevention strategy, more so in the weaker health systems in developing countries. Chakraboti also stresses the fact that this more veiled form of negligence is not only a potent health system obstruction, but a constant and serious threat to patient safety.

Chakraborti (2015) further emphasises the need to understand systemic negligence in the context of health provision. The hidden danger is that it could occur in a much larger context, and many more individuals can be involved than would be the case under the general understanding of negligence. It is not only an assortment of sporadic cases of medical errors and neglect by individual entities, but it is rather a more sinister, pervasively negligent deterioration in the general conduct of health provision. One of the more disconcerting features of this form of negligence is that it is not possible to point the finger at individuals. It is a lack of “due care,” which seems to be “faceless” in the sense that no one in particular but everyone individually in their own peculiar way acts negligently by omission or

commission. It stalks without clear identification as no premeditated actions are identifiable. Still, the fact is that this is not always wilful or intentional, but its dogged regularity of occurrence forces one to admit that it is not entirely innocent and accidental. Also, if it is detached from individual action, it does not make it less contemptible, but rather requires more vigilance and persistent, determined involvement to eradicate it from a health system. Another feature that is not in doubt is that systemic negligence is a much larger concern in developing countries than in the developed world as the incidents are numerous and the consequences less conspicuous even in the weaker public health systems than in the private health sector. In South Africa, for example, various medical and non-medical factors worsen the entire situation, indicating system-level negligence in fulfilling certain core public health obligations. Bureaucratic decision-making processes are infested with corrupt intentions, which leads to money wasted on projects that do not bring tangible benefits to those who require it most. It is this kind of negligence and a rampant bureaucratic hierarchy which is known as systemic negligence.

An exposition of negligence in South African state institutions relating to hypoxic ischemic injury of the fetal brain during the perinatal period

The following article by Mark Heywood appeared in the Daily Maverick of 21 August 2019. It is thought to realistically and fairly reflect the stories that numerous women relate in affidavits regarding their treatment in South African state maternity institutions.

> Somewhere in the OR Tambo District of the Eastern Cape lives a mother and her soon to be a six-year-old child. We do not know their real names. In a recent judgement handed down by the Supreme Court of Appeal, they were known only as AN and EN. However, let me tell you a little about their story. On 2 October 2013, AN arrived at All Saints Hospital in Engcobo to give birth to her first child. Fortunately, her pregnancy had been an uneventful and healthy one. The delivery was expected to be uncomplicated. However, her good fortune had run out. AN was admitted to the hospital and then left in labour for 12 hours.

> During the night, nurses ignored her cries for help. The standard guidelines on delivery were ignored. This is how Judge Mahube Molemela described what happened (I quote it at length for reasons that will be understood later): "… after her admission to the hospital, she was taken to the labour ward. The nurse who attended to her performed a few vaginal examinations but did not monitor the fetal heart rate at any stage. During the night, she experienced excruciating pain that rendered her unable to walk, as a result of which she had to crawl whenever she had to go to the toilet. As there was no staff member at the nurse's station closest to her ward, she received assistance from fellow patients whenever she had to go to the toilet. According to her evidence, at some point, she requested that a caesarean section be performed, seemingly because of the severe pain she was experiencing. The attendant nurse dismissed her request. At 06h00, a vaginal examination was done, after which the appellant was moved to the delivery room. This examination, too, was not accompanied by the monitoring of the fetal heart rate. According to the appellant, after examining her, the nurse told her that the baby was about to make its arrival and instructed her to start pushing. The nurse in question then left the ward and never returned. The appellant was left unattended until a member of the cleaning staff, who happened to be passing by, raised the alarm after noticing that the baby's head was partially out but seemed stuck in the vaginal opening. In response to the cleaning lady's call for help, a nurse came to the scene and delivered the baby." But it was too late. The damage was done. EN suffered severe brain damage during birth, described as a hypoxic-ischemic insult. Today she lives with cerebral palsy.

South African children die or are physically and cognitively permanently impaired during birth due to a recurring pattern of systemic professional negligence. The article in The Daily Maverick is not unusual; it is the story that recurs over and over in sworn affidavits from mothers that have been subjected to professional standards in labour wards in South African state institutions. This article brought a single case to public attention. The current study relates to the thousands that are never heard of where nursing staff failed in every aspect to adhere to the principle

of non-maleficence. If negligence is the absence of due care, then this is advertent negligence or recklessness in its worst form. In the scenario sketched in the article, an agent or agents knowingly and intentionally impose unwarranted risks of harm. Negligence needs to be appraised by identifying professional conduct that does not equate or falls below a standard of care that has been defined in legal and moral standards with the specific intention of protecting citizens and members of communities from the unnecessary and careless imposition of risks. The rendition presented in the article represents an action that is much worse than falling below a standard of care; it is a cynical disregard of human dignity.

Thus, for the reprehensible dereliction of duty, child EN would not have lived in a state of spastic quadriparesis. AN and her husband would not have been burdened with a child that requires full-time care. The community would not have been burdened to accommodate this near hopeless situation in an environment without a supporting social security network, and South African taxpayers would not have been compelled to pay millions in compensation. The term proximate cause suggests that consequences can be foreseen. It intends to protect a person for being accused of negligence in the case of unpredictable outcomes that can result from his or her actions or non-actions. The injuries that follow the prolonged partial injury are as predictable as clockwork.

Lastly, to win a negligence claim, there must be damages or injuries involved. This study is limited to cases of prolonged partial hypoxic ischemic injury with intent. It has been shown that prior to developing irreversible brain damage, a state of fetal distress sets in. Abnormal fetal heart rate and decelerations that do not return to normal after a uterine contraction are clear indicators of distress. At certain defined *alert* and *action* lines on the partogram, the need for a caesarean section becomes mandatory. It is a premise of this thesis that in this situation, a failure to respond and to alert an obstetrician timeously that a potential obstetrical emergency is pending implies the negligent failure of duty.

In assessing the underlying factors that result in a definitive pattern of systemic negligence, one cannot escape the fact that the moral attitude prevalent in the higher echelons of South African state institutions has a dominant influence. To illustrate and underscore this statement, it is essential to briefly recall an incident that has been labelled "the greatest cause of human rights violation in democratic South Africa" (News24, 2017). In the final report regarding the circumstances surrounding the deaths of 144 mentally ill patients in the Gauteng province, Professor Malegapuru Makgoba, Health Ombudsman of the Republic of South Africa (2018), established the following: The Gauteng Department of Health decided to terminate a contract with Life Esidimeni around October 2015. The motivation was based on financial considerations and also concerned an initiative referred to as deinstitutionalising psychiatric patients. This process was clearly not well thought through, but nevertheless, around 1300 patients were relocated to different entities that included families, certain unlicensed non-governmental organisations (NGOs), and an array of smaller hospitals. Some witnesses described the process as total chaos. Objections started being voiced in September 2016 when the Head of Gauteng Health, Qedani Mahlangu, announced the death of several of the translocated patients. Subsequent evidence revealed several efforts to convince the health department to reverse the decisions of translocating patients to NGOs unqualified to deliver the specialised care that psychiatric patients require. The warnings were ignored, and there were situations of intentionally even misleading the courts. By late 2017 the full extent of the catastrophe became apparent. Even then, there were attempts to conceal the extent of the disaster. Post-mortem examinations had been conducted on only 26 of a much larger number of individuals who had succumbed. Many death certificates indicated that patients died of natural causes, although in some instances, hypothermia and dehydration were listed. Patients were reported to have been seen naked, and some froze to death. There has up to now been only minor consequences. Substantial amounts of money were awarded to the families in March 2018 by arbitrator Dikgang Moseneke, Deputy Chief Justice of South Africa. However, in December 2018, several hundred families reported that they

had not yet received any payments. I argue that the prevalence of HII in the South African context, as documented in this thesis, may, similarly to the Life Esidimeni case, indicate systemic negligence in the state healthcare system

Conclusion

In this chapter, I presented an ethical appraisal of the concept of negligence that, in the medical context, implies a lack of due care. The principle of non-maleficence rests on the maxim to do no harm, and is defined in terms of not causing injury or harm to another person. Prolonged partial hypoxic injury, occurring in any institution equipped to perform a caesarean section, implies negligence and, in turn, results in massive harm to the child, the parents, communities, and the country at large. Systemic negligence in the South African context is at the heart of the problem. It is pervasive and "faceless" and yet it is everywhere, including the higher echelons of the State. During the birth process, and more specifically the first stage of labour the fetus is at the mercy of health care workers who should be competent and conscientious in monitoring for fetal distress. They should initiate a deliberation to surgically remove the fetus from an anoxic intrauterine environment. These considerations are carried into the next chapter where I will inquire whether the fetus at this stage of development, possesses the moral status to be protected under the law of the land.

A brief survey of different theories of moral status will provide a background for the discussion of a moral cut-off point of fetal development, after which the mother-fetus relationship drastically changes. The fetus continues to develop in-utero but has unquestionably acquired the capability to survive on its own. With this critical developmental leap, the individual, in the context of the articulations in this thesis, should also acquire the concomitant moral status to be fully acknowledged as a juristic person under the law of the country.

5 Moral Status

Introduction

In an attempt to develop a framework for an accurate account of moral accountability, I need to understand the moral status of an unborn fetus at an advanced stage of development in the context of the South African Constitution. In this chapter, I will argue that there is a logical inconsistency in making a distinction between the moral status of the same individual at the same level of neurocognitive development during and after the process of childbirth. This same individual, having passed through the birth canal, is afforded full rights under the constitution of South Africa and is recognised as a natural juristic person under the law of the country. The individual, once born, is entitled to an environment that is not harmful to health or well-being in accordance with the constitution. However, a short while earlier, (mostly under an hour), the same individual in the intrauterine environment has a significantly restricted moral status under the Choice on Termination of Pregnancy Act. This act takes a graduated approach to abortion, allowing late abortion only under very specific conditions that indicate some implicit recognition that the fetus gradually increases in moral status as the pregnancy progresses, even if this does not qualify them as having the same (full) moral status as an individual once born. This restricted moral status still bars the unborn fetus from protected rights under the Bill of Rights to an intrauterine environment that is not harmful to health or well-being. To explore this inconsistency further, I will briefly discuss various theories of moral status before arguing in favour of separation-survivability as a logically defensible account of when the fetus should acquire full moral status.

Theories of moral status

Beauchamp and Childress (2013:62) explored why obligations are owed to specific individuals and why certain individuals have rights and others not. Law has instated the term moral status into ethics. Moral status refers to a particular level of moral prominence. On the other hand, moral status refers to having rights or the

functional equivalent of rights. To have moral status entitles the owner to deserve at least some of the securities secured by moral norms. This includes values, laws, and rights. Only if individuals can be morally wronged, are they perceived to be entitled to these protections. For an entity to count in its own right, qualifies that entity as a direct moral object entitled to rights and protection. Beauchamp and Childress (2013:65-90) present five theories of moral status, which collectively provide a general framework. Each theory presents a believable viewpoint on a moral status that qualifies for consideration, but no theory in isolation can stand alone. The first theory holds that only the unique properties that belong to humans (i.e., the species Homo sapiens) qualify for moral status. The second theory revolves around a specific collection of cognitive properties. Moral agency defines the third theory, and sentience - consciousness in the form of feeling, especially the capacity to feel pain - forms the basis of the fourth theory. A fifth and final theory assesses relational conduct, suggesting that relationships that establish roles and obligations define moral status.

Theory based on human properties

The theory based on human properties holds that only distinctive properties of Homo sapiens confer moral status; all humans, and only humans, have moral status. An individual has moral status only if human parents conceived that individual and if it is an organism with a human genetic code. In an article on the moral status of the human embryo, Robert George (2005:202) quotes a concise statement regarding the human fetus by two members of the President's Council on Bioethics (2001-2009):

> Fertilisation produces a new and complete, though immature human organism. The same is true of a successful cloning. Cloned embryos, therefore, ought to be treated as having the same moral status as other human embryos. A human embryo is then a whole living member of the species Homo sapiens in the earliest stage. Human embryos possess the epigenetic primordia for self-directed growth into adulthood - We were then, as we are now, distinct and

> complete. To deny that embryonic human beings deserve full respect, one must suppose that not every whole living human being is deserving of full respect. To do that, one must hold that those human beings that deserve full respect deserve it not in virtue of the kind of entity they are, but rather in virtue of some acquired characteristic that some human beings have, and others do not, and which some human beings have in higher the degree than others … [Even embryos] are quite unlike cats and dogs … Like humans, they are members of a natural kind – the human species. Since human beings are intrinsically valuable and deserving of full moral respect in virtue of what they are, it follows that they are intrinsically valuable from the point at which they come into being.

Patrick Lee (1990:81) further argues the standpoint that the inception of the human embryo or development of the fetus from conception onwards, does have a complete moral standing and a right to life:

> Why someone might object, should having the same potentiality as adult humans give embryos, fetuses, and infants the same moral status as adults? Shouldn't what a thing *does* actually count more than what it has the potentiality for? Why should we be concerned so much with potentiality? The answer - and I think it is a very important point for this whole controversy - is that our actions, our choices, primarily bear upon potentialities, on what can or could be. If I kill someone, I do not, strictly speaking, take away from them their actuality. It is too late to deprive them of what they have been or what they are. My action, rather, deprives them of what they could have been; it brings it about that they will never actualise their possibilities. In other words, it is too late to deprive them of their past or present; if I kill them, what I deprive them of is their future. And so, our actions and our choices bear primarily upon potentialities. Therefore, killing an unborn child is, in this respect, worse than killing an adult, because it robs from him or her more of his or her life.

Peter Singer (2002:188) opposes arguments that suggest a zygote or early human embryo has a right to life on the assumption that it is an innocent human being. Placing Singer's arguments into the appropriate context requires scrutiny of his

perspective on "potentiality" as related to the beginning of human life. The point he makes is whether there is any difference between the "potential" of the human embryo and the “potential" of the egg and sperm when still separate (2002:198). He concludes that the embryo lacks the capacity which confers moral status.

> The early embryo is not a being with the mental qualities that generally distinguish members of our species from other species. The early embryo has no brain, no nervous system. It is reasonable to assume that, so far as mental life goes, it has no more awareness than a lettuce (Singer, 2002:194).

Speciesism is Singer's main objection to treating human and non-human animals differently on the perception that one is viewed to be superior to the other; only on the basis that they are a member of the species Homo sapiens. Arguing the point of race being nearly always irrelevant to how a person is treated, the species of a being should also be irrelevant.

Theorists construct their theories in such a way that what constitutes a person refers precisely to the entities that they advocate for, thus judging these entities as persons and other entities not. This first theory of moral status seems salvageable if human biological properties, as well as distinctive human psychological properties, such as awareness, cognition, motivation, intention, volition, and action, are included. However, the properties of humanity decidedly form a basis of moral status and provide the foundation of the claim to human rights. The suggestion that some combination of human properties is a sufficient but not a necessary condition of moral status is in this, as in other instances, an acceptable stance.

Cognitive theory of moral status

This theory sets a specific set of cognitive properties as essential requirements for moral status. The basic illustration for these properties is the competent human adult. Individuals have moral status because they can make contextual sense of

their environment. They earn moral status because they can reflect on life and death and, unlike incompetent humans and non-humans, are self-determined by their beliefs.

The question can rightly be asked: Why do cognitive properties determine anything about moral status? The alternative question would be: If a fetus lacks cognitive properties, why should moral status and moral protection be absent? The answer seems to lie in the fact that most theories that focus on cognitive capacities explain why cognitive properties are relevant for moral status as they give one the capacity to have interests (which can then be set back or advanced) or the capacity to value one's own life.

Theory of moral agency

The premise of the theory of moral agency lies in moral status being derived from the capacity to act as a moral agent. The condition of a moral agent is satisfied if i) A person can judge from a moral perspective if a certain action is right or wrong; the individual is capable of making moral judgements about the rightness or wrongness of actions, ii) A person's motivations can be subjected to moral scrutiny. This occurs if, and only if, one knowingly governs oneself following universally valid moral principles. This governance provides the individual with intrinsic worth or dignity, which finds expression in actions as an autonomous agent. Being a moral agent is undeniably a sufficient condition of moral status, and moral agents are paradigmatic bearers of moral status. If the notion holds that being a moral agent is a necessary condition to attain moral status, then many humans who enjoy the protection which moral status affords will be stripped thereof. The same applies to the unborn fetus who, during the first stage of labour in an in-utero environment, would lack moral status despite an undisputed potential to qualify as a moral agent. The theory of moral agency as a condition of moral status, is therefore counterintuitive. The argument that there is a definite need for a morally appropriate response to vulnerable parties such as the unborn fetus who need

special protection should not be whether they are moral agents, at least as the primary consideration in assessing their moral status.

Theory of sentience

Sentience is defined as consciousness in the form of feeling, especially the capacity to feel pain or pleasure and to suffer, compared to consciousness as perception or thought. This fourth theory, based on a consciousness of pain or suffering, is explained by Jeremy Bentham's famous statement: *The question is not, Can they reason? Nor can they talk? But can they suffer?* (Burns & Hart, 1996:283).

The central gist of the argument has a clear utilitarian foundation that pain is perceived to be evil, and pleasure in the widest sense of the word is good. The obvious conclusion is that one harms an entity when causing it pain. Thus, to cause pain to any entity is to harm it. Many beings can experience pain and suffering, and harming them is typically to wrong them. These harm causing actions are morally prohibited unless one has a morally justifiable reason. Creatures that do not possess human traits such as cognitive capability, moral sensitivity or definitive biological features experience pain and suffering. Species membership and the fact that cognitive and moral capacity is absent plays no role in whether pain exist. There is one overarching norm, and that is that pain and suffering matter. It follows logically that all creatures that can experience pain and suffering possess moral status and can be morally wronged when others cause them pain and suffering. It is thus generally accepted under this view that the capacity of sentience is not only a sufficient condition of moral status, but that it is both necessary and sufficient for moral status (2013:73).

Peter Singer (2002:119) suggests that discrimination against beings not being members of our own species, known as “speciesism”, lies at the root of opposition to sentience as a sufficient and necessary requirement for moral status. In Chapter

Three of *Practical Ethics* (1979), he suggests a reciprocal approach is indicated. If we as humans accept the principle of equality as a fundamental moral basis for relations with our own species, then we have no choice but also to accept it as a solid moral basis for relations with those that do not belong to our own species. These are the non-human animals.

> If a being suffers, there can be no moral justification for refusing to consider that suffering. No matter what the nature of the being, the principle of equality requires that its suffering be counted equally with the like suffering - in so far as rough comparisons can be made - of any other being. If a being is not capable of suffering, or of experiencing enjoyment or happiness, there is nothing to be considered. This is why the limit of sentience (using the term as a convenient, if not strictly accurate, shorthand for the capacity to suffer or experience enjoyment or happiness) is the only defensible boundary of concern for the interests of others. To mark this boundary by some characteristics like intelligence or rationality would be to mark it arbitrarily. Why not choose some other characteristic, like skin color? (Singer, 1979:57)

Theory of relationships

This theory postulates that relationships between parties account for moral status, and those relationships that specifically establish roles and obligations take a central significance. One of these relationships centres on medical needs and the provision of an acceptable standard of care. Once this specific relationship is established, the patient gains a right to care. The patient in a different situation, independent of the established relationship, is not entitled to this status, and the caregiver also has no obligation outside the relationship.

According to Strong and Anderson (1989:25-26), human fetuses and newborns develop moral status as a result of special relationships that are associated with unique bonding over time.

> The attitude that they (newborns) are persons, or at least that they should be regarded as having the same moral status as persons, is widely encountered. This attitude is reflected in the law, which regards newborns as legal persons. Similar, but perhaps less secure, intuitions are held concerning fetuses near term. We argue that a matrix of social interactions between fetus and others is usually present well before parturition. Factors contributing to this social role include the psychological attachment of parents to the fetus, as well as advances in obstetric technology that permit monitoring of the health status of the fetus and treatment or early delivery when needed. Since birth does not constitute a sharp dividing line between those with and those without a social role, there does not appear to be a morally relevant difference between infants and fetuses of sufficient degree to justify the view that infants have moral standing while fetuses near term do not.

It is not clear how determinative this theory can be made. Once fetuses are detected in-utero and examined with state-of-the-art, three-dimensional sonography, they become part of a social matrix and gain a certain measure of moral status in the process. Beauchamp and Childress (2013:78) acknowledge this, although also stating that despite its attractions, the theory based on relationships can only explain how morals status and resultant protections evolve. If taken as the sole basis for moral status, then only social bonds and unique relationships determine moral status.

The role of the relationship between parties becomes acutely accentuated during the first stage of labour when a biologically, fully developed infant becomes completely dependent on the attending obstetrical nurse. Monitoring of fetal health parameters, specifically, the fetal heart rate, and accurate documentation of the results on a partogram, is central in ensuring controlled and effective progress of the birth process. According to this theory, the fetus has a right to appropriate care.

Dependence for survival centres on this relationship as only the nurse's surveillance, integrity, trustworthiness, and conscientiousness can determine the

outcome. At this stage, the relationship between the attending nurse and the fetus guarantees the moral status of the fetus and the right to an intrauterine environment that is not harmful to health or well-being. The whole exercise intends that the nurse carries the responsibility to set in motion the process of removal of the fetus from this environment if health and safety can no longer be guaranteed.

Beauchamp and Childress (2013:79) highlight that each of the five theories has elements that merit acceptance. The problem encountered in the tendency for each theory to identify a singular property as alluded to above highlights the solitary measure of moral status. Each theory becomes unduly narrow as a general theory of moral status unless it accepts some criteria in the other four theories. They then recommend accepting the specific elements proposed in each of the first four theories as an acceptable universal criterion for moral status. That implies the criterion is sufficient but not necessary. The fifth theory should be added as another relevant dimension to these theories. The suggested implication is to isolate the outstanding features of each of the five theories and to unify these constituents into a multidimensional, coherent account of moral status.

Separation-survivability as moral cut-off point

In contrast, a well-considered and well-motivated position on the moral status of the fetus appears in an article by J.A. Malcolm de Roubaix and Anton A. van Niekerk (2005:206-223) with the title *Separation-survivability as a moral cut-off point for abortion*. They argue that “separation-survivability is a significant developmental fetal milestone beyond which abortion is only rarely and exceptionally morally justifiable”.

The hypothesis that is central to their theory is quoted verbatim as the choice of specific terminology best conveys its impact:

> The continuous nature of prenatal development and simultaneous parallel development and actuation of intrinsic and contingent potentiality eventually

> results in the development of a person capable of moral thoughts and deeds, which implies continuously incremental moral significance.

They present a sound proposal that the requirement of a "moral inquiry" or an internal dialogue should form the basis for the moral of the permissibility of each instance of non-therapeutic pre-viable termination. In defining a moderate standpoint on abortion, they contend that arguments should present with an incremental increase in power to surpass the sliding-scale increase in prenatal moral significance. They agree that sentience is morally substantial; however, they hold that survivability is vitally important since:

> human beings who have the potentiality of separate, relatively independent lives should, usually, be allowed to continue living. The logical conclusion is an argument for a moderate position on abortion (De Roubaix & Van Niekerk, 2005:206-210).

The authors summarise different viewpoints in the ongoing controversy around the status of prenatal life and abortion. Their main contribution, in my view, is the identification of a morally justifiable cut-off point for abortion, a "point in fetal development, after which it would be morally unacceptable to submit the fetus to an induced abortion that would effectively end its life" (De Roubaix & Van Niekerk, 2005:206-210).

The same argument applies to oxygen starvation of the fetus in-utero. At which cut-off point has the fetus attained a level of moral status that affords him or her the right to a healthy and stable environment? Is there a point of development at which it should, in a legal context, be afforded full human rights under the Constitution of South Africa as it would automatically attain once it has passed through the birth canal?

In my consideration of the term fetus in an intrauterine environment at the time of the first stage of labour, De Roubaix and Van Niekerk (2005) provide the answer in terms of separation-survivability as a morally significant milestone. The rationale follows that at about 25 weeks gestational age (and here I again find it necessary to quote verbatim as the specific choice of words is essential):

> the gradual development of the prenatal human being reaches the stage where it can survive separation from its mother, should it be born alive at that point. This radically alters pre-personal moral significance; with no justifiable moral basis to differentiate between a specific (normal) neonate and a specific (normal) viable fetus in the last weeks of pregnancy, these entities, the same human being, although in different phases of development, are entitled to equal treatment (De Roubaix & Van Niekerk, 2005:206-210).

The above position not only secures the moral status of the in-utero fetus but unequivocally places it on the same level as the newborn infant. Because the in-utero environment and the external environment are separated only by the birth canal, it would logically follow (in the context of the above position) that if the newborn child is entitled to an environment that is not harmful to its health or well-being under the Bill of Rights, the in-utero fetus at the same stage of physical and neurocognitive development is also entitled to an environment where there is an adequate supply of oxygen and an equal chance to enter the world in a healthy state, with his or her brain intact. The same moral prohibitions against harming his being via negligent behaviour, therefore, also hold.

The statement underscores the viewpoint that I formulate in the paragraph above that separation-survivability is a crucial “marker” concept that confirms the “actuation of a significant level of pre-personal potentiality”. Therefore, the assertion that, by the capacity to sever its umbilical bonds and by implication dependence, the pre-person becomes analogous to the neonate or infant, emphasising the implications for the moral status of the fetus during the birth

process. This renders the association between female and fetus relational prior to this point; a relation that the female can terminate at any time since the particular fetus can have no relation with any other person. At 25 weeks, the situation changes conclusively as the fetus is now no longer “locked” into this particular physical and emotional relationship and has acquired the potential to enter into relations with other subjects as it gradually becomes a subject in its own right. It remains dependent upon human care and protection, as are all neonates, infants, and toddlers, but others can assume the caring role.

This potentiality, in line with other neonates, infants, and toddlers, contains the fundamental implication of a change of moral status of the fetus in an in-utero environment. Neonates, infants, and toddlers enjoy full protection under the Bill of Rights of the South African Constitution. The infant in the intrauterine environment, having passed the morally justifiable separation-survivability cut-off point, has a significantly restricted moral status under the Choice on Termination of Pregnancy Act. Although this Act seems, at least, to signify an element of implicit recognition that the fetus gradually increases in moral status as the pregnancy progresses, this does not qualify them as having the same (full) moral status as an individual once born.

This is morally and legally unacceptable. The well-being of neonates, infants, and toddlers is protected under the law of the land, and the Bill of Rights guarantees their right to a clean, non-toxic environment. I have shown in this study the extent of harm that unborn children suffer during the first stage of labour as a result of systemic and professional negligence that fails to ensure that they are timeously removed from a toxic, oxygen-depleted intrauterine environment. This has to change. The intrinsic potency of a moral cut-off point that defines separation-survivability suggests that it should be accepted in this country, if not universally, as a marker of the arrival of a new person, guarded and protected by the full power of the law of the land.

Conclusion

In this chapter, I examined the moral status of the fetus. In line with the argument of De Roubaix and Van Niekerk (2005) that separation-survivability is a significant developmental fetal moral milestone beyond which abortion is only rarely and exceptionally morally justifiable, I submit that this milestone also marks the point at which the fetus attains personhood and acquires a moral status equal to that of the newborn infant. From a legal perspective, it is confirmed that the fetus only enjoys limited protection under the Constitution. Furthermore, the legal profession recognises that our common law must conform to the values of the Constitution and that its development must promote the "spirit, purport and objects of the Bill of Rights".

In the next chapter, tracking the fundamental goal of this study, I intend to delineate an argument in favour of the recognition of the right of the fetus to an intrauterine environment that is not detrimental to its health or well-being. I also advocate the constitutional right of the fetus to be removed from this environment, should it become toxic or anoxic during the birth process. The reasons why a healthy environment is central are explored in terms of the universal recognition of human rights under liberal constitutions in the context of the global environmental crisis.

6 The Environmental Rights Revolution

Introduction

The previous chapter encompassed a discussion about the moral status of the mature fetus at an advanced stage of biological and neurological development, identifying separation-survivability as a morally significant milestone. The rationale proposed holds that at about 25 weeks gestational age, the gradual development of the prenatal human being reaches the stage where it can survive separation from its mother if born alive. This radically changes pre-personal moral significance to the degree that I argue that the fetus should be recognised as a juristic person under the Constitution. The right to be removed from an intrauterine environment that has turned toxic or anoxic is indisputably supported by the fact that the individual can survive cutting of the umbilical cord and removal from the uterus. This (now) neonate, at 25 weeks gestational age, is perfectly equipped and capable of surviving independently in an incubator with the necessary care and support.

In this chapter, the importance of the right to a healthy environment is expounded in the context of growth in the magnitude and awareness of the global environmental crisis that has led to a universal recognition of human rights. A wave of new amended liberal constitutions has resulted in a human rights revolution. This chapter deals with a concept that is situated at the convergence of three developments – the constitutional right to live (or survive) in a healthy environment.

The Revolution

David R. Boyd (2012) explored this concept of a constitutional right to live in a healthy environment:

> In recent decades three striking and related developments have taken place around the world:

- A wave of new and amended constitutions in both emerging and established democracies.
- The human rights revolution.
- Growth in the magnitude and awareness of the global environmental crisis.

> The first of the three broad developments contributing to the constitutional right to a healthy environment is a remarkable shift toward constitutional democracy across the globe in the countries of Eastern Europe, Latin America, and Africa, and also in nations that have long traditions of parliamentary democracy. The tragic legacies of fascism, colonialism, and communism contributed to this unprecedented wave of constitution-making. More than half of the world's national constitutions have been written since the mid-1970s, and many more have been substantially overhauled (Boyd, 2012:4).

In broad terms, it can be postulated that a constitution represents the highest or supreme law in a nation. The constitution establishes the formal rules that direct and contain government powers, defining the relationships between government institutions, and most importantly, protecting individual rights both in the context of the relations between individuals, but equally important, the power relationship between citizens and the state. In the words of a leading constitutional scholar:

> A country's constitution is the set of fundamental principles that together describe the organisational framework of the state and the nature, the scope of, and the limitations on the exercise of state authority (Monahan, 2006:3).

Stotsky (2004:109) found that more than 80 nations endorsed constitutional reforms that are intended to oversee that certain powers are handed over from democratically elected establishments to judiciaries. According to Stotsky (2004), one of the outstanding and most significant political advances in democratic societies in the recent past was transferring power to the courts to annul legislation and administrative acts. He also perceived the remarkable spread of a tidal wave

of democratisation across the globe and emphasises its fundamental respect for and dependence on the rule of law and the role of the courts.

The human rights revolution is the second factor to consider briefly. In this regard the change in the political climate is captured in the communication of Mubangizi (2004:127) who compares the dispersing of men and women from the land and the withdrawal of their means of subsistence to standard instruments of the repressive exercise of power. He also views the legal status of the human right to a clean and healthy environment as currently conceived and practiced, including the inclusion of an environmental clause Section 24 in the South African Bill of Rights, as representative of an important step in the constitutional recognition and protection of human rights.

According to Michael Ignatieff (2007), rights have a double-sided relationship with democracy. Rights endorsed into law by democratically elected representatives express the will of the people. However, there are also constitutional rights, the intention of which is to protect people from the will of the majority and to define the constraints to what majorities can do. The intention, born out in practice, is that human rights and constitutionally guaranteed rights are considered to have a unique immunity from restraint by the majority. This allows them to act as a bulwark for the freedom of the vulnerable. Thus, the rights revolution has been about both the right to be equal and the protection of the right to be different. Trying to do both, that is, augmenting equality while safeguarding difference, is the essential challenge of the rights revolution.

The emergence of a global environmental crisis in the latter half of the 20th century is the third factor driving the advancement of the right to a healthy environment. It is well recorded that concerns about human impacts on nature date back centuries. It was, however, In the 1960s that pervasive public awareness of global human environmental impact emerged. This arousal was triggered by the publication of Rachel Carson's *Silent Spring* and a series of notorious and widely publicised

ecological disasters. The Torrey Canyon oil spill off the coast of England immediately comes to mind.

Humans developed into a geological force on the back of technological prowess, a consumptive appetite, and the ever-increasing drive for global economic growth. The warning signs lead some scientists to conclude that the Holocene epoch has concluded, and we have entered the "Anthropocene." A valid observation that aroused concern is that approximately 7 billion people populate the earth today, with the population expected to reach 9 billion by the middle of the century (UN Population Fund, 2002). Rockström summarises:

> Agriculture, transportation, housing, industry, consumer goods, and day to day human activities are placing an unprecedented level of pressure on natural systems of the planet. The web of life, upon which our future depends, is jeopardised by the interrelated problems of climate change, extinction, and toxic pollution (Rockström et al., 2009:472).

Boyd (2012:3) suggests that beginning in the 1970s, public recognition of worldwide environmental degradation led to the realisation that state responses had proved hopelessly inadequate. The collective perception of impending disaster stimulated constitutional changes and recourse to the powerful language of human rights. Therefore, one may ask how widespread the environmental rights revolution is in today's world, and to what degree it is affecting laws, public policies, court decisions, environmental performance, and human well-being. Boyd (2012) concludes that something extraordinary is taking place in many counties, societies, and communities all over the globe. The following description captures the significance of this development and its influence on future events:

> The constitutional right to live in a healthy environment represents a tangible embodiment of hope, an aspiration that the destructive, polluting ways of the past can be replaced by cleaner, greener societies in the future (Boyd, 2012:18).

It is clear from Boyd's account that what he describes are only small steps in the right direction. While no nation has yet achieved the final objective of ecological sustainability, all indications point to the powerful and potentially transformative effect that constitutional protection of the environment can have in the years to come.

The right to a healthy environment

Human rights are historically linked to specific historical injustices. Attempts to right these wrongs from the past manifested in trailblazing initiatives such as the *Universal Declaration of Human Rights* (1948), the *International Covenant on Civil and Political Rights* (1966), and the *International Covenant on Economic, Social and Cultural Rights* (1966). At the time of these monumental advances, human awareness of the looming disaster related to environmental degradation was not sufficiently sensitised and was thus not addressed as an entity during the era in which these accords were drafted and negotiated (Gormley, 1976).

The first stirrings of awakening to a major threat to mankind and that there should be a human right to a healthy environment came from Rachel Carson (1962):

> The Bill of Rights contains no guarantees that a citizen shall be secure against lethal poisons distributed either by private individuals or by public officials. It is surely only because our forefathers, despite their considerable wisdom and foresight, could conceive of no such problem (Carson, 1962:12-13).

Ironically, in her final public speech before dying of cancer, Carson was acknowledged to the extent that she was invited to testify before President Kennedy's Scientific Advisory Committee:

> A much-neglected problem, that of the right of the citizen to be secure in his or her own home against the intrusion of poisons applied by other persons. I speak

> not as a lawyer but as a biologist and as a human being, but I strongly feel that this is or ought to be one of the fundamental human rights (Cronin & Kennedy Jnr. 1997).

In 1972 the *Stockholm Declaration* officially recognised not only the right to a healthy environment, but defined a complimentary responsibility:

> Principle 1: Man has a fundamental right to freedom, equality, and adequate conditions of life, in an environment of a quality that permits a life of dignity and well-being, and he bears a solemn responsibility to protect and improve the environment for present and future generations.
> Principle 2: The natural resources of the earth, including the air, water, land. Flora and fauna and uniquely representative examples of natural ecosystems must be safeguarded for the benefit of present and future generations through careful planning and management as appropriate (Stockholm Declaration, 1972).

Section 24 of South Africa's Constitution echoes these universal initiatives on the environment. It provides guidance on the preservation and conservation of the country's natural resources. It also addresses the legal implications that govern economic, social, and educational issues deemed essential for protecting our biodiversity. The main focus of the South African Constitution's section on the environment is on all the inhabitants of the land. The overriding provision and the one significantly aligned to the focus of this thesis relates to the notion that all persons residing in South Africa have *a* right to an environment that is not harmful to their health or well-being.

The astuteness that accompanies this provision implies that people require an environment in good health in order for themselves to continue in good health, and forms the basis for the Constitution's position on the environment. Reality teaches that enforcing the legislation to protect the environment while simultaneously promoting the well-being of people is a strategy paved with good intentions, but it

proves exceedingly challenging in practice. The relationships between people and the environment are complicated as accountability is often lacking when it comes to enforcing obligations and responsibilities.

Regardless of criticisms, the Constitution places a duty on citizens and government institutions to take rational initiative steps to ensure that South Africans live in a sustainably developed country by protecting it from pollution in the air, water, food, or soil. While the country faces many issues relating to environmental protection, it has received several awards and global recognition, including being named one of the top 10 countries harnessing solar energy in 2014.

The fetus in the intrauterine environment

As noted throughout this thesis, the intrauterine environment has a definitive influence on pregnancy outcome. The placenta and the umbilical cord together form the only supply line of the fetus. Oxygen remains the most important requirement, but otter nutrients, hormones, and a stable equilibrium of optimal temperature and surrounding fluid volume of the uterine environment profoundly affect fetal development. Therefore, during critically sensitive periods of fetal development stable homeostasis is essential. Intermittent or fluctuating changes, as well as longer-term alterations in the intrauterine environment, could have irreversible, debilitating consequences. Oxygen supply via the placenta and umbilical cord is the most critical demand on the fetal side of life. The fetus is able to compensate for a decrease in oxygen uptake or distribution for whatever reason. When oxygen levels drop abnormally, a process of redistribution of oxygenated blood commences automatically by process of autoregulation that directs flow by way of vasoconstriction or vasodilatation. The process redistributes the flow of blood to organs to sustain survival. The heart and brain, along with the adrenal glands, receive a significant boost in blood flow, but this surge cannot be maintained indefinitely. As oxygen deprivation continues, cerebral blood flow will eventually decline, and this triggers a compensatory mechanism in the brain that

diverts flow to centres in the brainstem and diencephalon that are essential for life. There is a price to pay for every action. Rerouting blood to sustain life in the cerebral circulation ultimately results in hypoxic ischemic encephalopathy, an irreversible form of brain injury in the neocortex (human brain).

I explained the prolonged partial hypoxic ischemic brain injury in Chapter Two. In this thesis, I not only underscore the total dependence of the fetus on a stable, oxygenated, and healthy intrauterine environment but also assert that the fetus having passed the 25-week cut-off mark, acquiring the moral status of a human being that can survive independently in the process, possesses a fundamental human right to an environment in which survival and good health is guaranteed. Beyond the moral milestone of separation-survivability, this right entails that the fetus should be removed from a toxic or hypoxic intrauterine environment by caesarean section, if and when it becomes necessary. The contention focuses specifically on the first stage of labour when the fetus is completely dependent on attending professional obstetrical nursing staff for monitoring the status of the intrauterine environment indirectly, by surveying vital parameters, such as heart rate for fetal distress.

Conclusion

Against the background of endemic systemic negligence during childbirth and the inadequate response of overseeing bodies and the law to act against this systemic negligence, it becomes clear that a fetus that has developed beyond the milestone for separation-survivability survives in a precarious and insecure situation. The fundamental aim of this thesis is to seek protection for the fetus under the Bill of Rights of the Constitution. The moral milestone of separation-survivability defines the point at which the gradual development of the prenatal human being reaches the stage where it can survive independently after separation from its mother, should it have to be removed from an anoxic or toxic environment by surgical intervention. I fully support the inference that pre-personal moral significance is

radically transformed with no justifiable moral basis to differentiate between a specific (normal) neonate and a specific (normal) viable fetus in the last weeks of pregnancy. These entities, the same human being, although in different phases of development, are entitled to equal treatment and to a fundamental human right that guarantees an environment that is not detrimental to health or well-being.

In the following chapter, I present a short survey of the thesis that includes extracts from reports that serve to support views expressed, with concern, about the moral dilemmas that the country faces, and whether morality can be restored. I return to the implications of the separation-survivability theory of moral status that I view as the foundation for an argument in support of fundamental rights of a fetus beyond the 25-week cut off point of gestational development. Implicit in the separation-survivability theory is the moral status that secures the right to life. Under the same theory, based on the fetus's ability to survive separation from the mother, I would insist that the fetus has attained the moral status that entitles a right to a healthy environment and the right to be surgically removed from this environment, should it turn toxic or anoxic after 25 weeks gestation.

7 Conclusion

Introduction

Human Rights Watch (2011) published a 66-page report, entitled *Stop Making Excuses': Accountability for Maternal Health Care in South Africa.* This document revealed that while maternal mortality rates throughout Africa are falling, they rose in South Africa from 150 deaths per 100,000 births in 1998 to 625 in 2007. Criticism is specifically levelled at the quality of service available to women seeking maternity care. They insist that patients require accessible, easily understandable, effective ways to lodge complaints about mistreatment suffered while accessing health services and receiving redress. The report emphasises the critical importance of holding accountable those responsible for past violations and for preventing the recurrence of similar practices in the future.

Health Minister Dr. Aaron Motsoaledi (2018) described the increasing number of medical malpractice litigation claims, more specifically relating to hypoxic ischemic injury during childbirth in South Africa, as an "explosion". Dr. Motsoaledi laments that the compassion-based practice of medicine is being replaced by defensive medicine and mistrust. The Life Healthcare Esidimeni Scandal involved the deaths of 143 people at psychiatric facilities in the Gauteng province from causes such as starvation and neglect (see Chapter Three). I return to this incident here to accentuate a different aspect of this occurrence, which concerns the attitudes of officials involved. It is named after Life Esidimeni, the private healthcare provider from which the state removed patients. The incident has been called "the greatest cause of human rights violation" in democratic South Africa (News24, 2017). In an article in The Guardian in this regard, Kate Hodal and Robin Hammond wrote:

> In his final judgement, Moseneke found that the officials had acted unconstitutionally and had behaved, literally, as though they would "get away with murder." "The death and torture of those who died in the Life Esidimeni

> [tragedy] stemmed from arrogant and irrational use of public power," he told the hearing. Perhaps, then, it is no surprise that many family members feel like no one in power is taking what happened seriously. Not a single official has been fired (Manamela and Selbano were suspended, while Mahlangu resigned), and there are no indications that anyone will face criminal charges. Even Cyril Ramaphosa, who recently replaced Zuma as president and has vowed to combat corruption, came under fire after he was photographed meeting Mahlangu, whom he described as a “comrade” and “human being like all of us” (Hodal & Hammond, 2018).

Against this background, a reference to disciplinary action taken in the healthcare services was found in a government publication (SAnews.gov.za):

> **Pretoria** – Four nurses, who turned away a highly pregnant mother from a health centre, have been dismissed by the Gauteng Health Department following a complaint of unprofessional conduct. The expecting mother was on 16 November 2012, turned away from the Soshanguve Community Health Centre in Tshwane District, and subsequently delivered the infant on the pavement outside the clinic. The matter was reported to the department and also widely covered by the media. An investigation was initiated and concluded on 22 November 2012. Gauteng Health MEC, Hope Papo said that the implicated nurses were charged, and the case concluded with a sanction to dismiss the nurses from the public service in April 2013. "Maternal and infant mortality and morbidity are a combination of the four quadruple burdens of diseases that our country faces. Forty percent of all maternal deaths are avoidable, much pain and suffering are caused when mothers die in childbirth. "It is a shame and unacceptable that women are forced to think twice about pregnancy simply because there is a high - but preventable risk of losing the baby or their lives," said a concerned Papo. According to the South African Nursing Council's (SANC) statistical report regarding details of persons against whom disciplinary action was taken in terms of the nursing act (1 June 2012), unprofessional conduct relating to maternity tops the list with 51% (South African Government, 2013).

South African children die or are physically and cognitively permanently impaired during birth due to a recurring pattern of systemic professional negligence. South African obstetric practice is, however, not in question. The injury is the direct result of substandard or absent monitoring of mother and fetus during the first stage of labour, which deductively implies professional negligence. These children are incapacitated for life, completely dependent, and a massive burden on their families and society. Many individuals suffer extensive harm and have a degraded quality of life. The following is a report on a judgement passed down in the Southern Division of the Gauteng High Court:

> **Judge slams Gauteng health MEC for botched birth tragedy:** Alleged negligence in a state hospital and clinic led to Tshianeo Kubeka's severe brain damage. A high court judge lashed out at staff at a Gauteng state clinic and hospital for their alleged gross negligence that caused a baby boy to sustain severe brain damage, saying disciplinary action against them should be considered to ensure that it did not happen again. Judge Moses Mavundla also severely criticised the attorneys acting for the Gauteng health MEC for wasting taxpayers' money by opposing the claim on technical grounds and taking more than six years before conceding liability, which he said, "bordered on the dereliction of duty." The judge took the unusual step of delivering a written judgement to raise his concerns after being informed shortly before a civil trial was to commence, that the Gauteng health MEC had conceded full liability for the damages suffered by Tshianeo Kubheka, now 11, and his mother, Patience Kubheka. Ms. Kubheka instituted a civil claim for R17 million on behalf of her son, who sustained severe brain damage resulting in spastic quadriplegic cerebral palsy, epilepsy, intellectual disability, and cortical blindness. This was due to the substandard care she received at the Daveyton Extension Clinic and the far East Rand Hospital in 2007 (The Citizen, 2018).

The incidence of hypoxic ischemic injury during childbirth is a devastating irregularity in the field of health provision in South Africa. It has existed for many

years, but in some way and for specific reasons, evaded the attention of the broader public. The problem has destructive outcomes, not only for child life and health but also on family structures and social environment. Successful litigation pay-out, calculated in billions, represents only a fraction of the total cost to the South African taxpayer. The ramifications of the entire disaster are multifaceted. However, I have attempted to show in this study that a relatively easily identifiable shortcoming, namely an absence of professional monitoring of mother and fetus during the first stage of labour is responsible for the overwhelming majority of cases. I could not trace any information that a single individual has appeared before a professional disciplinary board, and to my knowledge, no complaints have been directed to the Health Professions Council of South Africa.

Can the moral base be restored?

There may come a time in the history of a nation that it teeters at the abyss of moral implosion. South Africa has experienced such a crisis for at least the past decade. All indications are that under new leadership, we may be able to regroup and retreat from disaster. The stranglehold that sinister forces still seem to hold over our elected leaders and the complete lack of an attempt at enforcing accountability remain sources of concern. The cancer of corruption has so deeply infested our state bureaucracy that one questions the capacity to return to normal.

The national health department is particularly in question after we all witnessed incompetence, arrogance, and complete absence of moral leadership during the Esidimeni hearings (Robertson & Makgoba, 2018). This was not an isolated occurrence, as the same systemic abuse of position and power plays itself out daily in the high courts of certain provinces. An overworked and underpaid contingency of legal representatives associated with the previous National Prosecution Authority (NPA) has betrayed the confidence of the citizens of this country over the past decade. It is one of the essential pillars of the social contract, and if this institution loses its moral compass, society loses its cohesion.

On most occasions, the defendant's attorneys are professional and honourable men and women. In the Gauteng province, they provide the MEC for health with sound legal advice, although in most cases, no legal or moral basis exists to defend the litigation claims. The MEC, however, has the power to overrule decisions of the state advocate and to insist that defense proceeds irrespective of cost and wastage of professional manpower in an already overstretched state legal system. The motivation for this behaviour is exactly what we witnessed in the Esidimeni disaster - an indescribable arrogance leading to actions devoid of all morality: If this charade can continue long enough, the problem may just "go away".

There is persistent pressure for the health departments to improve their litigation strategy, as they lose virtually all their cases and should rather negotiate upfront and come to a settlement to avoid cases dragging on for years. With the advent of a new governmental structure in South Africa, citizens are hopeful that a new dawn has arrived. Professionally capable and ethical individuals now lead the NPA, and we are awaiting the critically important changes that will restore the confidence in our judicial system. Wheels are turning slowly, and one cannot escape the dread that dark forces may still have the upper hand. All that remains for the people of this country is to collectively pray, "Nkosi Sikelel' iAfrika".

These facts are central to the issues raised in this submission. The hypoxic ischemic catastrophe that has decimated an entire generation of young South Africans during the past decade has a no more definitive cause than a bureaucracy with no sense of moral accountability. Instead of acknowledging the facts, they have swept all statistics under the carpet. Nothing has changed, and if anything, the situation perceived from a particular vantage point is in steady decline.

The answer to this problem lies in the hearts and minds of the people of a nation. Suffice to make an emphatic assertion that nothing will change if the full extent of this disaster is not made public. Nothing will change if a MEC for health continues to manipulate and intimidate the legal system in the hope that the poor results of

mismanagement would be the answer to solve the "problems". It cannot change if true leaders with moral fibre do not rise and declare that we have done wrong, but we know that we can do better.

In this thesis, I introduced a fundamental aberration in health care provision in South Africa. I explained the pathophysiological principles of the prolonged partial hypoxic ischemic injury and indicated that, in most cases, it is easily preventable if the necessary diligence and responsibility is applied to fetal and maternal monitoring during the first stage of labour. In Chapter Three, I employed the counterfactual comparative account of harm to assess, more specifically in the African context, how much worse off these children are, in comparison to the situation they could have been had preventable brain damage not occurred. The negligence that I allude to was examined in Chapter Five. The fundamental objective of this study is to propose a different (some would say unorthodox) approach towards addressing the problem. The argument that the in-utero fetus should be afforded the same moral status as the newborn infant and that both should have the moral and legal status of persons has been formulated in line with the argument of Malcolm de Roubaix and Anton van Niekerk (2005) that was deliberated on in Chapter Five. This concept is central and crucial in support of the aim and argument of this thesis, and a brief return to the essence of the argument is deemed appropriate here. They define separation-survivability as a moral cut-off point for abortion. By implication, they also endorse the moral status of the fetus to be equal to that of the infant:

> The continuous nature of prenatal development and simultaneous parallel development and actuation of intrinsic and contingent potentiality eventually results in a person capable of moral thoughts and deeds. This development implies continuous, incremental moral significance.

They also agree that survivability is important because human beings who have the potentiality of separate, relatively independent lives should be allowed to

continue living. I would want to add that not only should they be allowed to continue living, but that their lives should be safeguarded under the same human rights afforded to all other persons enshrined in the Bill of Rights of the Constitution of South Africa.

Conclusion

Once established that the moral status of the term fetus in the intrauterine environment is equal to the newborn infant, it seems reasonable to postulate that both should qualify as persons concerning moral status and under the law. If this is the case, it follows logically that under Section 24 of the Bill of Rights of the Republic of South Africa, the term fetus has a right to an intrauterine environment that is not harmful to his or her health or well-being. The fetus is thus also entitled to be removed from this environment by caesarean section if and when this environment turns toxic or hypoxic. If this is true, then these small individuals, with the full moral and legal status of a human being, should be protected by the Constitution from the scourge of systemic professional negligence during labour (the focus of this study). If this is what it takes to ensure their right to enter into this world in a healthy state and with their brains intact, then yes, this right should be upheld by the Constitutional Court of the country. The challenge of this study was to convert the facts as presented above, stripped of emotive content, into professional academic terminology. Subsequently, the aim was to express the moral dilemmas in an unbiased academic study of applied ethics and to stand up and constructively challenge the powers that be to reinstitute an ethical and professional obligation to ensure that another generation never again suffers the same fate.

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