

**INVESTIGATING THE VIEWS AND EXPERIENCES OF FETAL MEDICINE
PRACTITIONERS OFFERING LATE TERMINATION OF PREGNANCY IN THE
WESTERN CAPE**

By

SYDNEY FRANCOIS

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Supervisor:

Associate Professor Jantina de Vries

Department of Medicine, University of Cape Town

jantina.devries@uct.ac.za

Tel: (021) 650 5716

Co-Supervisors:

Dr Andrea Palk

Department of Philosophy, Centre for Applied Ethics, Stellenbosch University

apalk@sun.ac.za

Tel: (083) 408 2283

Nakita Laing

Division of Human Genetics, Department of Pathology, University of Cape Town

n.verkijk@uct.ac.za

Tel: (021) 406 6373

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Abstract

Title: INVESTIGATING THE VIEWS AND EXPERIENCES OF FETAL MEDICINE PRACTITIONERS
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Introduction: Fetal medicine practitioners (FMPs) are responsible for making decisions about the appropriateness of a late termination of pregnancy (LTOP) based on their assessment of the severity of the prenatal diagnosis while also taking into account the practical, legal and ethical aspects. This study aimed to investigate the views and experiences of FMPs involved in LTOP decision-making in the Western Cape and how these views may guide decisions to offer LTOP. Specifically, the research questions guiding this study aimed to investigate FMPs views on the Choice on Termination of Pregnancy Act (CTOPA), No. 92 of 1996, as well as their attitudes towards the provision and ethics of LTOP.

Methodology: A total of six semi-structured, individual face-to-face interviews were conducted between February and March 2020 in the privacy of the participant's office. All interviews were audio-recorded and transcribed. Interpretive phenomenological analysis was used as a framework to analyse the data and transcripts were managed using NVivo 12 software.

Results and Discussion: Participants believed that the CTOPA is based on the principle of gradualism and that while women have reproductive choice, TOP becomes progressively restricted as gestation advances to protect the fetus. However, they felt that the specified cut-offs in the CTOPA are arbitrary and open to interpretation and believed there is a need for further documentation to guide practitioners as to which conditions should be considered for LTOP. When making a decision to offer

LTOP, participants considered various factors including fetal age, whether a feticide was required and the prognosis. Participants considered that conditions which qualified as severe were untreatable and would have a significant, long-term negative impact on the individual's functioning and quality of life. When considering acceptability of LTOP, participants felt that LTOP was justified to prevent suffering for both the future child and for the parents. However, participants did not believe that LTOP was justified to prevent all disability. Lastly, participants valued societal consensus when making morally demanding decisions and believed that decisions around LTOP needed to be made by multidisciplinary teams to ensure objectivity, as well as to share the moral burden.

Declaration

I, *Sydney Tayla Francois*, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Signed by candidate

Date: 07 October 2020

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List of Abbreviations

CTOPA- Choice on Termination of Pregnancy Act, No. 92 of 1996

FA- Fetal Anomaly

FMP- Fetal Medicine Practitioner

HCP- Healthcare Practitioner

IPA- Interpretative Phenomenological Analysis

LTOP- Late Termination of Pregnancy

PVS- Persistent Vegetative State

SA- South Africa

TOP- Termination of Pregnancy

UK- United Kingdom

List of Tables

Table 1: Summary of Chapter 4: Views on the Choice on Termination of Pregnancy Act, 1997.

Table 2: Summary of Chapter 5: Considerations in Decision-Making Around Late Termination of Pregnancy.

Table 3: Summary of Chapter 6: The Healthcare Practitioner as a Moral Agent.

Table of Contents

| | |
|---|-----|
| Abstract..... | i |
| Declaration..... | iii |
| Acknowledgements..... | iv |
| List of Abbreviations | 1 |
| List of Tables | 1 |
| Chapter 1: Introduction | 4 |
| Chapter 2: Background and Literature Review | 6 |
| Ethical Arguments and Concerns Around Termination of Pregnancy | 6 |
| The Choice on Termination of Pregnancy Act, 1996..... | 9 |
| Late Termination of Pregnancy in South Africa | 10 |
| Conditions for Late Termination of Pregnancy..... | 11 |
| Danger to the Woman’s Life | 11 |
| Severe Malformation and Risk of Injury to the Fetus..... | 12 |
| Disability..... | 14 |
| Empirical Evidence About Healthcare Practitioners’ Views on Late Termination of Pregnancy | 15 |
| Chapter 3: Research Methodology | 18 |
| Introduction | 18 |
| Study Design | 18 |
| Recruitment of Study Participants..... | 20 |
| Data Collection..... | 22 |
| Data Analysis..... | 23 |
| Ethical Considerations..... | 25 |
| Ethical Approval | 25 |
| Informed Consent | 26 |
| Privacy and Confidentiality | 26 |
| Potential Risks and Benefits..... | 27 |
| Chapter 4: Views on the Choice on Termination of Pregnancy Act, 1996..... | 28 |
| Participant Perspectives on the Law | 28 |
| Interpretation of the Act and Subjectivity | 33 |
| Guidelines, Policy and Standardisation..... | 35 |
| Summary | 38 |
| Chapter 5: Considerations in Decision-Making Around Late Termination of Pregnancy | 41 |
| Team Decision-Making..... | 41 |
| The Significance of Fetal Age | 42 |

| | |
|--|----|
| The Requirement for Feticide | 44 |
| What Counts as a ‘Severe Malformation’? | 46 |
| Considering the Mother’s Life and Wellbeing | 48 |
| Summary | 50 |
| Chapter 6: The Healthcare Practitioner as a Moral Agent..... | 52 |
| Professional Responsibility and Empowering Patients | 52 |
| Moral Values | 53 |
| The Importance of Non-Directive Counselling..... | 56 |
| Late Termination of Pregnancy and Eugenics..... | 58 |
| Summary | 60 |
| Chapter 7: Discussion..... | 62 |
| Gradualism and Fetal Age | 62 |
| Severe Disability..... | 65 |
| The Potential to Prevent Suffering | 67 |
| Consensus as a Value | 69 |
| Chapter 8: Conclusion..... | 72 |
| Recommendations | 72 |
| Limitations | 73 |
| References | 76 |
| Appendix A- Interview Schedule..... | 84 |
| Appendix B- Participant Information Sheet and Consent Form | 86 |
| Appendix C- Summary of Codes..... | 90 |
| Ethics Approval Letter..... | 91 |

Chapter 1: Introduction

The acceptability of termination of pregnancy (TOP) remains the topic of ongoing ethical discussion worldwide and legislation on TOP differs widely between countries. However, even in countries which take a more liberal approach to TOP, the law becomes increasingly restrictive as gestation advances. In South Africa (SA), the *Choice on Termination of Pregnancy Act (CTOPA), No. 92 of 1996* (1996), permits TOP after 20 weeks only in circumstances where the mother's life is endangered or when the fetus is found to have a severe malformation or be at risk of injury. Pregnancy termination after 20 weeks of gestation is called late TOP (LTOP) and is the focus of this study. While the CTOPA provides a list of the conditions for which LTOP is permissible, such as 'severe malformation of the fetus', the categories on this list leave a lot of room for interpretation. Therefore, in practice, fetal medicine practitioners (FMPs) are left responsible for making decisions about the appropriateness of LTOPs based on their assessment of the severity of the prenatal prognosis while also taking into account practical, legal and potential ethical aspects of the case. Yet, while there is literature on how FMPs make decisions about LTOPs in other countries, little is known about this within the SA context where the law and standards of practice are potentially different. This study aimed at investigating the ethical views of healthcare practitioners involved in LTOP decision-making in the Western Cape and how these views may guide decisions to offer LTOP.

Following this introductory chapter, Chapter 2 provides an outline of the ethical principles and arguments pertaining to TOP which are necessary to consider when addressing LTOP. That chapter also positions LTOP within the SA context and describes the conditions for which LTOP is permissible. Lastly, literature is provided from similar studies conducted in other countries to better understand how practitioners in fetal medicine make the decision to offer LTOP.

Chapter 3, describes the research questions that guided this study and explain the qualitative research methodology used.

Chapters 4, 5 and 6 provide the empirical results. Chapter 4 reports on participant views of the CTOPA, including their views on the advantages and disadvantages from a practical perspective. Chapter 5 entails a consideration of the various factors that participants felt needed to be considered when making a decision to offer a LTOP, including fetal viability, feticide and the severity of the fetal anomaly. Chapter 6 explores how practitioners' personal values may influence their views towards LTOP and how this aligns with their professional ethics.

Finally, Chapter 7, discusses four overarching insights arising from the study and integrates these with existing theory and concludes with a discussion of recommendations for practical implementation of the findings and addresses the limitations of this study.

Chapter 2: Background and Literature Review

This chapter describes the ethical views, legal aspects and medical perspectives that are relevant to understanding late termination of pregnancy (LTOP) within the South African (SA) context. The purpose of this chapter is not to attempt to tackle the enormous task of distilling all the available literature on LTOP, but rather to provide a theoretical framework within which the rationale for this study can be considered.

Ethical Arguments and Concerns Around Termination of Pregnancy

The ethical debate around whether or not TOP should be allowed is nuanced, rich and vast. While there is a plethora of philosophical literature available on whether TOP is morally right or wrong, at the core of the discussion lies the question of the moral status of the fetus - i.e. is the fetus “an entity towards which [we] have, or can have, a moral obligation” (Warren, 1997)? In other words, is the fetus entitled to certain protections and/or rights, including a right to life?

Those opposed to TOP often argue that the fetus acquires moral status at the moment of conception and that TOP is therefore equivalent to murder. The Catholic Church in its *Declaration on Procured Abortion by the Sacred Congregation for the Doctrine of the Faith* (1974) condemns TOP as such because every human is a child of God “from the time that the ovum is fertilized”. Secular arguments in support of similarly conservative views mostly focus on the fetus belonging to the human species. Some argue that the fetus is a human being by virtue of its genetic identity and that belonging to the human species is sufficient to warrant its protection (Noonan, 1968), while others focus more on the potentiality of fetus to become a human person through the natural process of fetal development (Wendler, 1999).

While all can agree that the fetus is a member of the human species by virtue of its DNA, many have questioned whether this alone is sufficient to grant the fetus the same moral status as a 'person', or as having 'personhood'. Beauchamp (1999) describes the difficulties in attempting to define the concept of personhood and the lack of consensus regarding the qualities or capacities that confer a being moral status. Contenders include: human species membership (as discussed above), sentience, and various higher order cognitive and psychological capacities, particularly the capacity for moral agency and motivation (Beauchamp, 1999). To illustrate how the requirement for personhood impacts the permissibility of TOP, let us consider argument put forward by Tooley (1972). He proposes that to have personhood, a being needs to be self-conscious and reasonably be seen to have a desire to continue existing. However, the acquisition of these attributes is linked to key stages of neurodevelopment which are thought to only occur sometime after birth. As such, Tooley (1972) questions whether it is morally wrong to destroy the fetus if it is not considered to be a person. For that reason, according to a liberal view of TOP, the absence of personhood should permit TOP at any gestation. However, the problem with this argument is that it also puts forward a case for some instances of infanticide (Tooley, 1972; de Roubaix & van Niekerk, 2006). This point aside, infanticide is largely seen as morally indefensible and thus illegal in most countries, however it is interesting to note that the Groningen Protocol in the Netherlands permits active neonatal euthanasia in cases of severely poor prognosis (Verhagen & Sauer, 2005).

A third, intermediary position suggests that the fetus becomes a person at some point during its development, and that TOP is morally permissible, up until that specified point in gestation when personhood and thus moral status, is acquired. However, as fetal development is a continuous process from conception until birth, it is difficult to discern in a non-arbitrary way, when exactly during fetal development this occurs. There have been various attempts to quantify the precise point when the fetus acquires personhood, thereby acquiring moral protection, but by far the most widely accepted threshold to have been proposed is the point at which the fetus is able to survive

independently of the mother. Known as viability, this is the point in gestation whereby the organ systems are sufficiently developed to the point that if the fetus were to be born, it would be able to survive ex-utero (Merriam- Webster.com Dictionary, 2020). Proponents of a moderate view consider that at this point, the fetus is realistically capable of becoming a person and should not be terminated (de Roubaix & van Niekerk, 2006). However, there are exceptions to this view which are discussed later in this chapter.

Until this point, the sole focus has been on the range of positions around the moral status (and right to life) of the fetus. However, pregnancy involves consideration of two human beings - the fetus and the woman - and one important challenge in considering TOP relates to balancing fetal and maternal interests. According to the conservative view held by the Catholic Church, reproductive choice does not justify TOP, a position that clearly holds that the value of the fetus' life and a prohibition against its termination are considered to be more important than the woman's right to bodily autonomy. However, as Hewson (2001) eloquently puts it, "denying women abortion is, on this analysis, unethical because it subordinates women to a reproductive end."

In opposition to the conservative view, the pro-choice movement advocates that a woman's right to choose to be pregnant or not should be upheld and that TOP is a means of reproductive autonomy. In her *A Defence on Abortion*, Jarvis Thomson (1971) presents possibly the most famous position in favour of the pro-choice movement. Using a series of thought experiments, she argues that in almost every instance, it would be unreasonable to expect someone to grant the use of their body to sustain the life of another person, even if only for a limited period of time. However, she acknowledges that there are certain circumstances where TOP would be "morally indecent", such as in the later stages of pregnancy.

The above paragraphs describe a moderate view which considers TOP to be morally permissible up to the point where the fetus could survive outside of the uterus. In line with such a view, Chervenak

& McCollough (2009) argue that at the point of viability, there is a shift from an autonomy-based obligation to a beneficence-based obligation in that from that point onwards, the practitioner has an obligation to protect the fetus which supersedes their prior obligation to respect the woman's autonomy. This is based on the idea that the fetus, which is now capable of surviving separately from the mother, is now considered to be a patient, in its own right, and thus, the practitioner also has an obligation to protect its interests.

The Choice on Termination of Pregnancy Act, 1996

While the paragraphs above only sketch the main arguments in the extensive philosophical literature around TOP in very broad terms, they do describe the general principles necessary for understanding the premises underlying the TOP law in SA.

In the preamble to the *Choice on Termination of Pregnancy Act (CTOPA), No. 92 of 1996* (1996), the state describes its view that TOP is aligned with respecting a woman's reproductive choice, which is paramount to upholding the values of human rights and freedom on which SA's democracy is based. Specifically, the CTOPA describes:

"2. (1) A pregnancy may be terminated-

(a) upon request of a woman during the first 12 weeks of the gestation period of her pregnancy;

(b) from the 13th up to and including the 20th week of the gestation period if a medical practitioner, after consultation with the pregnant woman, is of the opinion that-

(i) the continued pregnancy would pose a risk of injury to the woman's physical or mental health; or

(ii) there exists a substantial risk that the fetus would suffer from a severe physical or mental abnormality; or

(iii) the pregnancy resulted from rape or incest; or

(iv) the continued pregnancy would significantly affect the social or economic circumstances of the woman; or

(c) after the 20th week of the gestation period if a medical practitioner, after consultation with another medical practitioner or a registered midwife, is of the opinion that the continued pregnancy-

(i) would endanger the woman's life;

(ii) would result in a severe malformation of the fetus; or

(iii) would pose a risk of injury to the fetus.”

In this regard, SA takes a moderate position on TOP in that it recognises a woman's autonomy and respects her right to reproductive choice but this right is not unrestricted. In the earlier stages of pregnancy, a woman is allowed to elect to terminate a pregnancy for any reason without prior approval, and her right to autonomy supersedes the fetus' right to life. However, as the pregnancy progresses, and the fetus develops, the criteria for termination become more restricted, a position also known as gradualism. The principle of gradualism is described in greater detail in Chapter 7. Therefore, while the CTOPA respects the woman's right to reproductive choice, this right is subject to a gestational time-frame and thus the act also protects the interests of the unborn fetus later in the pregnancy (Pickles, 2012).

Late Termination of Pregnancy in South Africa

There is no upper limit stated for TOP after 20 weeks and therefore it can be assumed that TOP can be performed at any gestational age, provided the conditions of 2(c) are met. Apart from the potential medical complications associated with LTOP, the greatest concern with TOP at gestations later in pregnancy is the chance of the fetus being born alive. Survival prior to 21 weeks and 6 days is

rare, whereas survival after 22 weeks becomes increasingly more likely (RCOG, 2010). However, there is a poor prognosis for neonates born before 24 weeks, with less than 25% chance of survival without major disability (Levene, 2004). Viability is therefore generally accepted as 24 weeks gestation, although pinpointing an exact gestational age of viability is impractical as viability is dependent on many factors, including fetal weight and the intensive care resources available (Levene, 2004). LTOP is widely defined in the literature as TOP after 24 weeks (Alouini et al., 2011; Statham, Solomou & Green, 2006) however, as the CTOPA provides the cut-off of 20 weeks, LTOP is defined in this study as TOP at >20 weeks.

In order to achieve stillbirth as a result of LTOP, TOP performed after 24 weeks generally requires a prior feticide procedure, except in cases where there is a very high likelihood of fetal demise during or soon after birth. The most commonly used method for prior feticide is injection of potassium chloride (KCL) into the heart or umbilical cord of the fetus until cardiac asystole is achieved (Govender & Moodley, 2013).

At present, there is no national registry of published LTOP statistics in SA (Shahid & Soma-Pillay, 2019). At one tertiary hospital in Kwa-Zulu Natal, a retrospective audit showed that 253 LTOPs were offered between August 2003 and December 2008, of which 191 were accepted (Govender & Moodley, 2013). At another tertiary hospital in Pretoria, between January 2010 and July 2017, 100 feticides were performed (Shahid & Soma-Pillay, 2019). Although the number of legal LTOPs being performed every year is small, LTOP remains a highly contested area of fetal medicine, and the practice of feticide is a topic of ongoing national discussion among FMPs.

Conditions for Late Termination of Pregnancy

Danger to the Woman's Life

Even those who take a conservative view on TOP are generally accepting of TOP in instances where the mother's life is endangered by continued pregnancy. Jarvis Thomson (1971) argues that even if it

is granted that the fetus has a right to life that is morally worthy of protection (as is the case after viability), if the mother's life is threatened by the continued pregnancy, she has the right to defend her life and may 'kill' the fetus in self-defence. She goes on to argue that it is morally defensible for a third-party intervening to aid the woman in this situation. However, while the woman may protect herself if her life is endangered by the continued pregnancy, it would not be morally defensible to kill the infant if it were to be born alive.

Severe Malformation and Risk of Injury to the Fetus

The World Health Organisation (WHO, 2020a) defines congenital malformations - also referred to as birth defects, fetal anomalies, congenital disorders or congenital anomalies- as "structural or functional anomalies [...] that occur during intrauterine life". Fetal anomalies affect around 2-3% of pregnancies (Crane et al., 1994; Rydberg & Tunón, 2017), although some have indicated they occur in around 6% of pregnancies (WHO, 2020a). The exact aetiology is unknown in around 50% of cases however, congenital malformations can be caused by many factors including genetic mutations or in-utero exposure to teratogenic medications or infections (WHO, 2020b).

Fetal anomaly (FA) ultrasound scans are routinely performed at between 18 to 22 weeks gestation to identify any major malformations which may have implications for obstetric management, such as termination of pregnancy and identifying neonates which may require additional care post-delivery (Edwards & Hui, 2018; Crane et al., 1994). A recent Swedish study assessing the prenatal detection of fetal anomalies with a reported sensitivity of 44%, found major structural malformations in 0.8% of all pregnancies and minor structural malformations in 1.0% of all pregnancies (Rydberg & Tunón, 2017). Although FA scans are widely used for prenatal screening, they are unable to detect all malformations and further imaging, biochemical or molecular testing may be necessary to diagnose certain conditions (Edwards & Hui, 2018).

As previously described, the CTOPA allows for TOP after the 20th week of gestation in cases where there is the probability of severe malformation of the fetus. However, the problem with the terms “severe malformation” and other terms such as “seriously handicapped” is the ambiguity around which anomalies should be considered as sufficiently severe. Several studies conducted in different countries have shown considerable differences in opinion among HCPs with regards to the conditions which they believe are sufficiently serious to warrant LTOP (Statham, Solomou & Green, 2006; Habiba et al., 2009; Jacobs et al., 2015).

Certain conditions such as anencephaly, trisomy 13, trisomy 18 and renal agenesis are often referred to as “lethal malformations” or “incompatible with life” (Wilkinson, de Crespigny & Xafis, 2014), and are widely considered to fulfil the requirement of “severe malformation”, given the high rate of inter-uterine death (IUD) and neonatal mortality. However, there are considerable differences in opinion over which conditions are “lethal”, and even in those that are commonly listed, there are concerns over the ethical implications of classifying conditions as lethal, given that there are reported cases of long-term survival in most of these conditions (Wilkinson et al., 2012).

The real difficulty comes with assessing severity and eligibility for conditions which are non-lethal but have a high probability of significant short- or long-term suffering. This is partly because of the difficulties in making an accurate antenatal diagnosis, given the variability of outcomes and the limitations of antenatal imaging (Habiba et al., 2009). Acknowledging the uncertainty that practitioners face in deciding whether LTOP is appropriate, there have been a number of attempts at devising recommendations to classify severity. Chervenak and colleagues (1984) for instance suggest that LTOP is morally justifiable provided that: 1) if carried to term, the infant will not survive more than a few weeks or will have little to no cognitive function; and 2) the diagnosis is reliable. He argues that if these criteria are met, continued existence would not benefit the fetus and thus termination is morally justifiable. The Royal College of Obstetricians and Gynaecologists (RCOG) (1996) recommends that certain factors should be considered, including: the potential for

treatment; the potential for self-awareness and communication; the degree of suffering; and the degree of dependence on others. Dommergues and colleagues (2010) propose that grading of severity of fetal anomalies should be based on the type of abnormality as well as the paediatric prognosis. They suggest four distinct categories: 1) “lethal”- a risk of IUD or neonatal mortality >90%; 2) “substantial morbidity”- a >10% chance of survival but with significantly impaired functioning; 3) “isolated mental retardation”- intellectual disability with no physical malformation; 4) “unsettled”- conditions with a high chance of morbidity but where severity and prognosis are uncertain. To further complicate the issue, most countries report not having a guideline on the indications for which anomalies should be considered, particularly in the case of an uncertain prognosis (Alouini et al., 2011).

Another area of potential uncertainty is what exactly is implied by ‘injury’ to the fetus. While the nature of “severe malformation” can at least be articulated, albeit with some contestation, hardly any authors – in SA or beyond – have attempted to define or describe what may constitute an injury to the fetus.

Disability

On the other hand, some authors have critiqued the practice of LTOP for fetal anomaly as discriminatory and promoting passive eugenic practices by propagating the idea that disability is undesirable in society (Hall, 2013; Savulescu, 2001). However, it should be noted that disability rights advocates are not opposed to TOP as such, rather, they are opposed to the prejudicial implications of LTOP on the grounds of potential disability (Manninen, 2015). Therefore, the objection to TOP for fetal anomaly is that it supposedly implies that individuals with disabilities have a lesser quality of life or do not have the same right to life; not that TOP is necessarily morally wrong. There is a significant amount of literature on TOP for fetal anomalies and disability discrimination but further exploration of the nuances of this topic is beyond the scope of this study.

However, it is necessary to recognise that disability is a spectrum and that some individuals are more severely affected than others. Acknowledging the diversity of disability, the International Classifications of Functioning, Disability and Health (ICF) (WHO, 2001) provides a model for classifying disability based on the particular physiological impairment, together with the individuals' level of functional capacity and performance. Therefore, the term 'severe malformation' does not necessarily apply to all malformations that are associated with disability.

Empirical Evidence About Healthcare Practitioners' Views on Late Termination of Pregnancy

Across the world, healthcare practitioners (HCPs) such as medical doctors and midwives play a central role in making decisions about LTOPs. A key question in understanding better how decisions about LTOPs are made, therefore, relates to how HCPs think about this practice.

Statham and colleagues (2006) investigated the ethical views of doctors and midwives involved in LTOP provision in four fetal medicine units in the United Kingdom (UK) and found that when making decisions about LTOP, practitioners took into account a range of factors such as viability, the law, their professional responsibilities and their personal values. Importantly, rather than their personal beliefs about the ethical permissibility of LTOP professionals would in the first instance consider whether LTOP conformed to UK legal provisions. Participants in this study described the need to be consistent and stick to strict guidelines due to the possibility of being sued for either refusing a LTOP or providing an inappropriate LTOP. Furthermore, they gave significant weight to neonatal treatment options in their decision making, particularly when faced with uncertainty; specifically, if neonatologists saw realistic opportunities for beneficial clinical management then participants were unlikely to offer LTOP. Participants also noted that the attitudes were changing to less acceptance of LTOP for conditions such as Down syndrome and achondroplasia, where there was no longer consensus that these should be considered severe enough to warrant a LTOP.

Habiba and colleagues (2009) describe the attitudes towards LTOP of 1530 obstetricians in eight European countries using a survey study. Interestingly, while religion was important to participants in some countries, it was not referenced as an important factor in others, and those for whom religion was not important were less likely to support a more restrictive LTOP policy. There were also differences in attitudes towards feticide and the practice of feticide varied widely between countries. Furthermore, a reasonable proportion of obstetricians supported changes to a policy that was either more or less restrictive than the one in place in their own country.

In SA, HCPs have the constitutional right to practice conscientious objection (Constitution of the Republic of South Africa, 1996) and may therefore choose not to be involved in TOP provision. However, HCPs who chose to conscientiously object may not prevent the patient from accessing a TOP and have a legal obligation to refer to another HCP who will perform the TOP (section 10, CTOPA 1996). In light of this, Harries, Stinson & Orner (2009) investigated the attitudes towards TOP provision of HCPs in the Western Cape. They found that HCPs illustrated different degrees of willingness to participate in the provision of TOP services, varying from direct involvement, to limiting themselves to pre- and post-TOP counselling, or restricting themselves to performing ultrasounds with subsequent referral for TOP when necessary. Some factors influencing HCPs willingness to be involved in TOP provision include personal experiences (such as previous exposure to illegal TOPs or limited TOP access), moral reasons, religious beliefs and the reasons for seeking a TOP (Harries, Stinson & Orner, 2009).

A similar study by Harries and colleagues (2012) investigated the challenges that HCPs faced with providing second-trimester TOPs (between 13-and-20-weeks' gestation) in the Western Cape and found that fetal age, the method of induction, barriers to service provision and the reasons that women delayed seeking TOPs all impacted on HCPs perceptions on TOP provision in the second-trimester. While Harries and colleagues' study overlaps with certain aspects of this study, it differs in that this study specifically aims to investigate LTOP, which is arguably more ethically complex and

nuanced than second-trimester TOP. Furthermore, Harries and colleagues' study did not investigate the ethical perceptions of HCPs, which is a key objective in this study.

Although literature is available on the views of HCPs in other countries, it does not necessarily mean that inferences can be made about the views of HCPs within the SA legal and social context. SA is commonly referred to as the rainbow nation with people from many different ethnic, religious and socioeconomic backgrounds. This, together with past legislative restrictions on LTOP and social stigma related to TOP, may influence individuals' views on LTOP. —It is therefore necessary to understand how practitioners make the decision to offer LTOP and how their views on the law, viability, their professional responsibilities, as well as their personal values, may influence their decisions in the SA context. Furthermore, research into this area may identify areas in current decision-making processes where practitioners potentially need more guidance or clarity. The next chapter further elucidates the research questions guiding this study and explains how these will be addressed.

Chapter 3: Research Methodology

Introduction

The previous chapter provided the theoretical background to this study and highlighted the need to further explore the views and experiences of fetal medicine practitioners (FMPs) involved in late termination of pregnancy (LTOP) in the South African (SA) context. Based on this, this study aimed to provide insight into FMPs' views about LTOP in the Western Cape, and to explore whether, and how, their views affect decisions to offer or refer for a LTOP. In order to achieve this, the research questions guiding this study were:

- What are the views and interpretations of FMPs on the Choice on Termination of Pregnancy Act (CTOPA) of 1996 in light of their decision-making around LTOP?
- What are the perceptions of FMPs on the provision and ethics of LTOP and feticide?
- How do FMPs' views impact on their decisions to offer or withhold LTOP?

This chapter defines the methodology used in this study and describes the process of recruitment, interviewing, data collection and data analysis. Lastly, it states the considerations taken into account around ethics approval, informed consent, privacy and confidentiality, and the potential risks and benefits to participants.

Study Design

In order to address these research questions, it was necessary to investigate the underlying values, beliefs and motivations of FMPs and how these factors influence the framework in which practitioners make LTOP decisions. A qualitative research approach was best suited to this task as it seeks to understand the nuances of individual experience and allows the researcher to explore subjective experience in greater depth with the aim of understanding and better describing a

particular phenomenon (Fossey et al., 2002). Furthermore, as suggested by Braun & Clarke (2006), qualitative research methods are particularly useful in cases where the research topic has not received much attention in the literature and where little empirical evidence is available on a topic as it allows the researcher to explore novel ideas and concepts as they arise. Additionally, as this particular topic has not previously been investigated within the South African setting, a cross-sectional study design allowed the researcher to collect data once-off from a specific area, which is ideal when conducting an introductory study into a novel topic as it provides insight into the broader views of the population (Setia, 2016). The findings of the study can then be used to inform future investigations to better understand certain aspects of the phenomenon.

As the phenomenon being investigated is inherently subjective and informed by an individual's personal moral views, experiences and values, interpretive phenomenological analysis (IPA) was chosen for this study. The interpretive paradigm is concerned with understanding an individual's subjective perception of a particular experience, insofar as it can be explained objectively (Tuohy et al., 2012). This is done from the philosophical premise of phenomenology which aims to explore how an individual experiences, interprets and gives meaning to their own reality (Tuohy et al., 2012). Phenomenology takes an idiographic approach and does not attempt to define or make generalisations about a particular concept (Smith, Jarman & Osborn, 1999). Interpretive phenomenology acknowledges that while an individual is a product of their social, temporal and cultural environment, their personal experiences and the meanings that they derive from those experiences are constructed by their unique interpretation (Fossey et al., 2002). Research done within this paradigm seeks to analyse an individual's verbal accounts in order to better understand the hidden meanings behind their beliefs (Smith, Jarman & Osborn, 1999). In this study, IPA was used to identify similarities and differences between selected individuals' views on the same concept.

Interpretive phenomenology acknowledges that any attempt made to elicit participants' objective views are inevitably influenced by the researcher's own interpretive realities and conceptions, and the researcher is therefore viewed as being a part of the research itself (Tuohy et al., 2012). It is for this reason that transparency regarding the research methodologies is crucial, so that the reader is aware of how the researcher's own preconceptions and context may have influenced the study (Fossey et al., 2002; Noble & Smith, 2015). In this study, the researcher kept a reflective journal and noted important thought processes throughout the research process. Additionally, as part of the genetic counselling course, she was required to write a short reflective piece on the impact that the research process had on her. Throughout the duration of the study, she engaged with the literature in order to gain perspective on other views which may differ from her own pre-existing beliefs. Furthermore, the supervisory team met a number of times throughout data collection and write-up to discuss the process and data interpretation. The researcher has elaborated more on her personal impact on the study in the limitations section in Chapter 7.

Recruitment of Study Participants

In any research, it is imperative that the sample is appropriate to the question being asked (Fossey et al., 2002). As the research question involved investigating the views and experiences of practitioners involved in LTOP decision-making, the appropriate sample for this study was fetal medicine specialists, medical geneticists, obstetricians and gynaecologists.

Initially, the study was presented at two fetal medicine meetings at separate Western Cape tertiary public hospitals in order to get feedback on the study design and to identify any concerns. There were apprehensions around confidentiality and possible identifiability within a small and intimate group of fetal medicine colleagues and for this reason the sample was expanded to include participants from both the public and private sectors.

It is important to note that the public and private sectors often have different systems for LTOP decision-making and therefore may practice according to different procedures. In the public sector, cases in which prenatal ultrasound findings are detected that may possibly lead to the offer of a LTOP, are generally referred to tertiary hospitals where fetal medicine units are established and decisions are typically made by a large multidisciplinary panel. Furthermore, a few hospitals have LTOP policies in place to guide decision-making. In the private sector, the fetal medicine teams are generally smaller and specialists are consulted from various disciplines to provide input on LTOP cases when necessary. Due to these differences, recruiting participants from both the public and private sectors potentially improved the heterogeneity of the sample.

The initial intention was to include practitioners directly involved in LTOP decision-making, as well as practitioners who referred patients for LTOP. The purpose was to include practitioners with different ethical views on LTOP and possibly even those who conscientiously object to LTOP. However, due to sampling convenience, accessibility and time limitations, only practitioners who were directly involved in LTOP decision-making were included. This is a possible limitation of the study and is described in more detail in the discussion chapter.

Following the initial fetal medicine meetings with the public hospitals, the researcher identified individuals who could potentially be interested in participating. Key personnel were then approached to provide names of potential private practitioners who may be interested. This combination of convenience and snowball sampling was chosen to allow the researcher to identify possible participants with knowledge and experience of LTOP and those in private practice who may otherwise have been difficult to access (Naderifar, Goli & Ghaljaie, 2017). An introductory email was sent to prospective participants explaining the study and inviting them to participate. Those individuals who expressed a willingness to participate were sent an information sheet and consent form and arrangements for the interview were made.

Data Collection

Interviews are often used in phenomenological research as they are ideal for gathering verbal accounts of participants' subjective experiences (Fossey, et al. 2002). Face-to-face interviews were chosen to investigate this complex topic as there is less likelihood of misinterpretation of questions and the participant is more likely to respond with thoughtful answers (Shuy, 2002). Furthermore, interviews were strictly individual, given the sensitive nature of the topic and to ensure confidentiality, which allowed the interviewee to express feelings and opinions that they may otherwise not have shared. A semi-structured interview format was chosen as open-ended questions allow for more explorative potential when asking complicated questions (Fylan, 2005). The researcher wanted the interview to have a conversational style which would allow the freedom to explore key ideas and concepts in-depth as they arose in the interview. This resulted in richer data collection as participants were able to express their personal experiences and views in an unrestricted manner.

Following a thorough review of the literature, as described in the previous chapter, an interview schedule was designed around concepts pertinent to the research question (Fylan, 2005). The interview schedule (Appendix A) addressed various topics such as: participants' views on the law around LTOP; the circumstances for which participants feel LTOP is appropriate and; their values and beliefs around TOP. This was reviewed by a Departmental Review Committee and suggestions were incorporated into the final draft.

A pilot interview was conducted with a peer of the researcher prior to the start of data collection to assess the appropriateness of the interview schedule. Changes were made to the interview schedule where necessary to refine questions and improve the flow of the interview.

A total of seven interviews were conducted in February and March 2020. One interview was conducted telephonically due to the unavoidable restrictions of the COVID-19 national lockdown. One interview was subsequently excluded from the dataset for ethical reasons. Interviews were

between 30 minutes to one hour in length and were conducted in English. All interviews were conducted in the privacy of the participants' offices. Interviews were audio-recorded and transcribed verbatim by the researcher. Directly after each interview the audio files were uploaded to a password protected cloud computing account and deleted from the recording device.

Morse and colleagues (2002) explain that investigator responsiveness is a key component in ensuring the verification of the research. One strategy that they propose is that the researcher engage in an iterative process of continually checking the congruence of the research design, the emerging data and the existing literature and theories. This promotes flexibility throughout the research process whereby the researcher is able to adjust where necessary to ensure that the research remains focused and that validity and rigor are upheld (Morse et al., 2002). In this study, the researcher made notes after every interview and transcribed and coded the interviews within one week in order to assess whether the data were aligned with the research questions. The process of parallel data collection and initial analysis ensured that she continually reflected on how concepts which appeared in the data related to the literature and research questions.

Data Analysis

Smith, Jarman & Osborn (1999) expand upon Smith's (1995) earlier work to provide a comprehensive guide to conducting IPA which can take one of two approaches. The first is to use a case-study approach whereby the researcher analyses one interview in-depth and creates a master-theme list which is then applied to other interviews. The second is to identify broader shared themes that appear across multiple interviews and then to retrospectively take a more detailed account of the extracts under each theme to identify areas of similarity/dissimilarity between interviews. Given the small sample size and the complexity of the topic, the researcher was interested in capturing the nuances and depth of detail of each individual account, therefore the first approach was chosen.

The process of data analysis followed the practical five-step approach as defined by Smith, Jarman & Osborn (1999):

1. Looking for Themes in the First Case

The researcher began data analysis by reading the transcript and making detailed notes of her interpretations. She then re-read the transcript together with her notes and looked for any deeper insights. At this point, she imported the transcripts into the NVivo 12 data management software programme (QSR International, 2018). While NVivo 12 facilitates easier data handling, it does not execute analytical functions and thus analysis and interpretation were done solely by the researcher.

She proceeded to code the transcript by identifying and labelling various excerpts of text relating to a particular concept. Coding is imperative in data analysis as it allows the researcher to identify and compare common concepts between transcripts when searching for themes (Fossey et al., 2002).

2. Looking for Connections

The list of codes was then exported to an Excel spreadsheet and similar or overlapping codes were merged. This is an important stage in analysis whereby the researcher began to look for connections within and between themes and to understand how certain concepts may relate to one another in the bigger picture. Each code was then checked against the excerpts to verify that the meaning of the text was appropriately reflected by the code's description.

3. A Table of Themes

Codes relating to the same broader concept were then organised into candidate themes. In this way the researcher focused the data to that which was applicable to the objectives of the study. Candidate themes were defined and arranged into a table (Appendix C).

4. Continuing the Analysis with Other Cases

This processing was repeated and the candidate themes were applied to a total of four transcripts. The researcher and primary supervisor met to discuss the emerging themes and to finalise a coding frame which was then applied to the remainder of the transcripts. Any new themes that emerged in later transcripts were applied to prior transcripts in an iterative fashion which encouraged deeper insights and new interpretations throughout the process (Smith, Jarman & Osborn, 1999).

5. Writing Up

Prior to writing up, the supervisory team met to discuss the themes that had emerged and the researcher's interpretation of the data. The researcher presented the data in three empirical results chapters in which she took a narrative approach to describing the data followed by verbatim quotations to contextualise certain concepts (Smith, Jarman & Osborn, 1999). Structuring the results in this way promotes lucidity while also ensuring openness and authenticity by allowing the reader to make their own interpretations of the data (Fossey et al., 2002).

Ethical Considerations

Ethical Approval

Ethics approval was obtained from the Human Research Ethics Committee (HREC) at the University of Cape Town (HREC 642/2019). As the public hospitals included in the study fall under the jurisdiction of the Provincial Department of Health, the proposal was submitted to the National Health Research Database and approved by the Western Cape Provincial Research Health Committee. Institutional approval was granted from one of the four public hospitals that were originally approached; the others were therefore not included in the study.

This study followed the ethical guidelines around informed consent and privacy and confidentiality as outlined in the Declaration of Helsinki (2013). The precautions taken are described below.

Informed Consent

Before the interview, participants were sent an electronic copy of the information sheet and consent form (Appendix B) which they were encouraged to read through and ask questions about. Prior to the commencement of the interview, participants were provided with a hard copy of the information sheet and consent form to sign. Signed informed consent forms were scanned and stored electronically in a password protected cloud computing account and the hard copy was destroyed. In the case of the one telephonic interview, the consent form was signed and emailed to the researcher prior to the interview. Before each interview, the researcher reiterated that the participant did not have to answer any question they were uncomfortable answering and that they could withdraw from the study at any time, and that in that case all data would be permanently deleted. None of the research participants made use of either of these options.

All participants involved in the study were practicing healthcare professionals and it was therefore assumed that they were capable of providing consent.

Privacy and Confidentiality

Given the particularly sensitive nature of the topic, various measures were taken to ensure anonymity and confidentiality. As discussed previously, the sample was expanded to include participants from both the public and private sectors. As a precautionary measure to ensure confidentiality of the participants, the names of the hospitals have been omitted and participants are not identified as being from the private or public sectors.

In the presentation of the research results in the following chapters, participants are identified with a random three-digit number. Only the researcher and the primary supervisor had access to the transcripts. All data collected during the interviews was grouped per participant and stored on a

password protected cloud computing account. Data will be kept for no longer than two years following publication, after which it will be destroyed.

Potential Risks and Benefits

There were no risks to participants associated with participation in this study.

In this study, anonymity of healthcare practitioners was protected and thus those who wished to share their views on LTOP were able to express opinions that they feel are important, but may have felt otherwise too exposed to share. Given the controversial nature of the topic, practitioners may not be able to openly express their personal views on LTOP, particularly within a group setting, and therefore may have received a sense of catharsis from being able to openly share their thoughts and perceptions in an environment that is non-judgmental and ensures anonymity.

Chapter 4: Views on the Choice on Termination of Pregnancy Act, 1996

Chapter 3 describes the methodology used in this study. This chapter will explore the empirical results relating to participants' perspectives of the Choice on Termination of Pregnancy Act (CTOPA) (1996). This will provide a deeper look into their views on the advantages and disadvantages of the CTOPA as well as what they felt could possibly be amended.

Participant Perspectives on the Law

As a whole, participants felt that the CTOPA appropriately balances maternal autonomy and reproductive choice with fetal interests. They described that the law is based on the principle of gradualism – that women may have an elective TOP until the end of 12 weeks but after that point, the protection of the fetus gradually increases with advancing gestation. Whilst under South African (SA) law, the fetus has no legal rights, the CTOPA does provide a high level of protection to the fetus later in the pregnancy.

P853- "Although we all have this thing about the fetus doesn't have any rights, the fetus can't inherit, it's not a legal person and so on, but actually the law has a very strong protection for the unborn child in that it is completely illegal, unless the mother is dying, to terminate a normal fetus."

P977- "I like that between 12 and 20 weeks there is still that ability to stop but it's stricter because of course we're protecting two lives in the end, right? It's not just one."

In fact, some believed that if the fetus were to have legal rights, it would mean that the laws on TOP in SA would have to be far more conservative, which would compromise the intentions of the CTOPA.

P346- *“If you had any kind of fetal right to life then it would create a slippery slope which would actually undermine abortion law in totality.”*

Interestingly, participants spoke of the law as presumably reflecting what the majority of society agrees is morally correct and ethical. They described that as doctors, if they choose to interpret the law liberally then they are acting in opposition with what society deems to be acceptable.

P131- *“I think that if a very liberal interpretation of the law is not in line with what the general public would think and then as a doctor, you drift away from the general ethics and morality of the country in which you work.”*

Participants felt that the most important implication of the CTOPA is that it has made TOP legal and accessible and has allowed women to exercise their reproductive choice.

P977- *“In general I think it allows a lot of freedom for women [and] a lot of rights over their own body.”*

Participants described that a second major strength of the act is that it allows for late termination of pregnancy (LTOP) for severe fetal anomalies. Overall, participants interpreted the provisions made for LTOP in the act as aimed at preventing future suffering for a fetus that has serious and potentially life-limiting disabilities.

P131- *“I think it has the advantage in that it’s written from the point of preventing unnecessary suffering.”*

Although participants agreed with the general principles and criteria in the law, there were some aspects of the CTOPA that participants felt were either vague or outdated. Many felt that the 12-week and, particularly, the 20-week cut-offs were not relevant to current obstetrics practice. As

outlined previously in Chapter 2, the CTOPA allows elective TOP until the end of 12 weeks, TOP for socioeconomic reasons from 13 to 20 weeks, and TOP from 20 weeks in the case of endangerment to the mother's life; or severe malformation of the fetus; or a risk of injury to the fetus. Some suggested that due to socio-economic reasons and clinic capacities, it is often difficult for women to present to the clinic with a positive pregnancy test result prior to 12 weeks. However, despite this, they were apprehensive to move elective TOP to later than 12 weeks.

P997- "I think it's really hard for women to always present before 12 weeks and I think that expecting a woman to pay for a pregnancy tests to be able to make her choice before 12 weeks is really hard because you will not get into a pregnancy clinic for a booking before 12 weeks. So, you're sort of limiting that right she has in terms of the law but then again, I would feel uncomfortable offering it any later. I guess the healthcare system just needs to step up its game."

Some participants similarly felt that 20 weeks was also impractical as fetal anomaly scans are generally done at between 18 and 22 weeks.

P346- "The fetal anatomy scan is typically done at between 18 to 22 weeks which exactly straddles that time cut-off and so whether you're doing the same ultrasound scan at 19 weeks or 21 weeks can now lead to different interpretations and have different law applying to them which doesn't make sense."

More importantly, participants felt that the 20-week cut-off is arbitrary and does not align with any significant developmental milestone.

P346- "I think the big sort of difficulty that I have with it is that it isn't really aligned to current practice [...] that cut-off of 20 weeks is really quite an arbitrary number for me and

it's not aligned with any specific viability related or any other kind of logical reason for it being put there."

Furthermore, one participant felt that it didn't make sense that the CTOPA, which was supposedly meant to be more liberal than the preceding Abortion and Sterilization Act 2 of 1975, would be more restrictive in not allowing TOP for conditions for which it was previously allowed. In fact, many participants perceived there to be a grey zone between 20 and 24 weeks. They felt that the law intended that the principle of gradualism should continue to be applied after 20 weeks. For instance, one could consider TOP for Down syndrome up to 24 weeks but not necessarily at 40 weeks.

P853- *"The reality is that even with the old TOP act people had TOPs for Down syndrome up to 24 weeks and the new act is supposed to be more liberal; so I cannot believe that the intention of this act was then to now deny people termination of pregnancy for Down syndrome but that doesn't mean we feel that it is correct to continue offering TOP for Down syndrome up to 40 weeks of pregnancy. So, there is a gradualism that I feel is built into the law and although the law doesn't really mention certain cut-offs [after 20 weeks] in terms of gestation, the principle is very clear within the law."*

On this premise, they suggested there should be a grading of severity when it comes to TOP after 20 weeks as not all severity is equal. For example, TOP could be offered for less severe conditions between 20 and 24 weeks but that TOP after 24 weeks should only be permissible for more severe conditions.

P346- *"In a lot of ways, we think of severe differently if it's before 24 weeks and if it's after 24 weeks [...] maybe applying a different criterion to what constitutes a severe malformation is reasonable as well."*

As viability occurs at 24 weeks and that a feticide was required for TOP after this point, they felt that 24 weeks was a more significant and appropriate cut-off for LTOP. However, as viability is dependent on the neonatal care available, a suggestion was made that perhaps it could be written into the law that rather than a gestational cut-off, there could be a national consensus about the point in time that viability occurs at.

P131- “And you know, maybe that’s something else that could change in the law is that, instead of a week cut-off point, if they say well between the less strict and more strict, we use the limit of viability and that’s also a matter of national consensus that can change without writing it into the law.”

As the CTOPA allows for TOP after 20 weeks and does not state an upper gestational limit, participants felt that LTOP is permissible until very late in the pregnancy if the fetal condition is severe enough. As a feticide procedure is required for TOP of a post-viable fetus, participants felt that feticide was permissible under the CTOPA.

P346- “Feticide is just one of the techniques involved in late TOP and it is therefore mandated by the CTOPA, which provides for TOP throughout gestation and therefore, inherently includes feticide, although it is not specifically named, nor are other techniques of TOP named.”

A few of the participants mentioned rape or incest and felt that TOP should be allowed until 24 weeks if the pregnancy resulted from these. In the Abortion and Sterilization Act 2 of 1975, which preceded the CTOPA, TOP for rape or incest was permitted, although no gestational limits are explicitly stated in the act. Under the CTOPA, TOP for rape or incest is allowed until 20 weeks. Given that viability is now accepted to be 24 weeks, practitioners questioned why the law was more restrictive of rape and incest than previously.

P853- *“The current law is even more restrictive than the old one because in the old law you could have a TOP for rape [and incest] when you were 22/23 weeks pregnant and now you can’t. I personally think it should be a bit more liberal for serious things like that to allow it up to 24 weeks or how it was with the old law.”*

Interpretation of the Act and Subjectivity

Participants felt that the greatest weakness of the CTOPA is that the term “severe malformation” is vague and open to interpretation. For example, some may feel that Down syndrome qualifies as such while others may feel that it does not.

P346- *“You’ll find that different people have different opinions on how liberal the late TOP component of the act is and it will partly relate to what does severe mean? Some people will say Down syndrome is severe and some people will have a much tighter definition.”*

One participant also mentioned uncertainty surrounding what is intended by ‘injury’.

P346- *“Another term that’s quite hard to understand is the risk of injury because it is really so hard to understand exactly what was being meant by that. Is that physical injury? Is that injury by teratogens like alcohol or viral infection?”*

Furthermore, participants felt that as the law did not stipulate the requirements for “severe malformation”, that the responsibility of deciding whether to offer a LTOP was left to the practitioners.

P977- *“It leaves us in a tough spot where now you sort of feel like the responsibility lies with you to decide if it’s severe enough to offer a late termination”*

Participants expressed concern that this has led some to apply a more liberal interpretation of the law, with other practitioners providing LTOP for conditions that participants felt the law did not intend.

P346- "In theory if you use that criterion you could actually end up applying the law very liberally and you'll find that different people have different opinions on how liberal the late TOP component of the act is; and it will partly relate to what does severe mean?"

P811- "I think that when life and death come into play, one should have more black and white rules, it shouldn't be open to interpretation."

As the law states that only two healthcare practitioners need to agree, participants expressed worry over the lack of regulation, especially in private practice where they felt there were no large teams or systems in place to ensure objectivity in decision-making.

P131- "The biggest disadvantage to me is it's actually, especially in private, not policed all that well so that two doctors can agree or a doctor and a midwife can agree after 24 weeks, after 20 weeks actually, and decide that the case fulfils the criteria; and as long as the hospital management is okay with that, that would pretty much go."

Ensuring that there is consistency in TOP provision was an important point raised by most participants. The majority of participants claimed that there were discrepancies between what would be offered at different hospitals (both in public and private), meaning that women are offered or denied a LTOP based on which hospital they attend. They believed that these current discrepancies in LTOP practice between different hospitals meant that women are being treated inequitably, which they felt was morally wrong.

P131- *“I think it is for me problematic in that we’re working for the same government and different criteria shouldn’t be applied because someone stays literally on the other side of the street and she goes to one hospital and on the other side she goes to the other hospital. I think maybe it shows the problem a bit more acutely, but I think the same thing happens nationally... I don’t think anyone’s actually done a good survey to know what actually happens in each hospital. I mean nationally we should be doing the same thing and I’m pretty convinced that we’re not doing the same thing and that is problematic to me.”*

Apart from the personal subjectivity that could cause one to be more liberal, another proposed reason for this was that practitioners, especially in private practice, may be put under pressure by their patients to provide LTOP and choose to err on the side of caution due to the fear of litigation.

P853- *“They feel since it’s open to interpretation that they are going to be more liberal because they are scared of one day being sued for not being prepared to do a certain TOP.”*

P811- *“It places a bit of pressure on the doctor sometimes to be quite pertinent in saying ‘but that’s not what the law says’ because it’s so open to interpretation some patients might think that you are just being difficult.”*

Guidelines, Policy and Standardization

Although the CTOPA requires that only two medical practitioners (or a medical practitioner and a registered midwife) need to be in agreement about the appropriateness of a LTOP, the decision to offer LTOP is often discussed by multidisciplinary teams (Govender & Moodley, 2013). In more complex cases where the ethics and legalities are unclear, clinicians are able to consult with hospital ethics committees.

Participants suggested that another way of ensuring consistency is to have some sort of documentation that could provide guidance as to what should be considered for LTOP. Participants felt that the purpose of a guideline should be to standardise LTOP practice across different hospitals. Whilst some hospitals in the country currently have an internal policy in place, most do not. They felt that if all hospitals were following the same set of guidelines, this would reduce the inequality which is currently occurring whereby patients are offered different things depending on where they go and who they see.

Interestingly, the majority of participants expressed they felt that this needed to be a national guideline and some even contemplated whether it should be legally enforced.

P131- "The one thing that I would ideally like to see is that there's a national consensus, whether it's legally enforced I think will be difficult because the field changes so much, but at least the law could say that there has to be some kind of national consensus and you have to operate within that."

P811- "I just think we need a more structured document... it should come from the government as well not just the government sector health education or health department."

The consensus was that this document should be drawn up by the fetal medicine specialists with input from different disciplines involved in fetal decision-making, as well as ethical and legal experts. They felt that it should be based on the most up to date research in the field and would need to be updated on a regular basis.

P811- "Find everyone in the field and make sort of a what they call a Delphi consensus and start with different criteria get all the people with the most experience in the field together and start with a document and say how did everyone feel about this? And what's the

evidence on that? And systematically work through every single thing. It obviously takes time.”

P346- *“It includes people with a legal background, so not just ethics, but ethical-legal and a range of disciplines involved, so you would have paediatrics for example involved there which is relevant to fetal decision-making.”*

Furthermore, participants felt that a guideline would provide clarity around what conditions should be allowed for LTOP – in the recognition that it would be unrealistic to list each specific condition as some are complicated and difficult to define. To resolve this, they suggested that there could be certain conditions which are defined and that the more complicated cases would need to meet certain criteria in order for the anomaly to be considered severe enough for LTOP.

P131- *“There are always going to be patients where the condition is ‘is it this way or is it that way?’ That would be one with more discussion about it but the majority of patients you would know that this is what the guidelines tell us and this is what you’re going to do.”*

However, some participants were apprehensive as to whether it would be possible to draft such a document given the complexity of many LTOP cases.

P489- *“Late termination of pregnancy is difficult to put in a box; every case is individual. I think the best value comes from a very broad panel decision-making process. I don’t know that you could necessarily put it in writing.”*

Furthermore, one participant felt that a guideline document would not help guide the decision-making process in cases where there was uncertainty and that in these cases, the panel discussion was sufficient.

P489- "I don't feel a lot of uncertainty around certain conditions in our meetings, actually. So, I think we all agree usually; I think the points are very minor. I think most of us, when it comes to a feticide, we all agree."

In keeping with this, participants cautioned against creating a strict protocol which may hinder the ability to openly discuss and scrutinize contentious cases. Instead, they felt that any documentation or guidelines should supplement the multidisciplinary teams' discussions and streamline decision-making by making it clear what is permissible in the case of LTOP as this would aid teams in making practical decisions.

P489- "I don't know that you could necessarily put it in writing because you would have to [...] say 'spina bifida at this level gets [this], spina bifida at that level doesn't but actually spina bifida with severe ventriculomegaly and an AVSD is different too'. I think it's going to be difficult to put everything down on paper."

P346- "If you're going to have a policy that people are all comfortable with and outcomes that people are all comfortable with then you need to be [...] able to communicate how it works on a patient by patient basis."

Summary

This Chapter illustrates that participants felt that the CTOPA is fair in that it balances maternal agency with fetal interests. They felt that the primary benefits of the CTOPA are that it allows

reproductive choice and LTOP, both of which they thought to be meaningful and impactful aspects of their profession. They felt that the specified cut-offs in the law are arbitrary and not aligned with current clinical practice and suggested that these possibly need to be redefined. However, they thought that a weakness of the CTOPA is that the criteria for LTOP are open to interpretation and that some practitioners apply a more liberal interpretation which has led to differences in practice between hospitals and ultimately to inequalities in what women are offered. While they felt that the panel decision-making process was necessary, they felt that further documentation was needed to refine the criteria in the CTOPA and provide clarity on which conditions should be considered for LTOP. They felt that this would aid in standardising LTOP practice between hospitals and improve equality in LTOP service provision.

Table 1: Summary of Chapter 4: Views on the Choice on Termination of Pregnancy Act, 1997.

Participant Perspectives on the Law

- Balancing maternal and fetal interests; the principle of gradualism.
- Reflecting society’s morals and values.
- Allowing for elective TOP and LTOP for severe malformation.
- Arbitrary and impractical cut-offs.
- 24 weeks as a more relevant cut-off; grading of severity.
- Allows feticide.
- Cut-off for rape and incest potentially too restrictive.

Interpretation of the Act and Subjectivity

- “Severe malformation” is vague and open to interpretation; “injury” is unclear.
- Subjectivity and lack of regulation; inequality in LTOP provision.
- Reported practitioner’s potential fear of litigation.

Guidelines, policy and standardisation

- Suggestion of national LTOP policy or guideline.
- Difficulty in defining criteria and which conditions should be considered.
- As a supplement to guide multi-disciplinary teams.
- Needs to still allow for discussion of difficult cases.

Chapter 5: Considerations in Decision-Making Around Late Termination of Pregnancy

The previous chapter describes the perceptions participants had of the Choice on Termination of Pregnancy Act (CTOPA) and identified problematic areas that they felt needed to be addressed. This chapter attempts to shed light on the considerations that interviewees describe taking into account in decision-making around offering late termination of pregnancy (LTOP). While the law allows for LTOP, the role of the practitioner is essential as they ultimately decide whether or not a LTOP should be offered in particular circumstances. The chapter begins by exploring what participants viewed to be the significance of fetal age and viability and perceptions on feticide. Next, it describes what participants believed a “severe malformation” to be and how this corresponded with how these were described in the law. Finally, it explores other considerations taken into account in LTOP decision-making – such as danger to the mother’s life and the socioeconomic circumstances of the parents.

Team Decision-Making

As mentioned in the previous chapter, LTOP decision-making is often made by a multidisciplinary team. Participants unanimously agreed with the necessity of these teams in the decision-making process. They acknowledge that it was difficult sometimes to be objective as there are other factors of the case that may influence their thinking and that a team approach to decision making promoted objectivity and consistency in LTOP provision.

***P977-** “You have to work towards making it as objective as possible and you do that by having a diverse team that comes from very different sides [...] I think that how you try and overcome that subjectivity is by sitting in a group, having different discussions and by trying to say am I wanting to offer a late termination because I feel like it might be a little bit hard for her or because objectively this child has severe problems?”*

P131- *“I think that’s [...] where consensus is important, that there is a kind of graded scale of you know how severe is the condition and how much other factors are there involved.”*

Furthermore, they felt that it was important to them to know that the decision was supported by their colleagues, the institution and the law and was based on consensus.

P346- *“I’m doing it on behalf of the team, I don’t feel that I’m doing that on behalf of myself. And I’m doing it within the sort of constraints of the law and of our own sort of institutional policy.”*

Participants noted that an additional benefit of such teams was that the responsibility of decision-making was shared amongst a number of individuals and therefore no one person needed to bear the full weight of the moral responsibility.

P977- *“In the end it is not just your decision, you share that decision, that heavy burden of trying to make the right decision is shared and that’s what kind of makes it easier in the end.”*

The Significance of Fetal Age

As mentioned previously, participants perceived there to be a grey zone between 20 and 24 weeks based on viability occurring at 24 weeks. However, while they agreed with 24 weeks as the practical cut-off for viability, some participants felt that the point of viability was also part of the gradual development of the fetus and that there were no drastic differences between fetuses a week earlier or later than the point of viability.

P346- *“I have quite a direct sense of what a 32 week or a 28 week fetus does and can do and may achieve but I don’t know that that necessarily in my mind, even if you decided at 25*

weeks compared to doing a TOP at 23 weeks, I don't know that I would have an enormous distinction in my mind about those two things."

However, whilst recognising the significance of viability, other participants felt that the fetal age did not influence their view on the value of the fetus and that they viewed the fetus as having the same value at any point in gestation.

P489- *"So I [...] have this sense that it is a life from very early on. So, I mean obviously it has to only have legal rights when it's born, that's legalities, that's how it is. But I would still feel the same sadness around any gestation period."*

P811- *"To me it's sort of the same baby. I would only use the cut-offs of the guidelines but I think ethically the baby has the same worth at 20 weeks that it has at 24 weeks."*

Some participants suggested that the indication for a TOP needed to be more severe after 24 weeks as a feticide was required.

P346- *"You could argue that because a more technically and emotionally difficult procedure like feticide needs to be applied typically from 24 weeks then maybe applying different criteria to what constitutes a severe malformation is reasonable as well."*

The CTOPA does not state an upper limit on fetal age for LTOP and therefore in theory, LTOP can be offered until term for a severe malformation. Some participants felt that if LTOP were offered for a severe abnormality then the gestational age was not a limiting factor. It is important to note that there are practical medical reasons for trying to do a LTOP earlier rather than later and that participants did not necessarily disagree with these. Rather, they felt that in theory, LTOP could be done until very late in gestation if the condition were severe enough.

P811- *“Some things you can stop the pregnancy at 40 weeks or 36 weeks if it is a really, really severe thing where you know the outcome is almost certainly extremely poor.”*

P489- *“It doesn’t matter if you’re 34 weeks, 36 weeks, 38 weeks, if it’s for a major abnormality then it’s the same for me in my head.”*

The Requirement for Feticide

As described in Chapter 2, feticide involves actively stopping the heart of the fetus to ensure that the fetus is delivered stillborn. There was wide consensus among participants that feticide is an emotionally unpleasant procedure. Some participants expressed that this was because it was more active and felt more deliberate than an induction of labour.

P977- *“It would’ve felt easier or less like I did something if it’s just a medication and we start labour because it almost just feels like a miscarriage, whereas the idea of somebody having to inject something into a heart to make a heart stop is very active.”*

One participant even expressed that it would be easier for them if feticide were not an option as they find it morally challenging.

P853- *“It’s very much a burden. If feticide was illegal, it would actually suit me personally [...] I wouldn’t have to think about it; I wouldn’t have to challenge my own conscience the whole time.”*

However, participants were able to overcome this emotional burden and believed that feticide was “the lesser evil” in cases where it would prevent long-term suffering. It made it easier for them to know that the reasons for doing it were justifiable.

P131- *"I think the feticides is really the most horrible thing and I would only do it if it would be more horrible not doing it, if you can understand what I mean. You know I'd rather do this than know that this is a baby that's really going to have years of suffering and then die."*

Furthermore, they felt that the option to have a feticide was more humane for the parents as it offered them the choice of not having to deliver a live baby, which could ultimately reduce the trauma and guilt associated with LTOP.

P977- *"I feel that it would be way more dramatic for a woman to have to make a decision to have a TOP and then the baby is alive. I cannot imagine the trauma that you must go through if that happens. I think there are women that choose that and that hope the baby would live a while but I think a woman who expects the baby to not be born alive should not have to hold a live born baby and think that they did this to their child."*

Some participants felt that the requirement for feticide was taken into account in their decision-making as they were cognisant of the fact that it would involve an active intervention.

P977- *"It comes into my pre decision-making where I would decide I know this is so bad that you would have to do a procedure to stop this baby's heart, so I take that into account."*

In contrast, other participants felt that the requirement for a feticide procedure did not affect their decision-making as it achieved the same objective outcome as an induction of labour.

P131- *"If we take 21 weeks or 25 weeks, 21 weeks could be an induction of labour without any procedure before and 25 weeks you'd need a feticide beforehand. Subjectively it's different but I think objectively for me it's the same; it's a different means to the same end."*

Furthermore, participants felt that the opinion of the person performing the feticide should have weight in the decision-making as they have to be comfortable with doing it because they ultimately carry the heaviest burden.

P346- *“I think that the opinions of those people should weigh quite heavily because they’re probably the ones that bear the biggest emotional burden of doing it.”*

What Counts as a ‘Severe Malformation’?

The CTOPA prescribes that a TOP may be performed after 20 weeks gestation in the case of a “severe malformation of the fetus”. As described in the previous chapter, participants felt that the term “severe malformation” was vague and open to interpretation. Participants felt that there were differences in what could be considered to be severe.

P811- *“I mean to some people, not having an arm for example is very severe but according to that guideline [referring to an institutional guideline] it’s not something severe because you can continue working with your other arm. But also, you know that a person with one arm would not have the same quality of life that I have with two arms. It’s very difficult.”*

Participants unanimously felt that for a condition to be considered “severe”, there would need to be a profound negative impact on the functioning and quality of life of the future child. They felt that this included any condition that would lead to long-term suffering and disability.

P853- *“Especially after viability, it’s really about what quality of life will this individual have? If we can be pretty sure that it’s going to be a really poor quality of life or a very short life with a lot of suffering and a very low level of functioning, then that is the group I feel is intended by the law.”*

P977- *“For me the idea that you can have a really rough six months but if you make that six months, you’re going to be fine, I don’t always feel so comfortable offering a TOP for that... The perspective that I come from is way more long term.”*

Some participants felt that LTOP should only be offered in cases where there would be no treatment available to the child that would improve the outcome and that only palliative care would be provided. They felt that they would not offer LTOP for conditions where there was a surgery or treatment available which could resolve the anomaly, even if the condition was severe and life-threatening.

P853- *“There is a difference for me between what is medically severe in the context that it will need treatment- it’s not a trivial thing, it will need treatment- versus it’s severe in the context of you now offer the option of killing that person.”*

P811- *“It’s something that cannot be corrected, only palliated, so a child’s life may be prolonged but not necessarily result in normal function afterwards.”*

Participants articulated that just because the child hasn’t been born yet does not mean LTOP is justifiable. In this way, a post-viable fetus with a specific anomaly should be viewed as if it were a neonate with that specific condition and the treatment options available should be considered.

P853- *“Especially after viability, my argument will always be that now she’s 38 weeks but she could have delivered last week with a cleft lip and we would have just treated a cleft lip.”*

Participants spoke of uncertainty of the prognosis in certain cases and that decision-making in these cases was more challenging due to not knowing how severe the outcome will be.

P977- *“The hardest ones are the ones where you then sit with ‘I actually honestly don’t know’. I know the chances are high enough that I’m comfortable sitting here offering you this choice but might it be less?”*

However, participants felt that while there is the odd case where the outcome was not as severe as what was anticipated, that this does not mean that the system should be changed.

P346- *“One will see the occasional case when people declined a TOP and the outcome was not as bad as expected. So, there’s quite a lot of things that can give one pause for thought but that doesn’t necessarily mean that overall, the approach is wrong. So certainly, one needs to be thinking about it and learn from experience and feed that back into the way that the system works.”*

Considering the Mother’s Life and Wellbeing

In addition to considerations about the future health of the child, participants also felt that the mother’s health should be considered. In particular, participants felt that if the mother’s life is endangered then preference should be given to her life and not the fetus’ life. This is in agreement with the CTOPA which allows LTOP in cases where the continued pregnancy would put the mother’s life at risk. They felt that the woman is already an autonomous person with legal rights and a family and the consequence of losing her life would be greater than losing the fetus.

P131- *“I mean it still is a baby’s life but now the whole dynamic is different. So, in a sense it is an easier decision to make and you’re sort of forced into the decision whether you want to or not.”*

Similarly, participants warned against taking socioeconomic factors into consideration as it may lead to a slippery slope, which would ultimately complicate decision-making even further.

P811- *“If we started opening that, it would really open a can of worms and then there would really be no lines anymore, because then everyone will always have some sort of specific extra, extra unbearable kind of condition that adds to the weight of the consideration. I don’t think that that will help us in making decisions at all, it’s just going to make it more difficult”*

Furthermore, they felt that respect for life should be upheld in decision-making where there are difficult socioeconomic factors such as access to care or medical mismanagement.

P131- *“In the same way, you see someone who has accessed the healthcare from early on but she has just been managed very badly and now at 32 weeks it’s discovered that the baby has a serious problem, but not so much so that you would now think it’s serious enough to opt for a late termination. I can’t start preaching sanctity of life now but let’s say respect for life would then also be a strong argument in all of that.”*

In contrast to this, some participants felt that it was necessary to assess the ability to access the care available and that this is often influenced by socioeconomic factors. They felt that there should be some consideration of the potential for the child to receive the medical care that is needed if it would impact the severity of the condition. However, they felt that it was important to be cautious when doing this to avoid injustice or inadvertent discrimination.

P346- *“It’s important to be very clear that we don’t use for example, low socioeconomic status to discriminate against people [...] but if the socioeconomic circumstances change our assessment of the severity of the condition, that would be level of disability, degree of suffering involved, the burden of care involved, then that might make a difference. So, for example someone with a spina bifida in a far-flung rural area who might need to come to clinic reasonably regularly, that would be a bit different to someone who stays close to the hospital.”*

Furthermore, some participants felt that there should be consideration of the burden that would be placed on the family by caring for a child with a severe disability.

P489- "If you speak to the cardiologists, the paediatric cardiologists, they will tell you that a baby with a severe cardiac defect can tear a family apart because they aren't, you know the baby just takes all the focus of the entire family and for the two or three or four or five years of operation that those children go through, the other kids are neglected in that family, potentially. And you know, so I think if anything is going to require multiple medical interventions for an outcome that is not necessarily that clear then one must have choices around that anyway."

Summary

This chapter looked at the various factors that can influence LTOP decision-making including the significance of fetal age, whether or not feticide is required, the severity of the prognosis, endangerment of the mother's life and socioeconomic circumstances. The following chapter will explore the complexities of the moral dilemmas that practitioners are faced with in LTOP decision-making.

Table 2: Summary of Chapter 5: Considerations in Decision-Making Around Late Termination of Pregnancy.

Team Decision-Making

- A multidisciplinary team approach promoted objectivity and consistency.
- Decisions are supported by colleagues and the law and based on consensus.
- Shared weight of moral responsibility.

The Significance of Fetal Age

- Viability at 24 weeks, but also as part of continual fetal development.
- Some viewed the fetus as having the same worth throughout gestation.
- More severe indication for LTOP because of feticide after 24 weeks.
- LTOP could be done until late in gestation if the condition was severe enough.

The Requirement for Feticide

- Feticide is an emotionally unpleasant procedure.
- Some participants found feticide morally challenging.
- However, felt it was justifiable to prevent suffering.
- More humane option for parents.
- For some, the requirement for feticide influenced their decision-making, but not for others.
- More weight given to the opinion of the person performing the feticide.

What Counts as a Severe Malformation?

- Differences in what is considered to be severe.
- Profound negative impact on the functioning and quality of life of the future child leading to long-term suffering and disability.
- Conditions where there is no available treatment.
- Just because the fetus hasn't been delivered, doesn't mean LTOP should be an option.
- Decisions are more challenging when the prognosis is uncertain.
- Cases with a less severe outcome than expected doesn't mean the system should change.

Considering the Mother's Life and Wellbeing

- The mother's life should be favoured as she is an autonomous person.
- Warned against considering socioeconomic circumstances; "slippery slope".
- Respect for life should be upheld even in cases of medical mismanagement or delayed access to care.
- Some felt that socioeconomic factors which would influence the child's access to care could be considered if it would influence severity.
- Some felt that the burden on the family should be considered.

Chapter 6: The Healthcare Practitioner as a Moral Agent

The previous chapter described the considerations taken by fetal medicine practitioners (FMPs) when deciding to offer a late termination of pregnancy (LTOP). This chapter explores the morals and values of FMPs and how their personal and professional ethics might influence their views on LTOP provision.

Professional Responsibility and Empowering Patients

Overall, participants felt that as LTOP is accepted within the context of the law and that providing LTOP was within their scope of practice, it was therefore their professional responsibility to provide LTOP.

P811- *"I sort of feel that it's my responsibility because they can't go to anyone else."*

They felt that putting this professional responsibility before their own personal ethics was necessary and that it was not about how they felt about LTOP, but rather that it was their patient's choice.

P977- *"My view is if we feel something is ethically and legally correct, it's not up to me to make the decision if for that person it's correct."*

Participants described that having a child with a serious disability can be a major burden on parents. They felt that by providing LTOP, they were empowering their patients to make a decision which could potentially impact the course of their life and prevent them from having to endure the difficulties and challenges that are associated with having a severely disabled child.

P489- *"So giving the woman the right to not be in that compromised situation is a very important service that I can offer my community and my patients, particularly giving them the choice not to have a disabled child."*

P811- *“The child’s life will obviously change the parent’ life forever and if they are still of reproductive age, they have a chance of having a healthy child and a healthy future. They can save themselves from this very difficult job, very difficult road.”*

They felt that as LTOP was their responsibility, that choosing to not provide LTOPs conflicted with their moral convictions as it would result in suffering for the future child which could have been prevented.

P853- *“There are unpleasant parts in our job, I think we chose this job and you can’t just run away from responsibilities.”*

P131- *“If [late termination of pregnancy] actually means less suffering, then for me, I wouldn’t say cowardice, but I think one should step up as professionals and do that, instead of saying let mother nature take its course and let the baby die after minutes or hours or days of suffering.”*

Moral Values

Throughout the interviews, participants mentioned circumstances where they sometimes felt that their moral positions were potentially incongruent. For example, one participant described how there was a contrast between trying to retain a pregnancy for one patient and at the same time actively ending a pregnancy for another patient.

P489- *“The flipside is that often you will have times where you fight so hard to try and hold a pregnancy and at the same time as you’re actively terminating another one.”*

Another felt that in their work, there was a contradiction between advocating for patients with disabilities and offering LTOP for the same condition. However, in this case they felt that this aided

their counselling for LTOP as it enabled them to provide deeper insight into what living with a child with this condition might be like for their patient.

P977- "I think it is an unusual position because if you think of Down syndrome, [...] we're all very involved in Down syndrome decision making and all those things; but I feel like I can separate myself out and use that information to better guide people to say that this is what life is really like."

While they ultimately respected the parents' decisions, participants described how at times they were troubled when parents would choose not to LTOP in instances where they knew that the future child would experience suffering.

P346- "I don't think that offering those sorts of options per say troubles me, I think the decisions that people sometimes make do. Probably more often when they choose to continue a pregnancy when I know that there's going to be a lot of suffering and minimal quality of life."

P489- "I've got patients with spina-bifida children who decided not to terminate their children and every time I see them, I think 'oh my word'" because this child just is going to have a very difficult life and I don't think parents perceive that. They just take it as it comes but I don't know if they necessarily perceive ultimately what that quality of life will be and how difficult it will be."

Of those who spoke about their religious and spiritual beliefs, some felt that they were able to put aside their personal views over the loss of the fetus' life because they acknowledged that the choice to end a pregnancy is a difficult choice to make and that they were in a position to help those women and families. They felt that it would be worse if women were not given a choice and were forced to continue with a pregnancy.

P489- *“You have this duality between feeling sad about something and having this sense that a fetus is a potential soul and a part of this world and a life. And you have the other side of it where you realise that allowing women to make choices empowers them and that is overwhelming obvious.”*

P977- *“I can still subscribe to religion but somehow still separate out the things that don’t sit well with me but again I think it’s because I don’t feel like in my religious life I don’t feel like I need to explain it to a minister or the church I feel like it is something higher [...] I would rather be there for them and help them through that decision making than not be there and have somebody tell them what they have to do because I think that would be worse and that’s why I feel I can justify it.”*

Similarly, others felt that while they were morally conflicted because of their religious beliefs, they were able to disconnect from this because they felt that God had placed them in a position to help, even if it involved going against their religious views on TOP.

P811- *“It is a very difficult one because it sort of is against everything that I believe religiously. I think all Christians worry or wonder and think how does this...? There’s an internal struggle with that. I also believe that God places you in places to help people in strange ways that you wouldn’t have been able to foresee because it doesn’t make sense. It’s sort of an academic versus a religious brain.”*

Participants spoke of the personal burden that comes with the responsibility of making life and death decisions, particularly in circumstances where there is medical uncertainty. One participant shared that when looking back on past decisions in light of new knowledge, this sometimes made them question whether they had made the right decision. They felt that it was important for them to be compassionate with themselves and keep trying to make the best decisions at the time.

P977- *“It still feels that at the time we were doing what we felt was equitable and what was appropriate and what was right but if you look back on it now you think... But what can I do with that? I can only try learn from it. I can’t take it back, I didn’t do what was wrong at the time, I can’t hate myself for it because then you won’t get up in the mornings.”*

Furthermore, participants felt that at times their profession required them to put aside their personal ethical views, and act in accordance with the majority decision. For example, although they may be of the opinion that a certain condition warrants a LTOP, if the majority view is opposed to it, then they are prepared to concede.

P346- *“So at a personal level I would be prepared to contemplate it, and I know that that is a minority position in the world of people that do the kind of work that we do. And I’m prepared to kind of live with the discordance and go along with the majority opinion.”*

The Importance of Non-Directive Counselling

In line with promoting reproductive choice, participants felt that the decision to have a LTOP was the parents’ decision. They felt that it was important to be non-directive in their counselling and to provide information to the parents in a way that was unbiased to ensure that parents were not coerced in any way. They described how taking a neutral approach to counselling helped them retain their integrity as they were not making choices for their patients.

P346- *“I think sticking strictly to a non-directive approach with regards to the fetal condition sort of makes it easier to do the work, not just because it’s the right thing to do for the family but also I don’t have any real sense that I’m playing God.”*

P811- *“If we told everyone this is what you should do, then we would not be able to come to work. The burden would be too much.”*

Participants felt that it was their role to provide counselling in a compassionate way that enabled their patients to make the best decision for themselves. They felt that sometimes this required a more in-depth discussion with parents to encourage them to reflect on the possible outcomes and think about what LTOP meant for them in the context of their own beliefs and values.

P346- *“I think getting that information from someone who facilitates you making a decision and does that in a compassionate kind of way is really important.”*

P853- *“If I see people are doubting a bit especially for the anomalies where I think it’s going to be fairly self-limiting and short term then I’ll definitely bring out like they don’t have to have this feticide and they must really think about it carefully because it’s such a final decision that you can’t ever come back to and they must take into consideration their own psychological well-being for the next 70 years.”*

However, they questioned if it is possible to be truly non-directive in counselling. They felt that in order to be as neutral as possible and to preserve their moral integrity, they needed to be self-aware and reflective of their counselling.

P346- *“That does protect my own sense of integrity in the process. People have critiqued whether you can be truly nondirective. There are obviously limitations and I don’t know, maybe you do subtly somehow influence things as much as you try to steer away from that kind of thing.”*

P489- *“I think if you have a sense that you’re doing, if you sense that you’re providing the right support, if you sense that you have empathy, if you have a sense that you’re making a good calculated decision, if you have a sense that you’re listening to your patient and you know what she’s expressing to you, then I think you can sleep at night and be okay with it.”*

Late Termination of Pregnancy and Eugenics

As mentioned in the literature review, LTOP has been criticised for being aligned with eugenic practices. However, participants in this study felt that LTOP was not a form of eugenics as it does not take a paternalistic approach to enforcing LTOP for severe conditions.

P346- *“Eugenics was a forceful kind of thing- people were forcefully sterilized, people with disabilities were interned and worse. But to me it is quite fundamentally different [...] We’re not trying to cleanse society of Down syndrome [...] Those kinds of circumstances would start to make me feel a bit more uncomfortable about it.”*

Rather, they felt that LTOP in the context of severe malformation was about offering a choice to parents and respecting their choice to continue with the pregnancy. Therefore, the decision-making power lies with the parents and not with the practitioner.

P811- *“It’s not my decision, it’s still the patients’ decision, so I don’t have to believe that I’m at fault doing this.”*

P977- *“And that’s the thing I need to take accountability for. I can’t take accountability for what everyone in society will do. I can only try and help the person sitting in front of me to try and make the decision that they best know.”*

Additionally, participants also felt that LTOP was not intended for the purpose of reducing the incidence of disability in the population. They felt that although it may be a passive outcome of LTOP, it was not aligned with the key motivation, which was the prevention of suffering.

P131- *“I feel that one shouldn’t try to find the perfect baby. If you eliminate all ADHD and all that from the gene pool then I feel that we operate from the wrong premise [...] I think it’s outweighed by the suffering, the prevention of suffering for me far outweighs the little difference in variety.”*

Furthermore, given that LTOP is not commonly done, they felt any reduction in disability diversity resulting from LTOP was negligible.

P131- "I don't believe the very exceptional few cases of feticide [...] it's not going to have a big impact at all on the variety."

However, some participants felt strongly that LTOP should not be used for the purpose of preventing the birth of a child that would have a disability that would not greatly impact their quality of life.

P853- "Even if there are handicaps, if you can actually still function as a human being that you would regard as completely equal when interacting with them afterwards then you can't offer TOP for that."

P131- "You have a baby with some problems, it's not going to be the perfect baby but not a child that's really going to experience suffering or cause suffering."

Furthermore, they were uncomfortable with the intolerance of disability that parents sometimes expressed and felt that to do a LTOP for the sake of the parents not wanting a child that wasn't perfect would be morally wrong.

P853- "I'm not doing it just because mom doesn't want a baby that doesn't look perfect but I really do it because I really think this kid would have very poor quality of life. I'm actually trying to prevent suffering for the child that would otherwise be born."

Similarly, some participants felt that there needed to be a greater acceptance of disability in society and that efforts needed to be made towards improving access for those with disabilities.

P853- "I think we must focus on improving the care for everybody and especially the vulnerable rather than expanding our indications for feticide. I think in my mind it should be

for severe conditions with a poor quality of life and not just any life that isn't exactly like yours and mine."

Summary

This chapter described the importance that participants give to patient autonomy and how non-directive counselling promotes patient autonomy. Furthermore, it described how participants felt that offering LTOP is their professional responsibility and that it assists in reducing suffering. It highlighted various examples where participants reported sometimes experiencing a contrast of values within LTOP practice. Lastly, it described how participants view LTOP as promoting reproductive choice and distinct from eugenics.

Table 3: Summary of Chapter 6: The Healthcare Practitioner as a Moral Agent.

Professional Responsibility and Empowering Patients

- Participants felt the LTOP was their professional responsibility.
- They felt that their personal values should not restrict the choices available to others.
- LTOP empowered patients to choose to not have a disabled child.
- Those who felt LTOP prevented potential suffering felt that not providing LTOP would be against their morals.

Moral Values

- Participants reported sometimes being faced with moral dilemmas.
- Sometimes the decisions that patients made were unsettling because they conflicted with the practitioner's views on preventing suffering.
- Participants were able to put aside their religious views as they believed it would be worse to force women to continue with a pregnancy.
- LTOP decision-making can be morally burdensome.
- Participants were accepting of their opinions being different to the consensus.

The Importance of Non-Directive Counselling

- The choice needed to be the patients' and practitioners should be neutral.
- Sometimes counselling required more in-depth discussion aligned with patients' values and beliefs.
- Participants questioned whether it be possible to be truly non-directive and felt that self-reflection was important in preserving moral integrity.

Late Termination of Pregnancy and Eugenics

- LTOP does not take a paternalistic approach.
- The patient makes the decision.
- Any reduction in disability was a passive outcome of LTOP as the primary intention is to prevent suffering.
- LTOP should not be permitted to prevent the birth of imperfect children.
- Participants felt that efforts should be made to improve access for those with disabilities.

Chapter 7: Discussion

The aim of this study was to investigate the views and experiences guiding decisions to offer late termination of pregnancy (LTOP) of fetal medicine practitioners (FMPs) in the Western Cape. Chapters 4, 5 and 6 described the empirical results related to practitioners' interpretation of the law; the various factors they considered in LTOP decision-making; and how practitioners' values may influence their decision-making. This chapter focuses on exploring four overarching insights that arose during the data analysis.

Gradualism and Fetal Age

As a whole, participants described that while the Choice on Termination of Pregnancy Act (CTOPA) allows for unrestricted reproductive choice until 12 weeks gestation, it progressively affords a level of protection to the fetus by imposing greater restrictions from 12 to 20 weeks. They also considered that it is virtually illegal to terminate a healthy fetus after 20 weeks. They believed that although the fetus is not legally considered a person with rights, the restrictions outlined in the CTOPA suggest that the law takes a firm stance on the progressive protection of the fetus, a position which has previously been described by Pickles (2012). Based on this interpretation, some participants believed that the law is based on the principle of gradualism. The idea of gradualism as a premise for the CTOPA has also been described by some authors who felt that while it is not explicitly stated within the law, it is apparent through the gradual restriction on TOP that the fetal life is evidently granted greater protection later in gestation (Hall, 2013).

McMahan (2002) compares gradualism in fetal development as akin to the slow degradation of the brain seen in patients with Alzheimer's disease. In individuals with Alzheimer's, there is no definitive point in time that one can point to and claim that the higher mental functions associated with being a person ceased to exist. He argues that the same applies to fetal development, which is a continual process without specific, easily-identifiable neurodevelopmental markers. Based on this idea of the

fetus gradually gaining the capacity for the higher mental functions required for consciousness, it could be argued that TOP becomes increasingly morally wrong as the pregnancy progresses. While some participants seemingly agreed with this position, others did not hold this view and ascribed moral status to the fetus at a much earlier gestation and as such, did not necessarily feel that there was a change in the moral status of the fetus as gestation advanced. Interestingly, a number of these participants also expressed their religious/spiritual views about fetal life, which may influence their views on the moral status of the fetus. While there is insufficient data in this study to draw further conclusions, the importance of religion on LTOP views has previously been described by Habiba and colleagues (2009), who found that in countries where adherence to religion was higher, participants tended to support a more restrictive LTOP policy.

The CTOPA includes very distinct cut-off points. However, as fetal viability is largely considered to occur at 24 weeks, some participants questioned the significance of a 20-week cut-off and how it relates to fetal development. One participant suggested that a possible reason that 20 weeks was chosen was on the assumption that the gestational age at which fetal viability occurred would continue to decrease, thus 20 weeks was chosen as a reasonable gestation at which to draw a hard line. Hypothetically, another potential explanation for the 20-week cut-off is that the capacity for consciousness is thought to occur at some time between 20 and 28 weeks (McMahan, 2002). Consciousness is considered by some to be a requirement for personhood and thus a fetus capable of consciousness may theoretically have the potential to become a person (Tooley, 2009). For this reason, the CTOPA may have taken a conservative view based on the potential for personhood, which further solidifies the argument that the CTOPA protects the interests of the fetus. Regardless of the reason why the CTOPA chose 20 weeks as the cut-off, some participants thought it was impractical given that a fetal anomaly (FA) scan was generally performed between 18 and 22 weeks and argued that this could have potential consequences for those patients who received their FA scan at 22 weeks as opposed to 18 weeks. Participants felt that this could result in issues around

justice and equity if some women were offered a TOP and others were not based on the gestational age at which they received their FA scan.

Participants also felt, based on the principle of gradualism, that there may be a need for a difference in the criteria for severity the later in gestation the TOP is performed. For instance, a condition with a milder (but still significant) prognosis could possibly be permissible between 20 and 24 weeks but perhaps not after 24 weeks. While one participant stated that they do not believe there to be any substantial difference in the development of a 23-week vs a 25-week fetus, they felt that a gestational cut-off for LTOP needed to be made from a practical perspective. As a whole, participants proposed that 24 weeks could be a more appropriate cut-off for LTOP than 20 weeks as it allowed sufficient time for testing based on an abnormal FA scan, as well as aligning with the point of viability.

Some participants felt that this cut-off of 24 weeks was directly related to the requirement of a feticide procedure and that they were more hesitant to perform a TOP after 24 weeks because of feticide being a more morally demanding act than induction of labour, despite the fact that they result in the same outcome. This correlates with similar findings by Harries and colleagues (2012) who described that HCPs were more comfortable with medical induction than a surgical procedure - in this case dilation and evacuation (D&E)- as they found it less emotionally challenging. This possibly suggests that their discomfort with feticide is not necessarily related to them perceiving a change in the moral status of the fetus based on gestational age but rather has to do with the procedure and their ability to more easily morally distance themselves from an induction of labour. With feticide, the fetus demises as a result of cardiac asystole following an intracardiac KCL injection (which is direct); whereas in the case of induction of labour, fetal demise results as a consequence of the fetus being delivered too prematurely (which is indirect). Therefore, some participants' discomfort with feticide may infer their deeper beliefs about the moral difference between killing and letting die, a distinction addressed by Cartwright (1996) as it pertains to euthanasia. Furthermore, it could also be

that some individuals are uncomfortable with feticide as they believe that the act itself is morally questionable (deontology), whereas others feel that feticide and medical induction are morally the same as they result in the same outcome (utilitarianism) (Hursthouse, 1991).

In a similar study conducted in the UK, Statham and colleagues (2006) found that although the decision to offer LTOP is separate from the decision to offer feticide, respondents conflated LTOP and feticide as a single factor. Given that some participants in this study felt that the 24 weeks cut-off was directly related to the requirement of a feticide procedure, it could be postulated that participants felt that the decision to offer LTOP was dependent on the need for feticide.

The CTOPA provides no further cut-offs after 20 weeks and no upper gestational limit is given after which TOP is impermissible. Given this, participants believed that LTOP could be allowed at any gestational age provided the condition was severe enough. A thought-provoking counter-argument to gradualism in the case of severe disability is proposed by Statham et al., (2006), based on Paintin's earlier argument (1997). Paintin (1997) suggests that if the primary justification for LTOP, where there is a high probability of severe disability, is that it enables the woman the option of avoiding the struggles of having a severely disabled child, then LTOP should remain ethical regardless of when in gestation the diagnosis is made. Some participants held a similar view, that a LTOP performed at 36 weeks was the same as if it were performed at 32 weeks in the case of a severe abnormality.

Severe Disability

The discussion begins to get more ethically complex for LTOP in the case of severe malformation or injury. As mentioned in Chapter 2, some authors have argued that legislation which permits LTOP for a fetus with a severe malformation, but not for a normal fetus, is "discriminatory and eugenic" (Savulescu, 2001).

As a whole, participants in this study believed that LTOP should only be permissible in cases where it was expected that the future child's quality of life would be profoundly negatively impacted given the severity of the prognosis and a lack of available treatment; however, they were against the idea of LTOP being offered to prevent the birth of an 'imperfect' child. Participants therefore did not believe in LTOP for the purpose of preventing individuals with disabilities from being born. They believed LTOP should be reserved for anomalies in which there was little or no possibility of improvement to a degree that the individual may have a reasonable quality of life. If those criteria were not met, then they felt that LTOP should not be offered even if the fetus was 'malformed' in some way. In this, participants acknowledged that disability is a heterogeneous group of conditions or disorders and that some disabilities are more severe than others.

One participant raised an interesting point about what could potentially be intended by the CTOPA permitting LTOP in the case of severe malformation. They believed that if the future child were to have substantial handicaps, if they are still capable of functioning as a normal human being who would be seen by society to be equal, then LTOP should not be permitted. The same individual went on to argue that LTOP should not be offered just because the individual would have a "life that isn't exactly like yours or mine". What this could possibly suggest is that LTOP may be seen as ethically justifiable in instances where the future child would be impaired as to not be able to function as a normal human being, a view substantiated by Hall (2013).

Some participants believed that significant intellectual disability satisfies the criteria for severity. In individuals with severe intellectual disability, the neurological capacity for higher mental functions is often significantly impaired. Wilkinson (2006) describes intellectual disability as having an effect on an individual's ability to think, their awareness of themselves and their surroundings, the potential for communication and in the more extreme cases, even basic consciousness. Using anencephaly (a neural tube defect whereby the fetus' brain and skull are underdeveloped) as an example, he compares the infant as akin to an adult in a persistent vegetative state (PVS). With this in mind, he

highlights the difficulty in weighing up the benefits and burdens of existence in deciding whether such an individual would have an interest in continued existence. Similar ethical questions are considered in active euthanasia for individuals who are in a PVS (Shaw, 2007).

However, while there are certain conditions for which the prognosis is relatively clear, there are those conditions where there is a great deal of uncertainty. In these situations, participants found it more difficult to determine the acceptability of LTOP possibly because the potential quality of life was difficult to assess. From this, it could be suggested that some participants were only comfortable with LTOP in cases where the neurophysiological basis required for a level of functioning, which is thought to be necessary for an individual to experience a meaningful quality of life, is impaired.

The Potential to Prevent Suffering

As mentioned in Chapter 5, participants believed that the conditions which qualified as severe were untreatable and would have a significant, long-term negative impact on the individual's functioning and quality of life. Such a condition could therefore be thought to cause pain and distress for the duration of the future child's life. Participants did not view LTOP as a way of ending an unwanted pregnancy but rather, in the case of severe malformation, as an opportunity to intervene and prevent a lifetime of potential suffering. Even when discussing the personal burden of performing feticide, some expressed that they would rather endure the moral burden than to know that they had chosen not to intervene. Interestingly, some participants described feeling a sense of sadness when patients chose to continue with a pregnancy following the diagnosis of a severe malformation, potentially suggesting that this went against participant's personal morals, values, and beliefs about preventing suffering.

One participant mentioned that a child with a severe disability could "cause suffering". This could suggest that suffering was not thought to be limited only to the future child but that potential

suffering extended to the experience of families caring for a child with a severe disability. As mentioned by Petry et al. (2005), individuals with severe disabilities have limitations in their ability to meet their basic needs and thus rely on others for support in functions relating to quality of life, such as basic hygiene and nutrition. Furthermore, they often require regular medical visits and support aids which are necessary for their physical well-being. Therefore, caring for a child with a severe disability can be burdensome.

Acknowledging the heavy burden of care that is placed on the caregiver (which is predominately the mother), participants felt that women should be given the choice not to have a child with a serious disability. In this way, they viewed LTOP as a way of empowering patients to choose a better life for themselves, one free from the potential struggles of caring for a child who would require full-time care.

These findings reflect those made by Crowe et al. (2018) who describe how fetal medicine and social care professionals consider three main aspects when determining the acceptability of LTOP for non-lethal fetal anomalies. Firstly, professionals considered whether the condition could be 'fixed'- i.e. are there medical treatments available that would result in an improved outcome? Secondly, would the future child experience significant pain? And lastly, is it possible for the individual (and their family) to have a normal life expectancy?

Participants in this study were empathetic to the devastation that women may feel when receiving a poor prenatal diagnosis and respected the very personal nature of the choice that women had to make when offered a LTOP. Blakeley et al. (2019) presents a systematic review of the factors influencing parental decision making when faced with a poor prenatal diagnosis including the value that parents give to their child's life and their views on what is a life worth living.

Participants strongly believed that their role was to remain impartial and upheld the idea that the choice should remain entirely the woman's. In this way, some participants mentioned that this freed

them from the moral responsibility of making the ultimate decision. It is important to remember that while the role of practitioners is to decide whether a LTOP is medically, lawfully and ethically suitable, the ultimate decision is left to the woman to decide what value she gives to her future child's life. As such, they strongly believed that a paternalistic approach, whereby LTOP for severe malformations is not permitted, is wrong. Up until 2017, TOP was illegal in Chile even in instances where a lethal anomaly is diagnosed prenatally and women had no choice but to continue with the pregnancy. Casa & Vivaldi (2017) described that this restriction "violates [women's] human rights".

Some participants felt that the best way to counsel their patients in the case of a severe malformation was to focus solely on the medical information and remain non-directive as to allow the patient to make a choice free from bias or coercion. However, others took a different approach, particularly with very distressed patients, by helping them to identify which option- LTOP or continuing the pregnancy- best aligned with their values and would be better for their long-term mental health. All in all, participants felt strongly that in the case of LTOP, the woman's right to decide to end or continue the pregnancy should be hers alone.

Furthermore, some participants felt that offering feticide is necessary as it can remove the trauma of delivery a live fetus for a woman choosing a LTOP. From the perspective of the patient, it is noteworthy that 91% of women undergoing TOP between 20 to 23-weeks gestations reported that they preferred the fetus had demised prior to the TOP procedure (Jackson et al., 2001). However, this implies that 9% perhaps did not agree and highlights the importance of allowing the patient to make their own decisions regarding feticide.

Consensus as a Value

Although the law presumably outlines when a LTOP should be permissible, the decision of whether a LTOP is appropriate is ultimately left to FMPs. Participants in this study expressed feeling that there was little guidance with regards to the criterion for LTOP and felt that there was significant

variability in what HCPs considered to be 'severe' enough. This reflects findings by Habiba et al (2009), Jacobs et al (2005) and Statham, Solomou & Green (2006).

In order to reduce this ambiguity, participants suggested that LTOP decisions should be made based on the consensus of a number of individuals within a multidisciplinary team. Such teams are supposedly primarily focused on determining the probable prognosis and outcome of a specific case based on input from various specialists; therefore, determining whether the condition is sufficiently severe enough to warrant a LTOP. In this way, decisions are presumably less likely to be based on the subjective values of a few individuals but rather based on the objective medical prognosis. Shapiro and colleagues (2017) found that when dealing with uncertain cases within the neonatal or paediatric intensive care unit setting, physicians valued team decision-making as it enabled them tell their patients that all aspects of the case were considered in making difficult decisions. One benefit that participants mentioned was that team decision-making meant sharing the responsibility of decisions that are potentially morally burdensome. It could also be postulated that team decision-making on such contentious issues, such as LTOP, mitigates the risks of potential prosecution as the decision is supported by a number of experts.

Interestingly, participants expressed that there were times when they felt caught between two opposing moral standpoints. For example, one participant spoke of the apparent conflict between fighting to save one pregnancy while actively ending another. Another participant expressed being able to separate their religious views on the sanctity of life from their professional views on LTOP. In a way, both were torn by the seeming cognitive dissonance of prescribing value to fetal life while being involved in actively destroying it. This phenomenon of one individual holding two opposing moral views is known as moral ambivalence (Wong, 2006). As participants were able to justify both situations, this suggests that their personal values and their ethical views were not absolute, but rather that they were influenced by context. Participants acknowledgement of their moral ambivalence could suggest that they were aware of their own potential subjectivity and the

potential influence that their own personal values could have when making ethical decisions. To further support this claim, participants spoke of valuing the objectivity that comes with multidisciplinary teams being involved in decision-making, as a way of policing their own subjective views. Furthermore, some participants recognised that their personal views were different from their colleagues, and were content with decisions being made according to the prevailing consensus, even if this did not align with their personal views.

Additionally, participants expressed feeling uncomfortable with knowing that there were practitioners who were applying the law liberally and as such, were performing LTOP outside of the context in which it is intended. They felt that this had led to discrepancies and inconsistencies in the options available to patients and as a consequence, had possibly resulted in inequitable LTOP service provision. Moreover, they were more uncomfortable with the idea of subjectivity around LTOP as they believed that 'life and death' decisions should not be taken lightly. In order to address this issue, most participants felt that additional documentation or guidelines are required to stipulate exactly which types of conditions meet the criteria for severity. Clinical practice guidelines are used extensively throughout various areas of medical practice and are generally developed based on expert consensus. The development of guidelines has many benefits such as determining views on the appropriateness of certain treatments or procedures, as well as identifying contentious topics which may require additional discussion (Kea & Sun, 2015). Recommending the development of guidelines further supports the idea that participants valued consensus and desired regulation and standardisation within this morally challenging area of fetal medicine.

Chapter 8: Conclusion

Participants felt that TOP should become progressively more restricted as gestation advances in order to protect the fetus, particularly after viability. However, they felt that the 20-week cut-off defined in the CTOPA is arbitrary and open to interpretation. When making a decision to offer LTOP, participants considered various factors including fetal age, whether a feticide was required and the severity of the prognosis. Participants considered that conditions which qualified as severe were untreatable and would have a significant, long-term negative impact on the individual's functioning and quality of life. When considering acceptability of LTOP, participants felt that LTOP was justified to prevent suffering for both the future child and for the parents. However, participants did not believe that LTOP was justified to prevent all disability. Lastly, participants believed that while multidisciplinary teams are necessary in making LTOP decisions, there is a need for further documentation to guide practitioners as to which conditions should be considered for LTOP in order to ensure consistency and fair LTOP service provision across the country.

Recommendations

As described in Chapter 4, participants in this study felt that the CTOPA was vague in its specifications for TOP after 20 weeks gestation and had concerns around subjectivity and differences in interpretation among practitioners. They felt that the differences in the indications for LTOP have led to variability in LTOP provision, within and between hospitals, which has resulted in inequitable access to LTOP healthcare. Overall, participants believed this to be an issue of parity and suggested that introducing additional documentation to guide practitioners in LTOP decision-making would help to ensure consistency. Some suggested that this should be a national document which is legally enforced. This aligns with Alouini et al. (2011) who found that 17 out of 48 heads of maternal fetal

medicine units across 16 countries advocated for legislative changes to provide clarity on TOP for non-lethal congenital abnormalities.

However, they believed that a prescriptive list could be problematic and that this document should serve as a guideline and not replace the individual case discussions of multidisciplinary teams. This agrees with findings by Statham, Solomou & Green (2006) that practitioners in the United Kingdom who also called for clearer severity criteria but felt that a formal list had potential negative effects that needed to be managed and that multidisciplinary team discussions should not be replaced. It is also concordant with recommendations by the RCOG (2010) who consider a definitive list to be unreasonable and suggest that LTOP decision-making is done on a case-by-case basis. Therefore, further investigation into this topic with a larger sample size is recommended to discern whether the wider fetal medicine community in SA feel that a guideline document would be useful and if so, the logistics of how such a document should be developed and implemented. One possible way of collecting this data on a wider scale would be to conduct a survey like Jacobs et al. (2015) and Habiba et al. (2009) who had 869 and 1530 respondents respectively.

Limitations

Following approval of the study proposal from the ethics committee, the study was presented at two fetal medicine meetings. It became apparent from this that there was significant controversy around the topic of LTOP which had led to substantial animosity within one of the units. As such, recruitment from within this unit was strongly discouraged which significantly reduced the size of the sample pool. Amendments to the study protocol were subsequently submitted to the ethics research committee, which delayed the start of recruitment by approximately 6 weeks. Furthermore, as the student is a part of the genetic counselling team at the University of Cape Town, this may have led to clinicians who have a working relationship with the team being more or less willing to participate and/or to discuss this contentious topic.

Additionally, the research team made the decision to cease recruitment prematurely due to the inability to conduct face-to-face interviews during the COVID-19 lockdown. These unfortunate and unforeseeable restrictions resulted in a smaller than anticipated sample size and a total of six participants were interviewed, representing only a fraction of those involved in fetal medicine. As such, data saturation was not reached. While saturation is often thought of to be imperative when assessing the quality of qualitative research, some authors have argued that not reaching data saturation does not mean that the research is incomplete or untrustworthy, but rather that certain phenomena have been identified which could be explored at greater depth (O'Reilly & Parker, 2013; Fossey, et al., 2002). Furthermore, the quality of the research is more a question of whether the findings are an authentic reflection of the data and whether the research question has been addressed- i.e. do the findings and the researcher's interpretations accurately reflect the data and the context of the inquiry (Fossey, et al., 2002). For these reasons, the researcher team felt that the small sample size was sufficient for the purposes of an initial investigation into this topic given the quality and depth of the data collected.

A second limitation which resulted from the small sample size was the homogeneity of the sample population. All the participants interviewed shared similar views on the topics discussed (except where noted) and there were no drastically diverse opinions. This may have been due to the snowball sampling method applied, whereby the participants initially recruited recommended colleagues and they could unwittingly have suggested colleagues whom they felt held similar views to their own. It may also be that there is little diversity of opinion among those involved in fetal medicine in the Western Cape, although this is seemingly unlikely given the ongoing controversy around LTOP mentioned above.

Lastly, an inherent limitation of a cross-sectional study design is that, as data is collected only once and at a specific area and moment in time, casual relationships cannot be elucidated (Setia, 2016). Another potential limitation is that the data is prone to bias (Setia, 2016). For example, as this study

was conducted in the midst of national debate on the topic of LTOP within the field of fetal medicine, this may have skewed the data in a certain direction as opposed to if the study were conducted at another point in time. Due to these limitations, the findings of this study should be thought of as exploratory, rather than considered to be a definitive representation of the views of the field of fetal medicine.

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Appendix A- Interview Schedule

(For the purpose of this interview, participants will be asked to please ignore the legal issues and focus solely on the ethical issues that arise for them.)

Introduction:

Introduce the researcher and the research.

Provide an overview of how the research topic arose- the researchers' interest in the FMU and the collective decision-making of late TOP.

Topic 1: Participants Role

- Can you tell me a bit about your work in fetal assessment?
 - How long have you been involved in fetal assessment?
 - What is the nature of your involvement with patients?

Topic 2: Perceptions on the Choice on Termination of Pregnancy Act of 1996

- What are your views on the Choice on Termination of Pregnancy Act of 1996?
 - Has it affected your work? And how?
 - Would you change anything about it?

Topic 3: Perceptions on the provision of TOP and late TOP

- How do you feel about offering a TOP?
- Do your religious beliefs influence how you feel about TOP?
- Do you feel that there is a difference between TOP before 20 weeks and after 20 weeks?
 - What is the difference? (Procedural)

- Is there an ethical difference?
- *Optional: Is it something that you would rather avoid?*

- Does the reason for TOP affect how you feel?
 - How do you feel about TOP for severe fetal abnormalities?
 - How do you feel about TOP if the mother's life is endangered?
 - Are there any other circumstances where you feel a late TOP should be allowed? (Socioeconomic, delayed access to care)
 - Do you consider the mother's wishes in your decision-making?

- Have your feelings about TOP changed since you first began working in fetal assessment?

Topic 4: Perceptions on the Decision-Making Process

It is my understanding that some centres have a protocol in place regarding late TOP.

- Do you feel that a protocol is necessary?
- What are your views on the protocols in place at certain centres?
 - If you had an opportunity, what would you change about it?

Appendix B- Participant Information Sheet and Consent Form

Research Project Information Sheet and Consent Form

Title: Investigating the ethical views guiding decisions to offer late termination of pregnancy amongst healthcare professionals involved in termination of pregnancy decisions in the Western Cape.

Introduction and summary

South Africa's termination of pregnancy (TOP) laws are liberal compared to similar laws in many other countries. However, the incidence of second trimester TOP is high at around 20% of TOPs being performed after 12 weeks gestation. While screening technologies enable the detection of most fetal anomalies in the second trimester, barriers to access of early screening or technological limitations result in some fetal anomalies only being detected post 20 weeks gestation. The broad criteria stated in the Choice on Termination of Pregnancy Act (CTOPA) leave room for interpretation, meaning that healthcare professionals are left with the decision of whether or not to provide a TOP based on their interpretation of the law and their professional medical opinion.

To date, there is no literature that explores the views of healthcare professionals in offering TOP post 20 weeks gestation (referred to as late TOP), specifically regarding their consideration of ethical issues. This leads to the question of how healthcare professionals feel about this decision-making process and what ethical considerations are taken into account when determining whether or not to offer a late TOP. This study aims to investigate the ethical views guiding decisions to offer late TOP amongst healthcare professionals involved in TOP decisions in the Western Cape.

Objectives

The aim of this study is to investigate the ethical views guiding decisions to offer late TOP amongst healthcare professionals involved in termination of pregnancy decisions and referral in the Western Cape.

The objectives of this research project are to:

- Investigate the views and interpretations of healthcare professionals on the Choice on Termination of Pregnancy Act of 1996 and its 2017 amendment in light of decision-making around TOP post 20 weeks.
- Investigate the perceptions of healthcare professionals on the provision and ethics of late TOP and feticide.
- Investigate how healthcare professional's ethical views may impact on decisions to offer or withhold late TOP and feticide.

Participants

Participants are comprised of healthcare professionals involved in referral and/or provision of late TOP in the Western Cape. These include obstetricians, gynaecologists, sonographers, medical geneticists, neonatologists and genetic counsellors. Criteria for participation will include healthcare professionals with experience in either offering or referring for late TOP, who either do or do not wish to be involved in the provision of late TOP.

Methods

The study will be conducted through face-to-face interviews and will take place at the Genetic Counselling offices in the Division of Human Genetics on the 4th Floor of the Falmouth Building at the University of Cape Town Health Sciences Campus or at the participants office. The venue will be dependent on the availability and preference of the participant and all interviews will be conducted in English. The interview will be approximately 1 hour in duration and will be voice recorded.

Privacy

The participants privacy is of utmost importance and confidentiality and anonymity is guaranteed at all stages of the research process. Any identifying documentation will be password protected and kept separately from the data. A pseudonym or identification number shall be used to identify the participants and in the case of a quotation, a brief non-identifying descriptor may be used (ie, Participant 10). No personal information will be made available at any time for any reason.

Withdrawal

Participation in this study is entirely voluntary and at the volition of the participant. Should the participant feel uncomfortable with answering any of the questions, they are under no obligation to do so. Should the participant no longer wish to participate in the study, he/she is able to withdraw at any point without having to provide a reason. All recordings, transcripts and documentation will be discarded.

Contact information

Should you have any questions about this project, please feel free to contact us.

Statement of participation:

1. I am aware that my participation in this study is voluntary and that I may withdraw at any time.
2. I am aware that I am under no obligation to answer any question that I am not comfortable answering.
3. I am aware that the study is of a sensitive nature and that controversial topics may be addressed which relate to my personal values and beliefs.
4. I have received information about the study, including the aims and objectives, and have been allowed sufficient time to decide to participate.

5. I was given opportunity to ask any questions that I may have about the study and confirm that I understand the scope of the study and that I may ask any additional questions I may have for the duration of the study.
6. I declare that I have not been coerced in any way to participate in this study and that my participation is at my own free will.
7. With the assurance of anonymity and confidentiality, I agree that the results obtained from the study may be used for publication.
8. I am aware that I will not be reimbursed or received any financial incentive from participating in this study.
9. I agree to the interview being voice-recorded.
10. I agree to the use of quotations from the interview should they be relevant and add value to the research.

I hereby give my consent to participate in this study and that I am doing so at my own free will.

Name and Surname of Participant

Signature

Date

Appendix C- Summary of Codes

| Code | Description | Files | References |
|--|---|-------|------------|
| Choice on Termination of Pregnancy Act | Any reference in the data to participants' opinions of the Choice on Termination of Pregnancy Act; its strengths and weaknesses; the relevance of gestational cut-offs; gradualism. | 5 | 15 |
| Disability | Any reference in the data to disability; eugenics vs the prevention of suffering; quality of life. | 6 | 10 |
| Feticide | Any reference in the data to the feticide procedure; the emotional impact on the patient/practitioner; how it impacts decision-making around LTOP. | 6 | 14 |
| Healthcare systems | Any reference in the data to the needing to improve screening; the failure of the healthcare system. | 4 | 7 |
| Interpretation and subjectivity | Any reference in the data to differences in interpretation of the law; the law being vague; exploitation of the law; lack of regulation; the pressure put on practitioners by patients; fear of litigation. | 6 | 14 |
| Other factors in decision-making | Any reference in the data to the other factors one may consider in deciding to offer a late TOP including socioeconomic; when the mothers' life is endangered; access to care; and the burden on the family. | 5 | 8 |
| Personal burden | Any reference in the data to the personal impact of LTOP on practitioners; the burden of decision-making. | 4 | 10 |
| Policy and standardization | Any reference in the data to a set of guidelines/additional documentation for LTOP; the need for equality and justice; the need for multidisciplinary input; the need for consensus. | 5 | 18 |
| Professional responsibility | Any reference in the data to professional duty; the prevention of backstreet abortions; prevention of harm and suffering; acting in accordance with societal values; objectivity in decision making. | 5 | 9 |
| Shared responsibility | Any reference in the data to a team approach to decision-making; objectivity and consistency; reducing/sharing the burden of moral decision-making. | 3 | 9 |
| The counselling process | Any reference in the data to patients' decision-making; patients' knowledge and education about neonatal care; LTOP as a difficult choice for patients; the importance of being non-directive; the challenges of counselling. | 6 | 13 |
| The value of the fetus | Any reference in the data to the value of the fetus at different gestational ages; viability as a cut-off. | 5 | 7 |
| What is severe? | Any reference in the data to the criteria for severity; which conditions should be considered as severe; grading of severity; neonatal prognosis; uncertainty. | 6 | 20 |
| Other | Any reference in the data to other important ethical/moral positions that do not fit into the other nodes. | 4 | 10 |



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 406 6492
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

11 November 2019

HREC REF: 642/2019

A/Prof J de Vries
Department of Medicine
Office J52-16
UCT Clinical Research Centre
OMB

Dear A/Prof de Vries

PROJECT TITLE: INVESTIGATING THE ETHICAL VIEWS GUIDING DECISIONS TO OFFER LATE TERMINATION OF PREGNANCY AMONGST HEALTHCARE PROFESSIONALS INVOLVED IN TERMINATION OF PREGNANCY DECISIONS IN THE WESTERN CAPE (MMED DEGREE - MS S FRANCOIS)

Thank you for your response letter, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 November 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Ms Sydney Francois will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary - before the research may occur.

Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

HREC 642/2019

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code of Federal Regulation Part 50, 56 and 312.