

**SOUTH AFRICAN WOMEN’S EXPERIENCE OF THE DECISION, PROCEDURE
AND RECOVERY FROM “FETICIDE” AND LATE TERMINATION OF
PREGNANCY DUE TO THE PRESENCE OF SEVERE FETAL ABNORMALITY:
WOMEN’S AND HEALTH SERVICE PROVIDERS’ PERSPECTIVES**

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ABSTRACT

Routine antenatal care, including sonography and genetic testing, assist healthcare providers in identifying the presence of severe fetal abnormality. In countries where it is legal, the option to abort such a pregnancy may be presented to the pregnant person. When abortion takes place after the thirteenth week of gestation, it is generally referred to as a late termination of pregnancy and may entail the induction of labour or caesarean section. In cases where termination of the pregnancy is decided upon, and the gestation is further than 21 weeks and six days, the feticide procedure is recommended in order to ensure stillbirth. The feticide procedure entails the injection of potassium chloride directly into the fetal heart in order to ensure fetal demise. Existing literature on “feticide” and late termination of pregnancy (LTOP) owing to fetal abnormalities mostly takes a medical or psychological perspective in researching these procedures. Within the South African context, there are very few studies on feticide and LTOP, with none of these studies (to date – 8 January 2023) taking a feminist approach. This paucity of research that takes into account power relations, structural inequality and factors that affect decision-making and choice is one of the reasons that this study was undertaken. The main research question focused on in this study is: What are South African women’s experiences of feticide and late termination of pregnancy due to the presence of severe fetal abnormality, as related by the women themselves and the health service providers who perform the procedure or provide care? The sub-questions that initially drove the study were:

How do the women relate their experience of the process of coming to the decision, undergoing and recovering from the procedure, and how do health service providers relate the experiences of these women?

The methodological and theoretical framework employed in this research was a Feminist Social Constructionist approach to Grounded Theory. This reflexive, subjectivist, feminist lens encouraged awareness of the influence of gender, race, class and other structural and systemic factors on women's experiences within the two healthcare systems. Data collection entailed semi-structured interviews conducted with 12 women, who had undergone feticide and LTOP procedures between one and five years prior to the interviews, in either the public or private healthcare system in South Africa. Semi-structured interviews were also conducted with 13 healthcare providers. The providers included medical specialists and participants from the fields of clinical psychology, genetic counselling and nursing and were employed in public or private healthcare in South Africa. Data relevant to public healthcare users and providers were collected from one tertiary (academic) public healthcare hospital and data regarding private healthcare users and providers were collected from across South Africa.

Women's constructions of their experiences of feticide and LTOP included stark contrasts between public and private healthcare users in South Africa, as well as women experiencing "no choice" and their voices being ignored or silenced. Healthcare providers' constructions were frequently contradictory, referring to women as having freedom of choice and their needs largely prioritised within the healthcare system, while the providers within the public healthcare system relayed their own frustrations and emotional burden due to systemic failures. Findings from women and providers' constructions were synthesised into a theoretical understanding of women's experiences of feticide and LTOP in South Africa, which is grounded in, and emergent from, the data.

Women's experiences of feticide and LTOP in South Africa were conceptualised by framing the three phases of these experiences, namely the decision-making phase (I), undergoing the procedures and in-hospital recovery (phase II) and the recovery phase (III). The most prominent themes emerging in these phases included the schism between the public and private healthcare systems in South Africa, the lack of real choice women experience, as well as the silencing of women and providers with regard to feticide and LTOP. Underlying the three phases, and directly influencing the three prominent themes affecting women's experiences, were the underlying and insidious structural inequality that undermined reproductive justice with regard to women's decision-making, experiences of and recovery from feticide and LTOP.

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Dedicated to the memory of Ralph van Zyl (10/11/2011 – 10/11/2011).

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A NOTE ON TERMINOLOGY

Abortion and Late Termination of Pregnancy

“Abortion” is the process of ending pregnancy by pharmacological intervention or the removal of an embryo or fetus from the uterus before it is able to survive on its own.

Abortion can occur spontaneously (this is usually referred to as miscarriage) or purposefully, which is known as induced abortion. In this thesis, “abortion” refers to induced abortion.

Late termination of pregnancy (LTOP) is problematised in this thesis as it is frequently used in anti-choice rhetoric, particularly in North-America. However, this term is utilised throughout this study as it is the term most frequently used by healthcare professionals as well as in relevant international and national literature.

Disability

It is important to acknowledge that constructions and terminology surrounding differently-abled people are not problematised in this thesis as the assumption is made that women do not terminate their pregnancies based on the fetal condition in isolation. Rather, the systemic and structural constraints relevant to caring for a “special needs” child is fore fronted.

Fetal Personhood and Assumed Motherhood

The term “feticide” refers to the process of causing fetal demise and is problematised in this thesis due to the inference of fetal personhood and fetal killing – these constructions will be discussed in-depth later in this study. However, it is the only medical and academic term utilised to describe the procedure, and consequently, it will be utilised throughout this study. Participants refer interchangeably to “fetus” and “baby”, and consequently, I have used the

same language used by each participant. When I make general reference to the product of conception, I use the term “fetus”.

Women participants referred to themselves as “mothers”, which I adopted where appropriate throughout this thesis in deference to their self-constructions.

Gender Terminology

In the thesis, I use gender terminology that could be considered as problematic. For example, I use the term “women” to refer to the participants of this study. This does not mean that I am claiming that all the women in this study are similar or that they are a homogenous group of people. Rather, I use it as a general description of the participants and according to their own self-constructions.

I am mindful that not all pregnant people identify as female and that their partners do not necessarily identify as male. Consequently, I use gender-neutral terms wherever I am not referring specifically to participant constructions.

Racial Terminology

Race is recognised as a social construct and only referred to in order to better contextualise the impact of racial discrimination on certain groups. The terms used to describe different races are used as constructed by participants and relevant literature.

GLOSSARY OF TERMS USED IN THE THESIS

Word	Meaning
Adenomyosis	A condition in which endometrial tissue exists within and grows into the uterine wall.
Anencephaly	Anencephaly is a defect in the formation of the neural tube during development. A baby born with anencephaly might be stillborn or survive only a few hours to a few days after birth.
Apartheid	Apartheid was a system of institutionalised racial segregation that existed in South Africa and South West Africa (Namibia) from 1948 to the early 1990s.
Asystole	Asystole, colloquially referred to as flat line, represents the cessation of electrical and mechanical activity of the heart.
Clinical geneticist	A clinical geneticist is a doctor with specialist training in diagnosing and treating genetic conditions or disorders.
Digoxin	Digoxin is a medication used to manage and treat heart failure and certain arrhythmias, it also serves to ensure asystole in abortion.
Dormicum	A benzodiazepine medication used for anaesthesia and procedural sedation.
Duchenne muscular dystrophy	An inherited disorder of progressive muscular weakness,

	typically found in boys.
Epilim	Useful for the prevention of seizures in those with absence seizures, partial seizures, and generalised seizures.
Genetic counsellor	Genetic counsellors are trained professionals who help people and their families understand and cope with genetic conditions. In South Africa they are not medical doctors.
Hydrocephalus	The buildup of fluid in the cavities (ventricles) deep within the brain.
Hydrops fetalis	A condition in which large amounts of fluid buildup in tissues and organs, causing extensive swelling (oedema).
Hydroxyzine	Used to help control anxiety and produce sleep before surgery.
Intra-cardiac	Intra-cardiac injections are injections that are given directly into the heart muscles or ventricles
Maceration	One of the signs of fetal death. It is a destructive aseptic process that appears between 12 to 24 hours after fetal death. It may not be seen in a pregnancy earlier than 6 months. In this a separation of the skin from head and trunk occurs giving a bubble-like appearance.
Pauper's funeral	A burial paid for by the government.
Teratogenic	Relating to, or causing, developmental malformations.
Trisomy 13	Patau syndrome causes severe intellectual disability and

	physical defects.
Trisomy 15	Mosaic trisomy 15 is a rare chromosomal anomaly syndrome principally characterised by intrauterine growth restriction, congenital cardiac anomalies (incl. ventricular and atrial septal defects, patent ductus arteriosus) and craniofacial dysmorphism
Trisomy 18	Edward's syndrome symptoms include low birth weight, small abnormally shaped head and birth defects in organs that are often life-threatening.
Trisomy 21	Down's syndrome causes a distinct facial appearance, intellectual disability and developmental delays. It may be associated with thyroid or heart disease.
Skeletal dysplasia	Skeletal dysplasia is a category of rare genetic disorders that cause abnormal development of bones, joints, and cartilage.
Spina bifida	A condition that affects the spine and is usually apparent at birth. It is a type of neural tube defect. Spina bifida can happen anywhere along the spine if the neural tube does not close all the way.

LIST OF ACRONYMS

Acronym	Meaning
CGT	Constructivist Grounded Theory
CTOP Act	Choice on Termination of Pregnancy Act
FSCGT	Feminist Social Constructionist Grounded Theory
GT	Grounded Theory
HIV/AIDS	Human Immuno-deficiency Virus/Auto-Immune Deficiency Syndrome
HPCSA	Health Professions Council of South Africa
LTOP	Late Termination of Pregnancy
OECD	Organisation for Economic Co-operation and Development
PSM	Pregnancy Supportability Model
RCOG	Royal College of Obstetricians and Gynaecologists
SC	Social Constructionism
SCGT	Social Constructionist Grounded Theory
TOP	Termination of Pregnancy
UK	United Kingdom

CHAPTER 1: BACKGROUND TO THIS RESEARCH

My friend's baby was diagnosed with anencephaly in her third trimester of pregnancy. She and her husband were given the option of continuing with the pregnancy, and potentially spending decades of their lives caring for a son who would have all of the basic physiological functions, but would never know who they were. He would remain in an infantile state until his death, which may have been upon birth, within weeks, months or many years after his delivery. They chose to induce labour and he was stillborn. I was with her throughout, from the news of her pregnancy (long-awaited), to concerns about his condition, a diagnosis, the terrible waiting in between each visit, each medical investigation, each doctor's phone call, to the excruciating decision and procedure. Their grief, which continues today, along with the insensitive remarks they received, the guilt and subsequent bearing-with of loss that bereaved parents have no choice but to endure, was my first encounter with late termination of pregnancy (LTOP) due to severe congenital abnormality.

During my employment as a clinical psychologist at a tertiary hospital, I was asked to debrief a doctor who had performed her first "feticide".¹ The feticide procedure entails ensuring fetal demise prior to the induction or surgical delivery of the stillborn fetus and is usually performed when severe fetal abnormality had been diagnosed. The most commonly utilised feticide procedure entails using sonography guidance to inject potassium chloride into the fetal heart in order to cause immediate demise. Feticide is recommended by the Royal College of Obstetricians and Gynaecologists (RCCOG, 2010b) in all cases where LTOP takes place beyond fetal viability (22 weeks and six days' gestation and greater) in order to

¹ This term is problematised in this thesis due to the inference of fetal personhood and fetal killing. However, it is the only medical and academic term utilised to describe the procedure, and consequently it will be utilised throughout this study.

eliminate the risk of live birth as the woman had elected to terminate the pregnancy past fetal viability and there would still be a risk of the fetus being born alive. The consequences of such a live birth would be that the fetus may potentially suffer indeterminately, while causing distress to the woman who had decided upon termination.

This doctor had not realised the extent of the moral conflict and emotional and cognitive dissonance she would experience afterwards. I had not even known that this procedure existed. In hindsight, I suspect that I may have been more horrified than she had been during the session, at her description of inserting the syringe into the fetal heart, through the woman's abdomen, and the moment of fetal asystole upon administering the lethal injection. This was my first encounter with feticide.

The above encounters were where this thesis had its origin. I wanted to explore South African women's experiences of LTOP and feticide when there had been a fetal diagnosis of severe abnormality. And I wanted to include the healthcare providers' perspectives. My first taste of societal reaction to LTOP and feticide research was when I found it impossible to secure someone willing to supervise my research at the local university. The knee-jerk distancing and overt condemnation, not just of the procedure and the women who choose it, but even those wanting to research it, became routine. This seemed to be indicative of what most South African women who go through this procedure would surely experience. Or was it? It would take me five years of active sampling to interview enough participants in order to complete this project. Such was the unwillingness or inability to speak about feticide, which is reflective of the manner in which LTOP is stigmatised in South Africa. It is only upon some deep delving into social media sites that I was able to find posts on LTOP in South Africa, such as the one by a blogger with the moniker "Irresistibly Fish" (Anderson, 2014),

who posted Irma Oosthuizen's story under his "Taboo Topics" section. In this post, she disclosed her experiences of two terminations of pregnancy due to fetal abnormality (no mention was made of feticide). One comment under the post presents, in shocking clarity, the type of stigmatising feedback women in similar situations are likely to receive in South Africa:

Marce (Anderson, 2014): I don't think that there is any excuse for abortion. We have to suffer for our children and truly lay down our lives for them. Those born normal and not. Not just abort when the child doesn't look normal or [is] deformed. That's playing GOD. People died during child birth to give birth to babies that died, were sick and weren't normal. No amount of justification will remove the fact that you took away a life. I don't think God favours abortion under any circumstance. He is a God of forgiveness, yes, but this is coming across as someone who just took things into their own hands and doesn't have the faith that they speak so much about. Just my view. Thanks.

My reason for including this comment is because it depicts what women who undergo LTOP and feticide due to fetal abnormality may be exposed to within their communities and online environments in South Africa. In this chapter, I contextualise abortion in South Africa, and late termination of pregnancy in particular, as well as providing some context on South African women's experiences of feticide, although literature in this regard is extremely scarce. Contextualising the impact of caring for a disabled child in South African society is important as well in order to understand the implication of carrying a special needs fetus to full term and the burden of care associated with such a child within the currently available structures and resources.

I start the chapter with my rationale for this research, which is based on the paucity of knowledge on South African women's experiences of the diagnosis of a severe fetal abnormality, being faced with the decision-making process regarding LTOP and feticide, experiencing these procedures and how they experience recovery afterwards. What information we do have seldom reflects a critical health perspective, where women's rights to bodily autonomy and reproductive health services are prioritised. In the closing sections of this chapter, I introduce my theoretical framework and a brief overview of the rest of the chapters in this thesis.

1. Rationale

The main research question addressed by this study is: How are the experiences of women who have undergone a feticide and late-stage termination of pregnancy due to the presence of fetal abnormality described? The sub-questions refer to how women relate their experiences of the process of coming to the decision, undergoing and recovering from the procedure, as well as how health service providers relate the women's experiences.

In exploring the literature available in South Africa regarding women's experiences of feticide and LTOP, it is apparent that there is an immense need for further studies on this topic. The relevance of research focused on feticide and LTOP is reinforced by the improvements in genetic testing and medical technology with which fetal abnormalities are detected. These improvements have increased the number of fetuses diagnosed with physiological abnormalities and the subsequent late terminations of pregnancies (Africa Healthcare IT News, 2014).

There is a need for more research regarding the psychological experiences of women who have undergone feticide due to fetal abnormality (Graham et al., 2009; Larsen, 2013) and more especially, exploration of this experience and the decision-making process from the woman's perspective (McCoyd, 2007). This need for research is even greater within the African and South African contexts due to the extreme paucity thereof. McCoyd (2010) reported that women who undergo termination of pregnancy due to fetal abnormality in North America express feeling stigmatised and alienated from others while enduring this loss. No such research exists with regard to the South African context to date.

In light of the paucity of research available on the topic of feticide, a grounded theory approach is suited to exploring women's experiences of feticide and LTOP. Grounded theory is a qualitative research methodology where data are uncovered, rather than identified, and patterns between data are explored. The researcher constantly moves between gathering data and analysing the data, and in this way, a theory which is grounded in the data is developed (Glaser & Strauss, 1967). There are a number of different approaches to grounded theory which will be discussed in Chapter 3 of this thesis. For the purposes of investigating women's experiences of feticide and LTOP, a Feminist Social Constructionist Grounded Theory (FSCGT) methodology was deemed the most appropriate approach in order to facilitate reflexivity and a critical viewpoint throughout the research process.

It was important to include relevant healthcare providers in this study, as Galick et al. (2015) point to the hierarchical construction of medicine and the effect this may have on women's experiences within the healthcare context. Information from this research could assist in providing enhanced professional support to affected women (Govender & Moodley, 2013) and it may assist in providing effective contextually relevant mental healthcare to potentially

grieving women, possibly reducing negative psychological outcomes and stigma within this population. The findings from this research could serve to channel women's experiences and voices directly to South African healthcare structures and systems, with the goal of reducing stigma and disparity experienced by pregnant people carrying an abnormal fetus. Deviations between women's experiences of the feticide and LTOP procedures, and providers' perceptions of women's experiences provide meaningful information on gaps in understanding between the pregnant person and the medical structure. This research aims to not only highlight these gaps, but also to provide suggestions for bridging them, in favour of the best interests of the pregnant person. Recommendations based on findings are going to be compiled into a policy brief and supplied to the South African Department of Health in order to address aspects related to both public and private healthcare provision of feticide and LTOP procedures. I would also like to compile psychoeducational material, including relevant information and supportive resources for women during their decision-making process, as well as to assist them throughout the procedure and their recovery. This information would also serve to inform allied and mental healthcare providers in their care of women throughout the feticide and LTOP experiences.

2. Contextualising Abortion in South Africa

In order to understand constructions of LTOP and feticide in South Africa, it is necessary to first understand constructions surrounding elective abortion. Abortion as a construct and experience requires "situatedness" within the contexts of class, race, history and politics (Lewis, 2017). Within the South African context, abortion has evolved from being inaccessible to the majority of South Africans during Apartheid to a public health issue that affects and is affected by reproductive healthcare policy and service availability, and to a

rights-based issue in the post-Apartheid era (Favier et al., 2018). Under the restrictive Abortion and Sterilization Act (Act No. 2 of 1975) (Government Gazette, 2020), access to legal abortion services was biased toward White women, due to structural inequality enshrined by Apartheid and its legacy. White women could afford private abortion services (which required meeting onerous bureaucratic procedures to qualify for the grounds on which abortion was permitted), or access abortion providers overseas, while other racial groups – especially poor Black women – experienced discrimination and lacked the resources to access abortion care, which led to unsafe abortions.

Democracy and the adoption of the new Constitution, which enshrined bodily autonomy as a basic human right, laid the foundation for reproductive rights advocacy which led to the passing of the Choice on Termination of Pregnancy Act (Act No. 92 of 1996) (henceforth, CTOP Act). According to the CTOP Act, abortion is legal under the following circumstances:

- (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.
- (2) The termination of a pregnancy may only be carried out by a medical practitioner, except for a pregnancy referred to in subsection (1) (a), which may also be carried out by a registered midwife who has completed the prescribed training course.

There is no upper limit for performing a termination of pregnancy imposed by the CTOP Act, and consequently, participants who underwent feticide and LTOP within the public healthcare system in the 37th through 39th weeks of pregnancy are included in my research sample. This is not unusual, as over 34 per cent of the participants who underwent feticide and LTOP procedures at a tertiary (public) hospital in South Africa, who were included in a study published by Govender and Moodley (2013), were over 35 weeks pregnant at the time of their procedures.

The discrepancy between supportive legislation and the structural support needed for pregnant people to actually exercise these rights sadly continues to be evident. Hodes (2016) noted that various studies on abortion provision and access, as well as The Confidential Enquiries into Maternal Deaths in South Africa (Moodley et al., 2014), reported consistently high rates of illegal abortion in South Africa. Additionally, within the healthcare system,

abortion stigmatisation affects service provision. Jogee (2018) explained the reasons for the high rates of conscientious objection among healthcare providers in South Africa as being partially due to approximately 95 per cent of South Africans identifying as religious, with the five most prominent religions in the country condemning abortion. In order to contextualise attitudes toward abortion and potential causes of stigma, Mosley et al. (2017) analysed outcomes from the South African Social Attitudes Survey (Roberts & Struwig, 2016) and found that approximately half of South Africans surveyed had indicated that they regarded termination of pregnancy due to serious fetal abnormality as wrong (gestation at which termination took place was not indicated). Attitudes toward abortion tended to become more positive as respondents' educational level increased. Mosley et al. (2017) recommended interventions to address the social stigma associated with abortion, in order to increase access to safe medical services and to redress the reduction of women and healthcare providers who make use of abortion services to "less than whole and dignified humans" (Mosley et al., 2017, p. 12). Their final recommendations summarise the current need surrounding abortion services in South Africa: "The continuing application of a comprehensive human rights-based approach to abortion in South Africa will be needed to ensure all women are equitably supported to have safe abortions, to have children and to raise their children with dignity as they so choose" (Mosley et al., 2017, p. 13).

3. The Health and Economic Context of South Africa

Coovadia et al. (2009) contextualised the healthcare system in South Africa over a decade ago. They indicated that the proven mismanagement of the healthcare system had had a catastrophic impact on all residents, but no group more so than women of colour. Their description unfortunately remains accurate, as historical racial and gender discrimination,

migrant labour systems, violence and disparities in access to resources persist (Maphumulo & Bhengu, 2019). Progressive and liberal legislation has unfortunately not resulted in social injustice having been redressed; in fact, Favier et al. (2018) interviewed key stakeholders within South African reproductive services and advocacy, and reported that structural inequality continues to impede women's ability to access safe abortion services. Barriers to service access, the lack of functionality of existing services, and the impact of abortion objectors within the public healthcare system serve to reduce reproductive service delivery in South Africa. Service delivery failures on behalf of the Department of Health and excessive reliance on non-governmental organisations in certain regions have resulted in unsustainable abortion services within South Africa.

The division between the public healthcare system and the private healthcare system in the country is exceptionally distinct, with only 15 per cent of the South African population enjoying medical scheme membership (Phillips, 2022). Consequently, the vast majority of the South African population is dependent on the public healthcare system, which has a vacancy rate of 15 per cent and severe understaffing leading to doctors and nurses being overworked (Phillips, 2022). Providers who leave the public healthcare system in South Africa regard the poor working conditions, extended working hours, lack of security and safety in the workplace, poor management of the institutions, poor staff morale and the risk of exposure to infection as significant factors affecting their decision to leave. Phillips (2022) found that specialised medical professionals are more likely to seek employment in the private healthcare system due to the better work environment and greater potential for earnings. This has a direct impact on the availability of specialists who are able to diagnose fetal abnormality and provide feticide and LTOP procedures within the public healthcare system. The outlook for the South African public healthcare system is unfortunately bleak, with no

realistic hope of an improvement in service access or provision in the near future. As indicated by Phillips (2022, p. 71):

Around 85% of the country is dependent on an overstretched, under-resourced public health sector that battles to deal with the high burden of disease while widespread poverty and poor living conditions mean social determinants of health and disease contribute significantly to pressure on the public healthcare providers.

In light of the consistent decline in public healthcare access and quality, as well as the increasing demand placed on the public healthcare system, it is likely that abortion provision will continue to be a contentious issue for many years in South Africa. In 2017, Amnesty International reported that less than seven per cent of South Africa's 3880 public health facilities provide abortion services, with this rate expected to deteriorate. Jogee (2018) stated that the importance of protecting and endorsing women's reproductive rights in South Africa, against the history of oppression and prejudice, could not be overemphasised. Stigmatisation of abortion care and services creates structural and systemic barriers to these services, partly due to conscientious objection among healthcare providers and no formalisation of conscientious objection guidelines within the professions of healthcare (Favier et al., 2018).

4. Contextualising Disability in South Africa

The latest statistics indicating the number of South Africans living with a disability are based on 2011 Census data (Statistics South Africa, 2012), which indicates that approximately 2.8 million residents over the age of five are classified as disabled, which would account for almost five per cent of the general population. This large portion of the population

experiences significant challenges in accessing health and rehabilitation services, which is exacerbated by attitudinal barriers within South African society that serve to stigmatise and exclude disabled individuals (Hussey et al., 2017). Poverty and limited access to appropriate methods of transportation are additional barriers to disabled individuals accessing healthcare, as indicated by a survey undertaken by Vergunst et al. (2017). The living conditions of mothers of children with disabilities are relevant to this research, as the supportability of caring for a special needs child is a pivotal factor in women's decision-making process regarding whether or not to undergo LTOP and feticide, or not. The concept of pregnancy supportability was developed by Macleod (2016) and refers to the many personal, micro-level and macro-level influences that affect whether or not a pregnant person feels able to continue with a pregnancy. In the concluding chapter, I refer to the importance of the Pregnancy Supportability Model (PSM) developed by Macleod (2016) and the meaningful manner in which the PSM assists in creating greater understanding of women's decision-making when their fetus is diagnosed with a severe abnormality.

Mkabile and Swartz (2019) conducted semi-structured interviews with caregivers of children with intellectual disabilities in Khayelitsha, South Africa, and found that there was a dire need for structural, health and psychological support among these caregivers and their children. The respondents indicated that they experienced severe social isolation and stigmatisation due to their child having a disability (Mkabile & Swartz, 2019). Van der Mark et al. (2019) went as far as describing disabled children and their families in South Africa as being one of the most marginalised groups within our society. Factors that van der Mark et al. (2019) identified as contributing to this relegation included the gendered nature of the burden of care for disabled children, loss of employment and income due to childcare demands, gender-based violence, and the silencing and invisibility of these women caregivers. The

wellbeing of both the mothers and their children suffered significantly due to these circumstances (van der Mark et al., 2019).

4.1 Unwanted Disabled

Providers' constructions of severely disabled people that emerged from my research tended to focus on the burden disabled individuals place on the South African healthcare and other systems. They may communicate these beliefs in subtle ways during their interactions with women who are in the decision-making phase of the LTOP and feticide procedures. Women may feel pressured into terminating the pregnancy in order to avoid placing the "burden" of a disabled or ill child on society. Indeed, the procedure may be used as a means to manipulate the population growth of the disabled community (de Jong & de Wert, 2015). Advocates for equal rights for the disabled (Hall, 2013) regard the current South African legislation on selective termination of pregnancy on the grounds of fetal abnormality as constituting discrimination against the disabled. However, the Nairobi Principles (CREAWorld, 2018, p. 8) attempted to reconcile these tensions between women's reproductive rights and disability rights and established that: "Individual choices about one's own pregnancy are not eugenics, and nobody exercises discrimination when making choices about their own pregnancies." I align myself with these principles and locate this discussion within the complexities of the pregnant person's bodily autonomy and reproductive rights.

5. LTOP and Feticide due to Severe Congenital Abnormality: The South African Context

Shahid and Soma-Pillay (2019) referred to the paucity of data relevant to South Africa with regard to LTOP as well as the presentation of congenital abnormalities. This is affected by the absence of a registry for the feticide procedure, although feticides are performed at many tertiary hospitals in South Africa. The failure to capture data with regard to LTOP, feticide and fetal congenital abnormalities highlights the invisibility of these procedures and conditions and alludes to the stigma and silencing associated with them.

The causes of late identification of fetal abnormality may be attributed at least partially to the significant problem of late antenatal healthcare utilisation among pregnant women in South Africa. In their South African study, Jinga et al. (2019) identified various inadequacies in antenatal healthcare provision, including long waiting times, lack of resources, lack of trained staff, negative patient-provider interactions as well as women giving preference to traditional healthcare providers (traditional healers), rather than travelling far, waiting long, and possibly being turned away, at their local antenatal clinic. Lebesa et al. (2016) explored records of congenital disorder diagnoses in South African hospitals and noted that due to misdiagnoses as well as missed diagnoses, there is significant underreporting of cases. The late diagnosis of fetal abnormalities leads to an increase in the occurrence of LTOP and feticide procedures in South African (Shahid & Soma-Pillay, 2019). The context of structural inequality and barriers to accessing antenatal care have a direct impact on LTOP as sonography and genetic testing represent advanced medical care, and these services are even less accessible than routine antenatal care.

Ebonwu et al. (2018) reported that almost half of women accessing antenatal care in South Africa do so after 20 weeks' gestation. The World Health Organization (2016) recommended that pregnant people should have a minimum of four antenatal contacts with healthcare professionals during pregnancy. This delay in accessing antenatal care requires some unpacking in order to contextualise the reasons for women's late reporting for antenatal care. Okedo-Alex et al. (2019) undertook a systematic review of antenatal care use in sub-Saharan Africa and found that poverty, lack of access to education, being unmarried, living in rural areas, being multiparous, living far from healthcare services, having unsupportive partners, and women lacking information about pregnancy and services available to them, were risk factors related to women's late access of antenatal care. This is significant with regard to LTOP and feticide, as early antenatal care may reduce the incidence of these procedures due to early detection of abnormalities, and consequently pregnancies can be terminated earlier, avoiding the necessity of the feticide procedure (Shahid & Soma-Pillay, 2019).

Most fetal abnormalities are only detectable from the second trimester of pregnancy and with the assistance of ultrasound investigation; consequently, the choice to end the pregnancy frequently results in a late termination of pregnancy (Hayes et al., 2020). This is the point at which the healthcare provider supplies information to the pregnant person regarding the findings, diagnosis, possible treatment options, prognosis and possible decisions to be made with regard to the continuation of the pregnancy. In order to provide this information, it is usually necessary to perform a number of medical investigations, which may include blood tests, amniocenteses, scans and specialised genetic testing. It is standard good practice to include relevant specialists at this stage, which would often include clinical geneticists, paediatricians, paediatric surgeons and other experts in order to ensure accurate diagnosis and prognosis prediction of the condition (Wapner et al., 2012).

Abortions between 18 and 24 weeks of gestation are generally referred to as late termination of pregnancy (LTOP); however, Hayes et al. (2020) contested this label in Australia and highlighted the influence that conservative politicians and organisations have in establishing terminology that serves to stigmatise and restrict access to second trimester abortions. Particularly within the North American political context, the use of the term LTOP has become a point of significant debate, with anti-choice advocates using it to reinforce fear-mongering and radical ‘so called pro-life’ rhetoric (Planned Parenthood, 2022, October 13). Consequently, there has been increased awareness of the misuse of the term, with many feminist scholars regarding the description of abortion as either “late” or “late-term” as: “foetocentric – it measures time according to fetal gestation and does not map onto pregnancy” (Millar, 2020, p. 442). However, for the purposes of this thesis, I have decided to use the LTOP terminology based on the extensive use of the term within the South African medical field, and based on the available literature on later terminations of pregnancy that refer to the procedure as LTOP.

6. Fetal Politics, Fetal Personhood and Problematising the Term “Feticide”

Millar (2016) explored Michel Foucault’s work on biopolitics and the process of politicisation and control over the life and death of subjects and noted that the right to life has become prominent in increasing the size and wellbeing of the human population, while the right to die has been largely eradicated. Feticide is frequently equated to euthanasia within philosophical and ethical debates, and consequently, biopolitics are intricately tied to this area of research. Within the South African legal system, feticide refers simply to the killing of an unborn fetus. It is differentiated from murder, as murder requires the victim to have been

legally alive at the time of their demise (Radyn, 2019, April 1). Under South African law, personhood is only conferred upon a fetus once it has been born and taken at least one breath. The “feticide” (American English) or “feticide” (British English) term is utilised within medical circles to refer to a process of causing fetal demise after viability, but prior to birth (Graham et al., 2009).

From a critical feminist health perspective, the use of the term “feticide” is problematic due to the implication of fetal murder, which of course, also implies fetal personhood. However, it was important not to shy away from the use of this term altogether, as it is the only recognised medical term used to describe the procedure of terminating the fetus, prior to terminating the pregnancy, past the fetal viability demarcation point. This is also the only term used by health service providers during discussion of late termination of pregnancy with patients (B. Henderson, personal communication, 20 January 2016).

In light of the above, I decided to minimise the use of the term “feticide” during interviews and discussions with participants, except in my interviews with providers. Similarly I avoided describing women’s experiences as ‘an abortion’ and rather employed euphemistic phrases such as ‘termination’ (Kavanagh et al., 2018). The purpose of this research is to investigate women’s experiences of the feticide and LTOP procedures, and even though the use of the term is problematised, it needs to be utilised in order to explore the research questions. This inherent friction in using a problematised term while viewing it through a feminist lens speaks to the delicate balance critical researchers are required to make between using terminology in a pragmatic manner, in order to conduct meaningful research, while being aware of the stigmatising and potentially detrimental impact the terminology may have on pregnant people.

It is undeniable that the manner in which we refer to the preborn has an impact on the associations made by the pregnant person, healthcare providers as well as society, when the pregnant person takes the decision to end her pregnancy. According to Bilewicz et al. (2017), the terms used to describe the preborn carry with them subjective connotations that can serve to refute or legitimise specific moral positions. Social psychological research into the mentalisation of the preborn indicates that laypeople are prone to perceive the preborn as moral patients (humanised), although they may not regard them as moral agents (thus the preborn are seen as innocent, capable of suffering and to be protected) (Bilewicz et al., 2017). Fetal personhood creates a problematic separation between the pregnant body and the fetal body. As Samerski (2001) described, reproductive technology and the medicalisation of pregnancy have served to co-opt the uterus and its contents. The pregnant woman is no longer the primary patient – but rather conceptualised as the secondary vessel to the fetus. An extremely private biological process now requires public surveillance and management through the medical gaze, sonars, genetic tests and constant evaluation. Samerski (2001) applied Michel Foucault's work on technological governmentality to the pregnant person and concluded that women are disembodied by science and technology. The woman becomes the responsible fetal manager (Samerski, 2001) who is required to prove how responsible she is in her growing of the fetus; she is required to justify decisions she takes during the pregnancy and even in making responsible decisions to terminate an abnormal fetus. Duden (1993) stated that birth is no longer a beginning in the context of life, but that technology has created the fetus as a person from as early as conception.

6.1 *Severe Fetal Abnormality*

Sineke and Soma-Pillay (2017) explained that severe fetal malformation cannot be legally defined due to the severity of a condition being affected by diagnosis, timing and prognosis. The RCOG (2010b) advised doctors to consider the following aspects in deciding whether or not a pregnancy qualifies for LTOP due to severe fetal abnormality: relative potential for treatment of the fetal abnormality, the level of self-awareness and communicative ability the child could foreseeably attain, the potential for suffering, the probability of being able to live independently as an adult, and the extent of societal burden of care. The reality that the burden of care and cost of any child, more importantly, a special needs child, falls on the caregivers rather than on greater society should be acknowledged. In this regard, Nicolaou (2019) reinforced the importance of social justice and ensuring that basic structures and supportive systems are functional within a society in order to determine whether a child's life would be optimal or not, rather than merely focusing on physiological or biological conditions. Unfortunately, South African women find themselves in circumstances where the physiological diagnosis of the fetus will seldom be compensated for by supportive structures and systems, particularly if they are unable to afford these. Van Biljon et al. (2022) identified the most significant barriers confronting South Africans living with disability as including the lack of accessibility, affordability and adequacy of rehabilitation services. There is a disability grant provided by the South African government, which is set at R1 990 per month for 2023 (Pitsi, 2022, December 29) and in order to contextualise this amount, data indicates that an individual would require at least R5 582 in order to qualify for a "living wage" in South Africa (BusinessTech, 2022, February 8). Access to occupational therapy services was problematised by Ned et al. (2020), who found that the poorest South Africans requiring rehabilitation and occupational therapy, are least likely to receive these services due to the

costs involved with travel expenses, even though these are the very individuals who would benefit most from accessing these services. Bezuidenhout (2022, September 23) noted that the paucity of information available on rehabilitation services available to public healthcare users is due to the lack of data keeping on behalf of the South African government and this serves to ensure the following:

This lack of data limits civil society's ability to hold the government accountable and makes it impossible to apply vertical equity for marginalised groups when planning, budgeting for, implementing, or monitoring government services. Vertical equity applies when policymakers recognise that there is an inherent inequality in (health) access or outcomes for particular sub-groups and that particular sub-groups will require additional resources or efforts to ensure that they eventually get to the same health outcomes as the general society. But, without disability-related questions in key service surveillance, there is no data and information on disability to inform sectors to assess equity and monitor the inclusion of vulnerable sub-groups. These sub-groups are then simply 'invisible' in the data and lost among the many pressing issues of the general population.

Where the treating providers regard the abnormalities as severe enough to warrant providing the pregnant person with the option of termination, the RCOG recommends that feticide should take place prior to LTOP in all cases where gestation is over 21 weeks and six days, except where the diagnosis is so severe that delivery survival is deemed impossible (Sineke & Soma-Pillay, 2017). Performing the feticide procedure serves to ensure stillbirth of the fetus and to avoid the situation where, once born, the neonate would require medical care in accordance with the relevant medical, legal and ethical guidelines.

7. The Feticide Procedure

Available literature on LTOP and feticide due to severe congenital abnormalities in the South African context reinforces the importance of establishing a data registry in order to ascertain the prevalence of congenital abnormalities, as well as the number of LTOP and feticide procedures that take place (Shahid & Soma-Pillay, 2019). Anecdotal accounts by specialist obstetrician gynaecologists such as Govender and Moodley (2013) are limited to providing an indication that most women in their tertiary public hospital choose LTOP and feticide where severe congenital abnormalities were present.

Recommendations by the RCOG (2010) include that the feticide procedure should take place in a tertiary hospital within the fetal-maternal unit and be performed by an appropriately qualified practitioner, which would be either a specialist obstetrician-gynaecologist or a fetal-maternal specialist. The most reliable feticide method is when potassium chloride is injected directly into the fetal heart under sonographic guidance. There are options to utilise lignocaine or make use of intra-umbilical injection, instead of intra-cardiac injection, or to inject digoxin into the intra-amniotic fluid (Sineke & Soma-Pillay, 2017). However, the preferred method remains intra-cardiac fetal injection in order to ensure immediate fetal demise. Women who participated in my research included those who experienced fetal intra-cardiac injection, as well as injection into the umbilical cord and those who were injected into the amniotic fluid. The latter takes a much longer time for fetal demise to be achieved, and is consequently regarded as the least desirable method as it may increase the pregnant person's distress. Following the feticide procedure and fetal asystole, labour is induced or surgical removal of the fetus takes place.

8. Feminist Social Constructionist (FSC) Grounded Theory (FSCGT)

Exploring and contextualising South African women's experiences of their fetus being diagnosed with a serious congenital abnormality, understanding their decision-making process, gaining insight into how they experience the procedures, and how they experience recovery from feticide and LTOP, requires a theoretical lens and methodology that consistently prioritises participant voices and facilitates reflexive interaction between the researcher and the data. To this end, I utilised an FSC lens and Grounded Theory (GT) methodology in order to allow themes to emerge from the interviews with women and providers, and endeavouring to understand these from a feminist perspective.

Charmaz (2014a) defined social constructionism (SC) as a theoretical approach that focuses on how individuals and groups construct their realities through their opinions and behaviour. The social constructionist approach encourages the development of new interpretations of researched life, while grounded theory encourages interaction between the researcher, material, research setting, participants, colleagues and the intrapersonal world of the researcher in order to develop theory, particularly where the topic is under-researched (Charmaz, 2008). Charmaz (2014a) married constructionism with grounded theory in that she regarded social existence as being inseparable from the subjective experience.

Grounded theory is a research method where data are analysed with particular emphasis on categories and themes emerging from the data, rather than being searched for by the researcher. Data collection takes place systematically and sequentially, and analysis of data occurs parallel to the collection process, until saturation has been achieved (Charmaz, 2014a).

Reflexivity is prominent in that the researcher interacts with the data and participants and reflects on these interactions throughout the research process. Theoretical sensitivity in the grounded theory research process acknowledges the theorist's experiences, academic training and how the research process affects these aspects (Birks & Mills, 2015). The final product is a synthesis of individual experiences and interactions which are integrated into overarching themes by the researcher (Allen, 2011). Charmaz (2003) regarded social constructionist grounded theory as a suitable methodology in the study of sensitive and complex topics due to its facilitation of social justice research issues. The social constructionist orientation consequently informed my development of a grounded theory regarding late termination of pregnancy and feticide, by providing the lens through which categories and patterns were identified.

8.1 *FSC Lens and Motherhood*

A feminist lens facilitates the exploration of structural and gendered barriers pregnant people may experience in accessing antenatal care and in navigating the process of decision-making and undergoing feticide and LTOP procedures. Feminist social constructionism (FSC) is interested in the constructions of acceptable womanhood that are imposed on pregnant people and how these may affect their experiences of the feticide and LTOP procedures. These constructions relate to the idea of “compulsory” or “mandatory” motherhood, where every female body is expected to either fulfil, or at least seek to fulfil, the mandate to give birth, raise and care for children (Shchurko, 2012).

Pregnant people may encounter difficulty in their attempts to integrate their psychological conceptions of themselves as a loving mother of a wanted fetus, as well as a mother who

decides to end that fetus' life. Fisher et al. (2014) explained that this frequently leads to "disenfranchised grief" responses following the decision, where women feel undeserving of sympathy while grieving the lost child, due to them regarding the loss as self-imposed to an extent. Leichtentritt (2011) added that the discrepancy between how the women view the product of their pregnancy (as a "child" or "baby") and the healthcare and societal view ("fetus") adds to a sense of illegitimacy surrounding their loss. These women are also not entitled to refer to themselves as "mothers" by societal standards, even though this is how they construct themselves: as childless mothers. In this regard, it is important to note that I refer to the product of pregnancy as a fetus throughout this thesis, unless the participant specifically constructed her fetus as a baby, in which case I utilised this term.

Understanding the process of constructing an identity of motherhood during pregnancy is important in attempting to appreciate women's experiences of being advanced in a wanted pregnancy and then being confronted with the diagnosis of severe fetal abnormality. In creating a construction of motherhood, Jones et al. (2005) argued that during pregnancy, women start to create mental representations of their potential child and imagine what their lives would be like following giving birth. This change from embodied individuality to sharing a body with another constructed person, includes changes in thoughts, fears and fantasies and assists in making meaning of the bodily changes during pregnancy. Psychoanalytic text (Pines, 1972) refers to the experience of adjusting to a new identity as "mother", as the "crisis of motherhood" and acknowledges that this process would be different for each woman. Feelings of attachment to the fetus may be precluded by an antenatal diagnosis of abnormality and instead trigger a grief or loss reaction, which may result in denial and distancing in order to manage overwhelming emotions related to the

diagnosis, rather than the bonding that usually occurs between the pregnant person and a wanted fetus (McCoyd, 2010).

8.2 FSC Lens and Abortion Stigma

Kumar et al. (2009) described abortion stigma as negative attributes that are assigned to women who terminate their pregnancy, labelling them as having failed to achieve womanhood ideals. Divergences from ideas related to the “ideal of womanhood” include rejecting motherhood (e.g., through voluntary childlessness), terminating a potential life, or participating in non-procreative sex (Kumar et al., 2009). The pregnant woman is classified as either a “bad” or a “good” mother based on her behaviour towards her fetus, as she is either protecting the fetus (e.g., from suffering should it be born) or she is regarded as a “dangerous maternal environment” (Stabile, 1994, pp. 68-98).

Purcell et al. (2014) explored the stigmatisation of abortion in Great Britain’s print media and described how abortion and motherhood are positioned as opposites. Women who have abortions are constructed as distinctly “other”, irrespective of the reasons for the termination of pregnancy, situational factors or personal reasons.

9. Aims and Limitations

Throughout this thesis, the reader will find a theme of hearing the voices of women who have experienced feticide and LTOP. That is the basis for undertaking this research and the crucial fulcrum around which all else is built. South African women’s experiences of the decision-making process, the feticide and LTOP procedures and their recovery from these experiences,

in their own voices, will be presented here. Providers' perspectives on women's experiences of these procedures add to the contextualisation of women's voices and provide an additional layer in constructing the interaction between women and the healthcare system. Theorising focuses on understanding the factors affecting women's experiences from a critical feminist health psychology perspective, using FSC in a grounded theory study. In this manner the goal is to be able to expand upon the research and literature in these areas within the South African and international contexts. More importantly, I aim to provide pragmatic and achievable feedback to the public and private healthcare systems in South Africa, in order to address failures and gaps in service provision that, if corrected, can improve women's agency, reproductive choice, and wellbeing during the feticide and LTOP procedures, as well as recovery therefrom.

This study faced all of the expected challenges that most research entails, including financial limitations, time restrictions and structural and bureaucratic delays. Limitations particular to this research comprised extreme difficulty in obtaining sufficient research participants from both the population of women as well as the healthcare providers' population. This challenge had been anticipated, and both my supervisors and I braced for a long journey when we undertook this study. What I had not foreseen was that I would also experience abortion stigmatisation by proxy and the impact this would have on my research process, as well as my personal experiences, which will be explored in greater detail later in this thesis.

However, the greatest limitation to this study, far greater than any of the structural and systemic hurdles faced, is, in fact, my own. I am a clinical psychologist with no previous experience in undertaking qualitative research and no background in feminist theory. I am in many ways far from the ideal candidate and I certainly felt ill-prepared to undertake such a

complex and theoretically heavy research topic. In hindsight, this lack of being steeped in feminist, and qualitative research methods and theory, may have been an advantage in some aspects – as I entered the process acutely aware of my deficits and open to discovering the data, rather than imposing my academic conceptualisations upon them. My own perspectives would develop and take form as time passed with extensive reading and immersing myself in the field and, most importantly, in the data. I was also necessitated to carefully reframe myself as a researcher first, and psychologist second, particularly during my interactions with my participants. During the interviews, my clinical training served to facilitate deep listening with empathy and sensitivity to the emotional reactions of participants. These clinical skills assisted in containing the strong emotional reactions most women expressed and enabled me to gauge when to stop the interview in the best interests of the participant.

My professional training also affected my analysis of the data, where I was naturally prone to identify psychopathology and explain research findings from this viewpoint. It is an understatement to say that my supervisors had to provide a great deal of feedback and guidance in order to keep my academic focus and prevent me from entering my comfort zone of clinically-focused psychological theory.

In the final chapter of this thesis, I go into greater depth in discussing the reflexivity inherent to this study. I now conclude this introductory chapter by noting that I have endeavoured to compensate for my significant limitations, by elevating my participants' voices above my own. This is not my work. It is ours. In the chapters that follow the reader will hear the voices of courageous women, and providers, with my reflections, literature expansions and theories which emerged from detailed, extensive and thorough data analysis. It is not a good read, nor a pleasant one. But one of immense importance. Thank you for reading these words, which I

hope will add value to your understanding of women's experiences of feticide and LTOP in South Africa as well.

10. Thesis Overview

The importance and value of this research is evident from the above discussion. In the following chapter (Chapter 2), I provide a holistic and in-depth explication of the current literature available in this field, with particular emphasis on literature relevant to the South African context. I start by discussing the available literature on women's experiences of, and reactions to, the diagnosis of severe fetal abnormality. An exploration of literature on women's information-seeking behaviour and aspects related to the difficulty of the decision-making process follow. Next, I turn to research on providers' decision-making processes. I contextualise the decision-making process as it relates specifically to feticide and LTOP. I then explore literature available on women's experiences of the feticide and LTOP procedures as well as their in- and out-of-hospital recovery. The psychological support women require, make use of, and that is available is explored, with Chapter 2 concluding with a discussion of relevant literature related to stigma, shame and silencing as it relates to feticide and LTOP.

The third chapter provides an understanding of the theoretical basis of this study, and I start by providing background to Grounded Theory (GT) and, in particular, the various perspectives on this approach. These approaches include the classical, Straussian and Constructivist GT, including a brief discussion on Feminist GT and how this differs from Feminist Social Constructionist Grounded Theory (FSCGT). Then, I pay particular attention to the conceptual qualities of Constructivist Grounded Theory (CGT), including pragmatism,

symbolic interactionism and the perspective CGT takes on coding, the literature review, grand theories, and the researcher's approach to theory development. Finally, I conclude with an explication of objectivism and subjectivism with regard to Feminist GT and how FSCGT assists the understanding of this research topic through the application of reflexivity.

Chapter 4 describes the process of data collection and analysis I employed, in accordance with the FSCGT methodology. I provide an overview of the two sample groups I included in this study and go on to explain the interviewing methods I made use of, along with a description of the transcription procedure. Next, I turn to discussing my analysis of the data, which includes the challenges and strengths thereof. I provide evidence of the credibility and transferability of my data analysis and provide a thorough discussion of the ethical considerations relevant to this research. In concluding the chapter, I explicate issues of privacy, confidentiality and anonymity of the data, the potential consequences inherent to this research, as well as a critical, reflexive account of the methodological aspects related to this research.

The fifth chapter presents my first analytical chapter and focuses on women's constructions of the first phase of these experiences, which is hearing the diagnosis of fetal abnormality and the decision-making process. Women's constructions of their behavioural and biological culpability in causing the fetal abnormality, are presented, following which, the constructed difficulty of the decision is explored. This difficulty relates to women constructing the decision-making process as conflicted and as essentially representing no choice. The extent and nature of women's partners' involvement as well as the reactions of those around them during the decision-making process are presented and following this, the types of responses women receive and how they react to these responses, are explained. Then I turn to a

presentation of healthcare providers' perspectives of women's reactions to the news of fetal diagnosis, the constraints placed on their own decision-making with regard to giving women the option of feticide/LTOP and an exploration of the impact that providers' personal perspectives have on the first phase of women's experiences. The construct of time is then discussed as it influences the entire experience starting from women's late access to antenatal care, lengthy tests and gestational limits that are constructed. In conclusion of this chapter, I explore the constructs of "wise" or "foolish" decisions and how these are affected by providers' personal positions, and the medical and systemic implications of continuing with these pregnancies.

In the sixth chapter, I focus on women's constructions of their experiences of the feticide procedure as well as the delivery (either surgical or induced labour), which includes women's constructions of the fetal demise. Next, the focus turns to women's constructions of dealing with the fetus/baby, which entails issues related to viewing or holding the fetus, naming the fetus, accessing fetal remains and women's in-hospital recovery. Women's constructions of their interactions with staff are presented next, where power dynamics between providers and healthcare users are problematised. Family interactions and interactions with other patients conclude the section on women's constructions of their experiences of the procedures and the chapter then focuses on providers' perspectives of women's experiences. The significant themes that emerged from providers included their own experiences of the feticide procedure, issues related to providers' self-care as well as their constructions of the "good patient" and "good doctor" roles during the feticide and LTOP procedures. In this section, providers refer to the psychological support women require during the procedures, as well as the impact that their own religious beliefs, and resistance to stigmatisation, affect providers' constructions of these procedures. The final section of this chapter explores providers' constructions of

delivering the fetus, dealing with the fetus (including constructions regarding women holding/viewing the fetus and using symbolic objects to assist women in working through the grief). Providers' perspectives on women's in-hospital recovery, providers' checking on women and making referrals, the importance of support and emotional reactions concludes this chapter.

In Chapter 7, I turn to women's accounts of their out-of-hospital recovery experiences, which include themes of self-silencing, stressful partner interactions, experiencing a lack of understanding from those around them and feeling pressed to get on with life. Women's reliance on distraction to reduce their emotional distress emerged in this section, along with women benefitting from performing rituals of burial or remembrance. Specific topics that arose here were women's attempts to avoid reminders, while conversely also keeping reminders e.g., footprints etc. In this stage, women report experiencing longing, feelings of going mad and also feeling as though they had grown through these experiences. Following this, I present providers' perspectives on women's out-of-hospital recovery, which include their constructions of the importance of women burying their fetus in order to achieve closure and the implications of these procedures on women's further pregnancies. Next, providers present their perspectives on the lack of familial and institutional support women may receive, while emphasising the importance of both of these sources of support. In concluding this chapter, I present some of the women's experiences of the interview and how being made aware of this study affected them.

I then focus my lens on providing a concluding discussion of the theory that emerged from this study. Firstly, I provide an overview of the findings and then present the grounded theory emergent from the data, which includes three prominent themes across the three phases of the

feticide and LTOP experiences. These include the significant disjuncture between women's experiences of these procedures depending on where they receive their healthcare, be it in public or private. The second theme relates to the myth of choice and how women, in fact, do not experience true decision-making throughout the three phases of these experiences. Finally, the theme of women's voices not being heard, and how this impacts upon each of the phases of their experiences is presented. Next, I turn to presenting a detailed integration of findings and present the limitations and contributions of this study, as well as my reflections on this research. I conclude the chapter by discussing the recommendations that emanate from the findings and theory presented in Chapter 8.

CHAPTER 2: LITERATURE REVIEW

The introductory chapter provided an overview of the contextualisation and rationale behind the research questions explored by this study. The literature review chapter builds on this and presents an in-depth discussion of the most relevant research findings with regard to women's experiences of the diagnosis of severe fetal abnormality, their decision-making, experiences of the feticide and LTOP procedures, as well as their recovery from these experiences. In order to contextualise women's experiences, I included literature on providers' perceptions of women's experiences, as these studies tend to illustrate the medical perspective on feticide and LTOP, rather than the woman's lived experience and thus assists in identifying gaps between providers' perceptions and women's constructions of their experiences.

Grounded theory researchers are advised to conduct their literature review after data gathering and analysis, rather than prior to undertaking the research. However, within the SCGT approach, it is acceptable to explore relevant literature prior to data collection and analysis (Charmaz, 2017b). In this regard, I read literature prior to collecting data, during data collection as well as following data collection. Due to the paucity of research that has been undertaken with regard to the feticide procedure in particular, much of the literature presented does not refer specifically to this procedure, but rather focuses on the diagnosis of fetal abnormality and LTOP prior to fetal viability. Unfortunately, exceptionally scant research has been conducted with regard to this research topic within the South African (or broader African) context, and consequently, most of the studies included in this review were conducted overseas.

Research on severe fetal abnormality, feticide and LTOP attracts medical professionals working in the fields of obstetrics, neonatology and clinical genetics, and consequently much of the available studies focus on these procedures from a medical approach, where the interactions between provider and patient occurring within expected and acceptably differentiated power roles. Researchers from the fields of psychology, sociology and nursing also show interest in the topic and tend to bring a more nuanced perspective and place greater emphasis on women's emotional reactions as well as issues of patient care in facilitating recovery from these procedures. Research is, of course, also limited to countries where LTOP due to fetal abnormality is legal, which further narrows the range of literature available on the topic. A relatively large number of studies have been undertaken to explore a variety of aspects related to termination of pregnancy due to fetal abnormality, although few of these have focused upon the experience of such terminations in light of the feticide procedure specifically, and I was unable to locate a study that took a social constructionist viewpoint on this matter.

I start this chapter with an exploration of relevant literature related to women's experiences of the diagnosis of fetal abnormality, their reactions to this, and their adaptation to the diagnosis. Next, I present relevant literature on providers' decision-making process in determining whether or not to offer the option of LTOP to the woman, as they are the gatekeepers either denying or providing women with choice in this regard. Following this section, I explore women's decision-making experiences with regard to LTOP and feticide, and the factors that affect this process, with particular emphasis on women's beliefs and emotions.

The majority of research studies focus on the determinants of physical and psychological health, taking a medicalised perspective toward women's experiences of LTOP and feticide.

These orientations are seldom capable of examining the intricate power relations that underlie all facets of women's lived experiences and present opportunities for my research to assist in bridging significant gaps in current knowledge due to the FSC lens utilised. I explore literature with regard to women's experiences of the feticide and LTOP procedures, as well as their recovery from these and include a discussion of the effects of stigma and silencing on women's experiences.

1. Women's Experiences of the Diagnosis of Severe Fetal Abnormality and the Decision-Making Process

In order to provide a coherent discussion on existing literature, I decided to present the literature according to the sequence of events women experience with regard to the research question. Qin et al. (2019) conceptualised Chinese women's experiences of termination of pregnancy due to fetal abnormality as occurring in four distinct phases. The first of these phases is women's denial of the diagnosis. Secondly, information-seeking takes place, and the diagnosis is confirmed. Third, decision-making is entered into, and fourthly, recovery (Qin et al., 2019). Relatedly, but with slightly different emphasis, Lalor et al. (2009) reported that women in Ireland went through four distinct phases in a process conceptualised as "Recasting Hope" following the diagnosis of fetal abnormality. It is important to note that abortion was illegal in Ireland at the time of their research taking place, and consequently, those who chose to terminate would have had to do so elsewhere. The phases identified included women initially assuming that their pregnancy was normal, irrespective of indications to the contrary. Secondly, they experienced shock and devastation once a diagnosis of fetal abnormality was made. This phase was characterised by somatic symptoms, difficulty sleeping, denial, information seeking and anxiety. The third phase was called

“Gaining Meaning” and was entered into when women interacted with specialists and were able to pose questions and process the information regarding their options. Finally, once the decision was made to either terminate or continue with the pregnancy, the woman entered the Rebuilding phase. During this final phase, women searched for meaning and focused on the future (Lalor et al., 2009). The discussion below will broadly follow the phases outlined in my research questions.

2. Women’s Reactions to Diagnosis of Severe Fetal Abnormality

Researchers from clinical genetics and fetal-maternal specialities as well as psychologists and other mental health providers pay particular attention to how women respond to receiving the news of the fetal diagnosis. Reactions to confirmation of a diagnosis of fetal abnormality can include emotional shock, anxiety and existential questions regarding the fairness of life, as established in the Swedish study undertaken by Carlsson et al. (2016). A Brazilian study by Patrício et al. (2019) noted that many women expressed feelings of worthlessness and denial, while Côté-Arsenault and Denney-Koelsch (2011) reported that parents in North America experienced receiving the diagnosis as eliciting intense grief reactions and depression. Denney-Koelsch et al. (2015) analysed parents’ experiences of receiving a fatal fetal diagnosis during routine ultrasound investigations, where participants described this experience as representing a profound crisis, which became increasingly stressful when they were required to wait for a follow-up appointment to confirm the diagnosis.

During these appointments, the attitude of the healthcare providers made a significant impact on how the interactions were perceived – either they were sensitive and allowed for time and questions, or they were rushed and experienced as impersonal, which led to patient

dissatisfaction in a North American study (Denney-Koelsch et al., 2015). The lack of certainty with which the diagnosis and further information were conveyed (due to the complexity of antenatal diagnoses and trying to estimate prognoses) served to cause anxiety and confusion. In addition, the potentially traumatic and stressful psychological reactions to receiving the diagnosis and explanatory information reduced some Swedish women's ability to retain and process the information they received (Asplin et al., 2012), as will be discussed in the next section.

Women who participated in an Australian study expressed feeling ambivalent toward the pregnancy following the diagnosis, and the fetal abnormality seemed to amplify conflicting emotions such as fearing that they might miscarry, but also seeing this as a better alternative than purposefully ending the pregnancy (Jones et al., 2005). Uncertainty regarding whether or not the baby would survive birth and concerns regarding life expectancy as well as the severity of possible impairment (Jones et al., 2005) affected women's psychological status during this time. Prenatal diagnosis of fetal abnormality precipitated a grieving process for the anticipated healthy baby and certain women reported feeling guilt and shame at failing to form a healthy baby. The diagnosis leaves pregnant people with two difficult options, either to continue with the pregnancy and give birth to a severely abnormal baby, or undergo fetocide and LTOP. Lafarge et al. (2014) and Ramdaney et al. (2015) indicated that their studies, which took place in England and North-America respectively, found women experienced the fetal diagnosis as overwhelming and were unable to actively make use of psychological assistance during the period of diagnosis and decision-making.

The default assumption throughout the vast preponderance of literature is that pregnant people would experience psychological distress and trauma due to the diagnosis of fetal

abnormality, which necessitates psychological and social support. In accordance with this assumption, Lafarge et al. (2020) found that British women reported making use of internal and external coping mechanisms during and following receiving the fetal diagnosis. These internal coping methods included remaining hopeful and using positive reappraisal to reframe the information they received, in order to reduce their emotional distress. External coping methods focused on reaching out to their social network and to supportive healthcare, e.g., psychological support or supportive communities such as those provided by online groups. However, due to the perceived stigma associated with an abnormal fetal diagnosis, as well as having decided to terminate the pregnancy, many Swiss women reported feeling uncomfortable disclosing their situation to their support network (Fleming et al., 2016). One aspect that may be related to the stigma women experience during the fetal diagnosis and decision-making stage is due to the responsabilisation that women experience during pregnancy. Macleod and Howell (2015) described the pregnant person as being constructed as solely responsible for the progression and outcome of pregnancy, irrespective of the structural challenges that may be in place. Deviations from the ideals of “normal” pregnancy, which would include abnormality of the fetus, would imply failings on behalf of the pregnant person and serve to shame and stigmatise them. It is no surprise then that Maguire et al. (2015) identified self-blame as a significant outcome when North American women were informed of fetal abnormality and that their guilt feelings were assuaged in instances where the diagnosis was so dire that their decision to terminate was, in fact, irrelevant with regard to fetal outcomes. The guilt and self-blame women reported may point to their internalisation of stigma. The impact of stigma, shame and silencing permeates all aspects related to women’s experiences of LTOP and feticide and will be discussed extensively later in this chapter.

2.1 *Information Provision and Seeking*

A Swedish study exploring women's experiences of receiving the fetal diagnosis during ultrasound examinations found that women reported being confused by the amount, complexity and contradictory information they received during the fetal diagnosis, and their findings indicated that women require detailed, in-depth information regarding both the worst- and the best-case scenarios and outcomes of the fetal abnormalities (Asplin et al., 2012). Women require this information to be provided in non-medicalised language and by providers who are empathetic. Many women in their study experienced the information they received as insufficient or difficult to understand, which led to reliance on alternative sources of information that may not have been accurate, e.g., the Internet (Asplin et al., 2012). Another Swedish study (Andersson et al., 2014), which investigated the experiences of nurses caring for women who were undergoing second-trimester termination of pregnancy, confirmed that women rely on the Internet to provide information regarding the diagnosis of particular abnormalities in their pregnancy. While medical practitioners may see women seeking information on the Internet as problematic, this may also be indicative of pregnant people taking up their agency and actively checking the information provided by the healthcare system (Andersson et al., 2014). Similar findings emerged in a South African study (Ndjapa-Ndamkou et al., 2013) which explored the views of pregnant women who had been informed of the presence of severe fetal abnormality at a tertiary hospital in South Africa. Findings with regard to these women's experiences of receiving information from the multidisciplinary team show that women experience this interaction as overwhelming, and many women were unable to retain enough information for this to meaningfully inform their decision-making process (Ndjapa-Ndamkou et al., 2013).

In conveying technical and potentially emotionally loaded medical information, healthcare providers need to remain mindful of the impact that language differences between and among healthcare providers and healthcare users may have on women's perceptions of the information provided to them. Language barriers have a detrimental effect on both access to and the quality of healthcare in South Africa (Van den Berg, 2016). These language differences include the use of medical jargon as well as different languages spoken by both patients and medical personnel in South Africa (Watermeyer et al., 2021). By way of example, the home languages represented by my study's sample include Sesotho, isiZulu, IsiXhosa, Setswana, Oshiwambo, French, Hausa, Portuguese and Afrikaans, in addition to English.

Once a diagnosis of severe fetal abnormality has been confirmed and conveyed to the pregnant person, time becomes a complicating factor, due to the assumption that increased gestation infers increased personhood. A British study which focused on women's experiences of healthcare during termination of pregnancy where fetal abnormality had been diagnosed, indicated that women required sufficient time and opportunity to personally reflect on the diagnosis, prior to making a decision (Fisher & Lafarge, 2015). Time is a problematic issue, as hospitals tend to establish and follow their own clinical guidelines, which rely on gestational stages to determine when and which diagnoses are eligible for LTOP. This is usually clearly conveyed to the pregnant person, placing an additional burden of time limits on the space available for her to comprehend and integrate the new information, as well as to discuss and consider the options available to her. Fleming et al. (2016) explored parents' and providers' experiences of diagnosing severe fetal abnormality in Switzerland and concluded that the manner in which this information is conveyed and the timing of providing the information are of vital importance. This is due to women feeling less

traumatised by the news if it was provided in a sensitive manner and when they were given enough time to adjust to their new reality (Fleming et al., 2016).

In a North American study, Denney-Koelsch et al. (2015) found that parents tend to go through a period of fact-finding, which they termed “need to know” following the diagnosis, and would then move to a stage of “checking-in” when they attended follow-up investigations to confirm the diagnosis. Certain participants reported enjoying follow-up sonars in particular, as they allowed them “time with baby”, while others experienced the continued focus on abnormalities and deformities as very upsetting.

3. Decision-Making Processes

The decision-making process regarding whether or not to terminate a pregnancy where the fetus is diagnosed with severe abnormality has been analysed by a number of authors, though few have specifically focussed on the decision where feticide would result. In certain countries where LTOP for fetal abnormalities is offered, including South Africa, women are regarded as legally competent to decide solely to continue with the pregnancy or not, and they are entitled to do so free from coercion. However, the reality is that pregnant people are dependent on the value judgements of medical health providers to allow them the option of exercising their right to decide. In this section, I explore the decision-making process that providers engage in, once severe fetal abnormality has been diagnosed. Following this, I present a discussion on abortion decision-making and the contextual factors relevant to this process. I conclude this section by exploring decision-making as it relates to LTOP, the impact of constructions surrounding disability on this decision-making, as well as perspectives on choice and what choices are available to women during this phase.

3.1 Health Service Providers and the Decision-Making Process

In the South African context healthcare providers are positioned as legal gatekeepers, as they are responsible for making the fetal diagnosis and deciding to make the feticide and LTOP procedures available. Women are then given the choice to terminate, within the parameters laid out by the specialist, in compliance with the law. This situation is not unique to South Africa. Crowe et al. (2018) identified a number of pivotal factors used by medical professionals in the United Kingdom (UK) to determine whether termination was acceptable for a non-lethal diagnosis (i.e., when the fetus is viable and would likely survive delivery), which are similar to those described by healthcare providers who participated in my study. One such aspect Crowe et al. (2018) identified was whether the fetal condition was regarded as repairable, correctable, palliative or not. Diagnoses without meaningful treatment options were regarded as valid options for termination; however, there were certain exceptions where the condition, e.g., trisomy 21, although untreatable, was regarded as ineligible for elective termination. Another important factor identified by participants was whether or not a “normal” life outcome or trajectory could be expected. The fetus’s potential to be mobile and the extent to which supportive care and resources would be required following birth, were regarded as noteworthy aspects in determining the acceptability of allowing the choice to terminate (Crowe et al., 2018). It is evident that throughout this process of negotiating the acceptability of providing the pregnant person with a choice to terminate, her right to choose is not a salient factor in the decision-making process. Although it is regarded as morally virtuous to give her the choice, other considerations take precedence above this.

There is increasing interest in the non-medical experiences of healthcare workers and a number of papers focused on the impact of LTOP service provision, including feticide, on those who provide them. For example, Fay et al. (2016) explored maternal-fetal specialists' experiences of conducting feticide procedures in the UK. Their participants reported regarding feticide as an unpleasant yet necessary medical service. Feticide was constructed as a difficult and technically challenging process which did provide participants with work satisfaction. The British medical specialist participants also reported that the ethical and legal context of the work was complex, but a multidisciplinary decision-making system reduced individual distress, as long as decisions were congruent with their individual and group values (Fay et al., 2016). These findings were supported by a North American study undertaken by Kerns et al. (2020).

British specialists' style of counselling differs depending on the individual characteristics and beliefs of the doctor involved, and although healthcare providers are guided by professional guidelines, they frequently rely on their personal values to justify or negate their decision to provide the feticide procedure (Fay et al., 2016). These individual characteristics and values include religious beliefs, ideas about their professional role and ethics as well as their own sense of preparedness to deal with abortion, according to Loi et al. (2018), who executed a systematic literature review of studies in sub-Saharan Africa and Southeast Asia.

Interesting findings from the participants in Zwerling et al.'s (2021) study, undertaken in North-America, indicated that nurses who care for patients undergoing termination of pregnancy due to fetal abnormalities presented religious justification as their motivation for assisting with these cases. My interviews with healthcare providers (discussed in the analysis chapters of this thesis) reflect similar themes and, although the focus of this research was to

explore their perceptions of women's experiences, it became evident that the interview space invited healthcare provider participants to also explore and share their own experiences associated with their patients and the feticide procedure. Sheen et al. (2014) found that certain British healthcare workers could experience exposure to feticide as traumatic, and it is interesting to note that the presence of empathy (the more empathetic, the more likely the healthcare worker would be to experience vicarious trauma) as well as the presence of organisational stressors contributed to an increased likelihood of traumatic stress.

Palliative care in fetal-maternal medicine has become increasingly prominent since advances in medical technology have created many more options with which to treat neonates who would previously have been regarded as non-viable, although following delivery their prognosis remains poor (de Godoi Melo et al., 2022). In their research on maternal-fetal specialists in the UK who conduct feticide along with termination of pregnancy, Fay et al. (2016) established that these providers may not be more vulnerable to psychological distress than other specialists, as all healthcare providers are confronted with multiple scenarios related to patient suffering and death as a routine part of their work. However, unlike most other facets of fetal-maternal work, these specialists do potentially experience greater stigmatisation due to their willingness to perform feticide procedures. In order to manage stigmatisation, these clinicians tend to disclose this aspect of their work selectively.

3.2 *Contextualising Decision-Making*

The process of decision-making, and its relationship to constructions of choice, require some unpacking prior to an exploration of the literature available on women's decision-making with regard to feticide and LTOP. A thorough theoretical discussion on decision-making

theories and approaches is beyond the scope of this literature review. However, it is important to briefly present relevant research in this regard, including that of Sereno et al. (2013), who explored abortion decision-making in Portugal. They noted that this process includes the interaction of multiple layers of influence, including personal, social, economic, structural and legal aspects. Chiweshe (2015) summarised abortion decision-making as consisting of women weighing the benefits and costs of terminating the pregnancy or continuing with it to full term. This constant negotiation between reasons to continue with the pregnancy and reasons to terminate is significantly influenced by the pregnant person's individual circumstances. In this regard, Chiweshe (2015) recommended that group comparisons are irrelevant to the abortion decision-making process. Mavuso et al. (2020) described the abortion decision-making process on the individual level as being influenced by personal, micro-level and macro-level influences. It is clear that understanding the decision-making process requires an understanding of choice and what true choice entails.

DiClemente-Bosco et al. (2022) discussed women's empowerment in encouraging adherence to anti-retroviral treatment during pregnancy in Cape Town, South Africa and described the interaction between access to resources, agency and the ability to achieve the desired outcomes. If this model were applied to women's decision-making regarding feticide and LTOP, the resources available and women's access to these would interact with, and to an extent, determine her agency in mobilising these resources. Her decision-making capacity and ability to enact her choice to either continue with the pregnancy or opt for feticide and LTOP, is thus directly affected by this interplay between resources and true agency. In her book, *Abortion and Woman's Choice*, Petchesky (1984) described women's right to choose with regard to reproductive health decisions, as being subject to their specific social environment, which either supports or negates their agency in decision-making. Many

decades later, hers remains an accurate description of the efficacy of women's reproductive agency. In applying this abortion decision-making information to the feticide and LTOP decision-making process, it is even more evident that what women are faced with in this situation is certainly not what most would construct as choice in the truest sense. Hayes et al. (2020) studied Australian women's experiences of late abortion and went as far as actively avoiding the use of the word "choice", as they constructed this decision-making process instead as a "difficult decision", due to the lack of desirable outcomes.

Decision-making with regard to the termination of pregnancy requires contextualisation in order to understand the complex interplay of factors involved in the process. Macleod (2012) explored the systemic and structural factors that influence women's reproductive decision making. These include women's social support, economic resources available, health support, interpersonal support and reproductive histories, all of which affect the extent to which women are truly able to make empowered choices with regard to termination of pregnancy. Factors affecting whether women feel capable of raising a child (even more so if the child would have special needs), include perceived social isolation or stigma, potential lack of social support, lack of access to healthcare, wantedness of the pregnancy, access to economic resources, interpersonal factors and sociocultural influences (Macleod, 2012).

4. Decision-Making Regarding LTOP Following Fetal Abnormality Diagnosis

This decision-making process takes place within a context of reasonable uncertainty as the fetal diagnosis is frequently not paired with specific prognostic information related to severity of impairment and potential duration of life, should the baby be born alive (Fisher, 2008). Ahmed et al. (2008) found that Pakistani and British women in the UK were more likely to

terminate pregnancy for conditions such as anencephaly, trisomy 13, trisomy 18, quadriplegia and Duchenne muscular dystrophy, due to the perception that these conditions would cause significant distress for parents when faced with the death of the child, and that the affected children would suffer if they were born alive. Termination was less likely in diagnoses where the child was perceived to be able to lead a potentially “normal” life. However, there was also a great deal of variation in terms of what was regarded as “normal”. Definitions of quality of life also varied greatly, but tended to include perceptions surrounding acceptable potential physical and social life quality (Ahmed et al., 2008).

Mosley et al. (2017) emphasised the importance of improving the financial, institutional and emotional resources required to raise children with disabilities in South Africa. According to the research findings of both British research by Fisher (2008) and North American research by McCoyd (2008), women tend to weigh their own coping resources, as well as their societal, financial, lifestyle and family-related factors in the process of deciding to continue with a pregnancy that would result in a special needs child. Due to the stigmatising and isolating approach society tends to display toward disabled people, women require time to analyse their coping abilities as well as that of their relationships and other resources in making this decision (McCoyd, 2008). In addition to the uncertainty inherent in antenatal decision-making, the emotional pain felt, the shock of the diagnosis, and multiple factors contributing to this process, women would benefit from sufficient time to analyse their ability to care for a special needs child (Fisher et al., 2014).

The language used to describe and convey the fetal diagnosis and prognosis provide significant insight into value-based constructions of what type of life is regarded as worthy or being “less than human”. These covertly employed influences may be uncritically

internalised by pregnant people and prevent them from applying their personal construction of what it means to them to be fully human, whether death or life are preferable, and whether medically ending the pregnancy is to their benefit, rather than sparing the healthcare system additional palliative and medical care burdens (Denney-Koelsch et al., 2015).

As discussed earlier in this chapter, the concept of choice is contentious in these circumstances, as one option is not obviously more favourable than the other; rather a decision is made between two relatively unfavourable alternatives (Hayes et al., 2020). Choice with regard to LTOP is not as simple as making a decision; it involves navigating multiple barriers in order to enact that decision. Hayes et al. (2020) reported on the barriers to LTOP within the Australian context and included aspects such as limited time to decide between continuing with the pregnancy or terminating, needing to travel across states to access abortions, lack of adequate counselling, and a scarcity of surgeons who are trained and willing to perform the LTOP procedure. These challenges are surprisingly similar to those experienced by women in South Africa and speak to the universality of reproductive health barriers preventing women from accessing specialised abortion care.

When the pregnant person has formed an emotional bond with the fetus, this attachment complicates the decision to terminate the pregnancy (Ramdaney et al., 2015). The concept of fetal personhood was discussed in the first chapter of this thesis and is relevant to the impact that fetal-maternal bonding has on this decision. The greater the extent of the attachment, the more complex the emotional impact of loss is likely to be, and this relates to how advanced the pregnancy is (Morris & Orr, 2007). The options available may be seen as causing pain one way or the other: continuing with the pregnancy and potentially inflicting physical pain

on their expected child or deciding to terminate the pregnancy and bear the consequent emotional pain and guilt themselves (Carlsson et al., 2016).

Religion was found to be of greater importance in predicting decisions regarding termination of pregnancy due to fetal abnormality than cultural differences in Pakistan (Ahmed et al., 2008). In fact, more similarities rather than differences were identified between cultural groups. However, where the women hold certain religious or normative beliefs which condemn termination of pregnancy, this is likely to cause significant cognitive dissonance and emotional distress (Lafarge et al., 2013). Another aspect that may influence the choice is previous reproductive experiences. North American women who have experienced previous termination of pregnancy are more likely to opt for subsequent termination when fetal abnormality has been diagnosed, while previous births or miscarriages were not found to affect the decision-making process, nor did the gender of the fetus. (Hawkins et al., 2013)

Women included in McCoyd's (2008) North American study indicated that they did not experience any pressure from health service providers to make a certain decision regarding the pregnancy. However, some did acknowledge pressure from their spouse to terminate the pregnancy and that female relatives were more likely to encourage continuing with the pregnancy. South African researchers (Ndjapa-Ndamkou et al., 2013) reported that the majority of their participants regarded their decision to terminate or continue with the pregnancy as being influenced by their family members. Participants in a UK-based study described their male partners as being passive during the decision-making process, and many women felt abandoned by their partner during this time. In instances where the partner disagreed with the pregnant person's decision, this exacerbated trauma responses and led to women feeling isolated (Hart et al., 2022).

During analysis of the interviews of participants in my research, I noted a theme that presented differently among women who made use of private healthcare services and those who used public healthcare. This related to women in private healthcare feeling responsible for deciding to terminate the pregnancy as they regarded their pregnancy as mostly supportable. Women who made use of public healthcare consistently regarded their decision as being one without choice, due to the lack of support available to them should they continue with the pregnancy, and many reported not feeling guilty for making a decision that was conceptualised as inevitable. According to Lotto et al. (2016), women who “internalised” the responsibility for deciding to terminate the pregnancy reported feeling guilt and being “undeserving” of care. These ideas and how they relate to the themes identified in my study are explored in-depth in the analysis chapters of this thesis.

During the decision-making process, many women tend to want to differentiate their experience and decision from first trimester abortions, and in fact, even reject the term “abortion” and favour euphemistic terms related to the medical reasons behind terminating their pregnancies. This is possibly also an attempt to avoid the highly stigmatised word (Fisher et al., 2014) and avoid the negative impact of stigma. The decision whether or not to terminate precedes a host of related decisions following delivery of the baby and Hunt et al. (2009) found that North American women felt unprepared for the number of decisions they would have to take once having decided upon the feticide procedure. These included whether or not to view or hold the baby once delivered, decisions regarding what to do with the remains, whether or not to commemorate the birth and death with a religious service or burial, with whom to share what information, whether to name the baby or not, and many

other decisions related to commemorating, disclosing and acknowledging the event (Hunt et al., 2009). These are discussed in the following section.

5. Women's Experiences of the Feticide and LTOP Procedures

Due to the paucity of research focusing on women's experiences of feticide in particular, it is necessary to present a combined discussion of literature on experiences related to both LTOP and feticide procedures. However, it is essential to bear in mind that the feticide procedure represents a set of particular experiences quite unique to the process of causing fetal demise, and this takes place via sonography and fetal intra-cardiac injection. In the analysis chapter, I explore some participants' lack of awareness that a feticide had indeed taken place, as feticide in these instances occurred through an injection into their uterus, rather than directly into the fetus.

The feticide procedure is never decided upon by the pregnant person. Instead, providers decide when, and with which method, feticide will take place. Middlemiss (2021) made the significant observation that this lack of consultation in the UK with the pregnant person remains startling in light of the procedure taking place in and through the pregnant body. Decisions in this regard are made based on factors associated with the fetal body, even though the fetal body would not survive delivery. A British meta-ethnographical study conducted by Lafarge et al. (2014) found that feticide may elicit greater negative emotions among women, due to the awareness of the moment of fetal demise, than when LTOP takes place without a specific procedure to stop the fetal heartbeat. This is a salient narrative that emerged from my interviews with women who underwent a feticide procedure where they were aware that the injection into their stomach was actively causing fetal demise. As found

by Leichtentritt (2011), certain Israeli women indicated that being aware of the moment of fetal demise, and experiencing this on a bodily sensation level, triggered intense emotional reactions with long-term consequences. However, as found in a British study, women may also view the feticide as merely part of the whole process of terminating the pregnancy, rather than as a distinct experience (Graham et al., 2009).

Participants in the UK-based study undertaken by Lotto et al. (2016) felt unprepared for the physical experience of labour during the termination of the pregnancy. In the same vein, Middlemiss (2021) studied women's experiences of pre-viable termination of pregnancy due to fetal abnormalities in the UK, finding that women regarded the labour and birth as completely unanticipated, upsetting and shocking. It was also a common outcome that women experienced complications following vaginal delivery. Participants in my study shared this narrative and described their experience of the labour process as more painful than they had anticipated, with less support from nursing and other healthcare staff than they had expected. In Lotto et al.'s (2016) study, women reported a lack of access to midwives and expressed a feeling of being isolated during the delivery of the stillborn baby. Some women who participated in my research echoed this experience and many expressed having felt neglected during labour because they were not giving birth to a live baby. However, women making use of private healthcare were able to insist on having privacy during labour and have only a family member present rather than medical staff. This relates to women's comments included in the Swedish study by Carlsson et al. (2016) indicating the ameliorating impact of non-judgemental support from caregivers, who, importantly, were present during the procedure, as well as experiences related to the emotional and physical pain experienced (where women indicated that they did not receive adequate pain relief).

Contradictory attitudes toward and experiences of either viewing the fetus following delivery, or not, were expressed. Certain participants in the Swedish study of Carlsson et al. (2016) expressed regret at not having viewed the fetus, while others were content with not having been exposed to this additional potential stressor. There were also women who regarded viewing the fetus as having provided a degree of closure (Carlsson et al., 2016). Njapa-Ndamkou et al. (2013) reported that all of the patients in their South African study chose to see the fetus following delivery, and that validating the predicted deformities and abnormalities provided them with a sense of reassurance that they had made the right decision in terminating the pregnancy.

The issue of post-mortem examinations arose as contentious in a British study; parents who elected to have one performed expressed distress at delayed and inconclusive results as the fetal diagnosis could often not be confirmed (Lotto et al., 2016). A number of parents declined fetal autopsy in order to “spare” their baby from further medical intervention. However, there is significant pressure from clinicians to allow post-mortem examinations in order to advance medical knowledge and confirm antenatal fetal diagnosis in Germany (Dathan-Stumpf et al., 2021).

6. Women’s Experiences of the Recovery Process Following Feticide and LTOP

The assumption cannot be made that feticide due to fetal abnormality must necessarily result in negative psychological outcomes for the pregnant person. Similarly, the termination of any pregnancy in and of itself, divorced from the circumstances that gave rise to the unwanted pregnancy, cannot be assumed to result in depression or grief reactions (Macleod, 2012). Delayed grief reactions were found to be common among the British population of women

who underwent LTOP for fetal abnormality; feelings of grief, which may have been previously avoided or suppressed, may be triggered in future (Lafarge et al., 2013). Anniversaries of the termination date, the expected due date, becoming or failing to become pregnant again may elicit grief responses. Guilt, grief, mental pain and concern for their partner's ability to cope with the experience were identified as common emotional reactions to the termination (Lafarge et al., 2013). Sleeping difficulties were reported following the procedure, as well as grief responses such as becoming emotional upon exposure to reminders of the pregnancy. Feelings of loneliness and emptiness were reported, as well as social withdrawal in order to avoid disclosing information regarding this experience (Carlsson et al., 2016).

The disenfranchised grief some North American women in this situation experience is worsened by social isolation and silencing caused by internalisation of cultural, social and political polarisations and fear of being judged and stigmatised (McCoyd, 2010). Doka (1989) described disenfranchised grief as arising when the individual experiences a loss which is not socially recognised by their community or society, and which they do not feel entitled to grieve. These kinds of experiences arose frequently in my discussions with women who had experienced LTOP and feticide. Hendriks and Abraham (2017) and Lafarge et al. (2014) described that Swiss and British women, respectively, who experience termination due to fetal abnormality may feel socially and emotionally isolated due to the loss of a child that many women describe as only having existed in her own mind.

Many women expressed (Lafarge et al., 2014; Ramdaney et al., 2015) that they were unprepared for the grief process following termination and that they were then unsure how to communicate their needs or to whom to communicate them. Kersting et al. (2009) identified

grief coping strategies employed by German participants, which included journaling, increased self-care, time spent with family members and making use of professional and informal social support resources. Memorial sites, holding funerals, remembering specific dates and keeping certain objects assisted in the mourning process. Qin et al. (2019) found that Chinese women attempted to relieve their grief through a number of different behavioural strategies, such as seeking social support, avoiding reminders of the experience and attempting to face the situation 'positively'.

Kersting et al. (2009) compared psychiatric diagnoses of German women who terminated pregnancies due to fetal abnormality shortly after the loss with women who had terminated their pregnancy due to fetal abnormality 14 months prior. Their findings indicate that initial psychological responses may include acute stress disorders, disordered eating, affective and anxiety disorders, as found in the first group. The second group (14 months later) presented with depressive and anxiety symptoms (Kersting et al., 2009), which may be indicative of the long-term and possibly chronic changes in psychological health that result from the experience of termination due to fetal abnormality.

Korenromp et al. (2009) conducted longitudinal research among Dutch women who chose to terminate their pregnancy due to the presence of fetal abnormality and found that posttraumatic stress symptoms were present in 46 per cent of participants at four months following the procedure, with this figure reducing to 20.5 per cent at 16 months post-termination. Symptoms of depression were present among 28 per cent of respondents at four months and 13 per cent of respondents at 16 months post-termination, respectively. Significant psychological consequences were reported by 20 per cent of the women included in the study and these were present for over a year (Korenromp et al., 2009).

Few studies explored how women navigate the recovery phase, particularly with regard to their personal rituals and reminders which helped them through the grieving process. Pitt et al. (2016) wrote about Australian women's embodied experiences in this regard and found that some women found memory boxes or spaces of remembrance helpful at this time. Having these spaces and items allowed women to decide when to revisit memories of their loss, although it is important to note that not all women want to maintain this connection to the events.

Fears of a recurrence were highlighted in a study by Carlsson et al. (2016), who explored virtual (online) messages posted in an online community dedicated to this particular population. This Swedish research identified themes related to participants' fears regarding a recurrence of an abnormality during a following pregnancy, as well as their longing to have a child. In line with this, South African women reported wanting more prenatal testing in subsequent pregnancies and reported intense fears related to recurrences (Njapa-Ndamkou et al., 2013).

Women in Njapa-Ndamkou et al.'s (2013) study expressed intense longing for the child that they had been mentally and physically anticipating, which for many resulted in wanting to become pregnant as soon as possible following the procedure. Other respondents reported needing time to recover prior to entering into another pregnancy. Certain women acknowledged feeling immense joy at becoming pregnant again and that subsequent pregnancy was experienced as ameliorating grief (Carlsson et al., 2016). In Gammeltoft et al.'s (2008) Vietnamese study, women who became pregnant and delivered a child soon after

the procedure, as well as those who already had healthy children, were more likely to cope better with this experience.

Andersson et al. (2014) described certain positive emotions being reported by Swedish women during the recovery phase. These mainly focused on feeling relieved that the procedure had been completed. Certain British women felt empowered by discovering their strength and used the experience to increase their self-efficacy (Lafarge et al., 2013). It is then fitting that Graham et al. (2009) preferred to regard the emotional responses to feticide as being equally as complex as the experience itself. Andersson et al. (2014) noted that participants overwhelmingly chose to report their emotions as positive, even though they also indicated that “pain” was a significant emotion they experienced. Andersson et al. (2014) indicated that Swedish healthcare staff and society may be resistant to the idea that women could feel anything other than negative emotions having been through termination of pregnancy due to fetal abnormality.

It is clear that the majority of research undertaken to explore the psychological impact of pregnancy termination tends to enter the context with a clinical or pathological viewpoint. There is a distinct deficit of research into these experiences that takes a feminist or social constructionist approach. The socially acceptable reaction to ending a pregnancy is for the pregnant person to experience psychological discomfort and loss. Approaching this topic from a feminist social constructionist viewpoint enlarges the scope to include as many varying constructions of experiences as there are participants.

6.1 *Psychological Support Post Feticide*

McCoyd (2010) reported that North American women who undergo termination of pregnancy due to fetal abnormality may feel stigmatised and alienated from others while enduring this loss. This sense of alienation from others may prevent women from feeling able to reach out to both formal and informal support structures. A significant finding was that many women indicated at six weeks and three months post-termination that they had underestimated their need for support. In addition, as reported by Lafarge et al. (2013), many women experienced a lack of support and required greater access to resources in the recovery period than were available.

Grief reactions may be affected by women's perception that their loss is not legitimately recognised by society, leading to limited access to social support in Britain (Lafarge et al., 2013). Many of the messages women posted on a support site during their recovery revealed reactions indicative of social withdrawal, which may be related to the perceived stigma, guilt and shame associated with terminating a wanted pregnancy due to fetal abnormality (Carlsson et al., 2016). Withdrawal, avoidance of disclosure, stigma and silencing were also prominent themes uncovered in the analysis of participant interviews in my research.

Korenromp et al. (2009) focused their research on Dutch women's psychological wellbeing during this recovery period and recommended that psychological support should be offered to women who display low levels of self-efficacy, higher levels of uncertainty during the decision-making process and those who display significant signs of emotional distress during their follow-up consultations. These researchers placed emphasis on including partners in all aspects of the LTOP and feticide procedures as far as possible (Korenromp et al., 2009). An

Iranian study found that rather than psychological or formal support, partner support as well as support from peers, friends and family are prominent ameliorating influences with regard to reducing women's feelings of guilt and self-reproach during their recovery period (Kamranpour et al., 2019).

Kersting et al. (2009) took the approach that interventions should be provided to support women following LTOP due to the presence of fetal abnormality, in order to reduce psychological stress reactions and their potential negative effect on existing or future children. This speaks to the importance of psychological support in ameliorating the possible negative ripple-effects of a woman's grief on the entire family system. This is interesting in that the focus is on the woman sustaining her caregiving role, rather than purely supporting women in their recovery period. Due to the complex interplay of factors that contribute to women's experiences of LTOP and feticide, Lafarge et al. (2017) recommended that these "silent mourners" in Britain are best supported by being able to share their stories with, and hear the stories of, other women who have been through similar events. This is one modality of psychological support that was highlighted by a participant in my research as having had a significant impact on her psychological recovery, so much so that she went on to lead a support group for women who experienced pregnancy loss.

Many women do not return to attend their follow-up appointments following termination due to fetal abnormality. This creates difficulties in assessing their needs and making referrals to appropriate services. The failure to return may be associated with the sensitive nature of this procedure and the vulnerability women feel. Ramdaney et al. (2015) hypothesised that avoidance (also a significant symptom of acute and post-traumatic stress disorder) is thus possibly an important coping strategy and constructed by the researchers as a defence

mechanism employed to allow women to retain a certain sense of control over their environment. Such avoidance could be interpreted as women associating the providers and hospital with the trauma of feticide and LTOP, which they would rather avoid. This avoidance may also be affected by the stigma associated with abortion (Kumar et al., 2009). Some Australian women regarded the clinics and hospitals they attended during these experiences as “sites of devastation” and this played a significant role in their avoidance of attending follow-up appointments (Pitt et al., 2016, p. 174).

7. Stigma, Shame and Silencing

Scharp et al. (2022) used relational dialectics theory to explore women’s meaning-making of late abortions of wanted pregnancies and provided a useful conceptualisation of stigma. This construction presented stigma as the convergence of processes of labelling as different, associating negative characteristics to these differences, separating “us” from “them”, discrimination, and loss of social status (as a “good” mother). Scharp et al. (2022) went on to describe abortion stigma as predicted by contravention of societal constructs of womanhood, which include that female sexuality exists purely for procreation, that motherhood is inevitable and that women instinctually nurture the vulnerable. Women who terminate pregnancy consequently deviate from expected norms, unless their decision to end the pregnancy is framed as a sacrifice in order to spare their unborn child suffering, thus reducing their marginalisation in comparison to women who terminate their pregnancy in their own best interests.

France et al. (2013) interviewed North American women who terminated their pregnancies due to fetal anomalies and found that selective disclosure occurred frequently. These women

tended to provide full disclosure only to trusted, close people, and instead edited events to “miscarriage” when disclosing to others. This was due to fears of being judged, wanting to protect other people’s feelings, and the guilt they felt. McCoyd (2007) raised the important point that women in this position are stigmatised not only by their choice to terminate the pregnancy, but also by the fact that their pregnancy had resulted in a disabled or abnormal “product”.

Termination of pregnancy for fetal abnormality and, in particular, the procedure of feticide, are relatively rare medical experiences; consequently, it is more susceptible to silencing and taboo than more common procedures (Hunt et al., 2009). Leichtentritt (2011) rightly indicated that even the terminology used to describe the procedure of feticide is controversial, thus further reducing women’s opportunities to discuss and reflect upon their experiences, thereby increasing the social and self-silencing they experience. There is no word to describe the wanted as yet unborn fetus that is, in fact, viable. This makes it difficult to convey the experience of having to end the life of a fetus, which is already conceptualised as a baby within the women’s mind. Society does not formally (through social processes) acknowledge the loss of pregnancy in general and Leichtentritt (2011) indicates that there are no pre-established rituals to commemorate this form of loss – LTOP owing to fetal abnormalities.

It is also difficult to not equate the experience to other understandings of abortion (McCoyd, 2010); but such equation enables pro-life agendas to be furthered with regard to abortion in general. McCoyd (2010) described North American women who experienced termination of pregnancy due to the presence of fetal abnormality as frequently rejecting the description of their termination as an abortion. They framed the decision as being taken with the best interests of the potential child, their marriage and pre-existing children in mind. Once again,

framing termination as in the best interest of the fetus is a socially condoned narrative which salvages constructs related to motherhood and thus protects the pregnant person's social identity. The importance of women being conceptualised as being benevolent mothers sparing their potential children suffering is depicted in research indicating the importance of supportive relationships following LTOP, as Kumar et al. (2009) noted that abortion stigma experiences were ameliorated by perceived community and partner support in North America.

8. Conclusion

This chapter provided an overview of the most relevant and recent literature available on women's experiences of LTOP and feticide. The structure was guided by the outcomes of analysis of the interviews with women and with healthcare providers, as the grounded theory approach calls for integration of literature with data. Women's experiences related to the diagnosis of severe fetal abnormality were presented as being framed by the manner in which the diagnosis was conveyed, factors related to the type of information provided, the terminology used, and the sense of time urgency conveyed to her. Available literature describes the diagnosis of severe fetal abnormality as a distinct crisis and as being complicated by the lack of prognostic certainty many conditions entail.

Women's decision-making experiences were explicated in light of the construct of choice and how enacted choice is frequently not equal to the theoretical choice provided, due to social norms, religious beliefs, and access to resources to care for a potentially disabled child. This chapter provided an exploration of the decision-making processes that healthcare providers

are involved in and noted the possible effects their involvement in LTOP and feticide may have on them as individuals.

Feticide was discussed and described as a pivotal and specific experience in the entire LTOP procedure when women were aware that the injection stopped the fetal heart. The psychological reactions to experiencing LTOP and feticide were described with particular attention paid to the significant psychological impact it has on women. The importance of providing women who undergo LTOP and feticide with appropriate and continued psychological support was emphasised. The negative psychological responses were frequently connected to the importance of motherhood in women's conceptualisation of themselves, as is reinforced by society.

To conclude the chapter, I discussed the significant impact that stigma and silencing have on women's experiences related to LTOP and feticide. Stephenson et al. (2017) described the process of silencing that occurs within the healthcare setting, where once the option to terminate with a feticide is provided to the woman, it then becomes her sole responsibility to "make the right choice". Significant gaps in literature were highlighted, particularly with regard to the paucity of South African research, and then internationally, the lack of research that approaches the topic of feticide and LTOP from a critical health perspective. A schism exists in current literature between "choice" and "autonomy" and medical information (frequently with questionable diagnoses and prognoses being provided) that becomes vague or inaccessible due to ethical, legal or professional fears on behalf of healthcare providers. What follows in the next chapter is a comprehensive discussion of the research lens that was adopted during this research and how this aspect is related to the literature that has been presented in this chapter.

CHAPTER 3: THEORETICAL FRAMEWORK

Grounded Theory (GT) refers to various approaches to the categorisation of contextualised materials about social processes and interactions (Payne, 2008). These GT approaches span positivist, interpretivist and constructionist paradigms of qualitative research ontology and epistemology (Willig, 2001). In this chapter, I explore the philosophical origins of Charmaz's (2006) Constructivist Grounded Theory (CGT), provide a critical analysis of this approach and present reasons for using a feminist theoretical lens in my application of the FSCGT framework. Social constructionism (SC) is frequently employed as a critical theoretical orientation within sexual and reproductive research, particularly due to its attention to how language, power relations and social contexts shape experiences and people's knowledge about those experiences (Burr, 1995). SC as a philosophy, is eclectic in drawing on critical theoretical frameworks, research tools and methodologies to produce critical readings of existing empirical literature and experiences (Rimaioli & McNamee, 2021). Accordingly, the CGT methodology and epistemological orientation are sensitive to reflexive integration with various complementary theoretical lenses, including the feminist social constructionist perspective I employ in this study. This will be referred to as a Feminist Social Constructionist Grounded Theory approach (FSCGT). I will argue in this chapter for how an FSCGT is better suited to understanding women's experiences of LTOP and feticide than, for instance, Wuest's (1995) Feminist Grounded Theory.

In writing this chapter, and continuously deepening my understanding of the origins and philosophical developments of GT, and more importantly, CGT, I found myself increasingly challenged to disrupt the traditional guidelines into which I had been inducted with regard to positivist research. Having completed three postgraduate research projects from a positivist,

quantitative perspective, the world of qualitative research and FSCGT research felt transformative, empowering, stimulating and, at times, overwhelming. Consequently, what is presented in this chapter is both an academic discussion, which is demanded by the rigours of a Doctoral thesis, but also a personal reflection on my grappling as a novice feminist social constructionist and Grounded Theory researcher.

The path of this chapter is selective. The main aim is to produce a thorough understanding of Charmaz's (2006) CGT and a formulation of an FSCGT with the integration of a feminist social constructionist theoretical framework. To this end, a brief orientation of the philosophical and pragmatic origins of GT is provided, largely to establish common principles of GT approaches and what an FSCGT does differently and usefully adds. The philosophical and theoretical discussion that follows focuses on early positivist accounts of GT (Glaser & Strauss, 1967; Strauss & Corbin, 1990) to show how principles of constructivism/constructionism moved GT towards more an interpretivist paradigm of qualitative inquiry (Charmaz, 2006). Charmaz's (2006) CGT is not, of course, the only interpretivist or postmodern development of GT methods (see Dey, 1999; Clarke, 2003), and various GT approaches have attempted to integrate feminist epistemology into methods and theory-building (Plummer & Young, 2010; Wuest, 1990), but CGT forms the spine of this investigation, and its usefulness will be demonstrated.

1. Brief History and Overview of Grounded Theory (GT) Approaches

This section briefly introduces and gives a definitional platform for several GT approaches to situate the FSCGT approach that was followed in this study. These summaries are deliberately fairly abbreviated, and are followed by a more conceptual discussion of crucial

theoretical and epistemological features of particularly social constructivist or social constructionist applications below.

1.1 *Classical GT*

Barney Glaser and Anselm Strauss founded the Grounded Theory (GT) methodology almost 60 years ago in *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser & Strauss, 1967). This classical GT method was developed out of a research project concerned with exploring the experiences of dying patients in American hospitals in the 1950s and 1960s (Payne, 2008). This was innovative and transformative sociological research, and against medical practice at the time, which did not routinely share diagnoses or prognoses with patients or their families. Glaser and Strauss were thus not only grappling with taboo topics and traumatic processes with research participants, but there was very little existing empirical or theoretical literature to voice or frame these experiences; and the scholarly research environment was dominated by positivist quantification (Payne, 2008). Glaser and Strauss's (1967) classical GT was thus devised as a systematic methodological approach to gathering, engaging with, and analysing interview materials with a sample of participants, alongside observations and institutional documents, from particular "settings". The aim was to *discover, expose or identify* themes and categories that *emerged* via rigorous inductive coding concerning social processes which maintained secrecy around dying for patients (Willig, 2001).

Classical GT rested on the epistemology that reality exists objectively and is thus a phenomenon open to and capturable by positivist investigation; and Glaser and Strauss presented a qualitative methodology that, they argued, would result in the generation of a

valid, objective “theory” (Chun Tie et al., 2019), grounded by empirical research data (Kenny & Fourie, 2014). This “theory” was understood to be a conceptual description of the data, rather than an interpretation of participants’ meanings or by the researcher’s perspectives (Payne, 2008). The development of classical GT was partly due to Glaser and Strauss wanting to develop a qualitative research methodology that could hold its own in a research context dominated by positivism, which emphasised representative sampling, and objectivity in data collection and analysis. For example, Glaser and Strauss (1967) held that theoretical hypotheses derived from a classical GT inductive process should be empirically verified through external quality assurance procedures (e.g., inter-rater reliability coefficients) to rule out bias.

Several general epistemological points emerge from this brief summary of classical GT and Glaser and Strauss’s (1967) original research programme on dying in American hospital settings that will be germane to the investigation of LTOP and feticide in this study. Firstly, GT is most useful when relatively little is known about the topic area in particular settings, and there are few or no “grand theories” to explain the experiences or behaviours under investigation (Payne, 2008). Secondly, a foundational principle of pragmatism in GT methods emphasises the importance of creating “actionable knowledge”, which contributes toward practical application of changes within society (Kelly & Cordeiro, 2020), instead of engaging in philosophical discussions or interpretations related to the nature of reality (Morgan, 2014). This applied to Glaser and Strauss’s (1967) original research on the silenced experiences of dying in hospitals; it is crucially important in this study on LTOP and feticide, to ensure that research outcomes result in actual changes in the lives of women. Thirdly, there is a strong focus on social processes of meaning-making as interactions within particular *settings* as the unit of analysis (Willig, 2001). This is the influence of Symbolic Interactionism as a micro-

level sociological theory about how social bonds are formed and maintained, and influentially drawn on/in, in the accounts people give of their own and other's behaviour; and that social meanings are attached to "symbols" and these symbols are used in making interpersonal interactions meaningful (Crossman, 2020; Fine & Sandstrom, 2020). These complex ideas are returned to in more detail in the sections below to illustrate similarities and differences in how different GT approaches operationalised them.

1.2 Straussian GT

Glaser and Strauss would officially part ways when Strauss published the *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* with Juliet Corbin (Strauss & Corbin, 1990). The schism was reinforced by Glaser's (1992) rejection of the GT redevelopments proposed by Strauss and Corbin (1990) as based on "misunderstandings" and "misrepresentations" of classical GT. As Dey (1999) has suggested, these scholarly differences were probably due to classical GT being "looser" and thus, more ambiguous and open to various interpretations than Straussian GT; but the schism has led to copious positivist squabbling between GT researchers who dispute the methods and truth claims of either classical or Straussian GT. The schism produced distinctive "styles" of GT, encapsulated by labels of Glaser and Strauss's (1968) original approach as classical GT, and Strauss's further publications and work on GT labelled as Straussian GT (Kenny & Fourie, 2014). There were further schisms following constructivist redevelopments of GT (see below: Charmaz, 2006).

Straussian GT would firm up GT-design elements in relation to the philosophical foundations of pragmatism and symbolic interactionism, and provide more rigorous structure in the

deductive analytical coding procedures employed to develop theory-building (Kenny & Fourie, 2014). Symbolic interactionism emerged during the early part of the twentieth century, growing out of pragmatism and gained prominence as a sociological theory in America in the 1960s (Fine & Sandstrom, 2020). It is a micro-level theory based on the idea that social bonds are formed by the interpretations people make of other's behaviour, the meanings attached to symbols and how these symbols are used in interpersonal interaction (Crossman, 2020). Thus, as Payne (2008, pp. 67-69) explicates, this led to the formalisation of the dominant GT-design components we recognise as characteristic of "Grounded Theory" today, viz.

- *Theoretical sampling* which involves collecting further data, and asking further questions of participants in particular settings, based on the categories which have emerged during earlier coding processes and negative cases that challenge consensus;
- A complex coding paradigm that explicitly moves from (inductive) *initial or open codes*, through *axial codes* (putting codes into bigger "core" categories), towards *selective or theoretical coding* (the deductive work of linking categories into an explanatory – rather than descriptive – theory); and
- Various strategies for *constant comparison* which involves moving back and forth between data and categories, to refine theory-building and to ensure accuracy of claims.

Strauss and Corbin (1990) appeared to introduce movement and flexibility to the meaning-making process. However, the array of technical procedures and analytical steps were largely attempts to reassure positivists that the "discovery" of theory from data was not biased by subjectivity (Parker, 2005). Straussian GT thus maintained its "objectivist" orientation (Willig, 2001, p. 44). These GT-design elements are further discussed in terms of ontological

and epistemological foundations of pragmatism, symbolic interactionism, positivist realism and relativism, and so on, in the sections below.

1.3 Constructivist GT (CGT)

Kathy Charmaz studied sociology at the University of California in San Francisco under Glaser and Strauss, the founding fathers of GT, and would go on to complete her Doctoral dissertation in 1973. Developed from her Doctoral study, Charmaz's (1990) pivotal paper, "*Discovering chronic illness: Using grounded theory*", established the theoretical and methodological premises of her constructivist approach to GT. Charmaz's empirical study (1992) usefully further explored the kind of knowledge such an approach could innovatively produce. Her study was based on 140 interviews with chronically ill working- and middle-class adults (men and women) in North America, and was guided by the question: "How does chronic illness impact on perceptions of the self?" Charmaz (1992) argued that examining "silences" among the illness stories: allowed various social meanings and processes (for example, stigma) to come to the fore; noted dissonances between lived experience and accounts of it; brought up notions of the embodied self; and formally highlighted the researcher's subjective (and interpretive) stance in GT. Her theory-building included the impacts of trauma and suffering in/on accounts, and significant losses of self, a way of life and moral status through the experiences of chronic illness and accounting for it. However, there were also triumphant stories of courage, agency, self-knowledge and self-care, and a refashioning of priorities and values in living in the present and in moving forward with lives – what has come to be known as "post-traumatic growth".

Charmaz's (2006) book, *Constructing grounded theory*, established her as one of the most prominent theorists in the field of GT, and proclaimed another significant schism in GT approaches – as a paradigmatic “turn” towards subjectivism in the field, which Charmaz describes as knowledges about participants and the researcher “from the inside out” (Charmaz, 1995, cited in Willig, 2001, p. 44). Furthermore, Kenney and Fourie (2014) observed that Charmaz's “constructivist” approach to GT regarded the GT-design and analysis process as less a “discovery” of theory, than a “co-construction” of data and theory. Charmaz (2014a) regarded reality as fluid and knowledge as created through the researcher's interaction with participants and data. This researcher mediation is, of course, conducted through the medium of language from a symbolic interaction theoretical perspective, Charmaz would regard the world (of shared social meanings) as being constructed by language, inter-subjectively, rather than merely objectively represented by it (Kenny & Fourie, 2014). From Charmaz's (2002) study mentioned above, it is evident that ways of talking about chronic illness provide socially shared ways to justify experiences and actions, attribute or shift blame and create particular “selves” as identities; additionally, silences among the stories can function as sites of conflict, resistance or self-protection. The different languages available to women and/or (educated) middle-classed chronically ill participants shifted storied resources, meanings and selves presented in nuanced ways. This constructivism implies a self-aware and reflexive agent who is cognitively manipulating social meanings to position themselves in particular ways, for/with the researcher, rather than as a passive puppet of language (Willig, 2001).

It is noted that Charmaz (2006) is a sociologist and has – at various times – used the terms “constructivist” and “constructionist” to refer to her GT approach, seemingly interchangeably. While this might be philosophically justified in some social scientific

disciplines, psychologists do make a distinction between constructivism and constructionism; and critical social psychologists differentiate between different versions – softer and stronger – of SC (e.g., Burr, 2015; Parker, 2005; Willig, 2001). Alanazi (2016) described constructivism as a cognitive paradigm, where experience and learning are regarded as a process that takes place internally (inside an individual's mind) through interaction with the social environment. For cognitive psychologists, constructivism is associated with Jean Piaget (a Swiss cognitive developmental theorist) who theorised that the individual is the agentic centre of learning and that this process takes place through two mechanisms; accommodation (changing ideas of the external world based on new experiences) and assimilation (how people adapt to and acquire group attributes) (Brau, 2018). A more culturally embedded form of social constructivism is evident in the psychological theorisation of Lev Vygotsky, who saw individuals as active participants in the creation of their own knowledge, along the norms available to them in their particular social contexts (Burman, 2007).

It is assumed then that individuals make sense of experiences, and similar environmental stimuli, in uniquely creative ways, and may hold different perceptual and cognitive views of reality (Parker, 2005). Parker (2005) goes on to warn against naïve constructivist research endeavours which seek to unproblematically try to identify such hidden mental processes in the individual that apprehend or express things in ways that are unmediated by social meanings or social processes. To her credit, Charmaz's (2006) symbolic interactionism saves her from this narrow cognitive psychological pitfall. Charmaz's constructivist GT (CGT) rests on situatedness, contextualisation, the link between knowledge and action, as well as the idea that knowledge is "socially constructed" in, by or through social interaction (Gill, 2009).

From a critical social psychological perspective, “constructionism”, or SC, differs from constructivism in its explicit attention to how human experience is conceptualised as mediated historically and socially, and how the individual is seen within this process (Willig, 2001). Thus, experience is contextually bound by settings and powerfully shaped by language – what we think/talk about, and how – and instead of regarding meaning-making as an internal cognitive process, it is instead conceptualised as dependent on historical, cultural and social situatedness (Galbin, 2014). However, a social constructionist perspective is not unitary and there are “softer” and “harder” forms of theory, which relate to the degree of agency attributed to an individual in meaning-making about experience. For example, Parker (2005) describes a softer SC position as upholding the individual’s agency in negotiating meaning-making and positioning among influential social processes (i.e., *using* language to do particular things), and harder SC positions as critically unpacking how the ‘individual’ itself is constructed in particular ways, including these so-called ‘choices’ (i.e., *being used by* language and ideology in a particular way).

How participants (women and healthcare service providers) construct their experiences related to LTOP and feticide, and how participants position themselves and use their language to construct their experiences, relates both to Charmaz’s (2006) CGT, and to softer SC (as above). Adding a feminist social constructionist lens to this perspective serves to increase awareness of the impacts of medicalised language, power imbalances and structural inequalities on women’s experiences of LTOP and feticide – and examines how “choices” or “good decisions” (to terminate or not) are frequently coerced in particular ways. This draws in/on the harder SC perspective.

1.4 *Feminist GT vs. Feminist Social Constructionist GT*

A feminist perspective encompasses diverse feminist theoretical views, ideologies, research paradigms and approaches, which share the basis of being embedded in the lived experiences, struggles and voices of women within oppressive patriarchal social systems (Plummer & Young, 2010). The central concerns shared across feminist research endeavours include improving the opportunities and choices available to women and other gendered minorities, disrupting unequal power distribution and raising women's voices and experiences to prominence (Brooks & Hesse-Biber, 2007). The feminist theoretical lens seeks to critically examine taken-for-granted constructs that sustain inequality (Wigginton & Lafrance, 2019), which is pivotal to understanding what women who undergo LTOP and feticide experience. The transformative agenda is one shared by all research that ascribes to feminist theoretical principles, as is the commitment to social change, in order to reconstruct social structures and interactions, and thereby reduce power differences (Wigginton & Lafrance, 2019). The contextual, structural, power and systemic influences on the topic under study are salient in feminist research, with a critical lens being applied in asking why data presents as it do, rather than merely describing them (Mohajan & Mohajan, 2022). Feminist research is any research undertaken by an explicitly self-positioned feminist researcher, with an awareness of the reflexivity inherent to interactions between researcher and participant, and to the processes, impacts and expectations of a feminist epistemological framework within the investigation itself and the audiences of the published research (Mohajan & Mohajan, 2022).

These feminist ideas are not foreign to GT research (Mohajan & Mohajan, 2022; Plummer & Young, 2010). Judith Wuest (1995) is credited with leading another schism from mainstream GT approaches in her formulation of a Feminist GT. Wuest set out to deploy feminist

interests and activism within a GT design to expand knowledge of women's caring as a base for policy development, knowledge expansion, and acknowledgement and advocacy of diversity and change in nursing roles in Canadian hospitals. Sources of data were selected from a theoretical sampling of 65 women with diverse caring responsibilities as mothers of young/sick, carers of elders and survivors of abuse. The study was feminist in its focus on unequal social expectations of women as carers, and how they managed competing and shifting care-demands in real-life situations. Theory-building found a two-stage process of first, overwhelm, "fraying connections", and "falling apart" in responding to the care-demands; and second, a proactive resilience in new boundary-setting, negotiating and repatterning of care roles. These feminist strategies were taken as vital entry points for nurses' care-training and as empowering to women.

Wuest's (1995) GT method – in its theoretical sampling of women carers, and careful coding paradigm to unpack and theorise women's "caring" – straddled the competing objectivist traditions (and guidelines) of classical GT and Straussian GT. She was thus defensive about her application of feminist theory within a GT field and positivist audience that is suspicious of, and judgemental of, pre-existing "grand theories" (such as a feminist framework) that "skew" theory-building in particular ways (Plummer & Young, 2010). Wuest (1995) thus ended up spending a lot of space in her paper examining the so-called "tensions" created in applying feminist theoretical features to the GT method; and suggests that reflexivity is a curative means of ensuring that both classical and Straussian GT traditions are respected. She does not, unfortunately, take the constructivist/constructionist leap or turn towards subjectivity, which perhaps happened historically after her GT contributions. Below, I will briefly explore why and how a *feminist social constructionist* theoretical framework would work usefully within Charmaz's (2006) CGT approach.

Definitions of key theoretical terms (cognitive) constructivism, social constructivism and versions of SC have been introduced above. There appear to be many shared dimensions between feminist and social constructivist/constructionist principles that would be useful to this research study on LTOP and feticide. First is a rejection of essentialism in understandings and experiences of women, or gender, as true, natural or real (Wigginton & Lafrance, 2019). This critical turning away from essentialism encourages the researcher to explore language as a site of shared meaning, but also power, conflict and resistance, and to critically examine the intersectionality (between race, socioeconomic class, health status, etc.) at work alongside gender to produce oppressive effects (Burr, 1995).

Second is a commitment towards a subjectivist approach to research, which is critical of positivist and/or masculinist scientific methods – in other words, they offer resistances and alternate epistemologies that disrupt orthodoxies (Clarke & Braun, 2019). Varpio et al. (2020) explained that a subjectivist inductive research approach – upheld within Charmaz’s CGT – assumes that reality is socially and experientially constructed, and researchers consequently explore these subjectively constructed experiences in in-depth interviewing and reflexive analysis. This focus on lived experience “gives voice” to participants as well as regarding language as a reflection of the social meanings attributed to it (Clarke & Braun, 2019).

Third, both feminist and social constructionist lenses encourage the critical reflection of the data (Varpio et al., 2020), which seeks to use these understandings in order to transform socially sanctioned oppression and power differences by problematising the language used to legitimate and sustain these phenomena (Clarke & Braun, 2018). Consequently, including

feminist and (harder) social constructionist lenses to Charmaz's (2006) CGT – which assumes a social constructivist position (see above, and more on this in the sections below) – provides several advantages for a study of women's experiences of LTOP and feticide. These advantages include: focusing on women's experiences within medicalised reproductive health settings *and* critically analysing the use of language in the (social) construction of their experiences. For example, many participants in this research used language to position themselves as “loving mothers” who decided to end their pregnancies with fetuses diagnosed with severe abnormalities in order to protect their “unborn child”. Along with medical opinion, they constructed themselves as making a “good decision”, rather than a “foolish choice”, which would have resulted in suffering for the child and financial burden for the family. That women were not allowed to make a decision purely for “selfish” reasons is a reflection of the underlying societal expectations of women, and particularly pregnant women, to adhere to concepts of selflessness and sacrifice. The analysis chapters will present a rich discussion of these themes; however, it is helpful to use this example to illustrate the social constructionist and feminist views, where the construction of certain positionings is foregrounded rather than just accepted as a reality or women's nature or experience.

The approach extends Charmaz's (2006) CGT into a *Feminist Social Constructionist Grounded Theory* (FSCGT) and will be referred to as such. The theoretical and epistemological implications of this shift are addressed in sections below, for example, how the GT concept of theoretical sensitivity might be used to deepen reflexivity about the introduction of “grand theories” (feminist and social constructionist) into a CGT framework.

2. Conceptual Qualities of GT, with Special Attention to CGT

The sections above have introduced basic premises and shifts between major “schools” of, and schisms within, GT approaches, viz., classical GT, Straussian GT, Charmaz’s CGT, and a formulation of a Feminist Social Constructionist Grounded Theory (FSCGT). These approaches – despite some transformative paradigm shifts from positivist to interpretivist perspectives – continue to share characteristics that define these as “Grounded Theory” methodologies. These include theoretical sampling, the simultaneous collection of data and ongoing coding and category analysis, memo writing, using the constant comparative method, applying theoretical coding to develop new theory, sampling to saturation, and emphasising the value of theoretical sensitivity (O’Connor et al., 2018).

Glaser and Strauss (1967) outlined two characteristics of GT that set it apart from other qualitative methodologies of the time. These were constant comparative analysis and theoretical sampling. According to Glaser and Straus (1967), theory need not only be developed based on carefully coded propositions; instead, conceptual categories could form theory through a process of continuous exploration and discussion of the data. This process is described as their constant comparative method, where every element of data is constantly compared to all other parts of the data. Through this process, similarities, differences and gaps in the data are explored by using the flexible methodological guidelines (Hallberg, 2009). Constant comparative analysis entails the process of collecting data and simultaneously analysing data, in order to inform subsequent data collection. Cho and Lee (2014) described the purpose of comparative analysis as enabling theory development by reducing variables to conceptual categories and imbuing the formulated theory with generality. Charmaz (2004) provides a more flexible approach than the constant-comparative

method and encourages the iterative process to take place creatively. Thus, all three approaches to GT continue to utilise the constant comparative method; however, CGT does so in a flexible manner, encouraging methodological journeying between data, concepts and theories (Irwin, 2006).

These GT-design and methodological aspects will be discussed in detail in Chapter 4 (Methodology) of this thesis. What follows now is a discussion of the most salient conceptual diversions between the “positivist” and “interpretivist” GT perspectives, including the different philosophical underpinnings of how knowledge is conceptualised and approached. Special attention will be given to how Charmaz’s (2006) CGT provides – to some extent – a theoretical critique of positivist objectivist methods. The integration of a feminist social constructionist theoretical lens (into CGT) both strengthens and extends CGT in particular ways.

2.1 Pragmatism – Social Settings, Situations and Contexts Matter

The different approaches to GT diverge in the extent to which they ascribe to pragmatist philosophy. Pragmatism is a philosophical movement and epistemological framework with its origins in the late 19th century. It has evolved into various forms and applications, but, generally, it relates to focusing on practical approaches and solutions to problems – ones that will work in real-life, lived situations rather than abstract theories, principles or ideals from elsewhere (Kelly & Cordeiro, 2020). Thus, practical, actionable change, rather than purely theoretical debate is the priority of a pragmatist approach to research and useful knowledge-development (Morgan, 2014). The emphasis on contextually useful knowledge (and theory), emergent from particular situations, underlies the selected site of sampling for GT approaches

as *settings* where social meanings circulate and interact, rather than on sampling individuals per se (Cresswell, 2007).

Kelly and Cordeiro (2020) described pragmatism as relating to the emphasis on the interconnectedness between experience, knowing and acting. Thus, beliefs and actions are linked by the experiential process of decision-making or responding to contextual and situational influences (Kelly & Cordeiro, 2020). In this regard, situationalism is relevant, as it regards truth as situation-dependant; consequently, what is true or useful may differ according to the context in which it is situated (DeRose, 1998). Situationalism describes the person in relation to their situation, while contextualism refers to the surroundings, circumstances, environment, background or settings that affect or create the meaning or truth of an issue (DeRose, 1998).

Powerfully, then, for social constructivist/constructionist GT approaches specifically, and interpretivist approaches in general, pragmatism regards truth as provisional – facts and values are not regarded as separate, and multiple perspectives are acknowledged (Cresswell, 2007). Pragmatism's practical approach to solving problems and studying actions in this regard relates to situationalism's focus on the way humans respond to their direct environment and contextualism's description of what is true in this environment (Charmaz, 2014a). Both situationalism and contextualism are frequently applied to the analysis of language in constructing and conveying knowledge, particularly within the CGT and FSCGT approaches (cf. DeRose, 1998).

Thus, Charmaz (2017b) explored pragmatism as the foundation of CGT and described pragmatism as an ontological viewpoint that regards reality as social, contextual, processual,

fluid and temporal. Consequently, an idea or proposition is regarded as true if the practical outcomes thereof are functional and useful (Charmaz, 2017b). Charmaz's (2017b) centralises human agency and how decision-making and problem-solving are employed to affect their environment. CGT utilises pragmatism when social reform is central to the topic being researched, making this relevant to understanding women's experiences of feticide and LTOP, where the feminist epistemological lens focuses on social inequality and redressing this. Charmaz's (2017b) approach to pragmatism includes an emphasis on the importance of language as significant in people creating and acting upon reality as they construct it. Charmaz (2017a) noted that CGT goes beyond pragmatism to provide a method for studying perspectives, language, meanings, actions and temporality that affect lived experiences.

2.2 Symbolic Interactionism – Social Meaning-Making Processes Matter

Classical GT was influenced by pragmatism and symbolic interactionism, as Glaser (1978) regarded the researcher's purpose as comprehending the actions and meanings people give to their lived experiences in order to identify underlying psychosocial processes in a particular setting. Strauss and Corbin (1998) also instructed the GT researcher to enter into field work to discover and understand the shared symbolic world of the participants in order to generate theory from data. Aldiabat and Le Navenec (2011) see symbolic interactionism as a foundational ontological framework that seeks to understand humans' relationships with their societies, communities and settings by paying attention to the shared symbols that give meaning to our direct experiences – and see this is a crucial framework in all GT approaches. Thus, in terms of *ontology* (assumptions about the nature of reality and of personhood), both symbolic interactionism and GT regard reality as existing in the context of shared symbolic meanings for humans, in particular, social settings (Guba & Lincoln, 1994).

Alongside these ontological assumptions about reality and personhood, symbolic interactionism's *epistemological* assumptions (the nature of knowledge and relationship between the knower and the known) are inherent in all GT research processes, which regard the researcher and the participant as being interactively connected in a mutual relationship within the context under investigation (Aldiabat & Le Navenec, 2011; Creswell, 2007; Guba & Lincoln, 1994). The methodological assumptions that are shared by symbolic interactionism and GT include that humans and their shared meanings related to reality can only be studied and understood through interaction between the researcher and the participant within the relevant setting (Aldiabat & Le Navenec, 2011). Charmaz (2006) takes this a step further in her assertion of the co-construction of data and theory – the researcher working with participants to build knowledge in particular settings. The GT approach, in general, also includes this symbolic interactional epistemological framework in the incorporation of processual, iterative meaning-making methods of theory-building, which include ongoing theoretical sampling, analysing material as it is collected to inform later explorations, constant comparison, negative case analysis and theory-testing (Cresswell, 2007).

Kushner and Morrow (2003) have noted that symbolic interactionism neglects power and structural interactions inherent to social relationships. In other words, this framework does not have critical teeth to examine how some (shared) meanings become more dominant in particular settings and dynamics, where all meanings are not equal. Criticism of symbolic interactionism includes that it overlooks the macro-level of social interaction and fails to account for the effects of social forces, power disparities and institutional influence on individual-level interactions (Crossman, 2020). However, Low and Thomson (2021) presented an insightful defence against the alleged astructural bias present in symbolic

interactionism and described these perceived shortcomings as being due to the lack of researchers engaging with issues related to social structure, rather than deficits in the method.

Charmaz built on the foundation of pragmatism shared by symbolic interactionism and GT by including not only the shared meanings attributed to symbols during people's social construction of their experiences, but expanded the focus to why these meanings are constructed (Salvini, 2019). The CGT approach shares a deep respect for subjective interpretations of experiences, which is in line with symbolic interactionism as well as feminist theory (Alston, 2014); while moving beyond the individual perspective to emphasising the social, contextual and relational structures that interact to influence individual experiences and meanings. For the purposes of this particular research on LTOP and feticide, the integration of an explicitly critical feminist social constructionist lens with CGT – my approach named FSCGT reinforced the aim that issues related to power and silencing are directly explored.

2.3 Coding Categories and Constant Comparison

GT approaches proceed with “progressive identification and integration of categories of meaning from the data” (Willig, 2001, p. 33). GT is thus both a “process” of categorisation (a method) and a “product” of categorisation (a theory) (Willig, 2001). The methodological processes of coding, towards theoretical coding, will be covered in Chapter 4's Methodology; but it is worth focusing briefly on the epistemological aspects of theory building here – in light of principles of pragmatism (context) and symbolic interactionism (processes of shared meaning-making) discussed above.

All GT approaches begin with early/open coding (induction) and a progressive theoretical coding protocol throughout the research process (Cresswell, 2007). The coding spiral is variously articulated within the different GT approaches by way of inductive, deductive and abductive epistemological steps. These are not isolated or distinct theory-building strategies, but each is emphasised differently in different GT approaches. In order to preface my exploration of induction, deduction and abduction, I present a simplified, bare-bones definition of each of these concepts below.

Inductive data analysis involves building comprehensive codes, patterns, categories and themes “from the bottom up”, by interactively and back-and-forth processing and organising data into incrementally more abstract units of meanings (Cresswell, 2007). Induction can be regarded as a means to conceptualise a theory and entails moving from the specific (line-by-line analyses of interviews with participants) to the general (lumping several similar codes together into umbrella categories) – and thus, the researcher uses these interviews to create a “theory” that may be applicable more broadly than the particular group (Kennedy & Thornberg, 2018). Abduction is similar to induction in that both allow for a conclusion to be drawn based on available information. However, abduction entails selecting the most likely causal explanation for a phenomenon, while induction provides a general description in order to increase understanding or knowledge of a particular event or topic. (Kennedy & Thornberg, 2018; Kenny & Fourie, 2014). Abduction is applied in order to develop useful theory that has practical implications in the real-world context, by presenting causal explanations for phenomena. For example, if I am able to identify certain factors that affect how women experience LTOP and feticide, it becomes possible to identify aspects that need to be changed in order to improve their outcomes. Once a possible “theory” is developed (through induction or abduction), *deduction* entails verifying or testing the theory (as a

“hypothesis”), and then drawing specific conclusions based on the systematic analysis of the data (Kennedy & Thornberg, 2018). Consequently, deduction could be regarded as a means of objective verification of a truthful knowledge claim (Kenny & Fourie, 2014).

Kenny and Fourie (2014) describe Classical GT as demanding the researcher approach the data without former research questions to be proven or disputed. Rather, they should move inductively from data analysis to uncovering a theory. The objective of GT is to discover the theory underlying the data being researched, by systematically analysing said data (Kenny & Fourie, 2014). Research concludes with the researcher arriving at a hypothesis, which is a theory, conceptualising the topic under investigation. Consequently, Glaserian GT could be regarded as a strictly inductive research process. However, Glaser and Strauss (1967) outlined three characteristics of Classical GT that set it apart from other inductive qualitative methodologies of the time. These were constant comparative analysis, theoretical sampling and negative case analysis. According to Glaser and Straus (1967), theory need not only be developed based on carefully coded propositions; instead, conceptual categories could form theory through a process of continuous exploration, discussion and testing of the data. This process is described as their constant comparative method, where every element of data is constantly compared to all other parts of the data. Through this process, similarities, differences, gaps in the data, and instances that did not fit in with the developing theory are explored by using the flexible methodological guidelines (Hallberg, 2006). This might be seen as a deductive, hypothesis-testing process.

Similarly, Straussian GT is largely inductive in that the epistemological principle remains that a “theory” is conceptualised based on the data collected. Straussian GT does include deduction in that the theory is verified against the data towards the completion of the research

(Strauss & Corbin, 1990). Strauss and Corbin (1990) incorporated a more prescriptive and structured approach to coding data – moving from open/inductive coding, to axial or core codes, and then to selective, theoretical coding that searched for links between categories – in order to deduce and verify the theory (Kenny & Fourie, 2014). Constant comparative analysis, theoretical sampling and negative case analysis entail the process of collecting data and simultaneously analysing data, in order to inform subsequent data collection. Cho and Lee (2014) described the purpose of comparative analysis as enabling theory development by reducing variables to conceptual categories and imbuing the formulated theory with generality.

Charmaz (2009) indicated that her CGT approach originates in the inductive analysis of data, and then moves toward abductive logic in establishing creative hypotheses and checking these with more data from the setting in an iterative process. Charmaz (2020) regarded abductive inference as vital in exploring all possible reasoning, particularly when dealing with complex data. Charmaz (2004) emphasises flexibility rather than a slavishly technocratic approach to constant comparison (evident in Straussian GT) thus encouraging spiralling and methodological journeying between data, concepts and theories, within a particular setting (Irwin, 2006).

This interpretive process, described within Charmaz's CGT above, was employed throughout my study, as codes and categories were developed using an inductive process of constant-comparison; this evolved as the iterative process of data gathering and analysis continued, and extended into the abductive exercise of discovering and developing hypotheses and then linking these to existing theory and literature. My FSCGT approach added another dimension to the application of abduction in that abduction, together with a feminist social

constructionist theoretical lens (having a particular focus on issues related to power, inequality and advocacy), situated participants' experiences within their various contexts and allowed the researcher to explore beyond individual participant experiences, to how these experiences could be supported or transformed. The latter is of particular importance in my approach to my research topic as it highlighted discrepancies between women's LTOP and feticide experiences within private and public healthcare settings in a South African context.

2.4 “Grand Theories”, the Literature Review and Theoretical Sensitivity

The committed emphasis to a thorough-going inductive engagement with data from particular settings in the processes of GT theory-building – as an epistemological principle – raises questions about the role of pre-existing “grand theories” and timing of empirical literature reviewing in GT approaches, and raises the rather slippery concept of theoretical sensitivity. Thus, within Classical GT, Glaser and Strauss (1967) wanted the qualitative researcher to focus on emergent concepts and hypotheses, and remain true to the data, rather than force the data into a predetermined theoretical framework or set of codes from previous empirical studies. Glaser (1992) stated that a “grounded theory” should be formed by the collected data, rather than by preconceived theoretical orientations, and that the emergent, new theory should be relevant, modifiable and useful. This attempt at preventing contamination of data and “bias” led Glaser and Strauss (1967) to encourage GT researchers to ignore current literature and theory prior to their data analysis, in order to ensure that categories are derived from the data, rather than applying pre-existing concepts.

Glaser (1978) would later amend this naïve positivist, objectivist strategy of “bracketing off” (initially shutting out existing theoretical and empirical literature) by advising researchers to

read so broadly that they would enhance their theoretical sensitivity by being exposed to various theories and perspectives on the periphery of the topic under study (see more below on theoretical sensitivity). Only towards the completion of data analysis (when a core category had emerged) would Glaser (1978) recommend that the researcher delves into relevant literature in order to integrate the discovered data with existing theory. Due to the many difficulties this no apriori-theory, no apriori-literature approach creates, including resistance from research approval committees and the potential for redundancy in theorising, even Classical GT researchers generally favour a more flexible approach to delaying the literature review (Thornberg & Dunne, 2019). Straussian GT provides a less rigid approach to the literature review and regards prior reading as assisting the researcher in being sensitised to the phenomena under study (Corbin & Strauss, 2015).

Thus, Classical and Straussian GT regard theoretical sensitivity as essential to the data-coding, categorisation and theory-building process. This concept has been much debated and variously defined. Within Classical GT, theoretical sensitivity refers to the researcher's temperament and personal interests, their ability to theorise new insights and remain open (and sensitive) to the generation of new theory (Glaser & Strauss, 1967). Vollstedt and Rezat (2019) described theoretical sensitivity as researcher characteristics, which include being flexible and, significantly, unattached to one particular theoretical orientation, being able to maintain analytical objectivity, and the ability to persevere amid confusion and uncertainty.

Straussian GT takes a slightly different, and slightly more creative, view of theoretical sensitivity. Strauss and Corbin (1999) define theoretical sensitivity as “the ability to recognise what is important in the data and give it meaning” (p. 46); they argue that this sensitivity comes from a number of background sources, including pre-existing empirical and

theoretical literature, professional experience and personal experience. In addition, the lengthy analytic process within GT methods provides an additional source of theoretical sensitivity, given that insight and understanding would increase through interaction with the setting, participants and data. Strauss and Corbin (1990) formulate theoretical sensitivity as the balance between creativity and “science” (avoiding bias) by stepping back periodically to reflect on the fit between data and categories, by maintaining a sceptical attitude and by sticking rigorously to the GT procedures.

Charmaz acknowledged that each researcher would enter the field of study with their entire background of training, reading and experience influencing their approach (Charmaz, 2014b). Consequently, it would make sense for researchers to familiarise themselves with relevant literature prior to undertaking research, but to do so with a critical eye. Charmaz (2014a) regarded prior reading of relevant literature (both theoretical and empirical) as increasing theoretical sensitivity rather than detracting from it. One aspect in this regard that both Charmaz (2014a) and Glaser (1978) do agree on, however, is that in “idealised” GT research, the emergent theory should be integrated with available literature (grand theories and empirical literature) into the analysis, but only once it would no longer be capable of “distorting” the research focus. After all: “Theorising means stopping, pondering, and rethinking anew. We stop the flow of studied experience and take it apart” (Charmaz, 2006, p. 135).

However, from her subjectivist and interpretive perspective on qualitative research, Charmaz (2000) criticised both the Classical and Straussian GT methods for their positivist approach to data from the perspective of objective, “distanced experts” (p. 513) (see more on objectivist and subjectivist GT approaches below). Charmaz would revolutionise theoretical sensitivity

in her CGT perspective which views data as co-created and the theory as enriched by the researcher's interaction with participants and data. Furthermore, Charmaz (2006) has emphasised flexibility and usefulness in drawing on professional and personal resources, and even, judiciously, other theoretical and empirical resources, into the coding and theory-building spirals provided these foreground, complement and sometimes expand participants' voices. Charmaz (2006) challenges purely inductivist (and objectivist) approaches to GT in their "reification" of emergent theory as the truth (p. 135) and argues that external theoretical perspectives can often highlight interpretations, constructions and multiple perspectives of data – as above, intentionally to "think anew" and "take (things) apart". She upholds commitment to reflexivity for this critical expansion purpose, and not as a confession or correction of bias.

With regard to exploring women's experiences of LTOP and feticide in this study, I found the CGT approach allowed me to acknowledge and explore my professional training in clinical psychology, in relation to, for example, constructions of trauma and suffering expressed both by women and by healthcare service providers. Alongside this, my engagements with data from a feminist social constructionist theoretical perspective facilitated particularly useful critical attention to *language*, e.g., how feticide was talked about differently by women-patients, nurses, doctors and specialists. The social constructionist tools around "positioning" proved invaluable insight. Rather than trying to defend against the preconceived directions I assumed the data would take, I was able to reflexively interact with these ideas and observe the co-construction of the research process, as well as the evolution of my own ability to step in and out of my psychodynamically-oriented professional training, into a "GT-mindset" where all constructs are regarded as co-created *and* potentially imbued with power directionality, with greater awareness of situatedness and language used.

2.5 *Objective and Subjective Approaches*

What has emerged from the above sections is a clear demarcation between so-called “objectivist” and “subjectivist” approaches to GT, which cohere with divisions between positivist and interpretivist qualitative research paradigms. Charmaz (2006) explains that objectivist GT resides in the positivist tradition and “attend(s) to data as real in and of themselves and does not attend to the processes of their production” (p. 131). Charmaz goes on to criticise how this stance leaves out the social processes from which data, theories and knowledge emerge, for example, the influential positions and experiences of the researcher in the setting, and often the multiple interactions over time between the GT researchers and participants. In other words, “an objectivist grounded theorist assumes that data represent objective facts about a knowable world. The data already exist in the world; the researcher finds them and ‘discovers’ theory from them” (p. 131).

Classical GT provides an exemplar of this. The Classical GT viewpoint that data are discovered or uncovered refers to Glaser’s (1992) realist stance, where he embraced the idea that firstly, “objects” (like death, in his original study) do exist and are not constructed by others’ perceptions of them, and that objects exist independently, that is, even in the absence of humans knowing about the object, it still exists. The positivist philosophy underlying Classical GT encourages taking the perspective of an objective reality that can be accurately observed and discovered, without it being affected by the researcher or research process (if procedures are followed carefully and correctly).

Straussian GT, due to the stronger influence of symbolic interactionism, allows for a more reflexive perspective on the researcher and research process, which challenges the notion of

an external reality existing merely to be discovered (Kenny & Fourie, 2014). Consequently, Corbin and Strauss (2008) present an approach to GT that is less rigidly realist than Classical GT, but is more avowedly positivist in the production of rigorous technical coding steps and procedures to render any “interpretation” testable, and hopefully, correctable, to avoid bias (Willig, 2001). Against this, Willig (2001) has attempted to explain a more subjectivist GT approach as an exploration of multiple textures of meanings and experiences as a result of various social processes and relationships. For example, SC holds that all knowledge is relative to the context in which it occurs, and that this relativism supports radical scepticism towards all assertions of knowledge, particularly those adhered to by authority structures (Burr, 2003; Cruickshank, 2012). Charmaz (2008) advocated for relativity in the examination of the researcher’s positioning, perspectives and research approaches in her CGT model. Reality is thus regarded as multiple and open to varying interpretations. However, this is not akin to radical relativism (where “anything goes”), as the social constructivist and social constructionist perspective understands meanings as forged within real social processes and recognises that certain positions are endowed with greater power than others, due to structural imbalances (Appleton & King, 2002). This opens a space for contextually situated interpretations of (real) experiences.

For example, most of the women who participated in my study constructed their experience of LTOP and feticide as “traumatic”. Assuming a subjectivist and interpretivist GT approach – like CGT – would accept and acknowledge these experiences as true and real, even though the reasons for these descriptions and experiences, and meanings of trauma, may not be the same for all women. Shifting reasons and meanings of these constructions might be shaped by various contexts – thus, underpinning a relativist, subjectivist stance.

2.6 *Reflexivity*

Reflexivity in data gathering and analysis requires a careful balance between reflecting on the researcher's experiences and ensuring participant voices are heard as clearly as possible (Olesen, 2007). O'Connor et al. (2018) noted that although all versions of GT regard participant voices as essential to representing data accurately, each criticises the other in this regard. Classical and Straussian GT warn against elevating the researcher's voice and views above those discovered in the data (O'Connor et al., 2018). Glaser (2012) cautioned that regarding data as co-constructed may lead researchers to neglect disparate perspectives and instead preference theories that agree with the researcher's view.

From a subjectivist perspective, Charmaz (2014b) instead argues that data are co-constructed and in order to ensure that participant voices are heard, it is essential that the researcher explicitly reflect on, and state, their preconceptions prior to and during data collection, analysis and writing up. Consequently, Charmaz (2014b) warned that a failure to do so could potentially distort the analysis and resulting theory. Charmaz (2000) differed from both Glaser and Strauss in their positioning of researchers as "distanced experts" (p. 513), which aligns with the feminist lens in the facilitation of reflexivity and critical examination of the research process, context and data (Bryant, 2021; Kushner & Morrow, 2003). In order to stay true to the "grounded" nature of the methodology, while applying a feminist lens, researchers do have to ensure that participant voices and data are heard above the imposition of particular theoretical ideologies (Kushner & Morrow, 2003). This aspect, and other facets related to reflexivity, are thoroughly explored in Chapter 4, Methodology.

Charmaz (2020) stated that her CGT assists researchers in remaining reflexive, flexible, and attentive to language, meaning and context. CGT developed from interpretive and post-modern perspectives (Farragher & Coogan, 2020) and includes an emphasis on reflexivity, memo writing and researcher positioning. Reflexivity requires the researcher to reflect on their own perceptions and assumptions and how these affect the data. The researcher examines their own training and social context and explicitly states these, thus enabling the reader to note where data from participants interact with data co-created by the researcher (Farragher & Coogan, 2020). Reflexivity is also one of the key hallmarks of feminist research (Clarke & Braun, 2019), which increases the methodological and ideological compatibility of the two approaches. Approaching data as being co-constructed by the researcher and the participants presents several advantages (Charmaz & Belgrave, 2019), which include that data are problematised and layered and regarded as influenced and shaped by both researcher and participant context, language, positionality and prior meanings.

FSCGT provides a method and methodology that allows the researcher to specifically interact with those who find conveying their experiences difficult, due to this approach's inherent sensitivity to power differences, positionality and reflexivity. The imperative of FSCGT is thus that the researcher has to examine their own positioning and inevitable privilege (even if due solely to the power imbued with being an "academic") and how this affects data gathering and analysis (Charmaz & Belgrave, 2019). This emphasis on and sensitivity to the co-construction of data was a central focus throughout this research process and will be described in detail in the following chapters.

The addition of a feminist social constructionist theoretical framework to CGT incorporates feminist approaches. This includes the researcher's position, which may be regarded as

privileged above that of the participants, due to situatedness and social constructions of academia and professionals, being acknowledged and explored along with structural issues regarding race, sex, structural and historical processes (Irwin, 2019). The level of social order analysis includes all forms of group interactions, organisations and social institutions (Serpa & Ferreira, 2019). This analysis is vital to this particular study, as the participants are members of various social groups, while sharing their mutual experience of having terminated a fetus and undergoing LTOP. Dynamics of power, control, prejudice, stereotypes and bureaucracy are played out in the interactions between participating women and the various groups/institutions with which they interact during these experiences. In this study, the impact of these interactions is carefully explored in order to identify aspects that require change to reduce negative outcomes (not only physical, but in all spheres of health) for women who undergo feticide and LTOP.

FSCGT provides a means through which participant realities can be explored inductively, while theory can be developed deductively based on these data. Without compromising methodological soundness, researchers using GT are challenged to make justifiable adjustments to the manner in which GT is employed (Elliott & Higgins, 2012). Olesen (2007) described reflexivity as including a comprehensive explication of how the research process was handled and, in particular, how data were analysed. The researcher includes constant self-reflection and provides transparency regarding her background and theoretical influences. Researcher reflexivity would even include researcher emotions and reactions or concerns throughout the research process (Olesen, 2007). Olesen (2007) warned against grounded theory methodologies that neglect reflexivity as well as researchers who privilege their own experiences above those of their participants. Reflexivity is also important in analysing the ethical conduct of the researcher and includes analysis not only of decisions

made in research design, data analysis but also in the careful consideration that researchers need to give to how they think about and represent their participant experiences (Olesen, 2007).

3. Conclusion

In this chapter, I put forward a Feminist Social Constructionist Grounded Theory framework which allows for a feminist social constructionist take on CGT. In order to contextualise my FSCGT approach to this study, I firstly provided a brief discussion of the history of GT, which included the classical, Straussian and CGT approaches, concluding with a comparison between Feminist Grounded Theory and FSCGT. Here I explained why Wuest's (1995) Feminist GT would not suffice for the purposes of this research due to this approach not having included a constructivist or constructionist subjectivity, which I regard as vital to fully engage with and provide an understanding of women's constructions of their experiences of feticide and LTOP.

Next, I explored the conceptual aspects related to CGT, which include pragmatism, symbolic interactionism and coding and constant-comparison methods of data analysis. I provided further justification for the appropriateness of CGT to my research by referring to the paucity of "grand theories" in the field of feticide and LTOP as well as the flexible approach CGT ascribes to with regard the timing and integration of existing relevant literature. I argued that the CGT emphasis on theoretical sensitivity, with particular focus on researcher reflexivity, makes CGT well-suited to provide a framework for the exploration of women's experiences of feticide/LTOP.

I then turned to a discussion of CGT's move toward a subjective and interpretivist approach to engaging with data, as opposed to classical and Straussian objectivist viewpoints, which facilitates my feminist, relativist perspective on women's voices and experiences in this study. To conclude this discussion, I explored the value of reflexivity as it is employed by CGT and viewing data as co-created and interactionally formed through interactions between participants, contexts and the researcher, encourages a feminist commentary on the situatedness and social constructions of structural issues that influence these interactions. Having reviewed my literature in Chapter 2 and discussed my theoretical lens in this chapter, I now move to discussing the methodology employed in the study.

CHAPTER 4: RESEARCH METHODOLOGY

Women's experiences of feticide and LTOP are affected by multifarious factors that are beyond their personal control, yet impact their ability to exercise autonomous choice. I situated these experiences, and the constructions of systems and dynamics that affected them, within a feminist social constructionist grounded theory (FSCGT) methodology. This lens through which data were viewed assisted in situating the women's experiences within the contexts of power relationships and structural inequality. I was interested in gaining insight into how women in South Africa experience the diagnosis of severe fetal abnormality during their pregnancy, how they negotiate and experience the decision-making process, how they describe their experiences of the feticide and LTOP procedures and how they relate their recovery from these procedures. I was also interested in integrating how health service providers perceive women's experiences of feticide in South Africa. I hoped to understand the convergences as well as gaps in experiences of women versus healthcare providers' perceptions of these experiences. In this chapter I provide an overview of the research process which includes a description of the sample population and discussions of the data-gathering and data-analysis procedures associated with this study. The trustworthiness of the research and ethical aspects related to this study are also explored.

1. Research Questions

The main research question focused on in this study is: What are South African women's experiences of feticide and late termination of pregnancy due to the presence of severe fetal abnormality, as related by the women themselves and the health service providers who perform the procedure or provide care?

The sub-questions that initially drove the study were:

- How do the women relate their experience of the process of coming to the decision, undergoing and recovering from the procedure? And
- How do health service providers relate the experiences of these women (as they have their own direct experiences of feticide and LTOP aside from their perceptions regarding women's experiences)?

2. Feminist Social Constructionist Grounded Theory (FSCGT) Research Design

In this section, I discuss the overall research design: qualitative feminist social constructionist grounded theory study based on semi-structured interview data. I begin by discussing the recruitment and inclusion criteria of my participants and then explain my interview procedure and describe the women and health service providers who participated in this study. As the theoretical understanding and framework behind FSCGT has been discussed in-depth in the previous chapter, I do not repeat these aspects here, but rather focus on the practical application of FSCGT as methodology.

I entered the study with “critical scepticism” (Charmaz, 2017a, p. 5) towards FSCGT, and throughout this research, I engaged with each step of the process critically in order to ensure that I had a thorough grasp of the motivation behind each action I was required to take. According to FSCGT methodology, the researcher co-constructs the data and is equally affected by the research process as are participants. This constitutes the reflexive approach to data analysis (Charmaz, 2017b) which is discussed later in this chapter. Neither the researchers, nor the research, are neutral. Time, space, location, culture, social context,

power, methods, language, privilege and all factors affecting the human experience are at play and create data and theory. These are explored and unpacked in this chapter in the section on critical reflexivity.

3. Participant Recruitment

The inclusion criteria I decided upon was women who: had chosen to undergo LTOP due to fetal abnormalities, were 18 years or older at the time of the procedure, and had undergone a feticide procedure, in either private healthcare or public healthcare systems. The decision to include only those who were over the age of 18 at the time of the procedure was in order to exclude participants who would have had to deal with additional stressors due to their status as an ‘adolescent’ during the decision-making process. Fundamental to this study was working within an ethically sensitive framework, where participation in the research had to be completely voluntary and based on an active research relationship (Birch & Miller, 2008). Women should have experienced late termination of pregnancy and feticide between a minimum of one and maximum of five years prior to being included in the sample. These time parameters were decided upon in order to prevent too much time having lapsed since the procedure and thus affecting participants’ recollection of events. But of greater importance was the minimum time requirement which would protect women from being potentially re-traumatised should they be interviewed too soon after the experience. Enough time would also be required to reflect and emotionally digest the loss of the pregnancy and all of the circumstances surrounding this loss. Ramdaney et al. (2015) reflected on their research on the support desired by North American women following termination of pregnancy due to fetal anomaly (survey, not interviews), and found that participants were particularly vulnerable within the first months following the procedure.

The sampling method employed can be described as convenience, purposive and snowball sampling, as participants were informed of this research at the local tertiary hospital by their treating providers, which would be classified as convenience sampling. However, they were also carefully selected based on specific criteria, as mentioned above, which constitutes purposive sampling. Participants, specifically providers, would refer other appropriate potential participants to the research study, which constitutes a specific form of purposive sampling, namely snowball sampling (Naderifar et al., 2017). All of these sampling methods fall under the broader category of non-probability sampling, which means that the entire relevant population did not have an equal chance of being included in this research (Etikan et al., 2016). Credible referral sources included clinical geneticists who treated women in public healthcare settings prior to, during and following the feticide procedure, as well as private obstetric gynaecologists who had performed feticides. These referees served to inform potential participants, both women and health service provider participants, of the research. Here it is important to emphasise that none of these providers broke patient confidentiality, as they themselves informed their patients about this research and where women or providers indicated that they would like to participate, the providers conveyed the relevant information to them. Only at this point was I allowed to enter the communication, once potential participants had indicated that they consented to me contacting them. These and other ethical issues will be explored in-depth later in this chapter.

3.1 Receiving the Call to Participate

Ethical consideration was given to how best to inform potential participants of the research given the potentially upsetting reaction this may elicit. The public health care participants

were known to the antenatal genetics clinic and could consequently be informed of the research by the staff with whom they were familiar. They could then decide to contact the researcher or decline. Private health care providers; however, were more difficult to reach as they did not routinely follow up with a specific provider. Careful thought was put into ensuring that only women who would qualify to participate in the research would be informed of this research and given the opportunity to participate or not. This would prevent the scenario where women who did not meet the criteria would request to participate and need to be declined. Providers identified patients who were appropriate (the procedure had been undertaken between 1 and 5 years ago and a feticide had been performed, not only a late termination) and personally called them to inform them of the research and to provide them with my details. When women received the call from their healthcare provider informing them about the research, their initial emotional response reportedly was one of shock, which some said they shared with their partner. This must have been a triggering experience to be contacted by the provider associated with their trauma, as well as being confronted with their memories of the feticide and LTOP. The decision to participate was not made flippantly and most women discussed their participation with their partner and even turned to prayer in order to receive guidance.

Extract 1

Fay (W7 private): Even when Dr X (fetal specialist in private healthcare) called and told me about you (.) I told my husband about it [this research]. And then when you sent the document [information] I showed him the document and you could see that he was really affected by that. But then I told him that you know I feel (.) for me (.) it's fine to talk about it. It might help the next person.

Extract 2

Melissa (W6 public): Just when I got the WhatsApp [to arrange an interview date] I got such a fright! Then I sat there and sent it to my fiancée (.) then he says, “The Lord will guide you”. Then I sit there in my office then I talk to Lord Jesus then I think (.) maybe I should do it? Then it is off my [heart] for once and for all. It won’t go away (.) you know (.) a person does suppress your feelings and so (.) maybe something good could come from all of this. I prayed about it there at work. I didn’t work at all (.) I prayed at work and I sat like that thinking to myself and then I got, “Do it”. Just that voice, “Do it”, and then I agreed. Then I knew (.) I must come talk.

Extract 3

Melissa (W6 public): Someone said it [participating in this research] will open up old wounds. I said you know what (.) maybe it must open up old wounds (.) scratch off the scab (.) let it bleed again (.) so that it can heal for once and all.

Melissa turned to her religious faith to guide her in deciding whether to participate in this study or not, and felt that she had been told to “Do it”. Significantly she discussed wanting to help other women by participating – “maybe something good could come from all of this”. Many women believed that their participation in this research was important as they would be able to help other women going through similar experiences. Being able to speak about their experiences related to feticide and LTOP was an important motivating factor for women to participate. There was an anticipation of being able to “get this off my chest” and somehow being freed from the grief and trauma. Certainly, all of the women noted following the interview that they had experienced psychological relief and felt better. Melissa hoped that by coming to “talk”, she would get it “off” herself “once and for all”, and she told me that she

never wanted to speak about it again. The interview had been a form a closure for her. The emotional labour of remembering these confronting experiences, as well as the visceral experience of crying during the interview, left many women exhausted following the interview (myself included). Melissa described the interview as a process of scratching off “the scab” and opening up “old wounds” and allowing it to “bleed again” in order to allow healing to take place “for once and all”.

Health service providers who were directly involved with the feticide procedure were also interviewed. They included clinical geneticists, gynaecologists, fetal specialists and nursing and allied staff. It was of importance to me to ensure that health service providers’ voices included those who are positively inclined toward the procedure, as well as those who were not. This was in order to incorporate as realistic a service provider perspective as possible. Health service providers could be included in the study if they were currently service providers to women undergoing feticide and LTOP. Within the confines of ethical clearance,² I was limited to public health service participants (patients and employees) only from a particular province in South Africa, but was allowed to interview participants from across South Africa who worked, or were treated in, private healthcare. Within my capacity as clinical psychologist employed by the medical school in a particular hospital in South Africa, it was feasible to make use of my professional acquaintances on the medical platform in order to establish referral contacts. Particularly due to the sensitive nature of the research topic, I gained greater access to public service healthcare workers and their patients than an ‘outsider’ may have, due to these medical professionals already being familiar with me.

² Gatekeeper permission to conduct research within public health facilities is done at provincial, and not national, level, which restricts the research to that particular province. There are nine provinces in South Africa

There were certain aspects related to my professional experiences that assisted me in gaining access to participants. These included being well-situated within a university medical faculty and having established relationships with clinical geneticists and gynaecologists. I had also spent a number of years of my career working in the South African public healthcare system, and consequently, I am familiar with patient profiles, systems and procedures. These were distinct advantages in obtaining access to research participants compared to being an “outsider”, bearing in mind the particularly sensitive nature of the research topic. The separation between private and public healthcare systems in South Africa was discussed in the first chapter of this thesis and is relevant here, as private patients (women) were fewer in number than public healthcare participants, due to fewer late terminations and feticides taking place in private health services (as a result of earlier detection of congenital abnormalities) than in public healthcare services. This is not documented in literature, nor are feticides and LTOPs recorded by hospitals in South Africa; however, this is the consensus of feticide/LTOP providers interviewed during this study. The composition of the private versus public healthcare user sample is also in accordance with the general split of public/private healthcare users in the country. However, private patients may also have been more hesitant to participate in this research, whereas public healthcare patients may be less likely to decline the offer of participation due to the power differentials inherent to interactions between healthcare providers and healthcare users, which are more flagrant within the public healthcare system.

The process of contacting private obstetrician gynaecologists in order to inform them about my research elicited strong responses and was one of the first indications that I would experience vicarious stigmatisation due to my research topic. The relatively innocuous main research question elicited strong negative emotional reactions from inquisitive individuals in

my social network as well as from potential participant referral sources. These ranged from being shocked that feticide takes place at all and stating anti-choice sentiments, to sharing their personal stories of pregnancy loss due to fetal abnormality.

Gaining access to public healthcare providers was, surprisingly and frustratingly, challenging once I moved beyond my professional network. Due to the climate of dissatisfaction among public healthcare workers in South Africa, and specifically in this particular province at the time of data gathering (which unfortunately endures to date), healthcare workers shied away from speaking out about their work environment. This province, as with most of the South African public healthcare system, has been experiencing ongoing staff and resource shortages which result in sub-adequate patient care and healthcare workers expressing extreme dissatisfaction (Copelyn, 2022). This situation contributes to the ongoing movement of medical professionals from the public to the private healthcare system, as well as ongoing emigration of healthcare providers (Ellis, 2022) (in order to avoid identification of the province, I refer here to publications on the general state of South African public healthcare). Public healthcare workers shied away from talking about their workplaces due to their concerns that the information they would provide could further damage the reputation of their institutions, resulting in possible disciplinary action against them. Consequently, I decided not to indicate the province, nor the tertiary hospital where I gained access to my research participants within the body of this thesis, nor provide any identifiable information with regard to private hospitals where providers are employed. Private healthcare providers were also resistant to being interviewed, but this was rather the result of busy schedules with “time is money”, combined with avoiding being involved with such a stigmatised topic as feticide and late termination of pregnancy, even though many of them performed the procedures.

4. Participants

Twelve women and 13 healthcare providers participated in this research. Participants included women and healthcare providers from across South Africa.

4.1 *Women*

None of the public healthcare user participants were able to afford private healthcare at the time of their late termination of pregnancy and feticide. The majority of the pregnancies were unplanned; however, all of them were regarded as wanted. The method of delivery of the fetus is indicated in order to contextualise women's experiences of the procedures.

In order to protect the identities of participants, I decided not to link biographical information to particular individuals, as anonymity was of utmost concern to most participants. Instead, I refer to biographical data in general terms. Twelve women, who had undergone a late termination of pregnancy and feticide procedure between one and five years prior to the interview, participated in this research. Three of the participants were private healthcare users, who had been informed of the study by the fetal specialist who had performed their procedures. These women could afford private healthcare and could be classified as falling within the middle-class income group. One participant was Black and the other two were White. Race is regarded as a social construct (Moore-Berg & Karpinski, 2019), but remains of significance within the South African context due to the continued impact of the country's racialised past on structural and economic disparities between different race groups, as was explored in the introductory chapter of this thesis. Reproductive injustice affects Black women more than other racial groups due to this country's Apartheid legacy (Macleod, 2019)

and consequently remains pertinent to understanding women's lived experiences in this country and in accessing reproductive healthcare.

Nine women participants were public healthcare users who received treatment in this particular province of South Africa, although they resided in and around the province. These women varied in terms of education (primary school education to post-matric diploma), socio-economic status (dire circumstances where basic necessities were limited, to being gainfully employed and financially stable), marital status (unmarried, married, separated, divorced), existing children (none, infants, older children to adult children), age (the youngest participant was in her very early 20s, most were in their 30s and (two were above 40 years), culture, language and ethnicity (Afrikaans, English, Sesotho, Xhosa, Zulu and foreign nationals from other African countries), and religion (traditional African beliefs and various Christian denominations were represented, as well as atheist and agnostic beliefs). Table 2 outlines the participants' pseudonyms, the participant code allocated to them, their race, whether they used public or private healthcare systems and the method of delivery they experienced. Gestation of the participants' pregnancies varied between early second trimester to 38 weeks of pregnancy which may account for the surgical intervention required during delivery. However, it is important to note that South Africa presents with increasingly high rates of caesarean sections, with one in four babies in the public sector and up to 70% of babies in private healthcare being born this way (Solanki et al., 2020).

Table 2 *Women participant pseudonym, code, race and nature of healthcare, including delivery method (n = 12)*

Pseudonym	Code	Race	Nature of Healthcare	Method of delivery
Odwa	W1	Black	Public	Caesarean section
Patricia	W2	Black	Public	Induction NVD (normal vaginal delivery)
Mabatho	W3	Black	Public	Induction NVD
Jasmine	W4	White	Public	Induction NVD
Mpho	W5	Black	Public	Induction NVD
Melissa	W6	White	Public	Failed induction, Caesarean section, post-operative complications
Fay	W7	Black	Private	Caesarean section, post-operative complications and emergency hysterectomy
Janet	W8	White	Private	Induction NVD
Emma	W9	White	Private	Induction NVD
Fezile	W10	Black	Public	Induction NVD
Wilna	W11	White	Public	Failed induction, Caesarean section
Lelanie	W12	White	Public	Caesarean section

4.2 Health Service Providers

Thirteen healthcare workers were interviewed. Participants were heterogeneous in terms of their professional categories and included fetal specialists, a clinical geneticist, a genetic counsellor, a nurse, a nurse's aide, obstetric-gynaecologists, and a clinical psychologist. However, they were quite homogenous in terms of gender and race. Only two of these participants were male, and all of the participants fell within the middle- to upper-socio-economic status. One participant was Black, one was Indian, and the rest were White. One provider spoke Sesotho as a home language and eight were English home-language users. The remaining participants were Afrikaans-speaking. These participants resided and worked in the Free State, Northern Cape, Western Cape, KwaZulu-Natal or Gauteng provinces of South Africa. Eight of these participants were employed in the public healthcare system. According to an article by Clifford (2021) in Africa Check online publication, just over 40 per cent of South Africa's healthcare workers are employed within the public healthcare system, while 70 per cent of doctors are employed in the private healthcare system (Ngobeni et al., 2020) and consequently, my sample of providers is relatively consistent with the public/private healthcare employment ratio. However, I would have preferred to include providers who better represent the racial representation of providers in the country.

In order to protect participant anonymity, I provide a general description of this sample group: educational levels ranged from a Bachelor's degree to PhD and include only one participant who had not attained a "professional" qualification (nurse's aide). The majority of participants were married, and half of the participants were parents at the time of the interview. Participants include providers who identify as Afrikaans, English, Indian and Sesotho.

Table 3 *Health Service Provider participant pseudonym, code, gender, profession, ethnicity and healthcare system (n =13)*

Pseudonym	Code	Gender	Profession	Ethnicity	Nature of Healthcare
Annie	HSP1	Female	Genetic Counsellor	White	Public
Zelda	HSP2	Female	Obstetrician/Gynaecologist	White	Public
Peter	HSP3	Male	Fetal Specialist	White	Private
Tina	HSP4	Female	Fetal-Maternal Specialist	White	Public/Private
Amy	HSP5	Female	Fetal-Maternal Specialist	White	Private
Loni	HSP6	Female	Obstetrician/Gynaecologist	White	Public/Private
Ziva	HSP7	Female	Obstetrician/Gynaecologist	Indian	Public
Hugh	HSP8	Male	Clinical Geneticist	White	Public
Xenia	HSP9	Female	Clinical Psychologist	White	Public
Connie	HSP10	Female	Clinical Geneticist	White	Public
Bettie	HSP11	Female	Nurse's Aid	White	Private
Maggie	HSP12	Female	Nursing Sister	White	Private
Mathuli	HSP13	Female	Obstetrician/Gynaecologist	Black	Public

4.3 Narrative Summaries

In order to provide the reader with some orientation regarding the individual women's stories, I decided to include a brief narrative summary of each woman's story. I would also like to pay homage to each woman who participated in this research, with the recognition and

individual acknowledgement that she deserves. The decision to participate was a very difficult one to make and my aim is to honour each woman and her experiences. In order to acknowledge the provider participants as holistic people, not only functioning within their role as a healthcare provider, but also as participants who bravely shared their personal perceptions of their work, I decided to also include a brief narrative summary of each provider participant.

4.3.1 Women

Odwa (W1) shared her story of how her Christian faith and support from her family back in Nigeria, where she originally came from, helped her to cope with the LTOP (surgical delivery) and feticide procedures. She spoke of the social isolation she experienced in South Africa following the procedures because she is a foreign national. Odwa's experience was profoundly influenced by her pregnancy's advanced gestation, at 38 weeks, and she compared this to her sister's first trimester miscarriage. Throughout the interview, she was emotionally distraught, but so stoic and strong that I was in awe of her resilience. Financial stressors were a prominent theme in her interview, as well as an intense longing for the son (Odwa's own construction of the fetus) she lost due to LTOP. Systemic failures regarding her having been unable to access antenatal vitamins during this pregnancy (and Odwa's construction of this as a possible cause of the fetal abnormality) was a prominent theme in her making sense of the feticide and LTOP.

Patricia (W2) constructed her experience of feticide and vaginal delivery of the fetus at 38 weeks' gestation as one largely affected by feelings of guilt. Her fetus was diagnosed with hydrocephalus and anencephaly in her ninth month of pregnancy, as this was when she had

her first scan at her local clinic. Throughout her narrative, she presented a dichotomy between her traditional African ancestral beliefs and Western medicine. Much of her guilt was presented as residing in her perception that she trusted mainstream medicine rather than participating in traditional rituals that her family had recommended.

Mabatho (W3) shared her own experiences of her physical disability and impaired mobility, which affected her decision to terminate her pregnancy with a child who would have been physically disabled. This is a case where the abnormalities had been detected within the first trimester at a primary healthcare facility. However, due to the long waiting periods between referrals to the secondary and then tertiary hospitals, Mabatho finally had to undergo an LTOP and feticide rather than early termination of pregnancy (TOP). Conflicting ideas regarding the cause of the fetal abnormality were presented in her interview, as her family adhered to traditional African beliefs, whereas Mabatho favoured Western medical explanations. She also presented a clear difference in how she narrated her experiences to those she trusted (close family were told about the feticide) and the rest of the community, whom she feared would judge her decision (the LTOP was framed as miscarriage).

Jasmine (W4) constructed a story of her depression and experiences of living with a physically and emotionally abusive partner and his family. She recounted having been blamed for her miscarriage prior to the pregnancy that ended in feticide and LTOP. Jasmine constructed an experience of her aborted baby taking her last breath in her arms after delivery and it became apparent that she had either not understood that a feticide had taken place, or that she had understood that the LTOP would take place without a specific feticide procedure. Jasmine reported being cut off from her own family due to her being blamed for reporting the sexual molestation her grandfather had committed against her as a child, which resulted in his

incarceration. Her own mother was her only source of emotional support but was herself homeless and unable to provide Jasmine with support. Structural inequality and misogyny were striking in Jasmine's struggles to live and raise her two children, while dealing with the loss of two pregnancies. With her agreement, I referred her to tertiary psychiatric services, where she received psychiatric treatment for the depression and suicidality she reported during our interview, and was assisted to move to a shelter, along with her children, by social services. Hers was certainly the most emotionally upsetting interaction with a participant, due to the visible bruises on her body and her obvious fear when interacting with her partner who had brought her to the interview. I still worry about Jasmine and hope that she is safe, even though I did follow up with her a few times following the interview in order to ensure that she and her children had received psychiatric and social services interventions.

Mpho (W5) is a foreign national living in South Africa and shared her story of her fetus being diagnosed with either trisomy 13 or 15 (tests were inconclusive) and her journey of self-education with regard to congenital abnormalities. The unavailability of folic acid at her local antenatal clinic is something to which she attributes her baby's abnormalities. Mpho's story is one of taking up autonomy for her decision to terminate, as well as all further decisions with regard to her subsequent pregnancy. Being shamed at her family planning clinic for refusing contraceptives, the support of her family (telephonic) and her Christian faith are important themes that emanated from this interview. I was struck by how providers underestimate their patients' education and understanding due to language and nationality differences. Had she been South African and able to communicate with her provider in a language of mutual understanding, I think she would have received better explanations in response to her questions, and I wonder if her treatment at the public health clinics would not also have been more positive, had she been South African. Xenophobia is rife in South

Africa, with foreign nationals frequently being denied access to resources and being subjected to ethnic slurs and violence (United Nations, 2022, June 15).

Melissa (W6) shared her experiences of deciding to end her unplanned, but wanted, pregnancy at the age of 46. Her fetus had been diagnosed with trisomy 21 and with a severe heart malformation. Melissa conveyed her frustration with the public healthcare system due to the very delayed access she was given to amniocentesis testing. Her request for a hysterectomy following a caesarean section was ignored, and instead, she experienced a traumatic labour induction. Following delivery, Melissa was left with an infected wound and subsequently lives with a disfiguring scar on her stomach. Melissa experienced stigmatisation due to her age as well as due to her decision to abort her pregnancy. This led to silencing and her feeling unable to share her experiences with her adult children. Following our interview, I was left feeling frustrated with the responsabilisation Melissa experienced when fetal abnormality was diagnosed and the shame she was expected to feel due to a number of factors, including her age, her “irresponsible” behaviour becoming pregnant when she was unmarried, financially unable to care for the child and her lonely carrying of the loss.

Fay (W7) constructed a narrative of having to struggle to have her voice heard by her husband and her healthcare providers. This pregnancy would not have occurred had her request for a sterilisation been respected by her treating provider. Instead, she experienced an unplanned pregnancy in the presence of an intrauterine device. Her fetus was diagnosed with spina bifida and her husband was very resistant to termination. Fay almost lost her life due to post-caesarean section complications and underwent an emergency hysterectomy following the LTOP and feticide. Silencing in the community, the importance of burial rituals and religion, and female familial support, were significant themes in her interview. Fay is also

one of the participants who embodies resilience and pride in the strength she has shown throughout these experiences. She would say that there had been more positive outcomes for her, than negative ones, even though she had endured a great deal of emotional and physical suffering.

Janet (W8) constructed her story of experiencing the feticide and then having to travel a long way home in order to bury the baby in her hometown following delivery. Her experiences of carrying a demised fetus for almost two days and her longing for that same child, even though it had been conceived in an extramarital relationship, were poignantly described. Janet reflected on her grief and feelings of guilt, while being sure that she made the right decision for her and her existing daughter. The narrative of women having to bear the largest burden of childcare duties, as well as shouldering societal judgement for feeling unable to cope with the added weight of raising a child with severe disabilities, were significant themes in her interview. As she was a private healthcare user, I felt she experienced a greater sense of responsibility for having made the decision to terminate, as she did have more financial options available to her than public healthcare users and her expression of guilt was perhaps the most prominent from among all of the women I interviewed.

Emma (W9) shared her experiences of two previous miscarriages and two abortions and gave particular significance to the experiences of bereavement following pregnancy loss and termination where she described herself as feeling like an ‘unsafe vessel’ for subsequent pregnancies. She experienced facilitating a pregnancy loss support group as being helpful in processing her feelings of rage, loss and longing. Emma was the only participant in my

research (woman) who regarded herself as being pro-choice³ and did not have difficulty in discussing her TOPs, while so movingly explaining the difference in emotional response between choosing to end an unwanted or unsupportable pregnancy, and that of losing a wanted pregnancy due to fetal abnormality.

Fezile (W10) constructed a story of having recently moved to this province alone where she started a new job, her partner and two children having stayed back home. Fezile narrated the experience of undergoing a feticide and LTOP alone and in secrecy (only her partner and one female friend knew) due to fear of jeopardising her new employment and due to feeling shame for becoming pregnant again even though her parents were ‘burdened’ with caring for her two sons. Financial considerations made the prospect of raising a severely disabled child an impossibility, which served to ease her sense of responsibility for the decision to terminate. Her experience of giving birth to a baby with hydrocephalus alone and without pain medication (in a public hospital) highlights the deficient labour care provided in the South African public healthcare system and the particular neglect women who are labouring to deliver a demised fetus may encounter.

Wilna (W11) shared her story of how she had been unaware of her pregnancy until the third trimester as medical investigations had missed it due to the absence of amniotic fluid. Her fetus was diagnosed with severe congenital abnormalities and financial concerns made the decision to terminate a simple one; in fact, there had been no decision to take, in effect. She positioned herself as absolutely not having undergone an abortion and found limited support from her support system, including her husband, whom she experienced as directive and

³ Supporting the perspective that the pregnant person should have the right to abortion if this is their decision.

controlling. Wilna requested sterilisation during her caesarean section to ensure that she would not have to go through a similar experience again. Throughout our interview, she remained carefully protective of her emotional reactions and information she deemed too personal, which I respected.

Lelanie (W12) shared how even though she attended regular antenatal appointments in public healthcare, the fetal abnormalities were missed until she was in the seventh month of pregnancy. This was when she was informed that the medication she had been taking to manage the seizures she experienced due to the presence of a brain tumour had caused severe fetal abnormalities due to its teratogenic effects. Lelanie experienced her husband as emotionally detached and related making the decision to terminate alone. The difficulty of managing her existing young son's disappointment at the loss of his anticipated sister and creating her own burial ritual in the absence of having access to her baby's remains were significant aspects of her experiences. I still wonder how Lelanie is doing and if she was able to recover from the brain tumour. All of the participants do have my contact details and were invited to reach out at any time should they require a referral for psychological assistance and consequently, I respect their privacy should they decide not to do so.

4.3.2 Providers

Annie (HSP1) is a genetic counsellor who was involved in the care of many women who underwent feticide and LTOP within the public healthcare system. During the interview, I experienced her as open, passionate about the topic and open to pro-choice perspectives.

Zelda (HSP2) is an obstetrician/gynaecologist who had performed many feticide and LTOP procedures within the public healthcare system. Her interaction with me during the interview was open, vulnerable and very honest. She was able to reflect on aspects of her own service provision that had perhaps not been optimal in hindsight.

Peter (HSP3) is a fetal-maternal specialist who provided feticide services within the private healthcare system. He became emotional during our interview and I was struck by his immense empathy for his patients. His approach to patient care was one of absolute excellence, where patients' psychological wellbeing was just as important as the physiological care they received. His approach did tend to prioritise fetal wellbeing above that of the pregnant person at times.

Tina (HSP4) is a fetal-maternal specialist who had performed many feticide and LTOP procedures within the public healthcare system. She was outspoken in her support of women's reproductive rights and her pro-choice perspective.

Amy (HSP5) is a fetal-maternal specialist who provided feticide and LTOP services within the private healthcare system. This interview was one of the more challenging ones with a provider, as Amy shared some of her personal experiences with reproductive healthcare, as a woman, which affected her perspective with regard to abortion and disability. I appreciated her honesty and openness to self-reflect on her own potential service provision shortcomings within this interaction.

Loni (HSP6) is an obstetrician/gynaecologist who had performed many feticide and LTOP procedures within the public healthcare system. Her focus was mainly on provider wellbeing

and the impact of the procedures on providers. It is important to note that our interaction was very brief, and I was unable to explore other themes within the interview due to the interview taking place while she was on duty. She was also the only provider who noted that she received her own psychiatric and psychological healthcare in order to deal with the stressors of her work.

Ziva (HSP7) is an obstetrician/gynaecologist who had performed many feticide and LTOP procedures within the public healthcare system. This was also a brief interview due to the interview having taken place while she was taking a coffee break. This limited the scope for exploration, but Ziva struck me in her vulnerability and obvious discomfort at providing these procedures. She was also quite adamant that providers' mental health should receive a great deal more structural support.

Hugh (HSP8) is a clinical geneticist with decades of experience in counselling women prior to and following feticide and LTOP procedures due to severe fetal abnormality. This was one of the provider interviews which challenged me the most on a personal level, due to the offensive remarks he made at times, but also due to his immense empathy and commitment to patient care. His age and construction as a White, male specialist doctor who had been on the cusp of retirement, having worked his entire life in the public healthcare system of a country where segregation of care had been the norm for most of this time, was important to bear in mind in analysing his interview.

Xenia (HSP9) is a clinical psychologist who provided psychotherapy to in-patients who had undergone feticide and LTOP procedures within the public healthcare system. She was the only psychologist to agree to participate in my research, and she brought a very different

perspective to women's experiences of feticide and LTOP than those provided by medical doctors. Her understanding of these women focused a great deal more on their own interpersonal systems and support than medical providers did.

Connie (HSP10) is a clinical geneticist with extensive experience in counselling women prior to and following feticide and LTOP procedures due to severe fetal abnormality. The content of this interview was quite factual and laden with medical information, although Connie did share some of her own experiences in dealing with involvement with the procedures.

Bettie (HSP11) is a nurses' aid with many decades of experience being involved with patient care in a busy private fetal-maternal practice where feticides took place regularly. This interview provided a very different perspective from the rest of the provider participants, as Bettie had been working mainly with practice management at the time, and consequently added different layers to the data, from the perspective of the practice waiting room and informal interactions with women undergoing the feticide procedure.

Maggie (HSP12) is a nurse who provided patient care to women who had undergone feticide and LTOP procedures in a private hospital. This was the interview where the most blatant anti-choice stance was presented, and a striking contrast between service provision versus the personal perspectives of the provider. Her own personal reproductive experiences also coloured the manner in which she perceived abortion.

Mathuli (HSP13) is an obstetrician/gynaecologist who had performed many feticide and LTOP procedures within the public healthcare system. Once again, the provider's very

personal experiences related to disability and reproductive health significantly influenced her perspective on abortion and disability. It is important to note that Mathuli had been the only obstetrician/gynaecologist willing to learn the feticide procedure at the hospital of her employ when the previous providers had resigned. I was struck by her strength and resolute determination to advocate for women's reproductive health, even in the face of her own stigmatisation.

5. Interview Procedure

Semi-structured interviews were conducted with women who underwent LTOP and feticide as well as with health service providers who assisted with feticide procedures or provided care for women who had undergone these procedures. DeJonckheere and Vaughn (2019) explored semi-structured interviews in primary healthcare settings and discussed the importance of adapting the wording and sequencing of questions to ensure not only rich data gathering but also participant comfort. In accordance with FSCGT data gathering methods, it was important to regard the interview schedule as a guideline, with my adjusting questions according to new topics encountered in different interviews. Initially specific questions were decided upon based on the research questions and were used as a starting point or as topics to fall back on if participants were hesitant to speak; however, as the process continued, and in accordance with FSCGT, questions for further exploration and data saturation, were incorporated. FSCGT promotes the simultaneous collection and analysis of data beginning from the first interview (Charmaz, 2006). Consequently, issues surfaced in interviews were built into subsequent interview discussions as far as possible in order to identify data saturation, as well as gaps or silences. In order to provide a clear distinction between the

processes related to women and healthcare providers, these discussions of the interviews will be presented separately.

5.1 Interviews with Women

Interviews were conducted using the narrative interviewing technique, as this is an effective method of encouraging participants to talk about their experiences, while prioritising their perspective throughout the interaction (Anderson & Kirkpatrick, 2016). This is frequently used in qualitative constructionist approaches to research, where communicative practices and interactions are regarded as significant during the interview and analysis thereof (Langley & Meziani, 2020).

As the majority of residents in this province are Sesotho-speaking, a registered nursing sister, who specialised in genetic counselling, and is herself Sesotho-speaking, served as translator and was available during all interviews, should the participant require her presence. Only one participant opted to be interviewed in Sesotho. The impact that this may have had on the interview is important to note, as the process of interrupting the flow of conversation to translate changes the nature of the interaction. Consequently this process was undertaken with special care to ensure that the participant's voice was heard above the 'noise' of the translation process (Haldane et al., 2022). All other participants preferred to conduct their interviews in either English or Afrikaans, irrespective of their home language. The home languages represented included Sesotho, isiZulu, isiXhosa, Setswana, Oshiwambo, French, Hausa, Portuguese, Afrikaans and English.

Interviews with all but two of the women, who had made use of public health services, took place at the genetics clinic at the local tertiary hospital. This was familiar to them as they had attended their six-week follow-up appointments here and the offices provided us with a private, confidential space. Participants were offered the option of being interviewed in my consulting rooms as well and one woman preferred this space to the hospital, while another woman requested the interview take place in the paediatric clinic as her child had an appointment there. Four women who made use of public healthcare services were accompanied by a partner (who did not join us in the interview room) and two brought their baby along (born subsequent to the termination of pregnancy).

The narrative interviewing technique seeks to allow the participant to control the interview, and consequently, I set out to encourage discussion by posing an open-ended question, and following this with possible areas of interest which had been identified during previous interviews. Anderson and Kirkpatrick (2016) described the narrative interview as consisting of four sections. The first section of the interview includes an introduction, where the researcher and participant, introduced ourselves to one another and established if the participant would require a translator to be present. Then discussions and explanations surrounding informed consent, confidentiality and other practical issues would take place, which included reading through the informed consent documentation, in order to ensure that the participant understood everything and felt comfortable signing it. It was important for me to explain that I was not a healthcare provider employed by the Department of Health and that I was not aligned with the Department of Health other than having received their approval to conduct the research. Practical issues related to how long the interview would take in order to make transportation arrangements and ensuring that the interview space was comfortable, private and ensured confidentiality.

The second section of the interview begins when the interviewer prompts the participant to start narrating their story. In this regard, I would ensure that the participant was comfortable for me to start audio-recording our discussion and the interview would be “officially” undertaken. I asked each woman the following carefully constructed question: “Tell me the story of ending your pregnancy. Start from the beginning, when you realised that you were pregnant, to the present. Take as long as you want to. I will listen and not interrupt.” Due to the sensitive nature of the content of the interview, it was important to allow participants to start wherever they felt comfortable. Most women spoke as though a floodgate had been opened and I merely acknowledged what they were saying through non-verbal or verbal cues in order to provide some conversational feedback throughout. However, there were some participants who were reticent and, either due to language differences or the emotional content of the interview, or both, required greater prompting than others. I checked in with each participant during the interview to make sure that they felt comfortable and able to continue. When participants indicated that they were uncomfortable, in distress or did not want to continue, I immediately responded accordingly. Naturally, this led to frustratingly short interviews at certain times (with the shortest being no longer than fifteen minutes during the providers’ tea break and the longest being over 120 minutes long), or not being able to pursue certain aspects or questions, in others. However, my intention during the interviews was always to provide a containing space for women to share their experiences and to ensure that they left the interview without any adverse reactions, or ideally, even to have felt heard, contained and validated.

I audio-recorded all of the interviews, which allowed me to be fully present in the conversation and not feel the need to note everything that happened. Instead, I just noted

important observations, keywords, questions that came to mind or other topics that had not occurred to me before during the interviews. These notes and observations were used as prompts to my follow-on questions for the third phase of the interviews. Although this open-ended approach avoided my presenting assumptions regarding the participants' experiences, there were a number of women who disclosed that they were not sure where to start or what to say. In these instances, it became necessary for me to pose more specific questions. This is where the third phase of the narrative interviewing process begins, where the researcher asks for more detail or explores certain areas of interest (Anderson & Kirkpatrick, 2016).

FSCGT methodology also encourages repeated interviews in order to continue to explore gaps and points of interest that had been identified during transcription of the previous interview (Charmaz, 2006). This was unfortunately not possible (see explanation below), and I was required to compensate for this limitation by incorporating gaps or topics of interest from previous interviews as questions for further exploration during subsequent interviews with the next participant. These would then also form part of the third section of each interview, as I could introduce ideas or questions that had arisen from previous interviews. One example of this process of building upon previous interviews to explore specific aspects in subsequent interviews is when I became aware that many women held specific constructions of their fetus' abnormality as being related to witchcraft or their own perceived behavioural culpability. This, then, became one of the aspects I would explore if they had not touched on it during the narrative phase of the interview. However, I would take care to introduce the idea without inferring the participant's behavioural culpability or that the abnormality was caused by witchcraft.

Due to the sensitive nature of the topic, most of the women indicated that they would not like to be interviewed again, and indeed, upon analysing the data, I realised that it would be potentially harmful to contact them for follow-up interviews, in light of their obvious distress during the interview, and their reports at having felt better and contained following our meetings. I was thus necessitated to deviate from the usual format of multiple interviews with each participant, due to the aforementioned considerations, despite the fact that narrative interviewing does encourage repeated interviews in order to allow participants to build on their previous interviews (Anderson & Kirkpatrick, 2016).

The final phase of the interview is the conclusion. This is where I asked each participant if there was anything else they would like to add, and if not, I informed them that I would be halting the recording of our discussion. Once the audio recorder had been turned off, I would ensure that the participant felt emotionally contained, and this would often be a space where “off the record” statements were made, which served to add to my understanding of their experiences, e.g., most women would state that they felt surprisingly relieved after speaking about their experiences. Certain participants would add some additional contextual information about their lives that added to my understanding of their circumstances, and I was also able to observe their interaction with whoever had accompanied them, if anyone had done so.

5.2 Interviews with Health Service Providers

Healthcare providers were problematic with regard to follow-up interviews as well, due to their time-pressured schedules, and although unstated, I suspect that they experienced similar

emotional catharsis during certain of the interviews and were perhaps unwilling to undergo such an emotionally challenging interaction on this topic again.

I followed the same flow throughout the narrative interviews with providers, as I did with the women. Following the introduction, I presented the following question to health service provider participants: “Drawing on your experience, please tell me everything you know about how women experience ending their pregnancy as a result of fetal abnormality, from when they receive the diagnosis, to making the decision, undergoing the procedure and recovering after the procedure. Tell me everything that you think is relevant and I will simply listen. How do you think patients experience late termination of pregnancy?”

The interviews with health service providers were more formal and structured than those with the health service users and I hypothesise that this may be due to their familiarity with the usual question-and-answer format between provider and patient. During these interactions, I was required to pose questions more frequently than with the women participants. Perhaps this is partially due to providers’ greater experience with research, which may have caused them to follow socially constructed roles inherent to a research interview where the researcher poses fixed questions and the participant answers them. I did try to maintain a non-directive and semi-structured approach to our interactions in order to elicit spontaneous thoughts and responses; however, there were times when I was required to provide examples (e.g., how some women had indicated that they had felt uncomfortable being placed in the maternity ward during their LTOP) or to provoke comment or redirect the interview back to the research question. During data analysis it was important to acknowledge the more structured nature of the interviews with providers versus women, and to apply careful, critical reflection in order to address leading questions and the influence this may have had on data.

Providers were sometimes either very reticent and even avoidant, appearing to be very rushed, or they went on tangents which were unrelated to the initial question. Both of these instances required gentle probing and redirection. These interviews remained directed and paced by the participant, with care taken to move with their flow of thoughts, even if these were not relevant to the research question and consequently continued to adhere to the narrative interviewing approach.

Frequently interviews would take place in the participant's rooms and for a fixed and limited period due to time constraints. Providers' accounts invariably contained medical jargon and focused on the medical procedures surrounding feticide; nevertheless, all participants were quite reflective and able to explore their own emotional responses toward their patients and their experiences. Health service providers self-disclosed regarding their own emotional responses, religious, moral and ethical experiences with regard to participating in the feticide and LTOP procedures, even though I did not pursue these aspects in my interview. During these interviews, I tried to explore aspects related to women's choices with regard to diagnoses, timing (in pregnancy), systemic factors, how the procedure took place, how the health service providers perceived the women's experiences of the procedure and issues they felt could be improved with regard to service delivery.

6. Transcription of Interviews

I decided to transcribe the interviews myself in order to immerse myself in the data. It was useful in revisiting the emotional and interactive aspects of the interviews, rather than just reading the words from the page. Transcribing also made me aware of the mistakes I had made during the interviews (for example where I inserted leading comments due to my

reactions to the interview content or interrupting the participant), and I tried to avoid these in subsequent interviews. It is important to note that I purposefully did not edit participant grammar, but transcribed verbatim, and I tried to convey the tempo of speech, as this adds to creating a feel for the emotional content of the discussion, which aligns with the narrative interview technique approach. Women who were English home-language speakers struggled to express themselves at times, just as much as did those speaking in their second or third language, which may be due to the exceptionally emotionally laden content expressed during these interactions. Due to the centrality of women's voices and women sharing their experiences, from their own perspectives, in their own words, to this research, I felt it would be disingenuous, or worse still, condescending, to alter their grammar. In accordance with the critical feminist lens applied to the social constructionist grounded theory methodology utilised in this study, it was important to stay as close to participant voices as possible and to this end, I tried to limit the amount of influence my transcription had on the content of the interviews. To this end I used basic transcription conventions as adapted from Ian Parker (1992) and focused on ensuring trustworthiness of the written account of our interviews (Davidson, 2009). However, it is important to note that transcription is always a process of translating verbal data into written data. In this process, the transcriber inevitably makes decisions about where to place emphasis, where to insert transcription symbols, etc.

Table 1 *Transcription conventions adapted from Parker (1992)*

Symbol	Meaning
End of line =	Indicates that the next person interjected.
(.)	Indicates a brief pause between spoken words.
[pause]	Indicates a significant space of time

	between words.
[laugh]	A short burst of laughter from the speaker.
[laughter]	General laughter.
[crying]	The speaker has stopped speaking due to crying.
(Word?)	Indicates that this is what the word sounds like, but there is not certainty.
...	At the end of the sentence means that the speaker trailed off.
[]	Indicates editing or clarification (what the speaker most likely meant) or translation.
((text))	Additional comments from the transcriber, e.g. context or intonation.
CAPITALS	Capitals mark speech that is obviously louder than surrounding speech.

Transcribing the interviews became an extremely time-consuming, though exceedingly rich process in terms of immersing myself in the data. As a grounded theorist, I am proud that I can say that I was intimately involved in every aspect of this research process, and I do believe it adds to the quality of my understanding of the data and assists in ensuring the trustworthiness of the data presented. In order to ensure equivalence between audio recordings and transcriptions (to the extent that this is possible), I re-read the transcriptions while listening to the recordings twice after completing the transcription process. With regard to the translation of the Afrikaans interviews, I was able to both translate and transcribe these

in the same manner as I transcribed the English interviews, being fully Afrikaans fluent, as this is acceptable practice (Davidson, 2009). I translated and transcribed the interviews simultaneously in order to avoid losing nuance, were I to first transcribe to Afrikaans, and then translate this to English. Only the Sesotho interview, which had been translated to English, required a translator to read and validate the accuracy of the translation and transcription upon listening to the audio recordings again. Translation from Sesotho to English occurred during the interview and was audio-recorded. In this way, I could transcribe the interview in English and not feel one step removed from this particular participant versus having someone else transcribe only her interview while I transcribed all of the other interviews. The translator who performed the translation during the interview signed a confidentiality agreement, and the person who checked the transcription understood the limitations of privacy and confidentiality and was not provided with the participant's identifying particulars in order to ensure anonymity.

7. Data Analysis

Feminist social constructionist grounded theory is both a theoretical and methodological approach to research (Charmaz, 2017a). The approach conceptualises the research process itself as a social construction and regards data analysis as an ongoing process throughout the entire life of the research project, rather than a distinct and separate phase. One of the most significant limitations of this study was my own lack of experience with the grounded theory methodology and I spent months reading and rereading everything Cathy Charmaz has written, as well as the seminal works of Strauss and Corbin. However, I kept wanting a specific map to guide the data analysis process and had to accept that the process of social constructionist grounded theory is by its very nature, an organic one. What was helpful is that

I started the data analysis process immediately following the transcription of the first interview, which allowed multiple trials and errors in learning the coding process. The data analysis process started with initial coding (Charmaz, 2014a) where I studied and categorised words, concepts, incidents and lines into parts of data with a short, if possible, gerund-type, name (a gerund is a verb translated to a noun and usually ends in “ing”). This line-by-line coding was extremely labourious, particularly as I revised the gerunds based on further analysis in subsequent interviews, trying to refine the codes into a tentative interpretation of the content. Examples of gerunds I identified include: disabling (constructions surrounding disability as difficult), supporting women (women’s constructions of other women representing sources of emotional support) and silencing (when participants were, or felt, unable to speak their experiences). Carmichael and Cunningham (2017) regarded gerunds as process codes, or codes that assist the researcher in identifying observable, conceptual data. I was particularly interested in using gerunds to help me identify what social interactions and constructions were taking place in women’s narratives. This method of coding line-by-line transcriptions using gerunds proved to be the most effective manner in which to label data in order to later group them together into categories, even though it entailed repeated revisions of previous coding and took a great deal of time.

During the next phase of data analysis, I compared the 79 gerunds to one another and identified categories or themes that emerged from them. The constant comparison process described by Charmaz (2014a) continued with the categories until prominent themes were emergent (focused coding). I found the most effective way in which to conceptualise the areas where gerunds overlapped to form a preliminary category was by using a visual representation of the most prominent gerunds and then physically connecting them in order to identify areas of overlap, as well as gaps in the data. Gaps that were identified became

suggested topics or questions for further exploration in subsequent interviews as did new topics or areas of interest. The categories that started to emerge included themes such as “difficult decision”, which included a number of gerunds related to decision making, e.g., “difficulting”, “deciding”, “being lonely” and “having agency”. The iterative process of moving between interviewing, transcribing and coding aided me in developing concepts that I had not anticipated, and that I would have missed had I employed a different research methodology. For example, I had anticipated significant themes that would emerge from women’s interviews would be those of trauma, guilt and regret, probably influenced by my experiences as a clinical psychologist. Instead, a more significant theme emerged, one of agency, women feeling proud that they made the decision on their own and not regretting the decision.

The next phase was theoretical sampling, where the emergent theory was constructed by developing the themes to the point of saturation, the final product of which is a new theory (Charmaz, 2014a). Charmaz (2014a) discussed theoretical development as ongoing throughout the data-gathering process, and this process was supported by my constant memo writing, using the transcription of interviews and checking of transcriptions as additional opportunities to search for aspects I had missed or misunderstood. By midway through interviews with both women and providers, themes had started to be repeated, and I was able to anticipate most of the content of the interview, which was reassuring in that it indicated that data saturation would be achieved by the end of the interviews.

Data saturation would usually be determined by the extent to which participant stories have similar abstract themes (Morse, 2007). However, Charmaz (2017b) reminded us that grounded theory requires more than saturated themes. Here the researcher moves back and

forth between data collection and analysis. Consequently, during the latter interviews, I was purposefully searching for the prominent themes that had already been identified, as well as contradictions to these. Grounded theorists thus conduct data collection well into their study and may take longer than other methodologies to arrive at a refined analysis (Charmaz, 2017b), which certainly was the case with my research. I continued to interview as many women and providers as were willing to participate within the maximum time frame I could use in which to gather data, which assisted in ensuring data saturation. Due to the sensitive nature of the topic, my supervisors and I had anticipated that this process may pose challenges, and it certainly did. Midway through data collection and interviewing, I started to despair, thinking that I would not reach our target of a minimum of 12 women and 12 providers. Thankfully, due to snowballing on behalf of providers whom I interviewed and who obviously felt comfortable with the manner in which I was approaching the topic, I did recruit enough participant referrals.

Theory construction is valued above simply describing data and entails patterns, new ideas and theories being identified and developed, rather than applying pre-existing theory, all within the context of continuous interaction and constant change (Charmaz, 2017b). This was indeed my experience. I found myself constantly reading, rereading, engaging with and reflecting on each interview until I knew them off by heart. I also came to feel as though I had a relationship with each participant, or had developed an idea around their personhood. This process of gathering the data, engaging with it, coding, analysing, constant comparison, category development, saturation, identifying emergent themes and theory development, took four years to complete in my capacity as a part-time researcher. Chapters 5 through 7 serve to present the results of my data analysis, while the concluding chapter of this thesis endeavours to describe the theoretical analysis of the findings.

Feminist social constructionist grounded theory requires a pragmatic statement on how the theory may be used to affect public policy and professional practice (Charmaz, 2017a). To this end, it was vital that the theoretical framework of the data not only ensured that silenced voices were heard, but also that clear and practical systemic and procedural changes could be made based on the outcome. I intend on achieving this in practice by providing a thorough and serviceable document to the South African Department of Health, and private Obstetrics/Gynaecology bodies, with clear feedback and guidelines to improve service delivery and service as experienced by the women of South Africa. This document will be completed following submission of this thesis in order to ensure that it is based on information approved by external examiners of this thesis. I would like to expand on this by developing psychoeducational documents based on the findings of this research aimed at women as well as providers.

7.1 Challenges and Strengths of Data Analysis

Limitations of my application of the FSCGT methodology have already been touched upon during the preceding discussion; however, there are certain pertinent aspects that warrant explicit explanation. Accessing the population was exceedingly challenging, as explored earlier in this chapter, due to the sensitive nature of the topic. This impeded the variation of the samples I was able to access and include, particularly with regard to specific provider groups. I would have liked to include more than one nurse and one nurse's aide in the provider sample. Due to the nurse being the most outspoken anti-choice participant, it would have been meaningful to explore whether this was person-specific, or perhaps a theme taken up by other people in the nursing profession who work in this area. I would also have liked to

include a more demographically diverse sample of providers, as the majority were female and White.

Strengths regarding my analysis of these data often emerged from lessons learnt through the challenges, one of which was that due to my own insecurity with regard to my ability to correctly employ FSCGT as a methodology, I reviewed my analysis almost obsessively, with my supervisors also scouring the different levels of analysis I had employed. This rigorous process ensures transparency in the research process (Charmaz & Thornberg, 2021). I feel confident that this data analysis, and entire research process, may be regarded as credible due to the careful studying and analysing of the field that took place due to the vivid descriptions of participant voices, clear description of how conclusions were drawn and inclusion of diverse participants (as much as possible) across South Africa. Glaser (1998) described four criteria upon which the quality of grounded theory research can be judged. These include (1) workability, which refers to the pragmatic applicability of the developed theory within the field of study. In this regard, the outcomes of this research are anticipated to have a direct and practical impact on the field of feticide and LTOP by way of a policy brief to be directed to the Department of Health. As discussed previously, I also hope to expand the practical impact of this research by providing psychoeducational training that will be made available to private and public healthcare providers who are involved with feticide and LTOP, where practical feedback will be provided based on the outcomes of this research. I would also like to provide psychoeducational information to women who would like to access this, and will focus on the findings of this research that could aid women throughout the decision-making process, the procedures and their recovery.

This speaks to the second aspect, (2) the relevance of the theory to the people in this context, as I hope to create greater awareness of women's experiences and increase the support available to them. In addition, I would like to draw attention to the importance of providing psychological support to the providers involved with feticide/LTOP procedures.

The third aspect, the fit between the theory, categories and raw data, was ensured by thorough and rigorous data analysis, which included the iterative process of analysing the data while continuing to gather it. The constant comparison between raw data, categories and themes that took place assisted in grounding the theory in the data as it emerged from the interviews. Finally, the grounded theory presented in this thesis is flexible and open to modifiability as new data emerges from the field of feticide and LTOP, as it does not present a rigid theoretical framework, but rather a theme-based conceptualisation of women's experiences of these procedures.

7.2 Transferability and Credibility

The practical applicability of this research to the field and to the lives of providers and women was discussed in the previous paragraph – this relates to the transferability of the findings, as well as the potential for pragmatic impact on people and systems. Transferability is linked to the generalisability of findings, as Farragher and Coogan (2020) noted the criticism that is frequently directed towards qualitative research, and towards SCGT findings in particular: that data cannot be generalised to greater populations. However, the data speaks to the lived experiences regarding the research question of the specific participants involved. With regard to my research, the data provide in-depth insights into women's experiences of their pregnancy that ended in LTOP and feticide. Although not generalisable, it does allow

the reader to enter into and better understand the complexity of the situation. Polit and Beck (2010) explored the concept of transferability and generalisation within qualitative research and concluded that rich, detailed, thick data descriptions and analysis do allow for transferable theories to be developed.

In order to ensure that theory is relevant to other similar contexts and individuals, it is essential that the researcher needs to be immersed in the data, being so intimately acquainted with it, that they are able to deliver these thick descriptions, which entail detailed descriptions of the community, participants and contexts in which the data were gathered (Polit & Beck, 2010). In this regard, I feel confident that I have completely immersed myself in my data, having done the interviews myself, transcribed the interviews personally, as well as analysed the data painstakingly by hand. Each participant is a vivid energy present throughout this thesis, at least in my mind, and I hope that I do their experiences justice in my analysis of their interviews. It has been my goal since inception of this study that each participant will be able to read this document and feel validated and heard and, in fact, feel ownership of the product, as it is their co-creation as much as it is mine. The representativeness of the samples has already been explored and adds to the transferability of the findings of this research to the population of women who experience feticide/LTOP in both public and private healthcare.

Credibility of qualitative research refers to the extent to which the findings are accurate reflections of the raw data and whether these findings are plausible (Lincoln & Guba, 1985), which partially refers to the discussion in the previous section of this chapter. In addition to ensuring the rigour of the data analysis, the credibility of this research has been tested at various presentations of the data and findings, which include: a presentation at the Pan-African Psychology Union held by the Psychological Society of South Africa (PsySSA) in

2017 (international conference); a presentation at the international Abortion & Reproductive Justice: The Unfinished Revolution III Conference in 2018; and Work in Progress presentations to the entire Critical Studies in Sexualities and Reproduction Unit each year since registration until 2021.

8. Ethical Considerations

This study was approved by the Research Projects and Ethics Review Committee (RPERC) of the Psychology Department at Rhodes University, and the Rhodes University Ethical Standards Committee, before recruitment or interviewing were undertaken. Approval was also granted by the relevant provincial department of health as well as the local academic hospital management prior to any contact being made with potential referral sources or participants. Possible participants were identified by the Department of Clinical Genetics at the academic hospital. They were supplied with a letter by their providers outlining the details and purpose of the research and inviting them to participate. Once they agreed that I could contact them, I supplied them with a copy of the consent form, which summarised the expectations and rights of research participants.

All potential participants were assured that their interest in the study would not place them under any obligation to participate. Prior to the interview, I discussed the documentation with each participant and invited questions before asking them to sign the consent form once they were satisfied with the conditions of their involvement in the research. (See Appendix F for request for participation letter and Appendix A for the consent form). Throughout the research process, the fundamental best interests of participants were (and continue to be)

upheld by ensuring confidentiality, beneficence, non-maleficence and opportunity for referral to mental healthcare resources.

8.1 Privacy, Confidentiality and Anonymity in the Data

Due to the particularly sensitive nature of this research, it was essential to ensure that participants would not be identifiable and, to this end, participants were assigned codes and data were stored in encrypted password-protected format, to which only I had access throughout. Participants were invited to select a pseudonym and were encouraged to edit or withdraw any information or statements at any time during and following the interview up to the time of write-up, should they feel that the particular information would be identifiable or too sensitive. Mnyaka and Macleod (2018) described this as one of the processes by which participants are invited to exert control over their own identities during the research process. Privacy and confidentiality of participant partners, family members, places of work and treatment facilities were of great importance. To this end, I ensured that any identifiable information was edited or omitted, going as far as avoiding identifying information such as the province and specific hospital where the procedure took place.

Healthcare providers shared concerns regarding their identifiability for similar reasons, i.e., the sensitivity of the topic. However, the most pressing matter was one of protecting themselves from potential litigation, should their anonymity be compromised. The lack of clear guidelines and explicit legislation with regard to LTOP and feticide in SA left many healthcare providers feeling vulnerable to legal action, should their identities become known and their decisions surrounding terminations be questioned. Public healthcare providers reported an added fear – the threat of disciplinary action by the Department of Health, should

they state anything that could place this department in ill repute. In light of the above fears, I decided to avoid including any biographical or logistical information regarding participants that could allude to their identity in any way. Information that is perhaps less rich due to this becomes more telling in the light of the immense fear of shame, prejudice, condemnation and potential damage to professional standing. I was careful to ensure that participants felt that their anonymity would be protected – particularly as many statements were made regarding their place of employment that could prove potentially detrimental to their careers should their identities become known.

Of course, protecting health service provider anonymity also serves to protect the confidentiality of their patients' information and identities as well. There were a few sentences or sections of the interviews with which certain participants felt uncomfortable and they subsequently asked me to omit these from my data, which I did. This included health service providers who made statements about how they performed their service or particular sentiments about specific systems or patients that they felt, in hindsight, should be omitted. This is a fundamental component of freedom to participate as well as freedom to withdraw consent at any point during the research process and speaks to the importance of upholding participant rights even to the detriment of research content.

Transcribed hard copies and documents were stored securely in my consulting room's filing cabinet. The data will be stored in this manner for five years following completion of the research, after which they will be destroyed. Upon completion of the research, the data will have been seen by me, the research supervisor Prof. Macleod, co-supervisor Prof. Wilbraham and also researchers in the Critical Studies and Sexualities Research Programme, all of whom are bound by the same ethical considerations.

8.2 Potential Consequences of the Research

Being aware of the emotionally loaded and potentially triggering content of my interviews, and maintaining participant beneficence as my guiding principle, I frequently opted for loss of information or clarity, instead of upsetting participants (most of whom became emotional during the interview while relating their experiences). I chose not to probe when I felt my motivation was to further my research while potentially sacrificing participant wellbeing. Barker and Macleod (2018) affirmed the importance of ethics not being employed rigidly in order merely to protect the researcher and further the interests of the study, but rather to regard ethical research as living, flexible and responsive to the needs of researcher and participant.

Due to the nature of the topic, it was essential for me to ensure that each participant was completely comfortable with the situation prior to audio-recording our conversation. Many participants had questions prior to starting the interview – mostly regarding the importance of ensuring anonymity. Most women had discussed their participation with their support system and decided to participate either because they felt strongly that sharing their story could help others, or because a family member encouraged them to speak to “someone” about their experiences.

I ensured that all participants were calm and felt contained once the interview had been completed and I had stopped recording. In these moments, I frequently wished I could have included these interactions, as there were vulnerable moments where rich data were shared, but I respect that they were willing to discuss these matters only off the record. Some shared

stories regarding unhappy marriages, ill children, difficult in-laws, and difficulties at work, financial stressors and their own ill health. In these moments, most of the participants commented that they felt so much better having told their story. And all women noted that they hoped their participation could help other women in the same situation and that they felt sharing their experiences was an important thing to do.

Chiweshe (2015) found open-ended interviews on the termination of pregnancy (in this case, illegal and often unsafe) to have a potentially beneficial effect on women. Benefits to those participating in Chiweshe's (2015) research included: catharsis, opportunity for self-reflection, increasing awareness or support for the topic or cause, possibly helping others going through the same experience and the opportunity to talk to someone about a sensitive subject. Health service providers generally commented that it was important research and thanked me for doing it. Women participants all displayed strong emotional responses, self-reflected, were able to speak about their experiences in a safe and non-judgemental space and were able to access social welfare or psychological assistance where necessary following the interview.

8.3 Critical Reflexivity

Reflexivity requires the researcher to reflect on her own perceptions and assumptions and how these affect the data. The researcher examines her own training and social context and explicitly states these, thus enabling the reader to note where data from participants interacts with data co-created by the researcher (Farragher & Coogan, 2020). Lazard and McAvoy (2020) regard reflexivity as essential in ensuring rigour in contextualising the conclusions drawn from data as gathered and evaluated by a particular researcher, within a particular

social, theoretical, political, personal and historical period. To this end, I employed reflexivity from recruitment, through data collection and analysis to view each decision I made with a critical eye, questioning my motivations and the implications these decisions could have on my participants and their voices. Ensuring validity, rigour and credibility of this study was paramount in order to do justice to the participants' stories and enable pragmatic change to take place based on the outcomes of this research.

Lazard and McAvoy (2020) challenge researchers to turn their objectifying gaze upon themselves. Reflexivity acknowledges that neutrality and objectivity are arguably impossible constructs and that our closest representation of data would necessarily include researcher as researched. Reflexive analysis of the researcher's own positioning with regard to power, her positions within daily life and experienced privilege are essential in engaging with the lived realities of participants and entails scrutiny of the researcher's social class, gender, race, age, own experiences of what is being studied, professional status and much more. Self-reflexivity is essential in a feminist social constructionist approach to data gathering and analysis.

Women researchers have opened up many previously underexplored topics precisely due to their own experiences with critical health issues (Lazard & McAvoy, 2020). As a mother of two children, who has struggled with endometriosis and underwent a hysterectomy, I have experienced my own share of unpleasant experiences with reproductive health services and providers, even though these services had been accessed within the private healthcare system. These experiences range from not being listened to by my providers, to being told that my symptoms were not real, to having to convince the healthcare system to "allow" me to undergo a hysterectomy when I could no longer endure the pain associated with adenomyosis. When my participants spoke about the poor pain management they

experienced, their frustration at not being listened to and times where they had felt shamed by their providers, I was certainly not a neutral researcher, but instead a co-creator of a narrative of frustration, anger and resistance to these experiences women endure in seeking reproductive healthcare.

We, researchers, remain merely humans studying humans. We are positioned within our social contexts, gender, values and theoretical underpinnings. And we filter all of our experiences through these respective lenses, including our reading, interviews and data. Edwards and Ribbens (1998) explored the importance of acknowledging that our research explores intimate private spaces, experiences and knowledge, while we consciously share this information in public spaces and as public knowledge. Consequently, reflexive researchers are challenged to consciously balance their research needs with the intrusion into their participants' inner worlds.

Newton (2017) explored the complex relationship between participant and researcher in the context of sensitive topics. Newton (2017) discussed interviews on abortion experiences in particular, and acknowledged the grey space between establishing adequate rapport in order to elicit useful data, and maintaining participant beneficence and non-maleficence. In this regard, I found myself feeling at times guilty for asking participants to open up these potentially upsetting memories for what I perceived as my personal gain. However, their responses toward my research, and participants thanking me for taking on this topic, and their reactions to the interviews, reinforced the importance of creating a space for their voices to be heard. I also reminded myself of the end goal being to provide commentary to the Department of Health and obstetrician/gynaecologist and fetal specialist groups in South Africa, in order to provide feedback on women's experiences of their interventions and

suggest systemic and procedural changes that could benefit both women and health service providers' wellbeing. I have presented my data and findings to the Provincial Department of Health at their annual Research Day in 2017, 2018 as well as 2019, as well as to the medical faculty of the University of the Free State during their annual Faculty Forum in 2018, and the University of Stellenbosch's Department of Psychiatry in 2021. Audience responses from these presentations included stunned silence, many questions from those who are not involved in providing the procedures and affirmation that this is valuable, needed and even brave research.

The methodological self-consciousness described by Charmaz (2016) was relevant here, as I was required to reflect on how I was perceived by potential referral sources, as well as potential participants. Affiliation with a critical health psychology research unit brought with it particular assumptions regarding a feminist and liberal outlook, which may at times have had a negative impact on research participation and support due to the social stigma that continues to be associated with reproductive rights advocates. There was no 'good way to be'. I was judged to be too liberal and free-thinking or potentially too critical and narrow-minded. I was too objective as a researcher to really understand participant experiences or too prone to intrude on emotional content as a clinical psychologist. My own perspective was also challenged. As a White, middle-class professional person with two healthy children after two healthy pregnancies, would it be at all possible for me to ever enter into the position of a Black, unemployed woman living in poverty, with basic education and having experienced a feticide and late termination of pregnancy at a public hospital? We speak different languages. We lead very different lives. And so, I was challenged to continuously reflect on my positioning in terms of privilege and power, not only during interviews and data analysis, but in gaining access to participants and throughout the entire process. Feminist researchers

employ interviewing in an egalitarian and respectful manner in order to gain knowledge about participant lives and experiences, paying particular attention to power imbalances within the data, as well as between the researcher and participant (Roulston & Choi, 2018). This kind of respectful approach did, in my experience, build bridges across the divides mentioned above.

During the interviews with both women and health service providers, I became aware of the perceived risk participants felt their inclusion entailed (see above discussion), but also their bravery at deciding that it was important enough to take this leap of faith. I believe that my registration with the Health Professions Council of South Africa (HPCSA) and profession as a clinical psychologist, bound to maintain confidentiality and protect beneficence, were advantageous in reassuring participants of my integrity and trustworthiness. My being a woman and especially a mother, having experienced pregnancy and childbirth and the rigours of motherhood, were important points of connection with the women participants. I was, however, careful not to disclose these factors when they could affect rapport between myself and the woman, unless specifically asked. Does this constitute deception? Possibly. However, it seemed the kinder response to someone who was sharing her greatest loss with me, Someone who has been spared this experience.

My emotional responses toward the women were quite strong and empathic, particularly during times when they would cry or become very sad while describing certain aspects of their pregnancy termination and feticide. I perceived my display of emotion to have made the women feel more contained and in fact heard, even though my training as a clinician reinforced emotional distance. Mauthner and Doucet (1998) validated the importance of becoming self-aware of our emotions, our social and intellectual situation in comparison with

each participant and thus trying to grasp the narratives emanating from the data as they interact with our lenses and lived reality.

Mnyaka and Macleod (2018) discussed the difficulty therapists may encounter in adjusting to their role as researcher/interviewer and noted that this type of researcher may experience particular challenges in trying to establish rapport while avoiding a therapeutic approach. I had been particularly aware of the potential risk of falling into my comfortable clinician role, which was so much more familiar to me than the researcher/interviewer role (although psychotherapists utilise careful listening skills, asking questions and eliciting emotional reactions, which are essential to qualitative interview work.) Upon reflection, I found that I tended to pull interviews into leading directions at times, particularly chasing those emotional responses and especially with participants who were reticent. The following are some examples of the questions that obviously fall into the aforementioned category and in hindsight, I would have posed them differently or even omitted them:

This must have made your grief very lonely?

Do you feel guilty sometimes?

The nurses and the doctors, did you feel that they were, did they support you, were they helpful?

It must have been difficult waiting for him?

These questions are closed-ended, which can be answered with short or yes/no answers; they make assumptions which may not have been brought up by the participants and referred to

loneliness, guilt, support, help and difficulty, thus leading the interview and inserting these constructs into the discussion. Open-ended questions would have been better, e.g., “How was that for you?” or “How did you feel?”, “How did you experience the nurses and doctors?” and “What was it like waiting for him?” In the end, we are humans interacting in a human encounter, with all of the messiness, wrong-stepping and self-correction that this entails.

Roulston and Choi (2018) noted that researchers should use interviews that seemingly went “wrong” to explore what the underlying dynamics were and delve into these transcriptions and memos to identify aspects such as power imbalance or silencing, as well as researcher discomfort. I have many regrets and self-criticisms whenever I read over the interview transcripts. However, the interview that troubles me the most and where I feel I lost the most data through lack of exploration is the one with Wilna. This interview took place in the paediatric clinic of the academic hospital as requested by Wilna, due to her having to wait with her son for his appointment. I found myself a bit flustered by the unfamiliar (to me) setting. I found establishing rapport with Wilna very challenging. During the interview, I perceived her to be an exceedingly resilient and strong woman who was uncomfortable with the vulnerability created by the interview. Consequently, the interview was the most difficult one I performed, with stilted answers and a feeling of us both being a bit awkward, probably due to an interaction between Wilna’s reticence, my feeling unfamiliar with the clinic room and setting, and the outside noise intruding upon the interview space.

In the excerpt below, it is evident that I failed to pursue potentially important data due to my hesitance to upset her composure. This question followed upon Wilna disclosing that her husband had forbidden her from taking any photographs of their son following his stillbirth and her having become emotional describing the birth experience:

Extract 4

Angie: Do you regret that?

Wilna (W11): Even if it was just one [photo], but I didn't go against his word.

And I just left it at that and continued with a following question because I felt it too loaded a topic to explore. Now I read this section and wonder if I did not, in fact, add to her silencing by just moving past the obvious dissonance between her volition and her enacted autonomy. She had just birthed her dead baby and had to submit to her husband's ban on photographs. Conversely, I added the concept of regret without Wilna having explicitly named this emotion, which could be considered a leading question.

In my attempts to counteract my instinct to pursue emotional content, I managed, in most other instances, to allow participants to lead the interview instead of posing questions that may have opened up emotional aspects that could harm their wellbeing in any way. This included health service providers, who were surprisingly vulnerable during the interviews. Many health service providers became emotional during our discussions. I found myself packing tissues along with my voice recorder and file for each interview. Much to my dismay, I could not help but become tearful at times when participants became extremely emotional during their descriptions of their experiences. Stepping out of my role as therapist had somehow left me more vulnerable to reacting emotionally to the emotions of another. This led me to become conscious of how important the manner in which our roles are constructed, and perceived, is. Within my role as therapist, I hold certain professional and ethical expectations to maintain my composure, and perhaps the inherent power difference between therapist and patient adds to this ability to distance myself from my own emotional

responses. Finding myself in the researcher role felt a great deal more vulnerable and perhaps it was my unfamiliarity with this dynamic in interpersonal interaction that exposed me to my own emotional reactions. However, my emotional reactions did not appear to upset participants but rather served to validate their own responses and provided pockets of very authentic interaction (offering and using tissues, smiling between tears). Perhaps this is where research and participant support meet, in the space where sensitive research undertaken in a non-judgemental, even emotionally warm, environment could both provide rich data, and emotional catharsis and relief for the participant (Newton, 2017).

Many women and health service providers made statements that would be regarded as heteronormative, assuming fetal personhood or gendered and hegemonic in nature. Strong anti-choice sentiments were shared by women and health service provider participants. This is where Mauthner and Doucet (1998) reminded feminist researchers to keep ourselves rooted within our theoretical and ontological framework, without distorting participant voices. In these discussions, it was important to remind myself of my purpose in engaging in these dialogues, which was to gather participant perceptions and experiences, not to become involved in a discussion to contain or amend painful beliefs. However, leaving statements such as the following unchallenged was quite counterintuitive to a therapist, as Emma's expression of shame would be an important point to explore and challenge in a therapeutic process.

Extract 5

Emma (W9 private): I didn't tell anyone 'cause it's kind of embarrassing: "How dare you? Again you know this moralistic thing, are you killing somebody? What are you doing? You know?"

In retrospect, I would have liked to explore the emotional content in these statements, without trying to alter or psychoanalyse them, but rather in order to encourage Emma to expand on where the moralistic influence came from that made her feel so embarrassed. “Killing somebody” would have been an important statement to explore as well, e.g., where does this construction come from, and how does this influence her self-constructions?

Power differentials were most prominent in interviews with women who were public healthcare patients. There was an implicit supposition that I was tied to the hospital, doctors, medicine and a university. The assumption was made that, because I am undertaking my doctorate and am a qualified clinical psychologist, I am an expert with incumbent power. I tried to minimise this as much as possible by distancing myself from hospitals during the informed consent discussion, and reinforcing that I am ‘just’ a researcher. Private healthcare participants were a great deal more ‘equal’ in their interactions and treated me as a fellow working mother rather than someone with expert knowledge. The health service providers who were not medical doctors were open and met me as equals. Many of them had themselves completed a doctorate and they were supportive and helpful in their interactions with me.

Health service provider participants were aware of my role as a clinical psychologist outside the research context, and would assume that I knew certain aspects of their work environment, and even that I would share their views and opinions regarding patients and systems. Private healthcare user women responded to me in a manner that I perceived as more assertive than I experienced with the public healthcare users. I hypothesise that this is due to the inherent relational power imbalance between health authorities and patients being

exacerbated in public healthcare; where users are regarded as “having no other alternatives for treatment”, they tend to avail themselves to perceived “authorities” much more readily than the more autonomous private patient. Stevenson et al. (2021) discussed the concept of performing “doctorability” and how this concept relates to patients’ behaviour and reports of their interactions with medical doctors. Patients’ “doctorability” refers to the perceived “reasonableness” of their requests for healthcare, meaning how reasonable or legitimate their concerns or healthcare-seeking behaviour are when evaluated by the healthcare provider (Heritage, 2009).

Medical doctors, and particularly medical specialists, are positioned as “elite” within most South African communities. I work with medical doctors and specialists daily within my job at a university medical school, and consequently, they are humanised in my eyes. However, I was made aware of the “elite” nature of their positioning with regard to difficult access, limited timing and formal, structured interviews, frequently in their own rooms. I found my emotional responses toward the medical doctors varied between empathy for the taxing work they perform, to disdain for some of the archaic views they expressed regarding women, reproduction and psychological wellbeing. The latter is evidenced in the extract below.

Extract 6

Hugh (HSP8 public): If I’m in an exam situation, I probably will be criticised for being so harsh (.) but on the other side, you temper that down by saying: “This is what you must do in the next pregnancy...” But even (clinical geneticist colleague) used to just say: “If a woman wants to [pause] most women who drink [alcohol] are not going to stop. They must all be sterilised.”

This extract depicts the contradictions inherent in these interviews and this research. This specialist displayed immense empathy and kindness in his approach toward his patients, yet he also presented what could be interpreted as a prejudicial attitude towards women. The excerpt is particularly problematic when viewed in light of the practice of forced or coerced sterilisation of HIV-positive women in the South African context (Durojaye, 2017). Clearly, this statement reflects a discriminatory attitude towards women, while stated from “benevolent sexist”⁴ (Glick & Fiske, 1996) positioning. In this particular interview, my clinical training assisted me in not responding to a statement I found offensive, but rather to allow the interview to continue from a neutral stance.

8.4 Impact on the Researcher

A section on reflexivity would be incomplete within the context of this research topic, without acknowledging the emotional impact it had on me. Goodrum and Keys (2007) stated that the influence the participant had on them did not end with the interview. This resonated with me. In doing psychotherapy, I am often affected by the content of our discussions, but more often than not, I am also able to enjoy the rewarding experience of actively working through the emotions and thoughts within the session, in order to assist my patient in moving towards a new attitude, feeling state or mood. The interviews in this research process provided some catharsis and relief to my participants (according to them), but I was left with the niggle of having noted things we could have explored and worked through in a therapeutic setting. Of course, this was impossible, and created a feeling of unfinished business, which troubled me each time I worked through the interviews in transcription and

⁴ Benevolent sexism is a particular form of sexism where behaviour which conforms to traditional gender roles is received positively or reinforced.

analysis. This created some dissonance and frustration. However, the women's resilience and fortitude were equally as prominent as their suffering, which challenged me not to weigh one aspect of their experiences more heavily than another. As terrible as their experiences were, these women all reported finding meaning in them and growth from them.

A far more challenging emotional response was the grief and secondary trauma to which I was exposed. Vivid descriptions of malformed fetuses, the procedure of feticide (either by direct cardiac injection or infusion of the amniotic fluid), the imagery of birthing a dead (and sometimes macerated) baby and the immense grief women shared with me, affected me during data gathering, transcription, analysis and even now as I write this. I experienced vivid dreams related to these narratives and found myself at times avoiding my research because of the emotions the data elicited. Kumar and Cavallaro (2018) proposed a conceptual framework on researcher self-care in the context of demanding research. The authors presented the importance of researcher self-care and wellbeing, particularly in undertaking qualitative research where the researcher is one of the research tools. The compassion fatigue within research, which Kumar and Cavallaro (2018) described, often led to times when I struggled with the content of my interviews. However, my own psychotherapy, yoga, running and the firm belief in the importance of this work sustained me.

9. Conclusion

In this chapter, I have outlined the methods I employed in order to collect my data. I utilised convenience and snowballing sampling in order to gain access to my research participants, as the women and providers can be regarded as a hard-to-reach research population due to the sensitive nature of the topic. Twelve women who had undergone a feticide and LTOP

procedure, within one to five years prior to the interview, and 13 health service providers, who were involved with feticide and LTOP procedures, participated.

Due to the sensitive nature of the topic, ethical clearance and careful adherence to ethical standards were pivotal, as discussed in this chapter. Consequently, I described how privacy and confidentiality were maintained during the research process. During the critical reflexivity section, I discussed how my identity as a White female, mother and psychologist from a privileged background interacted with the manner in which I approached the research and participants.

In this chapter, I then moved on to explain how I applied the SCGT method, developed by Cathy Charmaz, to this research. I explored how I applied FSCGT methods in analysing my data and the implications this has for my study. Having outlined my methodology and the ethics and reflexivity relevant to my study, I will now present my findings. Chapter 5 follows and presents the analysis of data as it relates to the first phase of women's experiences of feticide and LTOP, namely the diagnosis of fetal abnormality and the decision-making process.

CHAPTER 5: PHASE I: THE DECISION-MAKING PROCESS – SOMETHING GONE WRONG

This research was undertaken in order to better understand and situate South African women's experience of the feticide and LTOP decision-making process, their experiences of these procedures, and women's recovery from them. In this chapter, the first phase of women's experiences of the feticide and LTOP procedures will be presented, following which providers' perspectives on women's experiences will be explored. Phase one relates to the decision-making process and includes themes related to the diagnosis of, and women's reactions to, the diagnosis of fetal abnormality, women's constructions of the decision-making process, women's perspectives of providers' input during this phase, women's constructions of others' reactions during this phase, and how women manage the information they provide to others about their experiences. In this first phase, health service providers' constructions of women's decision-making process include categories related to: the context within which the decisions took place, e.g., women's reactions to the diagnosis, as well as the parameters set by legal, ethical, policy and medical influences which filter provider recommendations, providers' personal positions on abortion (pro-choice, 'so called pro-life', conflicted); the time constraints placed on the decision (including poor antenatal care, lengthy diagnostic tests, and the need for time to make the decision); and providers constructions of the decision as "wise" or "foolish".

An excerpt from Peter's (fetal specialist in private healthcare) interview summarises the difficulty and complexity of the fetal diagnosis and, in particular, conveying this diagnosis – something wrong – to the unsuspecting woman who is then faced with one of the most difficult decisions she would have to make in her life:

Extract 7

Peter (HSP3 private): You know I have so much empathy for the poor people. It's almost the worst (.) to sit and scan and you see something is not right [with the fetus] and now I have to tell them [about the diagnosis]. That knowledge that they are still excited about sonar and I also can't let them live in a fool's paradise for the next half an hour. I have to tell them: "Here is something wrong, there is something badly wrong".

Peter's statement, "I have to tell them here is something wrong, there is something badly wrong", indicates the severity of the situation and how distressing the fetal diagnosis and decision-making process can be for providers ("it's almost the worst"), and for the women and families ("poor people"). It is to this process that this chapter speaks.

Women's Perspectives

During this first phase, women's constructions of their pregnancy were jarringly altered, and a process of rebuilding their conceptualisations of their fetus and pregnancy as "abnormal" began. Decision-making was introduced the moment that severe fetal abnormality was identified when providers presented the option of termination. For many of the participants, this was the first time that they had received any indication that there was something wrong with their pregnancy. Below, Fay (W7 private healthcare) describes her experiences of her consultation with her gynaecologist the day after a sonographer identified severe fetal abnormality.

Extract 8

Fay (W7 private): I went back to the doctor the next day and so he checked the baby. And when he saw (.) he explained to me that something is not right: “Now what you see (.) now is the baby has spina bifida. This is when the spine did not close properly (.) the fluids that are on the brain ((build-up of fluid on the brain causing it to stop developing)) of the brain (.) so it’s like the brain is responding and the part of the brain that ought to develop (.) there is no part.”

Receiving the news that “something is not right” and the diagnosis, as relayed by Fay above, shattered participants’ previous constructions of their pregnancy. These kinds of interactions provided the impetus for the cascade of experiences related to the first phase of the LTOP process, starting with the women’s reaction to the diagnosis, her understanding of the diagnosis and the cause thereof, which are discussed below

1. Reacting to Hearing About the Abnormality

Women constructed their emotional reactions as including the feeling that something within themselves had died, which may speak to the loss of the imagined future with a healthy child. It is important to bear in mind that each woman who participated in my research constructed her pregnancy as wanted, even if it had been unplanned. Consequently, it is understandable that they had formed an attachment to their fetus, particularly as fetal movement had been felt by all participants at the time of fetal diagnosis. In this regard, I shall be making use of the terms “fetus” and “baby” interchangeably, out of respect to the women who all referred to their fetus as a “baby” at various points throughout the interviews.

Extract 9

Janet (W8 private): To tell you the honest truth [in] the moment that I found out and I realised how severe it was and so on (.) and I am not at all (.) not at ALL someone who believes in suicide. I always think positively. Even if something negative happens (.) then I think there is always something better waiting for you. And things can always work out and nothing is purely bad and negative. But there was a split second where I felt that I did not feel like living anymore.

Extract 10

Lelanie (W12 public): I don't know (.) because you know (.) at that moment (.) you also died. I didn't feel anything. You know people could talk to me (.) they could do what they want (.) I didn't register. But I don't know.

Women's experiences during this first phase revolved around a shattering of their reality, which left many women feeling as though a part of themselves had died along with the news that their fetus would not be normal. Both Janet and Lelanie expressed how this feeling of loss manifested as the death of something within themselves. Janet's description of herself as generally positive underlines the severity of her reaction. Lelanie's description of her reaction to hearing the diagnosis depicts dissociation ("I didn't register"), which is a common response to traumatic or emotionally overwhelming news. However, Janet's reaction may be indicative of suicidality or the potential to harm herself due to the immense loss and dread she experienced upon receiving the news. Some of the painful emotions had to do with the sense of having to make a decision (discussed in more detail below).

Extract 11

Odwa (W1 public): It was bad. It hurt me and I cried a lot. I didn't know what to do. It started from [secondary regional hospital]. But it is not in my hand ((it was not under her control)).

Odwa's statement: "I don't know what to do" accurately reflects women's emotional confusion after hearing about the abnormality. The helplessness women may feel upon hearing this news is indicated by Odwa ("it is not in my hand") as they have no ability to change the diagnosis. Due to the pregnancies being wanted, women experienced conflicting emotions following the diagnosis and during the decision-making process. On the one hand, loving this potential child and wanting this child to join their family, and, on the other, knowing that the fetus would never have a normal life, with far-reaching implications for her entire family and for the rest of her life. One of the key reactions to hearing the diagnosis was trying to find an explanation, which is presented next.

2. Explaining the Abnormality

Once the severe fetal abnormality had been identified, the process of trying to establish a definitive diagnosis and prognosis began. Unfortunately, eight of the 12 women participants reported that a definite diagnosis could never be ascertained, or if it had, they had not been informed of this in an understandable way.

Extract 12

Jasmine (W4 public): The thing is they never really got (.) they still don't have an answer on why any of these pregnancies didn't work out.

Extract 13

Mpho (W5 public): Because they did [perform an] amniocentesis (.) they say the baby (.) according to what they detected (.) they just say maybe its trisomy 13 or 15. So they didn't come with the exact trisomy (.) [or what] the problem [was].

This lack of certainty created a blank slate for various hypothetical causes to be postulated by the women. These explanations ranged from ones in which biological causal mechanisms were sought to ones in which the women were deemed behaviourally culpable.

2.1 Biological Causation and Culpability

Three of the women who participated in this research were regarded as being of advanced maternal age (over 35 years old) and this was seen as a significant contributing causal factor to genetic mutations. Mabatho recounted that she was told that her age was likely the cause of the fetal abnormality, while Melissa (she was 45 years old at the time of this pregnancy) admonished other older women not to become pregnant due to her experience of fetal abnormality being diagnosed. Prejudice against older women is a common occurrence in reproductive healthcare settings. Mthethwa (2017) found that nursing staff, in particular, are prone to criticising older women who become pregnant. The messages conveyed to Mabatho and Melissa in the excerpts below clearly blame their age for the fetal abnormalities and Melissa internalised this criticism by stating that anyone in her position “must be mad”.

Extract 14

Mabatho (W3 public): And then they referred me to [regional academic hospital] where they told me that because of my age probably that might be the reason why the child is not fully developed.

Extract 15

Melissa (W6 public): Uhm they must think twice and especially at our age to fall pregnant (.) you must be mad if you want to become pregnant.

In these extracts, direct individual biological culpability is ascribed. However, other extraneous biological causations were also sought. In the literature review chapter of this thesis, certain medications and deficiencies were discussed as being directly indicated as causal factors with regard to certain fetal deformities. Lelanie described how the fetal abnormality was directly attributable to her having been on teratogenic medication, sodium valproate, prescribed to control her seizures due to the presence of a brain tumour, while Odwa spoke to a lack of access to antenatal vitamins.

Extract 16

Lelanie (W12 public): Then he [clinical geneticist] did say that it was the medication. So (.) but really (.) he gave me all the information on Epilim [following the fetal diagnosis]... And the medication they had me on was Epilim and no one told me that there was a lighter pill that you can take (.) than Epilim. Until the doctor told me that (.) but it was already too late.

Extract 17

Odwa (W1 public): The only thing is that the time I was going to the clinic with my baby [while pregnant with the abnormal fetus] they didn't give you medicine [antenatal vitamins]. Throughout the period of pregnancy. That's why I say maybe because I didn't take what I need to (.) how can somebody that is pregnant [have a healthy pregnancy] without taking any medicine? It's not good. If I went there each time I went there they will tell me no medicine for me (.) they say no (.) they don't have (.) it's out of stock.

During her interview, it was apparent that Lelanie felt resentment towards the providers who had not informed her adequately of the danger this medication poses to fetal development and, even worse, that none of the providers had identified the severe fetal abnormalities, or even suspected there may be severe abnormalities due to her medication, earlier in her pregnancy. She had to endure the consequences of this breakdown in communication and there is no justice or recourse with regard to the medical system that failed her. Odwa constructed her fetal abnormality as being due to not having had access to antenatal vitamins ("how can somebody that is pregnant [go], without taking any medicine? [antenatal vitamins]"). Women's access to antenatal vitamins, as well as women being adequately informed of the teratogenic risks associated with their medication, constituted systemic failures as Odwa described: "they don't have, it's out of stock" and Lelanie stated: "no one told me that there was a lighter pill". It is significant to note that Odwa was a foreign national, which may be an additional structural barrier to accessing antenatal healthcare, as Mathethwa (2017) found that foreign nationals are frequently discouraged from making use of antenatal healthcare services in South Africa due to discrimination on behalf of nursing

sisters in particular. In contrast to personal biological culpability or systemic failures, vague genetic causes were referred to.

Extract 18

Fezile (W10 public): Oh, they said so many things (.) I'm not even sure. Genetics (.) something went wrong with the genes (.) now (.) whatever whatever...

Extract 19

Angie [posing question to Odwa]: The genetic stuff is not always that easy for me to understand (.) did they (.) were they able to say it was something that happened one time (.) or is it something that could happen again?

Extract 20

Odwa (W1 public): They say that it happens to some people like us ((the implication is that it just happens without reason)).

Genetic mutations are frequently causal factors in fetal abnormality; however, there is seldom a directly attributable reason. The explanations of the physiological and genetic causes of fetal abnormality are often difficult to understand in lay terms, leaving women (and the researcher) without an accurate understanding of the biological factors that contribute toward the diagnosis of fetal abnormality. When a specific diagnosis cannot be made, this serves to create a space where self-blame (as discussed below) and uncertainty are produced. It is clear that Fezile did not receive an understandable explanation of the genetic aspects that may have caused the fetal abnormalities “whatever whatever” and Odwa is left with the explanation that “it happens to some people like us”. It is unclear what personal

characteristics “like us” refers to, and I did not probe further. Odwa is a Nigerian national living in South Africa, in a low-income area, where she is shunned by the community due to her nationality. As noted above, These Odwa’s capacity to access quality healthcare (including antenatal vitamins) were compromised.

2.2 Supernatural Causation and Behavioural Culpability

Some women were concerned that perhaps the fetal abnormalities were caused by witchcraft, which was allowed space due to their not having followed culturally prescribed rituals related to their pregnancy. Fear of witchcraft affecting pregnancy, and especially fetal development, is common among the South African population (Mthethwa, 2017).

Extract 21

Angie [posing question to Patricia]: Culturally – how do you explain why something goes wrong with the baby?

Extract 22

Patricia (W2 public): My grandparents (.) they think it’s a witchcraft. They think I should consult traditional doctors.

Extract 23

Angie [posing question to Patricia]: How does the bewitchment work? *Patricia (W2 public):* Maybe it was me. Because they [her grandparents] would say I must do the [traditional] rituals so that I can be cleaned. Maybe they [community members who may have bewitched her] didn’t want me to have this child. You know the reason that

the doctors they didn't see it [abnormality was identified late in gestation] I thought so
(.) because Black people (.) they know how to do their thing [witchcraft]. I didn't
think I should go [to a traditional healer]. The only thing I was doing was praying.

Extract 24

Mabatho (W3 public): The family influence (.) especially with this kind of thing
[pause] they will always feel it's got something to do with witchcraft. So, they took
me to a *sangoma* [traditional healer] (.) who obviously (.) the *sangoma* will say
witchcraft [is the cause] and things like that. But I went back to the clinic and I also
wanted to talk about it. And the sister explained to me that these are not witchcraft
things (.) but it's just the people will believe whatever that they want to believe. But I
am convinced that it's not witchcraft (.) it's just that things did not happen the way [it
was] supposed to. That's why the child was like that [abnormal].

In the discussion with Patricia, I, as researcher, introduced the notion of a cultural explanation, which Patricia readily took up in describing witchcraft as a possible explanation for the fetal abnormality. It is significant to note that both Patricia and Mabatho present ideas surrounding witchcraft as being based on family influence, rather than their own beliefs specifically. This may represent some social pressure being exerted on women, and indeed, Kortman (2020) found that family members, and mothers-in-law in particular, encourage pregnant women to consult with traditional healers. It is also possible that the women slightly distanced themselves from traditional ideas during the interview as they took place in a hospital setting and with a White researcher who is a member of the healthcare profession. Patricia ascribed the doctors not identifying the abnormalities earlier during her antenatal visits to the effects of witchcraft as well ("the reason that the doctors they didn't see it").

The tension between trusting medicine and conforming to traditional rituals and beliefs added an additional point of self-reproach when women doubted their decision to adhere to non-cultural practices. However, Mabatho described how she took it upon herself to verify what the medical system said caused her fetal abnormality, which appeared to provide her with some reassurance (“it’s just that things did not happen the way they supposed to”) that nobody was to blame for the diagnosis.

In this space of uncertainty, where a definitive causal factor is almost never identifiable, it was not a huge leap to start wondering if such a devastating event is somehow punitive, particularly if the woman felt she had morally failed or contravened social norms in some way.

Extract 25

Janet (W8 private): But the thing is (.) in that time (.) my husband and I had separated. And then I had met another man. And it wasn’t my husband’s child [the abnormal fetus]. And my husband and I patched up our things again and so on. The father knew...Was I now punished? Do you understand? Was I just punished?

Extract 26

Mpho (W5 public): You just ask yourself so many questions: “Why was it to happen?” But you can’t have an answer. So, it’s good to keep yourself free from those questions. For me it was hard, because I was asking myself: “I’ve never [had an] abortion then this thing [fetal abnormality] is coming to me.”

Janet felt that she may have done something wrong to cause (rather than alleviate, as in Patricia's case) the fetal abnormality, which was punishment (from a vague source). Mpho considered the unfairness of the diagnosis, which could have been sent to her as a punishment had she had an abortion previously. Diagnosis of severe fetal abnormality and being posed with the choice to terminate was thus constructed as a punitive experience by Janet and Mpho.

Although Janet and Mpho do not specify the source of the potential punishment, Melissa constructed the diagnosis of fetal abnormality as caused by God. However, she depicts it as a lesson or guidance from God in order to correct her behaviour, rather than as punishment:

Extract 27

Melissa (W6 public): Maybe the Lord wanted me to move closer to Him. Because I went through a time where I lost the way a bit. Maybe He just wanted to show me again that He's in control (.) not us.

According to Melissa, the fetal diagnosis may not be punitive, but rather a method to guide her back as she had "lost the way a bit". Behavioural culpability is implied here to a lesser extent, while the motivation behind the fetal abnormality is benevolent, to bring her back, rather than to harm her.

3. A Difficult Decision

Women indicated that when health providers presented them with the choice to terminate the pregnancy, this was posed to them as their decision in line with their legal rights. However,

the manner in which the decision was communicated and posed affected women's perceptions and constructions thereof. The decision-making process was frequently described as difficult, causing many conflicting emotional responses and uncertainty. Time and how the decision was constructed added a sense of urgency to decision-making. Ultimately a significant theme that emerged was that of women essentially having no choice.

3.1 Conflicted and Difficult

Melissa described the decision-making process as “difficult” and Janet regarded it as “terrible”. In understanding women's experiences of this decision-making process, it remains important to bear in mind that these are wanted pregnancies, and consequently the conflict is expressed around ideas of the fetus being “human” and constructed as a “child”, whereas women who terminate an unwanted pregnancy may not necessarily regard the fetus as a ‘child’. Janet frames her conflict with her ideas related to the right to life when she stated: “you still don't have the right to do something like that”.

Extract 28

Janet (W8 private): You can't (.) it's almost [pause] [a] person can actually not (.) this is now difficult (.) to say it like this but (.) a human is a human (.) you cannot (.) but the thing is that that child (.) didn't have a life. But you still don't have the right to do something like that (.) but (.) that's a difficult thing. It is. It is terrible.

Extract 29

Melissa (W6 public): It is a decision (.) it is not an easy decision (.) it is a difficult decision [pause]. And it was difficult.

This category presented a significant theme emerging during the first phase of the theory-building. The difficulty and contradictory internal narratives and emotions are clearly depicted in Janet's extract where, with multiple pauses, she wavers between "a human is a human" and the child not "hav[ing] a life". Although none of the women reported feeling doubt that they had made the best decision to terminate, the difficulty incumbent on the choice to terminate a wanted pregnancy, and the fetus which is constructed as their child, created excruciating cognitive and emotional conflict. The difficulty associated with making this decision was equally distressing in both private and public healthcare settings.

3.2 No choice

Women constructed the decision to terminate the pregnancy as one without viable alternatives. Women justified their decision to terminate by describing the constraints placed on them which preclude them from raising a special needs child:

Extract 30

Wilna (W11 public): I have peace with my decision that I took. I couldn't punish my child (.) I didn't have the finances to, if the child survived, to care for him. He would have had a pipe in to help him pee and whatever, he would not have been able to walk, all those things (.) I do regret that I lost him, but not that I took the decision. He's in a better place.

Extract 31

Melissa (W6 public): I didn't just blindly go and say I don't want the child. I wanted her very, very badly. But the negatives were just more (.) hopelessly too many

negatives than positives. We would probably have had to go and live in the White squatter camp...

In these extracts, the reality of the burden of care and resources a special needs child requires effectively nullified the construct of choice – “hopelessly too many negatives”. Termination was also constructed as benevolent in preventing the fetus from suffering once born (“I could not punish my child”). In truth, there was no alternative to decide against. The implication of raising a special needs child was, according to Melissa, that she and her partner would have had to move to a “White squatter camp”, constructed here as a dramatic metaphor of threatened poverty due to the financial costs of supporting a special needs child. Due to the historical inequalities in South Africa, it has become usual for many Black South Africans to live in poverty in “squatter camps”; however, imagining White people living in the same conditions is constructed as dire or even shocking circumstances – a position that Melissa possibly felt that I, as a White researcher, would appreciate.

Although Wilna and Melissa spoke in terms of having no real choice in terms of circumstances, they still spoke of making a decision. In doing so, they were at pains to position themselves as good people – “I do regret that I lost him”; “I didn’t just go blindly”. In Lelanie’s rendition, however, not only is there no choice, but the decision does not reside with the woman.

Extract 32

Lelanie (W12 public): But you can’t decide. That decision is made for you.

Lelanie constructed the decision as being “made for you”, which is significant. Did she mean that there is just no alternative to termination or had this been how the situation was constructed during her interactions with providers? My suspicion is that it is due to a combination of both, as will be explored in the section later in this chapter where providers’ interviews are discussed.

3.3 Partner (Non) Involvement

Women indicated that they made the decision themselves without interference from their partners. This solitary decision-making process, although lonely, afforded women agency in taking the decision without coercion from their partner. The perception that women are forced into certain decisions by their support structure was presented throughout the providers’ interviews, which will be discussed in the following section of this chapter. However, women adamantly held that they had made the decision themselves; even when coercive influences were present.

Extract 33

Mpho (W5 public): Not when I decided. I decided myself. Although I explained everything to him. But that time because now he’s a boyfriend not a husband (.) I couldn’t let him decide for me. Because if I let him decide for me maybe he could say: “No let’s keep the baby” (.) but I was risking my life (.) so I had to make the decision. I alone.

Extract 34

Angie [posing question to Fezile]: Could you discuss the decision with anyone?
((during the decision-making process))

Fezile (W10 public): I called him [the father] told him what was happening. And I told him that I would be doing the termination (.) so in a way we were not that close (.) it was my decision after all. So there I was in that moment and I had to make a decision and I was all by myself. I decided that let's do the termination.

Extract 35

Lelanie (W12 public): But my husband will not be able to handle it [fetal abnormality]. He can't deal with things like this. He just isn't that type of person. He gets very anxious about things like this because he doesn't know what to do. We spoke about it and he actually said that it is my decision. But he said (.) for the both of us (.) it would be the best [to terminate]. It's not easy (.) but it's the best for both of us.

Women acknowledged that their partner had the right to be informed of the situation ("I explained everything to him"), while the partner's right to have input in the decision-making process was dependent on factors as determined by the woman. It is significant that Mpho's partner lacked the authority to assist in the decision-making process due to his position as a "boyfriend" rather than a husband. In making this decision on her own, Mpho had been able to protect herself from harm, whereas she had not trusted her boyfriend to do the same, had he been allowed to give input. Fezile attributes the lack of input to the fact that they "were not that close".

Embodying pregnancy places all authority to continue with the pregnancy upon the pregnant person's shoulders from legal and moral viewpoints. Although this may be perceived as empowering, it may also be perceived as imposing the full burden of accountability in

deciding to end the fetal life on the woman. Consequently, many partners deferred the decision-making to the woman and distanced themselves from the process; Lelanie described her husband's inability to navigate the decision-making process with her as being due to: "he can't deal with things like this". However, he provided his opinion without participating in the choice ("it's not easy, but it's the best for both of us") and, in a sense, was able to exert his volition without bearing accountability for making the decision. It is also interesting to note that Lelanie described her husband in somewhat fragile terms, as though he is incapable of dealing with anxiety or emotionally challenging situations. Traditionally gendered perspectives on women's roles as the facilitators of men's emotional expression in heterosexual relationships is relevant here in Lelanie's construction of her husband as emotionally avoidant and inept.

3.4 Others' Reactions

Women perceived the input from their surrounding social network as either supportive or non-supportive. Non-supportive responses included complete avoidance of the experience and lack of acknowledgement of their decision, or judgement and curiosity rather than empathetic inquiry. Supportive responses included receiving messages women constructed as being in solidarity with their experiences within this phase of decision-making.

3.4.1 Non-Supportive: Silence or Judgement

Several women spoke of non-supportive behaviours from others.

Extract 36

Odwa (W1 public): So little support. Like the place we are living (.) the people that we are living with (.) I don't know whether it is because we are foreigners now (.) so maybe (.) they didn't ask me [what happened to her baby]. I thought that maybe [it is because] we are not from South Africa (.) we are foreigners (.) that's why they are ignoring me.

Extract 37

Fezile (W10 public): I didn't tell anyone about this one. Except the father of the baby (.) [and] some of my colleagues I was working with. But my family I couldn't tell anyone. So there I was in that moment and I had to make a decision and I was all by myself.

Odwa constructed her experiences of being ignored by the community she lived in as being due to her status as a “foreigner”, which may be a significant factor, although the category related to silence or just no response surfaced in most of the women's interviews. This may be due to the community's silent condemnation of the decision to terminate, or a self-protective strategy employed by women to avoid the difficult emotions and moral conflicts they may have experienced. Fezile only disclosed her decision to the people who were essential to inform, such as: “some of my colleagues” and the father of the fetus, while choosing not to disclose to even her family (“I was all by myself”). This silence flowed both ways, from the social structures around the women, as well as from the women themselves. When women felt ignored by their social network, it created a sense of “othering” and isolation in their decision-making process. Silence was also utilised by women to protect

themselves from possible negative outcomes should their family members, employers or broader social network find out about the decision they were making.

Women feeling fearful of being judged emerged prominently in their interviews and this was across public and private healthcare users.

Extract 38

Mabatho (W3 public): With the community (.) the people outside (.) when they were asking (.) because even if you don't tell them (.) they will ask (.) so I just told them that I had a miscarriage. I was afraid to be judged. An' that's what the community usually does [to judge].

Extract 39

Janet (W8 private): And a person doesn't really want to talk to anyone about it. Perhaps (.) because the first thing is you get judged.

Silence was constructed as a reaction from others, and a response from the women themselves, in an attempt to control or avoid anticipated judgement. Consequently, women were exceedingly selective in deciding whom to disclose the fetal diagnosis and decision to. The uncommon event of a heavily pregnant woman returning home without her child, not unexpectedly elicited attention and speculation from the community, which women anticipated during the decision-making process and attempted to manage. Mabatho clearly felt that the community was not interested in her wellbeing, but rather that their attempts to probe for information were purely for the purposes of gossip and judgement. It is interesting

that Janet constructs the first reaction upon hearing about the fetal diagnosis and the decision-making process to be judgement. Not interest, empathy nor shock even, but judgement.

3.4.2 Supportive

Women reported receiving supportive, concerned responses from certain social structures, particularly maternal figures, siblings and acquaintances who had lost a pregnancy or dealt with a special needs child in the past.

Extract 40

Janet (W8 private): Luckily I received a lot of support and so on and they were with me and so (.) but my family knows me (.) they wanted me to talk about it (.) but they didn't push me...

Extract 41

Fay (W7 private): And later (.) I spoke to my husband's sister (.) she had incidences where she gets pregnant and the babies just died. She only carries them up to five, four months. And we sat down and we spoke and I told her: "You know it is not that I do not want the child (.) I was already in love with my baby just from the first day that I heard he's there. I was in love with him (.) but to think the lifestyle that he's going to lead ((implying that he would have suffered too much had he been born))."

Janet described the supportive concern she received from her family and importantly, touched on their inputs being tailored to her needs, rather than their own expectations. Her family and social network had been able to accommodate her particular ways of coping with the

decision-making process. Women noted the importance of being able to talk to other women who had also been through some form of pregnancy loss. Fay described being able to disclose her fetal diagnosis and decision-making process to her sister-in-law (who had also experienced pregnancy losses) as a significant source of support. This connection served as a space for mutual disclosure within the safety of a non-judgemental environment and allowed the women to feel truly understood.

4. Managing Information Provided to Others Regarding the Decision

During the decision-making phase, women were exposed to internalised, as well as the expressed, societal prejudice attached to abortion in general. The women very quickly learnt to edit the information they allowed others to access in order to protect themselves against hurtful and upsetting feedback. Consequently, the information that was released to those around the women was managed by a number of strategies, including non-disclosure, partial disclosure and re-storying.

During the decision-making process silence (non-disclosure) or partial disclosure emerged as an important method of self-protective management of the information provided to others. Although most women were able to disclose their situation to close family and friends, there were women (like Melissa and Lelanie) who were unable to disclose their decision to members of their significant support structures.

Extract 42

Melissa (W6 public): I think my children would have raised her [laughing]. Especially the eldest one [Melissa's eldest daughter]. They don't know that I aborted. I told them

that her heart had stopped beating. My children don't know. Especially not the youngest one (.) she is my difficult child (.) she would have resented me for it. And also the eldest one. But still I think they would understand (.) but I prefer that they think that her heart stopped beating.

Extract 43

Lelanie (W12 public): My sister-in-law just asked me when I went home: "What happened?" but I didn't tell her everything. I just said that I lost the baby and that's that. I didn't specifically say why I lost the baby. I didn't want to share it with them [her in-laws]. It stayed with me [crying] I thought they'd think funny things of me. That they would judge a person. That's why I kept it to myself. Now you just have to cope with it.

A strategy that was frequently employed by women during this phase was to acknowledge that the pregnancy had been lost (as in a miscarriage), but to omit that they had, in fact, chosen to end it. This served to mobilise social support and empathy without being confronted with the anticipated judgement and condemnation should full disclosure take place. Melissa indicates to her children that the fetal heart stopped, and Lelanie simply states that she lost the pregnancy to her family. Here partial disclosure – "I didn't tell her everything" – served a protective function, buffering the women from the negative reactions they had anticipated from family ("resented"; "think funny things"). Melissa's refusal to fully disclose the circumstances surrounding the decision to terminate to her adult daughters may be due to her construction of her own sense of motherhood being tarnished in the eyes of her daughters should they know the truth. This deception allowed her to retain relationships with her daughters, even though she could not receive completely congruent emotional support.

From my viewpoint as a clinical psychologist, this partial or non-disclosure served to isolate the women during a time when interpersonal relationships would have been exceedingly helpful in providing them with emotional and structural support. This perspective reflects my own constructions of interpersonal interaction and communication as necessarily healthy and facilitative of any decision-making process. Viewing partial or non-disclosure from a feminist perspective, however, enables an understanding of how these actions were performed in order to manage perceived negative backlash and stigmatisation.

Certain participants presented their experiences as pregnancy loss and not abortion, due to the wantedness of the pregnancy.

Extract 44

Wilna (W11 public): Look there were some of my family from my dad's side of the family who thought that I went for an abortion [pause] I said to her, "Look here now hey (.) if you think I would give my child away because I don't want him (.) there's the door. But I am telling you now this is not an abortion. I can't help that the child is like this."

Wilna was adamant that she had not aborted her pregnancy ("this is not an abortion") as she effectively had no choice. She is vociferous about this, outlining an incident where she wanted to chase a person who suggested that she had had an abortion out of the room. In this way, she re-storied the LTOP, allowing her to protect her and others' sense of her as a good mother. Thus, women chose to misinform certain people in their lives or to re-story the event in order to protect their relationships with these people.

5. Healthcare Providers' Input

The input received from the healthcare providers was constructed by women as comprising, variously, coercion in the form of warnings with regard to the implications of continuing with the pregnancy, denigration, comfort and support. Women conceptualised providers as focusing on explaining the fetal condition and medical and social implications of continuing with the pregnancy.

5.1 Coercive Warnings and Denigration

Coercive messages were not directly identified by women. However, many inputs from providers, as described by the women, included subtle and overt directions indicating that termination was the wise choice.

Extract 45

Mabatho (W3 public): They [clinical geneticist and obstetrician-gynaecologist] gave me options. They explained that the child is not going to be a well child (.) and the child is going to let me struggle a lot [financially and structurally] because he will be having too many complications. So I felt (.) because I am also not physically completely able [limited mobility due to leg deformity] I was going to struggle with the baby. So I agreed to terminate.

Extract 46

Mpho (W5 public): Okay they [obstetrician-gynaecologist and clinical geneticist] gave me options. They told me: "You can wait till the baby is born (.) but in that

period [while] you are waiting maybe you can burst ((uterine rupture)) (.) the amniotic can burst (.) maybe you will die or you'll both die. Then the second thing (.) where the baby (.) because it was on one side [of the uterus] (.) is not moving (.) you can get damage there and you won't get pregnant again. And you are too young (.) so it's good you make a wise decision because you have many years to live and you are young you can get another baby."

Extract 47

Melissa (W6 public): Then we went to a GP ((private practice)) in town and he said: "Your ovaries are rotten! You must leave it [reproduction] to the children." But still I didn't take it in that this is what is happening [fetal abnormality].

Mabatho, significantly, notes that she "agreed to terminate" as though this were the only option presented to her, despite her starting with "they gave me options". The descriptions provided, "not well", "struggle", "too many complications" and "not able", paint a bleak picture that makes agreement to terminate the only real option. It is important to bear in mind that Mabatho herself had been born with a congenital abnormality and the implicit message that disabled people are undesirable and a burden to those around them, must surely have had a more pertinent psychological effect on her than it would have on someone without such a disability. Mpho describes the "options" she was given as including waiting and "maybe you can burst", "maybe you will die" and "you'll die and the baby won't survive", which quite clearly present coercive non-choice options. She is confronted with the threat of losing her reproductive ability and is encouraged to make a "wise" decision. Certainly, only a very foolish person would decide to continue with this pregnancy under the threat of her own death and the loss of her reproductive health, and consequently only one viable option is

available to Mpho in this clearly coercive interaction. Melissa recounted a provider describing her ovaries as “rotten” and that she should “leave it to the children” to reproduce. It is noteworthy that Melissa constructed this denigrating input as being received from a healthcare provider who was not directly involved in the care and treatment of women undergoing LTOP and feticide procedures, but rather from a private practice General Practitioner. This input related to overt blame for carrying an abnormal fetus and the perceived irresponsible behaviour that led to the fetal condition (conceiving at a late reproductive age) and was posed from the perspective of a male GP. This pejorative statement represents some of the stigmatising and even victimising messages pregnant people over the age of 35 are exposed to within most healthcare sectors, only excluding specialised fertility or reproductive care units or hospitals that cater specifically for older women. The gendered nature of this message is also significant coming from a male doctor, using particularly denigrating language to describe Melissa’s reproductive organs, certainly succeeding in eliciting shame and embarrassment on her behalf.

5.2 Supportive

Providers’ input emerged as important and helpful support for some women during their decision-making phase. Women constructed providers as being empathetic allies during this process.

Extract 48

Odwa (W1 public): After the doctor (.) is it the genetic [clinical geneticist], or Dr X [consultant clinical geneticist] he started explaining to me about all this genetic DNA. We sat and talked about the whole thing. He explained the whole thing to me.

Extract 49

Janet (W8 private): I must say (.) in this whole thing that I went through (.) Dr X [fetal specialist] and them [his nursing and administrative staff] were really very supportive (.) you know they understand (.) and because at that time you feel terribly guilty (.) but they don't make you feel [pause] they don't judge you.

Extract 50

Lelanie (W12 public): Dr X [clinical geneticist] actually encouraged me (.) it was very difficult for me (.) it really was a very difficult decision.

Women received a great deal of information during the decision-making phase, much of which included input which was constructed as new and complex to comprehend. Generally speaking, understanding the fetal condition, causes thereof and prognosis is needed in order to make a truly informed decision. This is depicted in Odwa's statement above: "he explained the whole thing to me". Such biomedical fact-sharing can, however, be utilised as a coercive tactic in convincing women to take a certain decision as these discussions present "facts" that cannot be argued against and serve to exclude other psychological constructions of the events.

It is important to indicate that Janet and Lelanie were referring to the specialist doctors who are involved in the information-providing and decision-making processes. The information providers convey to women regarding the medical or genetic aspects of the fetal abnormality and "options" available to her, were generally constructed as supportive by women. Janet and Lelanie described an emotive component that they perceived from providers; for example,

Janet noted that “they don’t judge you” and Lelanie described the provider as having “encouraged” her. However, from a social constructionist perspective, and particularly when viewed through a feminist lens, these interactions cannot be regarded as merely neutral and supportive in the context where one person is the specialist with knowledge and authority and the patient is the “ignorant” recipient.

Health Service Provider Perspectives

In this section of the chapter, I explore providers’ perspectives of women’s experiences of the decision-making process, in order to contextualise these experiences. Providers constructed women’s reactions to the diagnosis as ranging from anger, denial and threats, to relief, as needing to ascribe culpability, and as uninformed. Time played a central theme throughout the decision-making process and added perimeters and a sense of urgency to the process. Providers’ personal and professional positions inevitably affected how they presented the options available to women and the extent to which they regarded each choice as preferable or not.

6. Constructions of Women’s Reactions to Something Gone Wrong

In the section that follows, the emotional responses referred to by the providers are divided into emotions that are perceived as negative (anger, denial and threats) and relief, which is constructed as a positive emotion. Constructions of women’s reactions included women needing to ascribe culpability and lacking full understanding of the fetal diagnosis.

6.1 *Constructions of Emotions*

Providers spoke to women experiencing negative emotion, which is neatly laid out in the excerpt below by Bettie. Bettie, a nurse's aide who performed mainly administrative and reception duties in a specialised fetal-maternal private practice, described how women and their partners reacted with anger, denial and blame towards the providers who diagnosed the fetal abnormality during the diagnosis and decision-making process.

Extract 51

Bettie (HSP11 private): Sometimes they are angry with Dr X [fetal specialist] (.) because he did it [performed the sonar] and because he brought the news [fetal diagnosis]. And we also had a husband who said (.) they deny [the fetal diagnosis] which is also one of the reactions (.) you know denial (.) this doctor is now just one of those doctors who want to (.) some say money (.) ((doctors accused of making up fetal diagnoses in order to make money)) I don't know how you would make money like that (.) but anyway that's the story. But anyway it is all part of the normal process of pain being worked through and we try to see it that way you know. It's ok. You know. And some of them [pregnant person and partner] threaten to sue you and you know it's part of their pain they just need to get to resignation. And then it will get better. You can't react to it you know. You just say that you're sorry, you're sorry, you're very sorry.

Bettie regarded anger, denial and threats as a normal response upon receiving the fetal diagnosis and framed these reactions as understandable: "part of the normal pain being worked through process". While understandable, they are also, however, framed as somewhat

ridiculous by Bettie – husbands making up stories about doctors fabricating diagnosis to make money and threats to sue. Thus, due to the emotionally charged nature of the fetal diagnosis as well as the decision-making process, it is expected that women and their partners may respond with intense and negative emotion, and direct these towards the providers involved. But the ultimate goal in the process is constructed as being “resignation”, and providers are constructed as being obliged to respond apologetically. It is noteworthy that none of the anger or accusations made against the providers is regarded as founded or reasonable. Instead, these reactions are labelled as emotional expressions of denial and ignored or humoured until the patient and their partner come to a place of acceptance where they once again comply with the medical system without further protest.

In contrast to the negative emotions, providers depicted some women as being relieved, particularly those who were unable to terminate their pregnancy within the first trimester when abortion should be available on request (note that these providers are talking about women in general and not the women in my sample, who all had wanted pregnancies). Access to ordinary abortion services becomes relevant here.

Extract 52

Mathuli (HSP13 public): If it's the sixth or seventh pregnancy (.) it's usually really a mistake pregnancy (.) and then it's usually also the mom who is 42 or 43 or 45 and they are to a certain extent aware of the increased risk of a baby with a fetal abnormality. So they tend to be [draws breath in] almost this of “let's do it and get it over with” (.) they are a lot of the time quite relieved that they can get a termination (.) because: “I tried to get a termination but they told me it was too late”. So some of them are almost relieved that they can actually still get a termination.

Extract 53

Zelda (HSP2 public): I many times wonder about (.) if they didn't perhaps take something (.) to try to abort that child (.) and then it didn't work and then there are abnormalities as a result of what they tried. And then you have to terminate in any case.

In the excerpt above, Mathuli (obstetrician-gynaecologist in public healthcare) touched on the issue of women who may become pregnant with an unplanned and unwanted pregnancy; however, due to various factors, they were unable to access an early termination of pregnancy. Consequently, the option to abort late in the pregnancy comes as a relief, particularly once fetal abnormality has been diagnosed. The relief Mathuli referred to may relate to Zelda's suspicion that some of the fetal abnormalities are caused by women trying to induce abortion. When these methods ("to try to abort that child") fail and the fetus is severely abnormal, the option of feticide and LTOP come as a relief to the pregnant person. A significant gap in both Mathuli and Zelda's constructions of the "type of women" who are relieved that they qualify for feticide and LTOP, lies in their lack of reference to health inequities. The narrative of the structural barriers women face in accessing contraception and early abortion services is completely absent in their constructions of women's reactions to being offered feticide and LTOP. This striking absence of contextualisation is perhaps even more apparent as both providers are employed in the public healthcare system, where they are confronted with structural inequality and the impact thereof on women's reproductive health on a daily basis.

6.2 Ascribing Culpability

As noted above, the women participants in this study sought explanations for the fetal abnormality, sometimes ascribing personal biological or behavioural culpability. This was picked up by health service providers as well.

Extract 54

Hugh (HSP8 public): I mean the first thing that the mom asks herself after a diagnosis or after an abnormal baby is: “What did I do wrong in pregnancy?” And I’ve actually gotten to the stage [where] I give them [pregnant person] a little bit of a biological explanation: “And do you understand that?” “Yes.” “Do you see why you did nothing wrong in pregnancy to cause this?”

Extract 55

Connie (HSP10 public): I find that the father’s family (.) the in-laws especially the mother-in-law will in a lot of cases blame the mom a lot and there’s been quite a few cases where she told me that her mother-in-law said it’s her fault that this happened. So if the dad comes with and he can see what’s happened then he can explain to his family: “No, this is what the problem is” [not the pregnant person’s fault] so I think that in that sense it helps.

Hugh (clinical geneticist in public healthcare) constructed self-blame and feelings of guilt as significant normative emotional reactions women display when receiving the fetal diagnosis. Addressing this reaction is presented as an important part of the explanation and counselling phase of his interactions with these patients. It is interesting that Hugh relies on his expertise

and medical knowledge (“a biological explanation”) to address these emotional responses, rather than utilising other strategies. He reports spending significant effort in undermining women’s sense of personal culpability. However, this may be less altruistic than it is constructed by Hugh, as he makes the automatic assumption that women would (and should) feel responsible for the fetal abnormality, along with the consequent shame and guilt. His perspective is affected by his gendered subjectivity as well as his positioning as a specialist doctor.

As seen in the women’s narratives, providers indicated that blame was attributed to women by those around them in certain instances. Connie (clinical geneticist in public healthcare) referred to “especially the mother-in-law” being prone to ascribing culpability to the pregnant person. In the excerpt above, Connie explained why she preferred to include the woman’s partner in the counselling where she explains the fetal diagnosis, in order to enable him to “explain to his family” and consequently alleviate blame placed on the woman. The woman’s partner is constructed as potentially acting as a buffer between the woman and her in-laws, which may indicate her lack of agency within the within their family system. Once again women are “othered” during this time of decision-making.

6.3 Lack of Understanding

Confusion and a lack of understanding surfaced as a relevant perspective in providers’ constructions of women’s responses to the diagnosis and recommended procedures.

Extract 56

Xenia (HSP9 public): Despite the explanation the patient would say but she doesn't understand at all, she doesn't know why this [feticide and LTOP] must be done. And then afterwards I will just make sure that genetics [clinical geneticists] were there and I ask if someone has explained it to her [pregnant person] and they [the sisters] will say, "Numerous times". But it could be that they [pregnant people] lack understanding, or once again it could be denial that: "I don't want to hear this". So it can be both. But yes. They [pregnant people] don't always understand. I will often ask them why they are going for the procedure then they will say: "I don't know". Then I say: "But it is your body! You have the right to ask!" So I also don't know if perhaps the information is conveyed to them on a too high level (.) or perhaps it's from the doctor you know [women feel like]: "I can't ask questions".

Xenia (clinical psychologist in public healthcare) dismissed denial as a reason for the confusion. Instead, she linked denial to women's inability to interact with providers in an agentic manner so that the "high level" information becomes understandable. The contrast between other providers' perspectives of the cause of this confusion ("I ask if someone has explained it to her and they [the nursing sisters] will say "numerous times") and Xenia's perspective is significant, particularly as Xenia is a clinical psychologist, so somewhat external to the medical system. She is, therefore, able to construct the responsible health service providers as either explaining "on a too high level" or as being insufficiently approachable.

Within the public healthcare system in South Africa communication between providers and patients is challenging due to our country having 11 national languages and bearing in mind

that only 16.6 per cent of South Africans are able to speak English (the lingua franca in the country) proficiently (Galal, 2022, June 15). It is consequently very likely that many public healthcare patients may be seen by a provider who is unable to converse with them in their first or even second language of preference. Aside from language barriers, there are also barriers to understanding technical medical information if it is conveyed without making the terms and concepts understandable to non-medically trained people. Only 59 per cent of 25- to 64-year-olds in South Africa have attained a high school qualification (OECD, 2019) which indicates that at a substantial proportion of the patients attending healthcare services in this country may encounter difficulty in understanding complex biological and genetic information. Indeed, I, with all my advantages educationally, at times struggled to follow the explanations provided to me by the “experts”.

When I asked Zelda (obstetrician-gynaecologist in public healthcare) how she explains the feticide procedure to her patients, she indicated that she used euphemisms in describing the process:

Extract 57

Zelda (HSP2 public): I think I use the word ‘stillborn’. “It will be a stillborn.” So (.) I don’t know if I ever use the words: “We are going to kill the baby” type of thing (.) or if I just say: “I’m going to give you an injection so that the baby can be stillborn”. I think that is usually my go-to sentence. So that is maybe some tiptoeing around the (.) the harshness of it. And maybe it takes some of that responsibility away (.) [the woman can say that] the baby died during birth. Instead of [pause] what it really is. I don’t think I ever really use the word “feticide” with the patient. But in medical

circles that is the word we use. But when I talk to a patient (.) I speak of, “We will give you an injection so that the baby can be stillborn”.

The above excerpt emerged as extremely significant in contextualising some of the women’s experiences of the feticide and delivery. Four of the 12 women who participated in this research presented accounts of their experiences that indicated that they had not been aware that the injection administered would directly cause fetal demise. Zelda’s statement provided a potential explanation for the lack of “understanding” Xenia (clinical psychologist in public healthcare) encountered among women undergoing feticide and LTOP procedures. Zelda confessed that her explanation of the feticide procedure included “some tiptoeing” and that this allowed women to feel less of the “responsibility” for causing fetal demise, as they would be under the impression that the “baby died during birth”. Zelda re-stories the feticide and LTOP as a stillbirth or pregnancy loss, and constructs doing so as being in the best interests of the woman undergoing these procedures. This benevolent undermining of the woman’s right to fully informed consent constitutes not only a breach of standard medical practice, but also serves to erode the woman’s ability to make agentic decisions. Upon reflecting on this interview with Zelda, I wondered if her “tip-toeing” around describing the feticide procedure may have been less to protect the women, and perhaps more to buffer herself against her own discomfort with the procedure, as it was evident that she found the feticide procedure itself quite emotionally distressing. I also doubt whether she would use these same euphemisms in a private healthcare setting, where the risk of litigation is much greater due to the private healthcare population being positioned to have high expectations of ethical and professional behaviour, whereas public healthcare patients are used to accepting whatever care they receive due to their lack of financial resources.

7. Constraints on Decision-Making

Before women are presented with the option to terminate late in their pregnancy, the possibility is passed through layers of legal, ethical, medical, institutional and personal filters. The choice is introduced within time limitations imposed by medical, structural and ethical parameters and the wisdom of the decision is adjudicated by providers based on their own ideologies and their perceptions of the systemic and medical implications of the decision.

Providers spoke about the legal limits to women's access to feticide and LTOP as well as ethical and professional guidelines relevant to feticide, while the multi-disciplinary team surfaced as an essential body in interpreting legislation and ethical guidelines. These may have constrained the individual woman's, as well as providers' decision-making but also provided a perceived moral safety net for individual providers.

7.1 Law/Constitution

Unsurprisingly, the legislation governing LTOP emerged frequently in provider interview transcripts. The CTOP Act, in particular, provided the legal parameters around the decision-making process: from 13 to 20 weeks gestation, a medical practitioner must recommend the procedure; above 20 weeks, a medical practitioner in consultation with another medical practitioner or a registered midwife must authorise the procedure.

Extract 58

Peter (HSP3 private): Here let me show you the guidelines: you see the law could be interpreted very liberally so that termination could take place any time right before birth (.) but the spirit in which it was written is to protect the interests of the child and

with our Constitution it cannot be the intention of the law [to allow termination right up to before birth]. Now they say inherently it always goes in favour of life. You know and so the arguments must be very substantial to go against this.

Extract 59

Annie (HSP1 public): But we shouldn't choose for people that's the thing. I think what you might hear [during the interviews with providers] is the different healthcare professionals and different people and their beliefs. By law you can't really do that [have a guideline that determines up to what gestational stage you will offer termination for which conditions] because it's such an iffy [vague] law in South Africa so actually doctors are not wrong in performing feticides [irrespective of condition or gestation] because according to law (.) and remember also I think if this baby is going to affect your life or put your life in danger (.) a doctor can still (.) with a second opinion decide to do a feticide for a normal baby. So the law is written in such a way that it's open to interpretation.

The fact that there is no limit placed on LTOP within the law is referred to by Peter in the excerpt above. However, he adds that "the spirit in which it was written is to protect the interests of the child", which is clearly his interpretation and not evident from the manner in which the law is worded. Peter's construction of fetal life as equally valid as the life of the pregnant person possibly emerges from his position as a male fetal specialist in private healthcare. In contrast to Peter's positioning, Annie, a female genetic counsellor who worked in public healthcare, addressed the impact of providers' interpretations of the law on service provision and noted that, in fact, compiling guidelines to interpret the law, may serve to misrepresent it ("by law you can't really do that [have a guideline that determines up to what

gestational stage you will offer termination for which conditions] because it's such an iffy law"). Both provider gender and field of specialisation appear to impact upon their constructions of reproductive rights and how the laws associated with these are interpreted. For example, Annie, as a genetic counsellor, is trained to view her patients systemically and to interact with the pregnant person on an emotive as well as medical level of communication. In the excerpt above, Annie described her more holistic approach to the decision to offer feticide or not. She includes "personality", "relationship", and the effect on "your life" along with mental, physical and emotional aspects as being central to determining the "validity" of the termination request. Fetal specialists, on the other hand, are highly specialised doctors who interact with their patients from a constructed (even if not self-imposed) power and authority discrepancy.

7.2 Hospital Panels, Teams and Guidelines

Amy (a fetal-maternal specialist who performs feticides in private healthcare) referred to "a panel" that looked at decisions "from all angles" in the excerpt below. Indeed, in order to provide some structure and perceived formality, certain hospitals have established medical ethics committees to guide providers in when to make the option of LTOP available to women. Only a handful of hospitals in South Africa have a functioning medical ethics committee. However, providers in different hospitals reported referring to these committees' decisions and policies in guiding their own decision-making. The official purpose of such committees is to provide ethical guidelines for decision-making in order to uphold patient rights (KwaZulu-Natal Department of Health, n.d.).

Extract 60

Amy (HSP5 private): I think sometimes in our setting (.) always in our setting [fetal-maternal care in private healthcare] (.) the feticide decision is often made with a panel so one feels part of that and one feels that the decision is being looked at from all angles and that the weight of the decision is sometimes not so heavy. I feel very strongly that the parental (.) that the mother has rights over that fetus ethically and I so I feel that as long as we feel that ethically we can offer that feticide (.) if she consents then that is her right to consent.

Although these panels are established in order to uphold patient rights, Amy (fetal-maternal specialist in private healthcare) noted that they serve to ease the burden of the decision for the providers, making it “not so heavy”. It would appear that these committees serve to impose providers’ ethical concerns in order to adjust or interpret the CTOP Act “we feel that ethically we can offer that feticide”. Despite Amy stating that “the mother has rights over that fetus ethically” and “that is her right to consent”, this is not what happens in practice, due to the influence of multiple layers of decision-making such as those created by hospital panels. It is interesting to note how Amy constructs the woman’s *right to choose* as her “right to consent”. The latter implies a decision or position having been taken on behalf of the woman to which she then agrees, rather than a woman being allowed to exercise choice between options.

Some of these hospital committees mentioned above have drafted and established working policy documents which determine what conditions qualify for feticide and LTOP at which gestational stages. Amy suggested that the panel in her institution made the medical practitioner’s decision “not so heavy”. Indeed, many providers referred to such committees

and policies as creating a sense of diffused responsibility and reduced legislative and ethical risk in their decision to provide women with the choice to end the pregnancy. This may be due to individual liability (both legal and moral) being perceived to be reduced by the panel and guideline's influence. In the excerpt below, Amy referred to the fetal medical team relying on the medical ethics committee's guidelines in their decision-making process and how this was "supportive" toward the healthcare providers.

Extract 61

Amy (HSP5 private): I think for us (.) our fetal medicine team (.) bearing in mind I'm in private [working in the private healthcare sector], but I have access to them [public hospital guidelines and team] is quite supportive in that sense. I mean you know there are very clear indication guidelines about what we can do.

These legislative and institutional regulations provided variable levels of support or autonomy in the woman's decision-making process. Peter (fetal specialist in private healthcare) referred in an extract above to "the interests of the child", and the Constitution going "in favour of life", suggesting little room for women to make agentic decisions regarding LTOP. Arguments must, according to Peter, be "very substantial" to allow a LTOP. Amy (fetal-maternal specialist in private healthcare), on the other hand, drew on "rights" to indicate, somewhat tentatively, that the woman had "her right to consent" – but only once the panel had made a decision (based on medical ethics or guidelines).

In contrast, Tina (fetal-maternal specialist in public and private healthcare settings) presented a pro-choice perspective on the impending impact that such committees and guidelines may have on providers' application of the legislation relevant to abortion, stating that "I am quite

radical but I feel like the woman should always be able to decide to terminate, irrespective of the condition”.

Extract 62

Tina (HSP4 public and private): I think what is helpful is to have a team involved with the treatment of the patient. So it is not just one doctor making the decision and performing the procedure. But I must say that I am very much more liberal than I think most of my colleagues because I am not religious at all (.) and I really don't have a problem doing feticides. In fact I think I am more towards the side of preferring feticides above mothers having to go through the whole pregnancy, delivery and potentially weeks or months or years of suffering and for what? I suppose I am quite radical but I feel like the woman should always be able to decide to terminate, irrespective of the condition – whether it be Down's Syndrome etc. But we do follow guidelines compiled by a team at the hospital and that is what we need to abide by. However, personally I would have no problem performing a feticide whenever the woman decides she cannot raise that particular child.

The impact of guidelines and policies created by medical ethics teams on providers' interpretation of the CTOP Act is described by Tina, in the excerpt above, where she indicated that these guidelines, in fact, served to limit her agency in providing feticide and LTOP services. It is clear that Tina adheres to these guidelines against her personal and professional preferences in certain instances. In this excerpt, Tina suggested that the medical panels are not only influenced by medical expertise, but also by the panel members' religious and political leanings. She labelled herself as “liberal” and later “radical”, which suggested that her colleagues were perhaps conservative, or at least more so than she was, and she

described herself as “not religious at all”. Significantly, Tina expanded that these religious and political orientations translated into her giving much more weight to the woman’s choice (“should always be able to”) than perhaps her colleagues do.

Other than panels, the multi-disciplinary team referred to by Connie (clinical geneticist in public healthcare) in the excerpt below surfaced frequently as a source of moral and perceived legal support in providers’ decision-making process when debating whether or not to offer LTOP and feticide to their patient. In the excerpt below, it is interesting to note that Connie referred to “specific third trimester criteria”, which are, in fact, not based on legislation, but rather on a policy document compiled by one academic hospital’s ethics committee, which relied upon various inputs rather than legislation.

Extract 63

Connie (HSP10 public): We try to make a team decision about [each patient] (.) so it’s supposed to be at least two relatively senior medical practitioners in our setup [at a tertiary public hospital] the person running the [ward], the gynaecologist running the high-risk antenatal clinic along with the geneticist (.) but as many people as possible in the team. But usually in our setting it’s the obstetrician and geneticist. And then we discuss the option of a termination of pregnancy with her [pregnant person] because according to law women are allowed to get the option of a third trimester termination of pregnancy under specific third trimester criteria. So then we are actually obliged to offer her the option.

Connie’s reference to the high level of medical practitioner involved (senior; gynaecologist; geneticist; obstetrician) weighed heavily against the “option” that women are allowed. At the

end of the extract, Connie fumbled, eventually indicating that the high-level medical practitioners are “obliged to offer her the option”. Thus, the executed purpose of panels, guidelines, and teams appears to focus a great deal on creating ethical and moral interpretations of legislation in order to influence how and when LTOP is offered, and, it could be argued, to oppose liberal interpretation of abortion legislation.

7.3 Personal Positions

The above legal, ethical, medical and systemic parameters are influenced by the providers’ personal viewpoints and, in particular, their perspectives on abortion. Certain providers positioned themselves as pro-choice, while one positioned herself as anti-choice, and the majority of providers found themselves somewhat conflicted with regard to their personal stance on feticide and LTOP.

Only two of the providers who participated in this research spoke in ways that aligned with a pro-choice viewpoint with regard to abortion.

Extract 64

Tina (HSP4 public and private): However, personally I would have no problem performing a feticide whenever the woman decides she cannot raise that particular child. Why do we not listen to the mother who is telling us that she cannot see herself being able to raise this child?

Extract 65

Mathuli (HSP13 public): And everyone [other obstetrician-gynaecologists in her department] was like: “I’m not going to do it [learn the feticide procedure].” Initially I was also you know [hesitant about terminating a] 38-week pregnancy. But then you start to see the spectrum of abnormality and even just on textbook knowledge you sort of start to understand that this mom (.) even if she’s not from poor socio-economic circumstances (.) say me or you (.) if I had (.) nobody gave me an option (.) I had to have this baby with the severe disability and knowingly go through with it [give birth]. When I know myself not to be psychologically, emotionally, physically able to care for such a person. Why would we?

In describing her personal ideology toward feticide and LTOP, Tina (fetal-maternal specialist in private and public healthcare) noted that she would have “no problem” performing these procedures based solely upon the woman’s choice and questions why providers disregard women’s decisions (“why do we not listen”). Mathuli (obstetrician-gynaecologist who performed feticides in public healthcare) explained her progression from hesitance in providing feticide and LTOP to women very late in their pregnancies to coming to the realisation that she would feel unable to raise a severely disabled fetus herself, despite her relatively advantaged position (highly educated, high income, employed, physically healthy) in comparison to that of most of her patients. This changed her perspective and she remarked, “why would we?” with regard to forcing women to continue with these pregnancies. Her use of empathy, which entails being able to contextualise someone in their life and imagine how they experience this, enabled her to move beyond her own established viewpoints (hesitance to perform feticides) to re-evaluate and adjust them accordingly.

The majority of providers who participated in this research presented their involvement with feticide and LTOP as conflicted. On the one hand, they did not explicitly align themselves with abortion as a woman's choice; on the other hand, they regarded feticide and LTOP as the lesser of two evils (better than a disabled/suffering baby being born).

Extract 66

Peter (HSP3 private): You know if you think about, if you do not do it [the feticide], it is a little one with suffering for his entire time on earth. I think that helps [in justifying performing the feticide]

Extract 67

Ziva (HSP7 public): I'm always trying to bargain with my mind trying to find the rightness or the wrongness of the whole situation [feticide] and it usually actually takes a long time to actually find a place where I'm comfortable [with performing the feticide procedure]

Extract 68

Zelda (HSP2 public): But you really get some of those people that you can see right up to the old end they are not really comfortable with the choice [to terminate]. And then either they have some family pressure and it is very difficult for me to do it for them. Just now (.) a month or two months ago (.) I had a girl who said to me in tears: "No it's right we must continue with the feticide" but it doesn't necessarily make your heart [it is upsetting] (.) so I also sat and sobbed while I did the feticide because she is sobbing. So you know it's not really what she actually would prefer.

The above excerpts presented positions that were expressed by the majority of providers who participated in this research – either justifying their involvement in feticide and LTOP by focusing on alleviating fetal “suffering”, as Peter (fetal specialist in private healthcare) stated, or continuing to feel conflicted and morally discordant with regard to the procedures, as Ziva (obstetrician-gynaecologist in public healthcare) noted (“trying to find the rightness or the wrongness of the whole situation”).

A prominent theme that emerged with regard to providers’ personal viewpoints is that the feticide and LTOP procedures elicited sadness and emotional distress from them for various reasons. Zelda described the conditions under which she experienced distress at performing the procedure as being when the woman herself was conflicted and distressed (“so I also sat and sobbed while I did the feticide because she is sobbing”). Zelda refers here to what is known as abortion coercion, where family members or partners put pressure on a woman to terminate a pregnancy. Instead of unravelling whether the woman truly chose the LTOP and feticide, or merely buckled to pressure, Zelda proceeds with the procedure and shares in the woman’s distress. For the most part, the absence of reference to the woman’s agency and respecting her decision, irrespective of providers’ personal viewpoints, was striking.

Only one of the providers interviewed identified as being anti-choice with regard to all types of abortion. She was a nursing sister who provided care to women who had undergone feticide and LTOP procedures in private healthcare.

Extract 69

Maggie (HSP12 private): We had to work at the TOP clinic which is under 12 weeks’ terminations. That was for me (.) ((women requesting TOP)) “I just don’t want the

baby”(.) I am completely anti-that [TOP on request] because you know what? (.) You must look after yourself. In the first place why did you get pregnant in the first place if you don’t want the baby? But that type of termination is a different matter. That is difficult. That doesn’t work for me. Just don’t make this available.

Maggie explicitly positioned herself as being anti-choice (“I am completely anti-that”), although she provided care to women, following their feticide and LTOP procedures, in the maternity ward in which she worked. While Maggie did not extend her anti-choice sentiment to those facing LTOP and feticide, it is possible that her care for these women would be tainted by this anti-choice ideology. Her suggestion of individual culpability (just don’t get pregnant) fails to contextualise women’s lived experiences. This could be generalised to, for example, women in their older reproductive years who undergo an LTOP – “why did you get pregnant in the first place?”

8. Aspects that Impact on Time as a Limitation in the Decision-Making Process

The structural and systemic parameters to the decision-making process health service providers identified included barriers to accessing antenatal healthcare, which included early sonography and genetic testing. The process of antenatal fetal diagnostics tended to take a few weeks for results to be available, which increased the importance of ensuring that screening was conducted as early as gestationally possible in order to allow for the option of earlier termination of pregnancy. These barriers and their effects and implications on women’s experiences of feticide and LTOP, as constructed by providers, are presented below and most relate to conditions and experiences within the public healthcare sector in South Africa.

8.1 Antenatal Care and Sonography: Structural and Personal Limitations

Connie (clinical geneticist in public healthcare) acknowledged that women in the public healthcare sector are prevented from accessing adequate and timeous antenatal care, and she positions these systemic failings as acting paradoxically to create space for greater flexibility in providing women with the option to terminate late in pregnancy.

Extract 70

Connie (HSP10 public): It's the minority of women that actually do get a sonar sometime in their pregnancy [in public healthcare]. If all women had access to anatomy sonars then the major congenital abnormalities will be picked up late in the second trimester. There are various things that influence the poor antenatal services but one of them is obviously long queues and the people get shown away so the moms have to come multiple times just to book their pregnancy [inaudible] and then by their third child they don't feel the need to go again early and stand in rows so many times. Then they book late because of the system not because they (.) it's something that they would have done in any case. Then the access to sonars is not good and then they, when problems are picked up some of them only get a date at the high-risk clinic maybe a few weeks later. And then the window of opportunity for second trimester terminations is also kind of closed. Then it's too late in the pregnancy so they are already in their third trimester because of delayed referrals in the first place.

In the excerpt above, Connie described what might happen in the public healthcare sector for pregnant women and she defended women who did not attend antenatal services due to

systemic failure (“so then they book late because of the system”). The perspective presented in this excerpt depicted the reality of women trying to access antenatal services in the public healthcare system, which entails long waiting times and delays in appointments for further diagnostic interventions. Being shown away at clinics and hospitals also presented as an additional systemic barrier that prevents women from accessing adequate antenatal healthcare. Consequently, severe fetal abnormalities are diagnosed very late in pregnancy, through no behavioural failings on behalf of the women.

In the excerpt below, Hugh (clinical geneticist in public healthcare) referred to systemic failures within the public healthcare sector in clinics and hospitals. However, he related these to women being blasé about their pregnancy and, in a sense, inferred their culpability in creating the situation where feticide is required. Hugh presents an assumption that some women are unperturbed by being pregnant and somewhat irresponsible in their accessing of antenatal healthcare.

Extract 71

Hugh (HSP8 public): Feticide is difficult for me. The big problem [that] comes in in the state sector particularly is that a lot of the patients present late (.) whether it’s a failure of primary healthcare or whether it’s just this mom who comes in: “I’m pregnant, I’ve had five children, I know what it’s about. I just need to book in time so that I can deliver in hospital”. Then at 30 weeks they do a sonar and then they find something major that could have been identified earlier and then there’s a sort of a rush and an expectation of a feticide.

In the excerpt above, Hugh presents two scenarios – primary healthcare failure and a cavalier attitude on the part of the women. He continues to construct these women as feeling almost entitled to feticide and LTOP, which is an interesting construction given that feticide is, in fact, a largely unknown procedure, particularly among public healthcare users.

8.2 *Lengthy Diagnostic Tests*

The practical reality of screening and diagnostic tests frequently taking significant time emerged as an important discussion point in terms of the time delay experienced by public healthcare users in particular. For example, Mathuli (obstetrician-gynaecologist who performed feticides in public healthcare) described this clearly:

Extract 72

Mathuli (HSP13 public): Sometimes the karyotyping [detecting chromosomal abnormalities] will take four weeks to have a definitive answer. So it's usually quite a lengthy process and that involves quite a lot of surrounding structures [liaising with national laboratory services etc.].

Extract 73

Mathuli (HSP13 public): So it's really something that takes quite a while [genetic testing] and you must just always create backing for yourself. Sometimes say for instance with a skeletal dysplasia, Dr X and Dr Y will ask for x-rays to be made for the final decision.

Mathuli went on to construct the genetic testing as both time-consuming and important (“create backing for yourself”) in justifying a recommendation that LTOP and feticide be offered to the woman. These tests and procedures caused time delays in offering the option to terminate the pregnancy, which results in time pressure due to the fetus then being regarded as “viable”.

8.3 *Decision-Making Time Constraints*

The public healthcare system seemed to compensate for delayed antenatal access and diagnosis by being flexible with regard to when (gestationally) the procedure could be conducted. This extended to allowing women a longer time in which to make the decision.

Extract 74

Mathuli (HSP13 public): But they are undecided sometimes [women] sometimes they take four weeks [to decide] and then they are 39 weeks [gestation] and they want to come back and say: “No, I want to do it”. But we will usually try and wait for them and try and accommodate them.

Extract 75

Maggie (HSP12 private): And you have to decide: “I must terminate today (.) tomorrow (.) the day after tomorrow. Or am I going to go the whole way?” So you have a day or two (.) maybe a week (.) to prepare yourself. It’s nothing. Because it stays with you for the rest of your life.

Mathuli (obstetrician-gynaecologist in public healthcare) referred to the length of time women sometimes need to make a genuinely autonomous decision, indicating that in the public system, “we will usually try and wait for them and try and accommodate them”. In this excerpt, and indeed in the interviews with women presented in the next chapter, it emerged that LTOP and feticide took place up until the very end of pregnancy due to partly to systemic failures and partly to accommodating women’s need for time to decide. This is not the same in the private sector. The emphasis placed on gestational limits within the private healthcare system was referenced by Maggie, who was employed within the private healthcare system as a nurse: “you have a day or two, maybe a week, to prepare yourself. It’s nothing.” The interaction between time-pressured decision-making and agency was evident. The public healthcare system attempted to compensate for systemic failures (and possibly avoid legal action) by allowing much greater flexibility with regard to gestational timing of the feticide and LTOP procedures. This flexibility extends then to decision-making time. In contrast, the private healthcare system appears to adhere to gestational limits as outlined in various clinic guidelines (referred to above). This introduced considerable time sensitivity pressure – to get it done quickly – on providers and on women making decisions related to these procedures.

9. The “Wisdom” of the Choice

Providers perceived women’s decision-making about feticide or LTOP procedures as “wise” or “foolish” depending on their personal ideologies, the systemic implications, as well as medical implications, that the decision may have. Providers’ perspectives in relation to motherhood, disability, systemic burden, physical risk, the woman’s age and her perceived beliefs underpinned their assessments of the choice. The most prominent theme to emerge

from providers' interviews was that the decision to terminate as wise, based on the elimination of the potential physical and systemic risk the pregnancy and severely disabled child would pose to the woman, her family system, the community and the healthcare system.

9.1 Provider Personal Positions

Providers' framing of a "wise" choice rested on a range of personal position. Firstly, when providers constructed the woman's decision not to terminate her pregnancy as "wise" and "commendable", this was connected to the providers' stated disapproval of abortion and LTOP. This was the case with Maggie (a nursing sister in a private hospital), who positioned herself as anti-choice (pro-life) throughout the interview ("in the first place it [the LTOP and feticide] is not nice for me"). The underlying perception presented in the excerpt below was that "good mothers choose not to terminate", while women who do decide on LTOP tend to experience worse emotional outcomes than those who do not terminate.

Extract 76

Maggie (HSP12 private): The one woman (.) it was quite severe [fetal] abnormalities. And she (.) there were two actually (.) that I know about. The prognosis was very very bad. But they decided to (.) they cannot terminate. That's not who they are. That's not what they are. So those people really had (.) she had nine months to build on. And get strong. And when the child was born (.) every absolute second they could have had with this child (.) they had. And they used it. And they handled it well and spent every moment with the child. Whereas the mummies who [decide to terminate] they are more unstable. Definitely.

In the excerpt above, Maggie positioned women who chose to terminate in contrast to women who continued with the pregnancy. In this way, the decision somehow inferred certain perceived character traits or moral indicators. The suggestion was that women who did not terminate, in effect, choose to spend time with their baby once born, whereas women who terminated reject this time and essentially wasted the opportunity to spend time with the baby. It is essential to contextualise Maggie's constructions related to "good mothering" – she works with private healthcare patients who mostly can afford the additional burdens placed on their functioning and resources in deciding to continue with the pregnancy and spend their time with the severely abnormal fetus until it would demise. The implications for the majority of women in South Africa would be dire, as they would be potentially unable to work, care for their existing dependents, maintain their household or afford to spend weeks or months with their baby while it receives palliative care in hospital. What Maggie presents is a viewpoint that reinforces stereotypes related to "good mothering" (self-sacrificing, motherhood at all costs) and which ignores structural inequality and the significant impact this has on women's decision-making. This gendered, conservative, patriarchal viewpoint condemns women who decide to terminate their pregnancy without any contextualisation of their actual choices available (none) or their lived experiences outside the privilege of middle-class South Africa.

Maggie's premises for punting the "wise" decision as being the one where the pregnancy is not terminated, was also based on the notion of women taking responsibility for 'poor behaviour'.

Extract 77

Maggie (HSP12 private): I am going to refer to one woman in particular who (.) the baby had Down's Syndrome and they decided due to financial reasons to terminate. Even though she smokes! That was not nice for me. In the first place it [the LTOP and feticide] is not nice for me. But that one specifically was hard for me because you can spend money on cigarettes but you can't look after your Down's Syndrome child?

When women decided to terminate, they became susceptible to critical evaluation of their lifestyle choices on behalf of all of those around them, including providers. In the excerpt above, Maggie presented her condemnation of the woman whom she constructed as having chosen to smoke above having a child with trisomy 21. This construction tackles women's (and families') lifestyles, employments and budgets in essentially prioritising mothering, and glosses the costs – both emotional and financial – this would place on a mother of a special needs child (and the family or household arrangements).

Secondly, what constitutes a human life and when it is worth living were areas of uncertainty and debate that came up in the interviews. Depending on the diagnosis, providers regarded the decision to terminate as progressively wiser as outcomes and fetal prognosis worsened. For example, Amy (fetal-maternal specialist in private healthcare) explained her perspectives on disability and the right to life in the excerpt below and positioned herself as regarding those with severe disabilities as negating a right to life:

Extract 78

Amy (HSP5 private): So you could argue that a child with severe disabilities has the right to a life of some sort. I get that, okay? I don't have that opinion. So I do feel that severe disabilities and fetuses that perhaps wouldn't survive (.) we can make those decisions [to terminate] ethically.

This construction suggests there might be a “continuum” for “wise choices” rather than a simple either/or; and deciding on the degree of disability should incorporate considerations of diversity that widen the bandwidth of ‘normality’ for children’s development and for the quality of a life.

Thirdly, the age of the pregnant woman was evaluated in providers’ constructions of “wise choices” made, and resources of maternal and life experience they drew on. Providers constructed young pregnant people as unable to make wise decisions due to a lack of experience and maturity, and that they lacked resources to make the pregnancy or mothering supportable. When young women decided not to terminate during this phase of the process, their decision was regarded as an “unwise choice” made due to their youth. Older women were regarded as being able to make better decisions as they were constructed as being more likely to opt for feticide and LTOP. For example, Zelda (obstetrician-gynaecologist in a public hospital) sees this age-experience dimension in this way:

Extract 79

Zelda (HSP2 public): I think it also depends a lot on the patient’s level of maturity. A 17-year-old with an abnormal baby and a 37-year-old with an abnormal baby are two completely different things. The 37-year-old definitely copes better I think because

she understands life better. The 17-year-old sees it [the baby] as a doll that is born and she's excited about the baby. But understand (.) it's not a baby. It's not a child that you are going to raise. It's not a child that you are going to dress nicely and that will play and that will become a little human.

In the above excerpt, Zelda constructed young women as having unrealistic expectations due to their lack of parenting experience, which is the reason they were perceived as being less likely to decide to terminate.

Similarly, and fourthly, some women who decided not to terminate were perceived as failing to protect their fetus from suffering after delivery and doing so due to so-called unjustifiable reasons related to religious beliefs or spiritual values. For example, Amy (fetal-maternal specialist in private healthcare) picks out “dogmatic religious reasons” as the basis for pregnant women's foolish choices in the excerpt below:

Extract 80

Amy (HSP5 private): Sometimes I am frustrated by patients who do not choose the feticide because I feel that the fetuses, the baby, and child, will have a very, very, very poor quality of life. But because of some dogmatic religious reason or some feeling that they cannot make work for them, they decline it.

Extract 81

Amy (HSP5 private): Coming to my office wanting a termination [when women do this] I have a problem. In my own spiritual life (.) I have a problem with that. But with feticide I don't feel that same distress.

Women's religious or spiritual beliefs tended to be constructed as foolish reasons by providers to continue with the pregnancy when severe fetal abnormalities had been detected. However, some providers cited their own spiritual or religious beliefs as being significant factors in their decision to provide feticide and LTOP procedures. For example, Amy used her spiritual beliefs to justify her anti-choice orientation with regard to abortion, but also in justifying her approval of feticide and LTOP. The social constructionist stance is useful in understanding that Amy's spiritual beliefs are important and valid to her and that these beliefs justify her comfort with the feticide procedure and her discomfort with elective TOP. I struggled with the lack of coherence between her reliance on her own spiritual views to guide her values and behaviour, while she felt frustrated by women who do the same during the feticide/LTOP decision-making process. However, according to the social constructionist perspective, multiple perspectives and viewpoints can exist at the same time and be utilised to make meaning of different issues in various ways. No one perspective is absolute.

Finally, fifthly, providers questioned the wisdom of women's choices to terminate pregnancies with fetal abnormalities (or not) based on the degree of autonomy and agency they displayed in the decision-making process. For example, Zelda (obstetrician-gynaecologist in public healthcare) saw women's decision-making in this way:

Extract 82

Zelda (HSP2 public): I think most of the time it is just family pressures too. I think it is very seldom that they [women] decide on their own. I don't necessarily know what their own decision would have been had it not been for the family influence. But there is definitely family influence.

In these circumstances, providers construct women as making foolish decisions based not on their *own* choices, but on the wishes of those around them due to their lack of agency and autonomy. Here Zelda constructed women as lacking agency in the decision-making process, and being unduly influenced by their partner and family around them. This, of course, negates that women would return to domestic and relational life within this family context following the decision (whether to terminate or not). Without financial support of her own, she may base the decision on ensuring her future security and harmonious relations within this household.

9.2 *Medical Implications*

When the decision to terminate was constructed as the wise choice by providers, it was very often strongly influenced by the health and reproductive repercussions of continuing with an “abnormal” pregnancy. These risks included those related to the woman’s medical condition (“you kind of have to counsel the mom to deliver for her own health”) as stated by Connie (clinical geneticist in public healthcare) in the excerpt below.

Extract 83

Connie (HSP10 public): If there’s a severe case of hydrocephalus (.) and continuing with the pregnancy - the baby’s head circumference will enlarge gradually in some conditions. So then that might result in an obstructive labour. Then it puts the mom at risk to have to deliver by caesarean section and that has implications for her future reproductive career. And it’s a major surgery so that also has its own risks. Certain cases of hydrops fetalis [can also occur] where the mom also gets sick. They call it

Mirror Syndrome. The baby has a lot of oedema and a lot of amniotic fluid and then the mom mirrors that by developing hypertension and oedema. She can [also] develop mora-oedema so she can develop respiratory distress and that can actually be very dangerous for the mom. In that case you kind of have to counsel the mom to deliver for her own health. That's also another angle. Not necessarily for the baby's health but for the mom's health. And that can actually be very dangerous for the mom [were she not to terminate].

Extract 84

Mathuli (HSP13 public): Say a lady has had two previous caesarean sections. If we are going to have to deliver by caesarean section for the third time, per definition she should get a sterilisation with her third caesarean.

In Connie's statement, it is the woman's health that is at stake, rather than that of the fetus. Connie positioned surgical delivery as an undesirable outcome due to the limitations it placed on the woman's future reproductive ability, as well as due to the risks associated with major surgery. These concerns emerged throughout interviews with providers, particularly with specialist gynaecologists, and accounted for their insistence on inducing labour prior to any surgical intervention ("to deliver by caesarean section and that has implications for her future reproductive career"). Connie's description of women's reproductive health as their "reproductive career" bears some unpacking as it implies that child-bearing is central to women's lives, reducing women's capacities and subjectivity to biology. Women who are unable to reproduce are constructed as damaged or unhealthy when reproduction is placed as central to their worth or purpose.

Mathuli (obstetrician-gynaecologist in public healthcare) explained that it is standard procedure to sterilise women following their third caesarean section (“per definition she should get a sterilisation”). The use of the terms “standard” and “per definition” imply that sterilisation in these circumstances is the sensible, logical next step, negating any negotiation or space for hearing the woman’s voice.

9.3 Systemic Implications

The choice of continuing a pregnancy and giving birth to a child with severe disabilities was seen by providers as placing a burden on two major system: the healthcare system and the family system.

Extract 85

Mathuli (HSP13 public): The unfortunate part of that is that sometimes it’s a little bit of a burden on the healthcare system then to have that baby there for almost 30 days and having had multiple procedures to try and make it [the baby] better.

Extract 86

Zelda (HSP2 public): It’s not just the children themselves. It’s the parents and then I think almost to a greater extent the community that has to live with it [disabled child]. Siblings are neglected because there is another child who actually needs more attention and grandmothers who get dumped with this child. Marriages that eventually [break down] (.) you know people eventually resent one another. And then you end up with this mom who ends up without a job because she has to care for the child (.) so she can’t go to work (.) so she has no income and an abnormal child.

The impact of a severely abnormal fetus on an already overburdened and struggling public healthcare system in South Africa was addressed by Mathuli (obstetrician-gynaecologist in public healthcare). Her role as a public healthcare service provider involved triage decision-making, effectively deciding who received treatment, who had a chance to live, and who would die. Within this logic, termination where there is fetal abnormality removed the financial, structural and emotional burden a severely disabled or ill baby would place on the healthcare system and its providers. Thus, feticide and LTOP presented an opportunity to solve the “*problem*” of what to do with the very disabled neonate following live birth. Using official public health terminology regarding “burden of care”, Mathuli described these babies as “a little bit of a burden on the healthcare system” in the excerpt. Zelda (obstetrician-gynaecologist in public healthcare), in contrast, constructed feticide and LTOP as, in fact, the “wise choice” due to the familial care, resources and structural burdens that a special needs child represented. It is clear that Zelda implies that the decision to TOP is a wise one, particularly where the woman making the decision lives in poverty and lacks access to the resources required to support families with a special needs child. The coerciveness underlying this construction lies in ignoring the woman’s personal choice and decisions and instead relegating her to the stereotypes associated with poor women making use of public healthcare.

Based on the content of all of the interviews with providers, and described by Peter in the excerpt above, a significant theme that emerged was one of doctors (and nurses) feeling unprepared or unable to deal with the emotional impact of the medical work they perform. This burden of care, and their lack of training in dealing with extremely emotive interactions with patients, would add to their own distress and, in turn, exacerbate provider burnout and

depression. This is a challenging section for me, as most of the people I do psychotherapy with are medical students, doctors or specialists. I have immense respect for the work they do and the circumstances under which they perform these duties and due to my subjective experiences with providers' own psychological suffering I found myself struggling with what I experienced as "being critical" of the providers who participated in my research. It is important to verbalise this and I know that my resistance to a more critical stance on the content of provider interviews was, at times, frustrating and even confusing to my supervisors (and myself). However, it remains essential to view interviews through a feminist lens in order to identify problematic aspects of patient-provider interaction as well as highlighting areas where providers are themselves abused within the healthcare system and, in particular, within the public healthcare system. Rather than a personal critique, I view my observations as a critical viewpoint on the system of reproductive healthcare and the influence these failings have on patients and providers alike.

10. Conclusion

This chapter presented the findings of women's experiences of the decision-making process related to feticide and LTOP, while providers' perspectives on these experiences added contextualisation to women's constructions. Women's experience of being informed that their fetus was severely abnormal, their making sense of the diagnosis and then endeavouring to understand what caused the abnormality, constituted the first layer to the experience of feticide and LTOP decision-making. Women constructed this decision to undergo feticide as difficult, conflicted and amounting to no choice at all. The decision-making process was nuanced by women's partners' involvement (or absence), the reactions of the providers during the decision-making process, the reactions of those around the women, as well as

women's attempts to manage the information they shared with others. Women's experience of the feticide and LTOP decision-making process is succinctly described by Melissa: "And it was difficult".

It is evident that women's experiences are directly influenced by the systems and structures in which they live, as well as providers' personal positions. Whether women receive healthcare services in public or private systems is also a factor that contributes to their experiences. Significant themes to surface during phase one of this process include providers constructing women as reacting with anger, denial, threats and relief, ascribing culpability to themselves, and lacking understanding. Women, indeed, tried to find explanations for the abnormality that include personal behavioural or biological culpability. Providers saw women as having autonomy to make a choice, or at least to consent, with regard to feticide and LTOP, whereas women often experience having no choice available to them. The decision to terminate is widely constructed by providers as "wise", while "foolish" decisions are those that create a negative outcome for the fetus, healthcare system, provider and community. During the fetal diagnosis and decision-making process, women make use of a number of strategies to protect their wellbeing on various levels, and these include using silence, partial disclosure and re-storying of events in order to maintain the resources and relationships to which they already had access. Although providers endeavour to present themselves as neutral, uninvolved, ethical and professional clinicians, their personal perspectives, emotional reactions and own discomfort with certain aspects of the decision-making process, directly affect women's capacity to make fully informed and agentic decisions. Women depicted healthcare providers as either supportive or as denigrating and coercive.

In the following chapter, the second phase of women's experiences of feticide and LTOP will be presented, where women's experiences of the feticide and LTOP procedures will be explored, along with providers' perspectives of these experiences. *Chapter 6 includes confronting and potentially triggering descriptions of medical procedures, death and intense emotional reactions and the reader should please bear this in mind prior to being exposed to this content.*

CHAPTER 6: PHASE II: THE FETICIDE AND LTOP PROCEDURES

The previous chapter presented women's experiences of the diagnosis of severe fetal abnormality, and their decision-making process in this regard. Providers' perspectives of women's experiences during the first phase of these experiences were also presented. What follows in this chapter is an explication of women's experiences of the feticide procedure as well as the late termination of pregnancy. Providers' perspectives on women's experiences are also presented, along with providers' personal experiences, where these assist in contextualising women's experiences of these procedures.

Women's Perspectives

The second phase of women's experiences, related to feticide and late termination of pregnancy, begins when the feticide procedure takes place. In this section, I explore women's experiences of the feticide procedure, as well as the subsequent termination of pregnancy, either by induction of labour and vaginal delivery or via surgical delivery. Themes that make up this phase include working on her body, dealing with the fetus/baby once delivered and her experiences of in-hospital recovery.

1. Working on Her Body

The first theme related to the second phase of women's experiences of feticide and LTOP revolves around the feticide procedure. The feticide procedure always includes an injection directly into the woman's abdomen. Depending on how the gynaecologist or fetal specialist performed the procedure, there would be sonography involved and the woman would be

consciously sedated under certain instances. Women experienced their bodies being worked on during the injection, the induction of labour for vaginal delivery and when they undergo surgical delivery of the fetus. Each of these experiences will be explored in the following sections.

1.1 Experiencing the Injection

Where women had been explicitly informed that the injection they were receiving was to terminate the fetus, the injection was a pivotal experience and constructed as exceedingly emotionally painful. Women who had been unaware that the injection into their abdomen had served to cause fetal demise will be discussed later in this chapter. Women described the feticide procedure as eliciting salient psychological and physiological experiences. Below are extracts describing the psychological impact of the injection:

Extract 87

Patricia (W2 public): When they put the injection [into her abdomen] to stop the [fetal] heart (.) it was very difficult. Because I wanted to have that baby but the situation didn't allow me to. And that night I spent knowing that I carry a dead baby (.) it was very difficult. The following day they induced labour.

Extract 88

Fay (W7 private): I went, but it is the most painful thing I've ever [experienced] it was very, very painful [inaudible] I was overcome with grief. And then he [fetal specialist] gave me a few moments.

Once again, the “difficulty” of the experience is prominent, along with the immense psychological pain and grief women described during the feticide injection. Patricia contrasts her desire for a baby with carrying a dead baby in her uterus, while Fay addresses overcoming grief directly.

The physiological experience of stillness following the injection impacted significantly upon women’s psychological constructions of the visceral experience. Pain can, of course, be experienced on both biological and psychological levels, which may interact in order to exacerbate the suffering incumbent on each. Due to the public healthcare system being severely resource-strapped, it frequently happens that women may undergo a feticide and then need to wait long, in certain cases days, before labour is induced or surgical delivery takes place. The implication on a physiological level is that their fetus would undergo significant maceration (a destructive aseptic process that appears between 12 to 24 hours after fetal demise and includes a separation of the skin from the head and trunk, giving a bubble-like appearance) prior to delivery, exacerbating the potentially traumatic nature of this experience. In private healthcare, labour is induced or surgical delivery takes place as soon as possible following feticide and the woman would only ever wait for hours or, at most, a day between the feticide and delivery if she had decided upon this (e.g., some women travelled back to her home town to deliver, but needed to travel to the fetal specialist in a major city centre for the feticide procedure). Fetal stillness was spoken about as a significant experience for women.

Extract 89

Janet (W8 private): I looked away and so on. And then they just pushed in the needle [into her abdomen] and gave the injection. And then afterwards she went quiet.

Extract 90

Lelanie (W12 public): What was bad was when they pushed me back to the room and you are so used to something turning. It feels like a butterfly, or whatever, and [then after the feticide] it's just dead quiet. There's no movement (.) nothing (.) just the stomach is there [laugh]. Oh well.

Extract 91

Emma (W9 private): So then it's this phase of just disbelief (.) then you've got a (.) the death is in you (.) which is the sensation of carrying death somehow (.) and [still] being [alive].

Embodying the sensation of stillness, quietness or death after the feticide procedure, having experienced weeks or, in some instances, months of fetal movement, was a stark shift in the women's physiological experiences. The loss was in their bodies and consequently, there was nowhere to move away from this experience for a reprieve from the loss.

What is striking is that women did not speak to providers acknowledging the magnitude of the moment. It appears that the women were required to manage their emotional reactions to this very confronting experience of constant uterine movement to absolute stillness, while still looking visibly pregnant, without any overt acknowledgement of their experiences. Instead, women are "given a moment" and wheeled out to receive the next medical intervention or management.

1.2 Constructions of the Moment of Fetal Demise

The extent to which women had been informed that the injection administered to their abdomen would result in either immediate or eventual fetal demise prior to delivery affected the manner in which women constructed their experience of the fetal demise. Women who had not been explicitly informed that a feticide had been performed experienced their fetus' demise as unexpected, while those who had been fully informed were prepared for a stillborn baby to be delivered.

During the interviews and analysis of data I noted that certain women spoke as though they had not been aware or informed that a feticide had taken place prior to delivery. It is difficult to establish if these women had not been adequately informed, or if their being "unaware" of the feticide may have been a psychological response to the trauma they experienced. Even if these women had been informed of the feticide injection and the purpose thereof, it is possible that due to various factors, including provider reluctance to overtly describe the procedure, language difficulties and the power disequilibrium inherent to patient-provider communication, that they had not fully comprehended what had been conveyed to them. This lack of preparation for fetal demise resulted in women constructing fetal death as "unexpected" in the excerpts below:

Extract 92

Jasmine (W4 public): When she came out (.) they put her in my arms. And she couldn't [see] she was blind (.) I don't know if some kind of [inaudible] or whatever made her blind. And then she went [breathes out] and that was her last breath. That

was her last breath [inaudible] and I still have that picture in my mind when I close my eyes...

Extract 93

Wilna (W11 public): When they took him out after the caesar the doctor told me when they took him out [that] he was dead (.) and it looks like he was paralysed as well.

Extract 94

Melissa (W6 public): But you hear the other babies' heartbeats and those rhythmical movements and stuff. And it's then [during labour induction in the maternity ward] I realised but I'm not feeling her anymore (.) and it is then that I became super irritated with the people around me and even with the sisters too.

In the excerpt above, Jasmine recounted her construction of her baby's moment of death as being in her arms and taking "her last breath". Jasmine noted that she still had "that picture in my mind when I close my eyes", indicating that this experience had been traumatic. Wilna recalled being informed by the doctor that her baby had been delivered "dead" and described the fetus as having been "paralysed". Melissa described her realisation that her fetus had stopped moving while in labour and her emotional response to this ("I became super irritated") as she had not been prepared for fetal demise prior to delivery. Should a lack of informed consent not be the cause of these women not accepting that their fetus had demised prior to delivery, due to the purposeful feticide injection, then this construction of the fetus as being born alive and demising just after birth, being blind or paralysed may indicate trauma responses. Melissa presents with anger at realising that her fetus had demised and projected these emotions onto the nurses around her in the ward, who had been a source of frustration

to her due to their not monitoring her fetal heartbeat (as she had not realised that her fetus was intended to demise), due to having to share a noisy ward with other mothers delivering healthy babies and due to the healthcare system not having listened to any of her requests or needs. It is noteworthy that all of these women who had not been explicitly informed of the feticide procedure were public healthcare users.

Women who had clearly been informed about the feticide procedure were able to recount their understanding of when fetal demise would take place. This prepared them for the surety of delivering a stillborn baby, as follows:

Extract 95

Mabatho (W3 public): They [obstetrician-gynaecologist] explained that they are going to take a needle and inject it through my abdomen into the child's heart. And that was going to kill the baby inside (.) and then they will give me the tablets to make me become in pains [induce labour] so that the child can come out.

Extract 96

Mpho (W5 public): They [obstetrician-gynaecologist] had to put the injector through [her abdomen] to kill the baby. They had to inject me so that I don't give birth to the baby when she's alive (.) and she [provider] warned me on how she [fetus] won't survive, so they had to inject her. They injected me and the baby died that time.

The language used by these participants is stark – “kill the baby inside”. Mabatho talks of the providers explaining, while Mpho speaks in terms of warnings and that the providers “had to inject her”. While Mabatho's rendition speaks to a slightly softer approach than in Mpho's

talk, it is clear that the direction of communication is very much provider to woman, rather than bi-directional. Women are informed about what will be done to their bodies, rather than being included in an interactive discussion where they are invited and comfortable to clarify concepts and ask questions.

Deciding on Delivery

Private healthcare patients experienced greater choice with regard to the method of delivery than those in the public healthcare system; however, this takes place within the limitations imposed by physiological concerns. There was only one public healthcare patient who had been given the choice regarding method of delivery. Concerns seem to have been related to the physiological impact of invasive surgery on women's reproductive potential (see earlier extracts), but, also, as Mathuli (obstetrician-gynaecologist in public healthcare) noted previously, the greater costs involved with surgical delivery, particularly in the resource-strapped public healthcare system and the limited theatre access available.

Extract 97

Mpho (W5 public): Okay the doctor told me I can choose either [normal delivery or caesarean section] but I decided it's not good to be seen out with a wound and they [family or community network] do not see what made you have that wound [no baby to show]. So I decided to give normal [birth].

While health and/or costs may have been the major concern for healthcare providers in deciding between the two options, this was not necessarily so for the women. While some participants opted for labour induction in order to avoid the invasive surgery and the resultant

scarring, Mpho (public healthcare patient) explained that: “it’s not good to be seen out with a wound” as family members and community members would ask questions if they see her with a wound or scar and no baby to show for it. The logical questions would be surrounding where the baby is and what happened to it; consequently avoiding such a visual, visceral mark of having terminated the pregnancy, Mpho is able to avoid disclosure regarding the feticide and LTOP. The embodiment of loss in the form of a visible scar is an aspect that a number of women who had undergone surgical delivery commented upon. They described it as triggering and upsetting.

Extract 98

Melissa (W6): I try not to look at my stomach [due to the caesarean scar]. It reminds me of it [the feticide and LTOP].

Three of the women who participated in this research underwent planned caesarean sections and two women eventually underwent caesarean sections following failed induction of labour. These women’s experiences are included in the section below.

Protecting Through Caesarean Section

If women decided upon a caesarean section, it usually took place under general anaesthetic in order to protect them from experiencing the surgery only to deliver a demised fetus.

Fay (private healthcare patient) underwent a caesarean section under full anaesthetic (“I was unconscious”) in order to spare her from consciously experiencing the surgery and stillbirth. Although providers regard full sedation during surgical delivery as buffering women from

experiencing the entire ordeal of delivering a stillborn fetus (see later discussion), there may be an aspect of disembodiment women experience due to their “absence” during the delivery.

Extract 99

Fay (W7 private): And that afternoon they, Dr X (obstetrician-gynaecologist in private healthcare) booked me in for a caesarean section, so, when they did the caesarean section (.) and I was unconscious and then I woke up. And I think a few hours later (.) and it's when I woke up (.) the first thing I asked about (.) can I see my baby? And the nurse brought the baby, and he was big.

Fay's immediate question, “Can I see my baby?” illustrates the mismatch between protecting her from delivering a stillborn baby and her desire to view the baby that she had wanted.

Conserving Through Induction

In most instances in the public healthcare system, labour was induced and allowed to proceed for lengthy periods of time even though the woman may have requested surgical intervention. This was due to providers having made the determination that vaginal delivery was preferable, based on conserving women's reproductive ability. According to providers, more than three caesarean section surgeries are not recommended due to the risks to the woman's reproductive health or capacity to reproduce (see earlier extract).

Suffering Through the Procedure

Women spoke of a great deal of suffering during the induction. This was partly related neglect or insensitivity on the part of healthcare providers, and partly to do with being faced with a dead baby. The kind of neglect referred to by the women must be seen in light of the generally poor services provided to birthing women in South Africa. What has been termed obstetric violence (physical, emotional abuse and neglect) has been paid significant attention in the last decade or so (Chadwick, 2016, 2018).

The act of labouring alone, as in Felize's experience, with no support despite "screaming" for help appears to have compounded her pain.

Extract 100

Fezile (W10 public): I think they gave me some pills [and an] injection. I went through a normal labour (.) it was so painful (.) I think more especially because I knew this was a termination (.) I wasn't giving birth to a normal baby. I think I went through that labour alone (.) because the sisters came after [delivery] because I was there in that room screaming: "Help me somebody! Help me!" (.) There was no-one there. When they came in, I had already pushed out the fetus.

In the excerpt above, Fezile (public healthcare patient) described her labour as "so painful". She related being ignored or abandoned by the nurses during her labour ("there was no-one there") even after her screaming for help. Melissa's experience below speaks to healthcare provider insensitivity.

Extract 101

Melissa (W6 public): It was a four-bed ward [where she had been admitted] then they [nurses] put heart monitors on all the others [labouring women] and then the first morning when they came to me [a nurse] wanted to put it on and the sister showed her ‘no’. I just feel if I had to go for something like that even if it is a public hospital [I would want a] separate room (.) not with others. I was admitted that afternoon [and] they did a bulb induction ((procedure where a catheter is inserted into the cervix and the ‘bulb’ is filled with saline to stimulate labour)) because they said they can’t give it chemically because they are afraid that the caesarian cuts would break [from previous deliveries]. That for me was a horrible experience (.) it was sore and the thing popped and I didn’t dilate at all. I lay there for a week before they did the hysterotomy ((incision into uterus)). I also asked them that if the uterus had not grown onto the bladder that they must do a total hysterectomy (.) not just sterilise me (.) I signed for both [but] they just tied my tubes. That was my last [request]: “Please do the hysterectomy”. But it was not done and my wound became septic.

In the excerpt above, Melissa (public healthcare patient) described her induction experience as “horrible” and “sore”. Being placed among other labouring or delivered women in the maternity ward made her feel “othered”, especially because all of the other women were fitted with fetal heart monitors, and she was not. Her need for privacy and confidentiality regarding the LTOP was not fulfilled. Her waiting for a week before any surgical intervention was introduced must have been excruciating. Melissa described her request to have her uterus removed during the caesarean section; however, this was not performed as only her “tubes” were tied. Her surgical wound would also become “septic”. The lack of psychological and even physiological care Melissa received during her LTOP is striking. Her experiences speak

to women in public healthcare being relegated to silent recipients of whatever procedures the providers decide upon, without any care given to either their physical or emotional distress. Reading between the lines, it is clear that these experiences left Melissa disappointed, angry and traumatised.

Women experienced the induction of labour in order to deliver a demised fetus as much more painful and challenging than vaginal delivery to a living baby.

Extract 102

Emma (W9 private): My goodness it was intense. I mean I had had two natural births. You know it is painful and really exhausting (.) but because there is a sort of a live product at the end of it, at least you're moving towards something. What is very odd about having to give birth to something that is not alive, is it's like an end to something (.) but it's a struggle (.) you need help (.) your mind plays against the natural course of things (.) particularly if you wanted the baby (.) if you didn't want the baby then it's easier. [crying] Because I think I was freaking out a bit [during delivery] (.) I kept on walking up and down to make things happen (.) although I didn't want it to happen. The drip was painful and all that pain! It's not, it's not nice. Your body suffers.

Emma compared her induction to her “two natural births” and noted that “because there is a sort of a live product” it is less of a “struggle”. Emma also touched on the difference it would make if the fetus had not been “wanted”, as the wantedness of the baby affected her experience of suffering during this induction (“your body suffers”; “I was freaking out”). She pointed to the painful dilemma of wanting the delivery to be over, but also not because of

what she will be confronted with (a dead baby). Emma's statement that "you need help" makes the neglect spoken about by other women that much more poignant. The lack of being listened to that some women experience in relation to reproductive healthcare is well-known, and leads to some suspicion regarding healthcare providers

Extract 103

Wilna (W11 public): They [providers] did try to get the child out naturally [but they] couldn't do it after trying three times. Then they took me for a caesar and I told her [the gynaecologist] to snip [sterilise] me. She said: "What if you meet someone else and he wants a child?" then I told her: "I am not going to have another child again because I don't want to go through this drama again." She says she snipped me (.) I hope she did (.) because if I have to get pregnant now again I will sue her.

Wilna (public healthcare system) shared enduring three attempts at inducing labour which finally ended in her undergoing a caesarean section. It is noteworthy that she distrusted the providers and healthcare system to such an extent that she seemed incredulous or doubtful that they did, in fact, sterilise her as she had requested and threatened to "sue" if the provider indeed had failed to perform the sterilisation. Wilna's anger and distrust with regard to the providers and public healthcare system permeated her interview.

Private healthcare did afford women certain concessions during the labour process. For example, Janet (below) was able to deliver on her own terms – which included not having the intrusions of constant monitoring and invasive vaginal examination by nurses, and without male doctors being present.

Extract 104

Janet (W8 private): I had an induction, but the thing is I don't like male doctors. Then I said: "I will be alone in here. You don't come into my room." And the doctor arranged that nobody comes in there (.) nurses don't come in all the time to examine me and blah blah blah...

This privacy and autonomy afforded Janet some reduction of her emotional distress and provided her with a sense of having some control over the situation, which is particularly important when women endure the labour process, which may feel completely out of their control as their bodies function beyond their conscious command. Making use of the private healthcare system allows women to choose their provider based on whatever criteria may be important to them. This is not the case with public healthcare users, who have no choice but to be seen by the relevant doctor on duty.

Women labouring to deliver a deceased fetus expressed their dismay at not having their pain managed adequately or at all. This despite there being no potential risk posed, by the administration of analgesics, to a living, viable fetus.

Extract 105

Fezile (W10 public): I went through normal labour. It was so painful.

Extract 106

Fezile (W10 public): The experience I had at that labour ward I mean, I'm not sure where they [nursing staff] were. Maybe they thought it [labour] would take some time (.) I don't know. I only received pain medication after the labour.

2. Dealing with the Fetus/Baby

Following delivery of the stillborn fetus/baby, women were faced with the decision regarding whether or not to view or hold the baby. Each of the women interviewed (bar one) had chosen a name for their fetus by the time LTOP took place. Wilna was never able to confirm the gender of her fetus due to congenital abnormality and thus did not name them. The topic of being able to, and wanting to, access fetal remains was a prominent theme across interviews. Some participants were unable to access fetal remains due to legislation at the time. Prior to legal interrogation of the interpretation and application of the Births and Deaths Registration Act, 1992 (Act No. 51 of 1992), which took place in 2022, women had been illegally prevented from accessing their fetal remains in the public healthcare system, when the fetus was delivered under 28 weeks of gestation. The various sub-themes in this main theme, discussed below, are viewing or holding the baby, naming the baby, and accessing fetal remains.

2.1 Viewing/Holding the “Baby”

The issue of women viewing or holding their fetus/baby following delivery elicited vastly different reactions from different participants. The first category that emerged related to fear of being exposed to the deceased. Some women were afraid to view their fetus due to fears they held regarding death.

Extract 107

Patricia (W2 public): But I don't see (.) me I don't see people that are not alive. I'm scared (.) it's not like I don't like it (.) I'm afraid (.) I won't be sleeping at night. I only saw her after I gave birth.

Patricia explained that she experienced anticipatory dread once her fetus had been delivered, noting that she avoided seeing dead humans. She did not explain if this was due to spiritual beliefs or due to previous experiences with deceased people that may have caused her to develop anxiety in this regard. What is significant is that her wishes should be respected, as she clearly would have been distressed and even traumatised when she “saw her after I gave birth”.

Secondly, women spoke about experiencing shock at viewing fetal remains, depending on the condition of these remains.

Extract 108

Janet (W8 private): And now she is SO disabled. So the whole back, you see her insides. Everything was open.

Healthcare providers, aware that women may be shocked or repulsed by the fetus, may try to dissuade patients from viewing it.

Extract 109

Emma (W9 private): I wanted to see him and they [nursing sisters] weren't quite sure that they would want to show me. I remember I had to insist and asked [her husband]

also and he said: “Well, are you sure?” One of the nurses came and you know he [fetus] fitted quite tightly into a kidney dish. So his head was a bit smaller than an orange and I wished I could have touched him (.) but I didn’t (.) because he was slimy and very macerated.

Even though Emma’s fetus was in a physical condition that could have been experienced as quite disturbing, it was, in her opinion and experience, in her best interests to view the remains. It is important to bear in mind that Emma was trained in allied healthcare and consequently may have been more comfortable with sensory experiences related to death that may be unsettling to “lay” people. She also pertinently referred to the fetus as “macerated” which may be a way for her to distance herself from the emotive reaction of seeing her own fetus in this condition. In the excerpt, the providers and Emma’s partner attempt to dissuade her from viewing her fetus, likely to protect her from seeing the remains in their “macerated” condition. It is significant that her agency in deciding whether or not to view her baby was very nearly removed and she had to “insist”. Her agency was founded on her professional medical (or allied health) training, where she knew her rights and also that this holding/viewing had psychological benefits. However, the condition of the fetal remains following delivery may constitute a significant shock to some women. Consequently, it is important that they should be prepared for the possible effects of fetal maceration or severe fetal malformation on their visual and visceral experiences, should they decide to view and/or hold their fetus.

Adoration and attachment to the fetus was a third category that emerged as significant with regard to viewing or holding the fetal remains. Women described their babies as beautiful and all participants constructed attachment between themselves and their fetus/baby. Themes

relating to beauty, cuteness and other expressions of adoration surprised me during data analysis, as amid the grief and experiences of death, the women remained enamoured with their stillborn baby. These were still “moms” seeing their “babies” for the first time and expressing their pride and love for the child they had wanted to have.

Extract 110

Janet (W8 private): She had the most beautiful little face (.) and the most beautiful little hands (.) and everything was so beautiful (.) it was the most beautiful baby (.) besides for the small head and all (.) but the little face is beautiful. And at 27 weeks a baby that comes out immediately are also not pretty (.) but she was really beautiful (.) and now she is SO disabled. So (.) the whole back (.) you see her insides (.) everything was open.

Extract 111

Melissa (W6 public): A bundle of joy (.) she was a pretty baby (.) even though she was a little disfigured. The face was (.) on the face you couldn't see [anything wrong] but the body you could [see deformity] (.) the body was enlarged.

In the extract above, Janet repeats the word “beautiful” seven times. She does so without hiding the fact that the baby was severely disabled. She speaks comfortably to beauty and disfigurement (“insides ... open”) simultaneously. Melissa, likewise, talks of a “pretty baby” and disfigurement in the same sentence. The emotive force of the words “bundle of joy” is clear here.

Fourthly, the women who chose to hold their baby experienced this as beneficial in dealing with the experience. They regard seeing and holding their baby as vital to their psychological acceptance of the abnormality and validating the diagnosis.

Extract 112

Fezile (W10 public): Because I think if I didn't hold him or see [the abnormalities] maybe I'll still be having questions. But when I did hold him (.) I did see the sonars were true. There was both that water [hydrocephalus] and the split lip [cleft lip and palate].

Fezile stated that "the sonars were true"; she noted that she would still have been doubting her decision, had she not witnessed the abnormalities herself when holding her baby.

For some women, *not* holding the baby was beneficial.

Extract 113

Lelanie (W12 public): It just shows you if I had held her (.) how that would have stayed with me? I just thought about that. I think it would have made it [the feticide and LTOP experience] worse.

Lelanie regarded *not* holding her baby as beneficial as "it would have stayed with" her, implying negative psychological consequences.

Finally, holding the baby enabled rituals of motherhood by the women. Where this was facilitated by the medical setting, it was experienced as very helpful in women's interactions with the fetal remains.

Extract 114

Janet (W8 private): They [nurses] left me with the baby. They allowed my mom to go and bath her. I mean even though she was dead. And the doctor gave me a blanket that I wrapped her up in. I held her for a long time (.) as long as I wanted to (.) and I could say to them: "Okay, take her, put her in the fridge" (.) and I think any mother would appreciate that. Because to me it feels like if you see that baby and you held her (.) it's okay. And I think if women could experience it like I experienced it (.) how they [providers] were all [supportive]. They were incredibly helpful. Terribly.

Janet's experience reflected the importance of tailoring the postnatal approach to each woman's preferences, as she reported having benefitted greatly from being given time to "mother" her deceased fetus (bathing, wrapping in a blanket, and holding). What appears to have been particularly significant to Janet was the humanising and caring manner in which the providers treated the fetal remains. None of the women who delivered in public hospitals were invited to perform similar rituals with their babies. This may be due to a lack of awareness on behalf of the nursing staff that these activities can be psychologically beneficial to women, or it could be due to a lack of physical resources available to facilitate these actions. Understaffing spreads nurses thinly across their wards and these additional duties related to "merely" facilitating women's psychological wellbeing are viewed as irrelevant in the public healthcare system, where the basics of nursing are frequently neglected. It may not

be something that all women would like to participate in, but it made a significant difference to Janet in her dealing with the loss and grief and would consequently be meaningful to at least offer women this opportunity. What emerged as important in this theme was allowing women to make their own decision regarding whether or not to view and hold the fetus.

2.2 Naming the Baby

The excerpts below serve to depict the personhood, family-belonging and meaning most women assigned to their fetus. Each participant in my research described her fetus/baby as wanted, loved and already constructed as a member of their family.

Extract 115

Fezile (W10 public): He had a name (.) he was to be called Tumi. It was Tumi.

Extract 116

Melissa (W6 public): Imogen (.) her name would have been Imogen. [crying]

Extract 117

Emma (W9 private): By that time we knew that it was a boy and it had a name. [He was] that one family member that never made it either.

Extract 118

Fay (W7 private): He was named after the father.

Extract 119

Lelanie (W12 public): Her name was Lea. At first I wanted to name her [after a well-known singer] because I am a big fan (.) but then I decided no (.) Lea. But oh well.

Extract 120

Patricia (W2 public): Gift (.) was her name.

The significance of naming the fetus/baby relates to the disappointment and loss women express. Following her disclosure of the planned name, Lelanie added, “but oh well” indicating the resignation she experienced with regard to the loss. Emma noted that her fetus was “that one family member that never made it”, indicating the construction of loss experienced by her entire family. The thought and significance attached to choosing the name are noted by Fay when she stated that her baby was “named after the father”, which indicates the legitimacy of this lost family member’s position in their family. The capacity to name their fetus/baby is powerful as it denotes the social value and connection between being named and being imbued with an identity that naming facilitates. Names and being named also serve to locate the “person” in the family matrix, which is irrespective of the length of the member’s life. This name is now included on the family tree and consequently, a sense of immortality can be bestowed upon the fetus/baby.

3. Dealing with the Fetal Remains

The fetal remains constituted a significant point of contention with regard to access, the cost involved in burial or cremation of the fetal body, fetal remains being used for research, and the performance of autopsies. Some women buried the remains in a traditional grave

following a small burial ceremony, while financial constraints prevented many women from accessing and burying their fetal remains. Emergent themes with regard to the fetal remains include the (non)options that were available to women, the legal difficulties certain women experienced, informed consent for medical research, and the conduct of autopsies.

Some women spoke about being given options regarding the burial of fetal remains – private or state. However, women’s choice was circumscribed by their ability to pay.

Extract 121

Mabatho (W3 public): They gave me options but I chose that the hospital take care of the child [remains]. They brought the social worker to come and speak to me (.) to tell me about the process. And then the social worker said anytime I want to come back to find out where he was buried and stuff like that (.) I can still come back to the hospital.

Extract 122

Lelanie (W12 public): Because we didn’t have money at the time (.) I asked the government to cremate her and stuff. I kind of think about that a lot (.) about the ash (.) but I don’t know if you really (.) you know (.) get her ash. Or are you going to [pause] you can’t say. But I know the woman [social worker] who phoned me and stuff (.) she said [that] any enquiries I have [or] if I maybe want some of her ash (.) I must ask. But then my husband said no. Then he said: “Let’s just leave it.” I actually regret it. But oh well.

Within the public healthcare system, few patients are financially able to afford the costs involved with the burial or cremation of the fetal remains. In these instances, they are provided with the option of a state funeral (colloquially known as a “pauper’s funeral”) and the hospital social worker usually facilitates the documentation and arrangements in this regard. Both Mabatho and Lelanie were assured that should they enquire, they would be able to locate their fetal remains. However, none of the women in my research sample who had selected a state burial (once again the choice presented is really no choice at all, as these women simply could not afford an option other than state burial) had ever enquired about the location of the remains nor visited them. It is important to acknowledge that the public healthcare system in South Africa is overburdened and struggles to take care of the living. Consequently, it is reasonable that Lelanie (and myself) was dubious about whether the cremated remains would actually be those of their fetus/baby.

I was struck by Lelanie’s statement that her husband had prevented her from trying to access the fetal remains (ash). This is particularly striking, bearing in mind that Lelanie’s husband had been absent and uninvolved during the decision-making process. Perhaps he believed that accessing the remains would further upset Lelanie. Irrespective of his motivation, the fact that Lelanie “obeyed” his command even though it was contradictory to her needs is noteworthy, especially as she says she regrets it.

The interpretation of legislation with regard to the disposal of fetal remains had a significant and devastating impact upon women who delivered prior to 28 weeks’ gestation.

Extract 123

Melissa (W6 public): They said [crying] that we may not have her. It's only from 28 weeks [gestation] (.) so I don't know how she [crying] (.) I asked (.) then they told me: "No you can only have the baby from 28 weeks." I think that is why I still struggle (.) when I talk about it then I bawl [sob] my eyes out. I try to block it out.

Melissa described her frustration at being denied access to her fetal remains within the public healthcare system as delivery took place under 28 weeks of gestation. She indicated that this added to her lack of closure and compounded her grief. In these instances, the remains were destroyed along with other "medical waste" as a matter of procedure. This practice took place until a petition was made in court and a finding was made that the Births and Deaths Registration Act (Act No. 51 of 1992) had been misinterpreted. In fact, the law did not require pre-viable fetuses to be disposed of as "medical waste" (Mametela, 2022). Consequently, all women actually had the right to access fetal remains, irrespective of the gestation thereof. Within the private healthcare system, providers were flexible in this regard and allowed women to request access to their remains as they would have done in order to access their placenta and in this manner, they were able to perform burial rites.

In certain circumstances, fetal remains were used for medical research purposes, and consent was negotiated with women for this.

Extract 124

Fezile (W10 public): So many people coming in and out [of the ward]. Lots of papers [documentation] signing this (.) signing that. [They say]: "We [are] gonna do research what what what [can't remember the details]. Can we use the baby?"

Extract 125

Jasmine (W4 public): I gave it [placenta] to the university to put in a bottle so that they can do studies on it. Because (.) so that other mothers (.) so they [researchers] maybe figure out something and find out what it is. So other mothers don't have to go through anything like that.

Two issues emerge clearly from the extracts describing these negotiation experiences. Firstly, Fezile (public healthcare) constructs a great deal of confusion and the manner in which informed consent took place appears questionable and unclear, with “so many people coming in and out, lots of papers”. This would have occurred at the time directly following the feticide and LTOP when emotions were aroused and possibly unstable. Secondly, Jasmine (public healthcare) allowed providers to keep her placenta for research purposes and her stated motivation – to help and protect other mothers – is noteworthy. None of the private healthcare patients were approached with the request to use their fetal remains for research, which is understandable as the tertiary public hospitals in South Africa are usually linked to tertiary education providers (universities) and consequently, research is conducted extensively in these settings. However, it is important to note that once again due to structural inequality, public healthcare patients are almost expected to comply with such requests as a *quid pro quo* for receiving free healthcare.

Wilna was offered the possibility of an autopsy. However, the clinical geneticist performed post-mortem examinations of each fetus and would often make hand and footprints for the women to keep. This did not always yield expected answers or explanations for what had happened; rather, it compounded confusion and doubts that persisted and made recovery

difficult psychologically. Wilna's (public healthcare) account of a post-mortem on her baby/fetus explores these feelings:

Extract 126

Wilna (W11 public): We gave permission for a post-mortem and we did give permission for them [pathologists] to say if it was a boy or a girl. They did say on the one hand that it was a boy and on the other hand they said they are not sure (.) it could have been a girl. [crying] I never got any answers (.) I even said that they can take some of the [tissue] because they said they would cut him open to see what is wrong inside. That's what I signed for. But as I say (.) even now (.) five years later (.) I still don't know if it was a boy or a girl. Even now I would still really like to know if it was a boy or a girl.

Extract 127

Melissa (W6): I have plaster imprints, the clinical geneticist made them and she left them in front [of the clinic] for me. I had a cooler bag and I told her I would hide the prints in there ((in order to avoid upsetting the other women who were not able to receive such prints)) (.) she could give them to me. She told me that there are lots of mummies who also wanted prints (.) but their babies were too disfigured to do it.

In most circumstances, a post-mortem is performed in order to validate diagnoses and assist in confirming certain information. However, as Wilna disclosed, sometimes, it is impossible to confirm even the fetal gender. This affected the manner in which Wilna could construct (and remember, and grieve) her lost child. In the above extract, Wilna's psychological distress is evident, as is her expressed anger towards medical practitioners who "promised

answers” which were never forthcoming. Wilna felt disappointed and let down by doctors and the hospital system.

4. In-Hospital Recovery

The last facet of this second phase as it relates to women’s experiences of feticide and the LTOP procedures addresses women’s in-hospital recovery following the delivery. In this space, women experienced interactions with staff, family interactions, and other patients.

4.1 Staff Interactions

Several themes were noteworthy in women’s reports of interactions with providers and hospital staff. These reports characterised differences in the quality of care apparent in public and private healthcare sectors. These themes discussed below included supportive interactions, including providers’ reciprocal and emotional mirroring interactions, unsupportive interactions and women not speaking up for what they needed or wanted.

Reciprocal or Mirroring Emotions as Supportive

The medical staff involved in caring for and treating the women during in-hospital recovery, in both public and private healthcare settings, were largely constructed as being supportive and caring. Women frequently noted observing their healthcare providers becoming emotional when they themselves were upset. This “mirroring” of emotions (particularly of overwhelming sadness) served to create a sense of validation and empathy, recognition of distress, and attachment/affection.

Extract 128

Jasmine (W4 public): I came straight to Dr X [obstetrician-gynaecologist] and she also said to the doctor: “This is my patient, you leave her alone now!” And she says this is like her baby (.) this is her baby as well (.) because she (.) I grew so attached to her. She was actually (.) if she sees me crying (.) she’ll start crying.

Extract 129

Mpho (W5 public): I was the one telling them [doctors and nurses]: “No it’s not a big deal.” Because you see their faces and they are sort of (.) even the nurses were supportive. In fact (.) I was the one consoling them instead of [the other way around] because I was telling them, “its fine”.

The relationship between Jasmine and her obstetrician-gynaecologist is striking in that it seems as though the specialist tried to advocate for Jasmine amid the public healthcare system which may otherwise not have provided her with adequate or supportive care. Jasmine relates the mirroring that this provider does (crying with Jasmine) in the context of an “attached” relationship. In the excerpt above Mpho related “consoling” the providers because she noted that they were upset. It is interesting that Mpho notes that “*even* the nurses were supportive” (my emphasis), as though this were unexpected and surprising.

Unsupportive Interactions

There were certain in-hospital interactions women recounted that indicated a lack of empathy or even basic service provision on behalf of providers. Fay and Melissa relate their post-

surgical experiences being ignored, or not listened to, by providers in both private and public healthcare settings in the excerpts below.

Extract 130

Fay (W7 private): So after that it was (.) I don't know (.) after that I just started paining. And ah, the lady [nurse] was like, "No, maybe it's just the stress or maybe the fact that you saw the baby." And my husband was there (.) I told the lady, "I can't carry the pain. Wait, wait, wait!" I feel she didn't know how I was paining and the lady [nurse] went. She took out the baby [after showing Fay the demised fetus] and the lady went (.) after a few minutes I was [inaudible] my husband called the lady [nurse] back and when she came in, she tried to recover me, she told me, they told me, that I was practically gone [deceased].

Extract 131

Melissa (W6 public): These things [points to her ears] they [providers] don't listen! I said to him: "I am not a professional doctor or a specialist (.) or a gynecologist. I am just a lay person (.) a housewife (.) a PA (.) but I think my hormones are a mess."

Fay's experience speaks to being ignored with near-fatal consequences. She felt dismissed by the provider ("she didn't know how I was paining"), who left the room despite Fay's pleas. Melissa recounted a similar experience of being dismissed by providers when she tried to explain how she felt following surgical delivery. Melissa phrases her accusation of providers ("they don't listen!") in a polite way by positioning herself carefully as "*just* a lay person" (my emphasis) in order to acknowledge providers' perceived greater authority and knowledge; but is still powerfully trying to convey her experience and her interpretation of

what is going on with her own body (viz. “my hormones are a mess”). Women’s voices, even when pleading and screaming, continue to be ignored across healthcare settings, with potentially deadly consequences, and certainly to their detriment and exacerbated suffering.

4.2 *Not Speaking Up*

Women often mentioned situations where they had needed or wanted something during recovery; however, they self-censored, not been able to voice their needs and instead accepted their circumstances. In both examples cited below, this “silencing” related to needs for privacy in communal, general maternity wards within public health sector hospitals to respect the intensity of the complicated feelings they were experiencing.

Extract 132

Melissa (W6 public): I’m not sure (.) it wasn’t nice for me. There was a stage where I felt (.) I wanted to scream at them: “Can I just get my own room!” Then I thought to myself: “Melissa, it’s a government hospital (.) here you must just shut your mouth and focus on one thing.”

Extract 133

Odwa (W1 public): It wasn’t nice (.) because after two days or three days [in the ward] there was a woman carrying her own baby and my baby is no longer [alive]. So I didn’t feel alright. [crying]

In the extracts above, both women needed “a room of their own”. Melissa’s statement that “it’s a government hospital, here you must just shut your mouth” clearly articulated her silencing as she realised her needs were impossible to meet in a public healthcare facility. Here she is silencing her ‘screaming’ needs, and also angrily noting that other more privileged women, in other hospital settings, may get better quality and more sensitive care according to their needs. Being admitted to a general maternity ward with many other women who had delivered healthy babies, and were breastfeeding them, was similarly exceedingly difficult for Odwa. She reports feeling “not alright”. Thus, these communal maternity ward situations have significant psychological impacts on women’s in-hospital recoveries following feticides.

4.3 Family Interactions

During their in-hospital recovery, some women constructed family support as “absent” or in some way lacking, either due to not having disclosed the situation to them, or due to practical or other barriers to their attendance at the hospital.

Extract 134

Fezile (W10 public): Because I was almost alone [during delivery the nurses had abandoned her]. So I wish I had had that family support (.) and this is not a normal thing [to go through].

Extract 135

Wilna (W11 public): My parents and them were reasonably supportive (.) my mom's sisters sent me messages all of the time and found out from her how it was doing. So (.) it was (.) there was a little support (.) but not as you expected.

Fezile expressed disappointment at the family support received particularly in light of the absence of staff support. Wilna indicates that the family was supportive, "but not as you expected". Fezile's reference to "this is not a normal thing" is important here, as such circumstances, in general, suggest that an increased amount of familial support is necessary.

4.4 Interactions with Other Patients

The in-hospital recovery entailed women interacting with other patients and frequently staying in the same maternity ward with a number of other women. During these encounters in public healthcare settings, women experienced supportive interactions as well as distressing comparisons with other women:

Extract 136

Melissa (W6 public): I was so irritated with the one [patient] opposite me. She sits out in the open and rubs her breasts or she stands and washes herself. She doesn't even close the curtains. The one next door (.) now their [pregnant person and partner] baby had not even been born yet (.) while they were listening to the heartbeat. The one opposite me (.) her baby had been born.

Extract 137

Mpho (W5 public): Because I remember when I was in the ward, after explaining to one of the patients there what was going on (.) she told me: “I will just tell you one thing, is it better to lose a one-year-old baby or is it better to lose the one you are losing?” Both are painful (.) I don’t know. She told me: “For you, you have never even seen that baby you have not interacted with the baby (.) you are not used to the baby (.) you’ve not bonded with the baby.” That’s when she told me: “I lost my one-year-old baby and in fact I bought the dress for her to wear on her birthday but she died before.” So, when I came to think of whatever she told me I said: “It’s good [to have experienced the LTOP] at least you lost something you didn’t know.

Melissa relayed her irritation (and anger) with the other patients in the maternity ward who seemed to her to be insensitively gloating about their live fetus/baby with various bodily displays and maternal behaviours. It is clear that Melissa felt envy and “othering” at being exposed to women/mothers who had not lost their babies, without them saying a word to her (whether supportive or not). She refers to the “the one opposite me” meaning in the bed opposite hers in the ward; but this woman might be subjectively the “opposite” to her too, being a mother who has given birth to a live baby versus (herself) a mother with a dead baby, or no baby at all. This exposure reinforces her abject loss, and her alienation from these other mothers. The reported interaction with one of the women-patients in the ward with Mpho may come across as harsh or unrelated. However, Mpho found solace in it. Perhaps it was that this woman had also endured child loss that affected the manner in which Mpho perceived this shared conversation. The message Mpho took away from this interaction was that she was somehow “fortunate” for having lost her baby before it had been born and grown – through its continued development and care – to love it. However, this construction of the

other women's "real grief" might invalidate Mpho's own feelings of grief; and she appears to be left feeling that she should be grateful for her feticide and that other women's losses are far more traumatic than her own.

Providers' Perspectives

Providers constructed women's experiences undergoing the feticide and LTOP procedures as significantly affected by the method used to perform the feticide as well as the competence of the doctor performing the procedures. In the private healthcare setting, women were said to have greater choice in certain aspects of the procedures, for example, opting for surgical delivery with full anaesthesia. Providers constructed certain aspects related to the procedure as vital to women's wellbeing and significant factors that would determine their recovery. These aspects include accurate communication about what the procedure involves, viewing the fetus, being provided emotional support following the procedure, and having the experience assuaged by the providers involved.

5. Working on Her Body

This section of the second phase will present providers' perspectives on women's experiences of the feticide procedure, which is frequently constructed as "traumatic" and "stigmatising", as well as the nature of the delivery. Providers' own experiences of the feticide and LTOP procedures are presented in order to contextualise their perspectives.

5.1 Providers' Constructions of Women's Experiences of the Feticide Procedure

Providers constructed women's experiences of the feticide procedure as traumatic and emotionally upsetting.

Extract 138

Peter (HSP3 private): I had to do the feticide in the ward [not in his rooms] (.) and just about everyone was in tears (.) and the patient (.) and the gynae (.) and the nurse and myself (.) and it (.) it just is that way. It is not something that you can just do blindly.

Extract 139

Amy (HSP5 private): So maybe the actual feticide is the most traumatic thing they'll [woman and partner] ever got through in their whole lives. You know?

Peter acknowledged that the trauma the women experienced was shared by the whole feticide team of providers. Amy indicated that the feticide was the most significant life event for both woman and partner. Peter argued that the feticide procedure cannot be performed "blindly", suggesting that providers are required to recognise the significance of the moment and not try to "unsee" the trauma of the experience. During these interactions it is possible that trauma is co-created by the provider and woman, and it would in fact have been preferable for providers emotionally contain women instead.

In order to reduce the women's, and their own, distress during the procedure, many providers sedate the woman.

Extract 140

Mathuli (HSP13 public): I give them [pregnant person] good conscious sedation. I give them quite a bit of Dormicum [hypnotic sedative] obviously with the monitoring (.) and then the mom is (.) she's not anesthetised during the procedure (.) but she's definitely quite unconscious. So I don't like her to feel what I'm doing at that time. Then the Dormicum has the benefit of the retrograde amnesia (.) so she doesn't remember the actual procedure. Sometimes they [women] cry a little bit during the procedure (.) but a lot of them they just sleep through it.

Mathuli indicated using clinical tools at her disposal (Dormicum) to sedate and blot out memories of the procedure. This is done, she indicates, because she doesn't "like her to feel what I'm doing at that time". She acknowledges that there still may be some trauma (crying a little), but for the most part, the women are oblivious.

5.2 Describing the Feticide Procedure Techniques and Competence

Providers focused a great deal on the methods and technicalities related to the feticide procedure. The excerpt below provided a comprehensive description of the providers' outline of the feticide techniques and the advantages and disadvantages of both. These medicalised constructions may serve to cut the procedures off from the context and emotive reactions they may elicit and thus allow the providers to maintain a "clinical" distance.

Extract 141

Mathuli (HSP13 obstetrician-gynaecologist in public healthcare): The standard way of doing the feticide is the intra-cardiac injection of potassium chloride. It's quite a difficult procedure because a lot of the fetuses are very mobile. There is a second option (.) to leave intra-amniotic hydroxyzine (.) just like when you do an amniocentesis (.) you confirm that you are in the amniotic sac (.) you get amniotic fluid and then you just inject the hydroxyzine into the amniotic fluid. It causes asystole [heart stops beating] as well, but it's a much easier procedure because you don't have to dart at the baby and feel terrible about poking the mom more than once and all those things. But the problem with that is that the asystole is not immediate so it can take up to 24 hours before you have asystole. That means that mum has to know that she might wake up and still feel fetal movements. Then only later during the day she might start to feel that the baby has now stopped playing.

Mathuli's medical account explains the two options for the feticide procedure. Both injections have pros and cons, but her evaluation of the intra-amniotic hydroxyzine injection is presented as backed up by "the latest literature" and is easier though less desirable due to delays in fetal demise (Sharvit et al., 2019). This understandably has physiological and psychological impacts on the pregnant person, and reinforces the need for very careful medical communication about the procedure and the slower process of fetal demise (viz. "that mum has to know that she might wake up and still feel fetal movements"). Mathuli's technical explanation was fairly devoid of emotion until she noted "feeling terrible about poking the mom more than once" and the needle "darting at the baby". The personhood of the

fetus was emphasised through the fetal demise being described as “the baby has now stopped playing”.

It is clear that the more technically challenging method (of intra-cardiac potassium chloride injection into the fetus) is preferable in reducing maternal distress, while possibly being more emotionally and clinically taxing on the provider. This difference between the two methods of feticide, and the manner in which the outcomes thereof are communicated to the women, presented a significant point of interaction which will be explored in detail in the concluding chapter.

Providers constructed technical competence as having a significant impact on women’s experiences of the feticide procedure. Hugh (clinical geneticist in public healthcare) and Connie (clinical geneticist in public healthcare) describe in extracts below:

Extract 142

Hugh (HSP8 public): At the moment my bigger concern for the parents is that feticide just doesn’t seem to be done properly. Regularly we’ve got somebody who comes in and the feticide fails or the feticide is repeated. It just doesn’t work the first time and that worries me. My thought process is if the mom’s sort of a little bit unsure and it fails first time (.) then she’s [thinking]: “Oh am I supposed to be doing this? Maybe it’s a sign I shouldn’t do it.”

Extract 143

Connie (HSP10 public): It has happened that the procedure [feticide] has to be repeated due to the clinician not being experienced enough.

Poor technique necessitated multiple attempts at injecting the fetus successfully, or even complete failure to ensure that the fetus was stillborn within the public healthcare setting and more disturbingly, in the tertiary healthcare system (an academic environment where skilled and experienced specialists are expected to train registrars in the various specialisation fields of medicine). Hugh disclosed these procedural failures and expressed his concerns regarding the impact of failed feticides on the women's experiences of the procedure. This failure may lead to further agonised decision-making, particularly for those women who may have been unsure of the decision to terminate the pregnancy, viz. "Maybe it's a sign I shouldn't do it". Feticide procedural failure was also noted by Connie, who regarded the reason for this as insufficient clinical experience on behalf of the obstetrician-gynaecologist performing the procedure.

5.3 Reducing Own Trauma During the Feticide Procedure

Providers constructed women's strong emotional reactions while undergoing the feticide procedure as upsetting to themselves. This is an interesting perspective, where the providers' emphasis is not on women's distress, but rather on implementing strategies to reduce their negative reactions and the psychological impact on themselves. Zelda (obstetrician-gynaecologist in public healthcare) admitted to performing feticides using a technique that potentially caused the pregnant person significant distress, rather than carry the burden of emotional discomfort herself, as is described in the excerpt below.

Extract 144

Zelda (HSP2 public): I did try the intra-cardiacs [injection into the fetal heart] but when you push that needle in and you feel how that needle then goes through the baby. And the baby starts to sort of obviously try to get away from needle and moves and your whole needle goes to the side (.) then it freaks me out a little bit (.) so I stopped doing intra-cardiacs because it was too much for me (.) just that to physically hurt a child before it actually dies was not nice for me. Whereas if you inject digoxin then it is the same as if you are drawing amniotic fluid but you are just injecting something. So the mom feels something (.) the baby I don't think (.) well the baby feels just nothing actually until the baby eventually dies. It just takes longer (.) it takes anything between two to six hours. Some take a bit longer [up to] twelve hours (.) so it's bad I think in the sense of if the mom lies there and she still feels her baby kicking until all of a sudden your baby stops kicking. So I think it is perhaps emotionally a bit more exhausting for the mom but I don't know (.) I mean if you don't have an alternative to compare it with (.) well it's still bad because you are still losing your baby. I don't know if there (.) in those four hours that you lie there necessarily makes your experience different. But it's for me (.) for me it's just too difficult to do the intra-cardiac injection and just to feel how that baby actually just stops (.) so the digoxin works better for me.

Throughout this excerpt, Zelda justified her preference for the feticide technique which resulted in protracted fetal demise by minimising or negating the impact this had on the woman. Instead, she emphasised her own emotional wellbeing (viz. "it freaks me out a little bit so I stopped doing intra-cardiacs"). She acknowledged that the latter method may be more "exhausting" emotionally for the woman but justified her choice by noting that the woman

had nothing else to “compare it with”. Zelda admitted that she was not sure if the protracted experience was worse for the women but confessed that “for me it’s just too difficult”.

Other than choosing the injection into the amniotic fluid, it was clear from the provider interviews with doctors performing feticides that they struggled to maintain ‘a professional stance’ during the feticide-injection procedure and they used several strategies to help with this, and to manage emotions that came up. The first was to ensure that the woman is a “good patient”. Loni (obstetrician-gynaecologist in public and private healthcare) constructs how “a good patient”, as in a woman behaving calmly during the procedure, makes it easier for doctors.

Extract 145

Loni (HSP6 public and private): The calmer your patient is and feels [the] less traumatic for the doctor. I have already been in situations where the patient could not handle the situation at all (.) and started to scream and cry during the procedure (.) and it was a terribly bad situation. This after someone else had spent a number of hours talking with her (.) so it wasn’t a new decision (.) she had had time to think about it too.

There is an intimation of resentment expressed by Loni in the excerpt above, where she reflected on the negative impact women’s adverse emotional responses had on providers during the feticide procedure. There is a sense of irritation towards the woman/patient who is “mis/behaving” unjustifiably, by losing control emotionally, given that she had had prior-procedure counselling. Thus, things did not go according to plan and “a terribly bad situation” ensued. Loni notes how patient-doctor cooperation is required for a “calm”

procedure, which by definition, might be less traumatic for everyone, but particularly for the doctor. The emphasis is on reducing provider distress, by reducing women's distress and a second strategy spoken to was assuming "clinical distance".

Extract 146

Amy (HSP5 private): If you step out of it [performing the feticide procedure] and you say to yourself: "Well, I'm doing a feticide this is very traumatic" you do feel that trauma in yourself. Mentally (.) emotionally (.) but you can just step back into the doctor role and you are somewhat protected.

Amy related that adhering to her role as a "good" medical healthcare provider assisted her in buffering against the upsetting nature of providing feticides, viz. "you can just step back into the doctor role". However, she did acknowledge that she experienced performing feticides as "very traumatic" and being affected "mentally" and "emotionally".

The third strategy was to engage in self-care, in particular avoiding burnout by taking time off.

Extract 147

Mathuli (HSP13 public): The more overworked you are (.) the more tired you are [for example] when it's been six months without leave (.) then those patients [women presenting for feticide] actually feel like [laughs] the Tuesday fetal clinic is the Tuesday clinic. When I walk out of there at three o'clock (.) I go home and cry (.) but when you've had a bit of a break and I've been on leave (.) and my mind is set

straight. Then I can still empathise with the mom (.) but without being too emotional (.) and too emotionally involved. Then I can comfort her without almost crying myself.

Extract 148

Peter (HSP3 private): I must say that I went through a time of taking poor care of myself. We worked hours that were too long but now we have two other fetal specialists (.) and also, when I go away on holiday, then she [one of the fetal specialists] takes over. So it allows me to go on holiday without working myself crippled before the time.

Mathuli (obstetrician-gynaecologist in public healthcare) explains how exhaustion contributes to feeling overwhelmed, making poor decisions, and burnout. She explained the preventative importance of providers taking adequate leave. The impact of being “tired” and “overworked” is constructed as impacting directly on providers’ ability to care for and empathise with patients, particularly women with fetal complications. “The Tuesday fetal clinic” is a label and metaphor to describe an emotionally draining day of work, and Mathuli postpones her emotional response until she gets home (viz. “I go home and cry”). Mathuli describes how being adequately rested gets her mind “set straight” and enables her to “empathise” without “crying myself”. In the pursuit of adequate service delivery, many providers reported sacrificing their wellbeing and self-care. These sacrifices had detrimental outcomes on providers’ health, “working myself crippled”, as Peter described his experience. Peter (fetal specialist in private healthcare) recounted a time of “taking poor care” of himself in the excerpt above. It is interesting to note that although the perception is that it is only

public healthcare providers who are necessitated to work excessively long hours and take little leave, it appears that this is a common experience in both public and private healthcare and may point to the shortage of medical professionals in South Africa in general.

The fourth strategy involved receiving psychological support either through peer support and being able to debrief to colleagues who are also involved or through formal psychological counselling.

Extract 149

Annie (HSP1 public): We've got this little WhatsApp group (.) the three of us [genetic counsellors] supported each other. We debriefed one another and that meant more to me than seeing the psychologist. I just think we think differently and you know that person [colleague] has probably experienced the same.

Annie (genetic counsellor in public healthcare) noted the importance of peer debriefing with colleagues with shared experiences. Others, however, felt that formal counselling is necessary.

Extract 150

Loni (HSP6 public and private): I just think it is important [that] if you are in such a difficult field [performing feticides] to go for psychological counselling and evaluation regularly. Even if it is just to find out that you feel ok. And to coordinate a person's thoughts into the right direction. Because it is easy for a person's thoughts to run in incorrect circles.

Extract 151

Ziva (HSP7 public): I think the medical field as a whole (.) in all spheres of medicine (.) is very poorly supported from a mental health point of view. I think healthcare workers are expected to be strong, suck it up and move on. I don't think obviously that's the right way for it to be approached. There need to be structured programmes (.) there need to be debriefings addressing psychologically stressful situations in the workplace. It should actually be standard (.) where we realise that situations are stressful (.) they are burdening (.) they can lead to negative incidence (.) poor work performance (.) and also affecting family lives and social lives.

Loni (obstetrician-gynaecologist in public and private healthcare) emphasised the value of providers receiving “psychological counselling and evaluation”, due to the “difficult” nature of their feticide work and constructed providers’ vulnerability to the potential negative impacts on their mental wellbeing.

Ziva (obstetrician-gynaecologist in public healthcare) related that providers were “poorly supported” in terms of mental healthcare. She presented the construction that providers are “expected to be strong” and to “suck it up and move on” and proposed that providers’ employers should put “structured programs” into place. These programmes would serve to address the “burdening” and “negative incidence”, “poor work performance”, “affecting family lives” and “social lives” that providers experience due to “stressful” work situations. Ziva was proposing that proactive structural support should be in place, rather than reactive management of providers’ psychological distress. The improved psychological wellbeing of

providers would serve to improve not only service provision, but also the psychological wellbeing of patients attended to by these healthcare providers.

The final strategy used was to draw on religious beliefs. While certain (Christian) beliefs created cognitive dissonance among certain providers when these collided with their professional practice as “good doctors”, religious and spiritual beliefs also emerged as supportive psychological structures in justifying providers’ involvement with feticide and LTOP procedures and reducing potential trauma.

Extract 152

Mathuli (HSP13 public): But like I’m saying (.) I’m Christian (.) and I struggle to place it [feticide and LTOP] as a terrible sin. So I decided I’m not going to think about it too much. I’m going to do the job that needs to be done.

Extract 153

Peter (HSP3 private): The sister who used to work with me and assist me is also a Christian. And I told her that she must really say if this [feticide] is something that goes against her grain (.) then she really must not do it (.) and I can’t remember how she phrased it, but then she said: “You know it is a broken world, and we must also try to be Jesus’ hands” (.) and I think in this way. And you know I think otherwise (.) I would not have been able to do it.

Mathuli and Peter explain how they align their Christian beliefs with practicality (“doing the job that needs to be done”) and with providing the most caring way serve (“like being Jesus’ hands”). Whereas Mathuli’s religious beliefs leave her conflicted and instead avoiding

thinking about the morality of feticide and LTOP, Peter's religious beliefs, in fact, assist in justifying his provision of the feticide procedure. The focus here is on alleviating fetal suffering, which validates the morality of the procedure.

5.4 Coping with Stigmatisation

Providing the feticide procedure was constructed as stigmatising by many providers. It is noteworthy that this perceived stigmatisation emanated from fellow healthcare providers. The stigma that usually accompanies abortion provision (e.g., that it is murder) was said to attach itself to feticide and LTOP as well.

Extract 154

Ziva (HSP7 public): I think colleagues love asking the question: "Do you perform feticides?" Especially those that are anti the procedure. Then they usually go on to give their opinion which is usually along the lines of it being tantamount to murder (.) and it's usually not with much insight (.) [in] to the actual procedure (.) [or the] indications for the procedure. It can become quite challenging to deal with especially as it is already an issue that is already quite unsettling for one.

Extract 155

Mathuli (HSP13 public): I've had nurses tell me that the babies are all going to wait for me at the gates of Heaven [slight laugh]. And it sounds like a joke (.) but it's not funny.

Ziva described that anti-choice colleagues, in particular, would ask her if she performed feticides. What follows would be their condemnation of feticide as “being tantamount to murder”. She noted that this would be “challenging” due to her experience of providing feticides as “already quite unsettling”, thus compounding her discomfort. Similarly, Mathuli related nursing colleagues telling her that the fetuses would “wait for me at the gates of Heaven”, insinuating a form of retribution or punishment for providing feticides. She went on to emphasise that “it’s not funny”, thus conveying how these statements disturbed her. What I find striking is how the doctors who perform the feticide and LTOP procedures are “othered” by their colleagues and, as such, they bear the stigma associated with abortion in a healthcare environment (South African healthcare, both private and public) which negates the narrative of reproductive justice.

To cope with this, providers, paradoxically, distinguished between the feticide procedure and routine TOP procedures or equated them.

Extract 156

Amy (HSP5 private): Actually sticking the needle into the heart of the fetus [which has] severe disabilities [based] on a panel decision has actually not posed me too much traumatic stress. I feel worse about an elective termination of pregnancy (.) I feel more distressed about that.

Amy sets out the different categories of termination in the extract above. Here, feticide is constructed as (more) morally justifiable because it is based on clinical evaluation and decision-making by a hospital panel of specialists, based on evidence of severe disabilities in the fetus. This is counterpoised against “elective termination of pregnancy”, which is more

distressing to her because women may decide to end their own pregnancies based on their own circumstances.

Of all the providers included in this research, only Mathuli stated that she regarded feticide and early TOP as similar.

Extract 157

Mathuli (HSP13 public): I think it's the same as early TOP. To think that [city] literally has just [district hospital TOP clinic] that's then run by a doctor from Cuba who is doing TOPs in the public sector (.) is for me [upsetting]. He is the only one who is willing to work there (.) no-one will work there.

Mathuli suggests here that there is no difference between early abortion of LTOP. She also indicates, however, that there was only one doctor, working at the TOP clinic in her city, due to “no-one” being willing to work there. Here she illustrates the impact of “conscientious objection” on women’s reproductive health and service provision as being dire.

6. Delivering the Fetus/Baby

The paucity of reference providers made to the late termination of pregnancy procedure, either normal vaginal delivery, or caesarean section, is significant in its absence. It may be due to many of the women defaulting on their follow-up appointments and consequently providers could not comment on this aspect of the process as they had not discussed women’s experiences of delivery with them. Where providers are not gynaecologists, their interaction with the women would have been limited to counselling prior to the feticide as well as their

involvement in the feticide procedure. This will be explored in the concluding chapter. The main provider constructions that emerged from their interviews focused on the risks associated with surgical delivery.

Extract 158

Mathuli (HSP13 public): But then we look at the patient profile. Obviously if it's a reliable patient who you know will be able to follow up with increased surveillance with that next pregnancy; you inform her about the possible complications with multiple previous caesarean sections. And the biggest one that we are scared of is uterine rupture (.) so if you've had three or more caesars then we're scared that if you fall pregnant again [that] we're going to have uterine rupture during the pregnancy. To follow you up more often and you will have to be reliable (.) have reliable transport that if you do see a problem it's not going to take you two hours to get to the hospital. There are those select patients that will find themselves in that situation and then you can sort of try and make an arrangement for them to say: "I'm going to give you a card [referral card for the antenatal clinic at a tertiary level hospital] already (.) so that you know already with your next pregnancy, they [primary healthcare] don't keep you – you come straight to [tertiary hospital]".

In the excerpt above, Mathuli constructed women as being either reliable or unreliable patients, based largely upon their ability to access resources such as transport and communication systems regarding their own reproductive health. "Reliable" women were afforded more reproductive choices than those who were not as able to access these resources and were, in fact, described as "select", somehow "better" than those who are "unreliable". Consequently, the method of delivery, either surgical or vaginal was, according to Mathuli,

determined largely by her evaluation of the patient's reliability. Mathuli explained (see earlier extract) that the standard procedure following a third caesarean, "per definition" is to perform "a sterilisation". While this may be a medical recommendation, women's reproductive agency should mean that the decision should be discussed with, and made by, the woman. Mathuli described a "reliable" woman according to her ability to access resources, "reliable transport", which directly impact upon her agency.

Another theme that emerged among providers' interviews was the perceived discrepancy between delivery in private versus public healthcare systems.

Extract 159

Amy (HSP5 private): In private [hospital settings] one often [well] sometimes, does a feticide under general anaesthetic (.) and then a caesarean section. So you know that is how one gets around some of the [traumatic] experiences (.) but that's because we've got access to that kind of thing. And it's not necessarily the best decision medically for the mother (.) but it's the best decision maybe, mentally for her.

Extract 160

Loni (HSP6 private and public): I did procedures in the state [hospitals] as well as in private practice. And I must say there is quite a big difference between the two set-ups (.) due to the availability of resources. And I think at the old end it is a much more bearable process for private patients, even though we do it in public healthcare with what we have as bearable as possible for everyone [involved].

Amy acknowledged that women in private healthcare settings have greater agency in the decision on delivery method than those in public healthcare settings. This is due (in Amy's account) to providers having "access to that kind of thing", referring to anaesthetic and surgical resources (interestingly, Amy makes a distinction between doctors' medical best advice, and the "best decision maybe, mentally" for the woman). Loni is able to compare private and public healthcare directly, and agrees that the resources in the private sector enable a much more "bearable" procedure than in the public sector. She is quick to add, though, that she tries to make it as bearable as possible in the public sector.

Other than the differentiation between public and private sector healthcare, the question of travelling to do the delivery after receiving the feticide was mentioned.

Extract 161

Peter (HSP3 private): So it's difficult (.) and uhm, practically, the most mothers deliver normally afterwards. Then I also try, if it is someone who comes from a hospital nearby, to do it at the hospital (.) but I have had women who undergo feticide here [in his rooms] and then fly back to the country they are from to deliver [where feticide is not legal in their country] (.) and I think that must be terrible.

In the excerpt above, Peter adds another layer to the experience of feticide, where some women are necessitated to travel to South Africa in order to undergo the feticide procedure, and then travel home to deliver, due to feticide being illegal in their country. This would only be available to women who could afford to travel for this procedure. Those who are unable to do so, would have no choice but to continue with the pregnancy.

7. Viewing/Holding the Fetus/Baby

Following delivery, some providers constructed women viewing or holding their dead fetus/baby as a significant experience in order to confirm the fetal diagnosis and to assist in recovery.

Extract 162

Zelda (HSP2 public): She didn't want to see her baby (.) her mom told her she doesn't think it's a good idea for her to see her baby now (.) and I told her: "I think you must see your baby so that you can remember." And she came back afterwards (.) a whole lot of times (.) and said she felt guilty (.) she feels regret. She feels shouldn't (.) she [should] rather have continued with the pregnancy (.) did she do the right thing? If you do do it [feticide] you must see your baby (.) so that you can understand why you did it.

Extract 163

Connie (HSP10 public): Some moms don't want to see the babies afterwards. But the ones that do want to see them (.) they kind of get a bit of (.) they realise that if they can physically see (.) ok this baby has very severe problems and would not have survived. They have a lot more closure. A lot more peace about their decision.

Zelda related a negative case incident where a woman-patient had not viewed her dead baby following a feticide and delivery and who presented with psychological adjustment issues following this. Zelda constructs the benefits of viewing the dead baby following feticide and delivery in unequivocal psychological terms – in concretising a memory of motivations for

why the procedure was necessary by witnessing the fetal disabilities. This is to resist the negative thoughts of regret, guilt and self-blame that challenge women's recovery and ongoing mental health following feticide. Zelda's psychological construction of acceptance, understanding and catharsis is positioned in this extract against the popular view of healing – espoused very plainly as *wrong* advice here, from the patient's mother – of seeing the fetal remains as too distressing and overwhelming, and thus, difficult to quickly forget about and move on. The psychological view (viz. "you must see the baby") is constructed as difficult in the short term, but with longer-term psychological benefits. Connie, likewise, related that some women did not want to view the fetus/baby; however, that the women who did view the fetus/baby experienced "closure" and "peace". However, other providers' perception, presented below, were less fixed than this and created space for individual woman and fetal differences.

Extract 164

Xenia (HSP9 public): To me it [the decision to view the fetus] feels like that is a decision that they [women] need to take. And preferably along with the husband (.) or a very close family member (.) to take that decision. I did have a patient who despite all the abnormalities, she took photos of her baby and it was it was ok for her. Because then she says then she can always remember her [baby]. Then you have the others who felt guilty because they didn't see the little child (.) or there was one who badly wanted to see the baby but they [nurses] took the baby away because she had been under general anaesthetic. So it goes both ways. But I cannot tell you [which is better]. It's a difficult thing (.) one patient was traumatised because she saw the little fetus and it was (.) there were a lot of abnormalities. So it was difficult for her.

In the excerpt above, Xenia emphasised the importance of respecting each woman's decision with regard to viewing and holding the fetus/baby; she also acknowledged that circumstances were always different for individual women, as were outcomes. Against Zelda's view (previous extract), Xenia is able to draw on several case studies of different contingencies, to demonstrate diversity of experiences and needs and to emphasise that it (viewing, holding a dead fetus) was another decision women themselves (or "with a partner or family member") need to take. There were apparently pros (benefits) and cons (re-traumatisations) that accompanied viewing the dead baby or not viewing it, for various reasons – viz. "it goes both ways" and there is no universal or unilateral best way to proceed. This is a psychological view which seeks to explore what works best for individual women, with individual women's interests and circumstances in mind. It is important to remember that Xenia's construction of women's experiences was from the perspective of a clinical psychologist, rather than a medical clinician. Hugh, on the other hand, made distinctions not on individual women's needs, but rather on the characteristics of the fetal deformity.

Extract 165

Hugh (HSP8 public): Most of the people [women] once they realise what has happened and they've seen the baby (.) then it most definitely helps [to see the baby]. There are a few that don't want to see the baby (.) and obviously the other thing that we speak about with the students [medical students] is the anencephalies [underdeveloped or absent brain]. I am actually very strict about that and if the parents want to see them [fetus] I say [to the student] to take a sheet and I cover the baby. So that you can literally just see the face (.) can't actually see the head or anything like that. If they [women] insist, then I'll open [the sheet]. That makes a big difference for the parents just to have seen this.

As with other providers, Hugh explained that women who viewed the fetus/baby were able to “realise” what had happened to their fetus. He noted that viewing the fetus made a “big difference” for the parents. However, this depended on what Hugh thought would upset the women. He described how he trained medical students to cover the more upsetting fetal abnormalities. The women would have to “insist” for him to “open” the sheet, thus displaying a somewhat patronising stance.

8. Using Symbolic Objects to “Work Through” Grief

A perspective that frequently emerged in provider interviews was their attempts to ease women’s experience of dealing with a stillborn fetus/baby through the use of symbolic objects. These attempts – using everyday objects – sought to normalise the stillbirth.

Extract 166

Maggie (HSP12 private): I like to ask them: “If you have something special (.) a blanket, a beanie or something” and then I take a photo in the first place with it (.) and I tell them: “I’m putting your child in his thingy and that is how we will cremate him.” That’s what I do. And I also take a photo of them [baby] with a flower and then I give her [woman] the flower. Then she has the photo (.) I just think it’s meaningful. It’s a connection (.) I think that’s how my heart also processes it.

Extract 167

Annie (HSP1 public): From the genetic counselling perspective we actually always had pads that we took along (.) ink pads. We took little footprints and took little

handprints (.) and we closed the babies up and took nice photos (.) and we kept that in the files so that when we see the mothers [for follow-up] they do have the option to actually have that (.) or see that at least. So that we can work through the grief.

Extract 168

Hugh (HSP8 public): We get a lot of moms that actually come in and say: “No I don’t want to see the baby” and then we offer to take photographs for them (.) and then those that come back after six weeks, they often ask to see the photographs (.) and to get a copy of the photographs.

Extract 169

Wilna (W11 public): At the moment all I have of that little one is the feet and hand prints. My husband refused to take photos.

Maggie described how she attempted to assuage the experience of viewing the abnormal stillborn fetus following delivery by presenting it as humanely as possible: “I just think it’s meaningful, it’s a connection, that’s what I do”. Maggie recounted using symbolic items associated with normal deliveries such as “a blanket”, which symbolises safety and comfort, “a beanie” or a “flower”, which is a common social gesture, with the fetus/baby and then photographing these together. The photographs allow for repeated viewing during the bereavement process. She added that this process assisted her “heart” in processing the experience as well.

Annie related genetic counsellors using “ink pads” to take “footprints and “handprints”. They would also take carefully constructed, “nice” photographs of the fetus/baby and keep these

items in the woman's file. This provided the women with the "option" to have the items in order to "work through the grief." In the last excerpt above Hugh noted that "a lot of moms" declined to view the fetus/baby. In these situations, providers "offer" to take photographs of the fetus for the women, which provided the women with an opportunity to "ask to see the photographs" and receive "a copy" at their six-week follow-up. These symbolic gestures enable a connection between the woman and the fetus beyond the awfulness of a diagnosis of abnormality in a wanted baby and the feticide/LTOP experience. In the extract above, Wilna commented that the hand and footprints were "all I have of that little one", because her husband had prohibited her from taking photographs of her baby.

9. In-Hospital Recovery

The major issue spoken to by providers in relation to in-hospital recovery was psychological adjustment. Providers spoke about assessing the women and making appropriate referrals. Providers emphasised the importance of ensuring that women could access psychological support during their in-hospital recovery and described observing women's emotional reactions during this time.

The process of checking on the women following delivery was usually undertaken by the clinical geneticist, who would most often request psychological assistance during the women's in-hospital recovery.

Extract 170 *Connie (HSP10 public)*: After the baby's delivered and after I've examined the baby (.) I do go speak to the mom (.) because it's after delivery and she's quite traumatised, usually, I just check that she's generally relatively ok

emotionally. I usually try and refer to a psychologist as well (.) usually the psychologists do see the moms in the hospital ward.

Extract 171

Bettie (HSP11 private): We arrange it then for the people who are terminated here, Wendy [pseudonym] sees them here in the hospital (.) she is our hospital psychologist.

Connie indicates that she would routinely examine the baby following delivery and “speak to the mom” as she regarded the women as being “quite traumatised”. Psychological support would then be requested either directly by Connie, or “the gynaecologist”. The distinction between private and public healthcare services becomes apparent in Connie noting that in public healthcare, “I usually try and refer to uhm or ask the gynaecologist to refer to a psychologist”, while Bettie describes psychological support as standard in private healthcare: “We arrange it then for the people who are terminated here.”

The clinical psychologist, Xenia, in the extracts below, was the only provider who pertinently commented on her perception that the women wanted to speak about their experiences following the feticide and delivery procedures. However, she was also the only provider who commented on the women’s in-hospital recovery context and the impact this could have on her emotional experiences.

Extract 172

Xenia (HSP9 public): Most of them [women who underwent feticide and LTOP] want to talk and they will (.) but they will be a bit reserved (.) but then they will begin to talk. I have never had one who said, “No, not at all” (.) so all of them want to talk.

Extract 173

Xenia (HSP9 public): Because in the beginning it was quite upsetting for me. When you walk in there [maternity ward] now here lie four mummies and there are two babies in that room (.) and this mom just lost her baby (.) and that really upset me quite a bit because how can you let this patient lie there amongst them? I also asked the nursing sister about this and she said but the patients choose (.) because they know the other mummies already [and] they [women who underwent feticide and LTOP] don't want to [be in a single room] so in a certain sense although they experienced the loss, there is support from the other mummies.

Xenia assumes that women who had just delivered a stillborn, would be upset sharing a ward with mothers and their babies. However, she “realised”, and was informed by the nurses, that the patients chose to do so due to the “support from the other mummies”. It is significant that the only provider to comment on the impact of women’s environment during their in-hospital recovery, was the clinical psychologist, who is trained to view women holistically and systemically. The nursing sister insisting that the women choose to stay in the maternity and labour wards is somewhat at odds with what some of the women participants told me (see Melissa’s Extract 137). It may instead be a further manifestation of the silencing women described earlier, particularly within the public healthcare setting, where they do not feel able to raise concerns, complaints or requests to hospital staff. Nevertheless, the support of other

birthing women may be important to some women undergoing feticide and LTOP, as seen in Mpho's Extract 137 above.

Indeed, emotional and psychological support represented an important aspect that providers constructed as having an impact on women's experiences of the procedures. The amount and availability of familial support during in-hospital recovery was regarded as extremely important in how women experience these procedures. Providers constructed the physical presence of supportive individuals in the medical setting during and following the procedures as helpful in reducing negative patient outcomes.

Extract 174

Xenia (HSP9 public): If they [woman's relatives] can manage to then they come in the afternoons and they come to visit but those are usually the patients whose families live nearby. The other patients really struggle (.) because they lie there (.) sometimes due to the other complications and so they lie there for a long time (.) and then their family is in [another town] or they are far so they have a hard time.

Extract 175

Annie (HSP1 public): When the moms go through this alone it's much harder (.) and you almost feel that you need to support that person from your side more (.) and you need to do more because they have no-one else.

Xenia compared the experiences of women who had familial support physically present during and following the procedures to those who endured the procedures alone: the latter "really struggle". Once again, women who have access to the required resources are able to

enjoy the in-person family support during their in-hospital stay. Annie took the position that it was the providers' imperative to step into the supportive role when the woman's support structure was not present following the procedures "you need to do more because they have no-one else". Annie's position – healthcare providers stepping in to provide psychological support – is not always tenable, however, as seen below.

Extract 176

Maggie (HSP12 private): We had a woman who had to terminate a while back [with] quite a huge abnormality (.) that woman was broken (.) she didn't want to talk to us. She closed her door [and] turned off the light (.) and the labour part was also not nice for her (.) it was a difficult labour (.) it was really bad. My heart broke for her.

Maggie refers here to a woman who completely cut herself off from any attempts at psychological support from staff ("didn't want to talk to us"; "closed her door"; "turned off the light"). While Maggie had empathy for the woman ("heart broke"), she nevertheless (it seems) respected the woman's decision.

Some providers contrasted women's responses with those of their spouses, partners or close family members. Providers constructed husbands or partners as being largely unseen during the feticide and LTOP procedures.

Extract 177

Bettie (HSP11 private): I say to them: "You're the woman, you feel it in your body, you have to go through this, but your husband suffers double as much because he sees

you suffer and the baby (.) and he must protect you (.) and it's his child and he must be strong and he doesn't work through the trauma and that is the problem."

Extract 178

Peter (HSP3 private): I also give a little Dormicum [conscious sedation] or so before the time to calm them [women] down (.) but you know then the father sits in (.) but there's no Dormicum for him because he has to take the wheel [drive them home] afterwards. Sarah [receptionist; pseudonym] often says she is actually more worried about the men often times. You know because they must keep their pose and do the practical things (.) but it also affects them.

Bettie constructed women as being at an advantage in terms of recovery due to their embodied experience of the feticide, viz. "you feel it in your body", and added that women "have to go through this", suggesting that it is women's fate. Her statement, "but your husband suffers double as much" drew off a "strong man" social construction of fatherhood and masculinity in which men must "be strong" and "protect you". Peter's rendition drew of a "stoic" construction of masculinity ("because they must keep their pose and do the practical things"). He noted that women were sedated, whereas their partners had "no Dormicum", suggesting that the partners' experiences were not eased in a similar fashion. These requirements are positioned as preventing partners from working "through the trauma". While these concerns for the wellbeing of a male partner are not misplaced, they may serve to re-entrench gendered power relations, which are not necessarily healthy for the women who are recovering from feticide and LTOP.

The experience of feticide and then delivering a stillborn fetus was regarded by providers as a stigmatising and embarrassing experience based on having failed as women and as mothers to produce a normal living baby.

Extract 179

Amy (HSP5 private): A while ago the *Lancet* magazine did a ream of articles on stillbirths and the social stigma that women feel through stillbirths and all of that. I've always thought one of the reasons why people don't do a feticide is to deliver a live baby is maybe socially more acceptable than to deliver a dead baby.

Extract 180

Zelda (HSP2 public): I think there is embarrassment. [Women feel] I failed so it's that guilt feeling of: "I could not have a normal baby" instead of realising but actually it's not your fault. I think the guilt feelings are point one: "I made an abnormal baby" and point two: "I got rid of my abnormal baby."

Amy discussed an article that led her to perceive hesitancy to terminate a pregnancy via feticide as being associated with women's attempts to avoid the social stigma attached to delivering a stillborn baby. She went on to note that delivering a live baby "may socially be more acceptable" than delivering as stillborn. Perhaps birthing a stillborn fetus/baby is particularly difficult due to the implication that the woman had failed at her 'most important' function – which is to procreate successfully. Consequently, she may experience shame at her inability to perform these biological functions and having failed to achieve 'motherhood' status. In the above excerpt, Zelda constructed women's emotional responses to having undergone feticide and LTOP and delivering as stillborn fetus/baby as "an embarrassment"

and a failure (“I failed”). Zelda went on to note that women probably experienced feelings of “guilt” due to having terminate the pregnancy (“got rid of my abnormal baby”), but also feeling guilty for having (“made an abnormal baby”). Guilt, shame and embarrassment are powerful social tools used to stigmatise women who fail to meet the socially constructed standards of “womanhood” and “motherhood” and serve to be distressing or unpleasant enough, that women choose instead to comply with these expectations.

10. Conclusion

This chapter presented the results of data analysis relating to the second phase of the theory: women’s experiences of the feticide procedure and the delivery of the fetus/baby, as well as women’s in-hospital recovery from these procedures. Significant themes emergent from this chapter include the pivotal influence structural inequality has on women’s experiences of these procedures, as women in public healthcare settings effectively lose their voice. Women in private healthcare have greater room for exercising their agency and expressing their needs, although the medical system is not always responsive to this. Listening to women, actually hearing their voices and respecting their decisions presents such a simple act, yet the absence of these approaches to providing women with reproductive healthcare results in dire physiological and psychological consequences. In the final results chapter, women’s experiences of their recovery following being discharged from hospital, will be presented, along with providers’ perspectives on these experiences.

CHAPTER 7: PHASE III: WOMEN'S OUT-OF-HOSPITAL RECOVERY

This chapter presents the final phase of women's experiences of feticide and LTOP: their out-of-hospital processes. The first section focuses on women's experiences of their recovery following their discharge from hospital and the second section presents providers' perspectives on women's recovery. In conclusion, women and providers' experiences of the interview process are presented in order to contextualise the interviews and facilitate the discussion presented in the concluding chapter of this thesis. In this chapter, I present findings of women's experiences of their out-of-hospital recovery. These experiences include: women self-silencing, stressful partner relationships, a lack of understanding for women's experiences and women finding distraction from their thoughts and feelings as helpful. Further, women are required to carry on with their lives, performing rituals and both avoiding and keeping reminders of the feticide and LTOP procedures. Women recounted that during this recovery phase, they feel fear of repetition of fetal abnormality in future pregnancies, as well as immense longing for the baby they lost. Although some women feel as though they are going mad during this phase, most feel that they experience personal growth due to having survived such difficult circumstances. I conclude this chapter by presenting findings related to the providers' perspectives on women's recovery once they are discharged from hospital. This section includes perspectives on the importance of burial for closure, concerns regarding the implications for future pregnancies and the lack of familial and institutional support women receive during this phase.

Women's Experiences

During their recovery following hospital discharge, women related a number of themes that constructed their experiences. These themes include being self-silenced, experiencing difficult partner interactions, experiencing a lack of understanding from others, and wanting to be distracted from their thoughts. Themes also related to getting on with life, performing rituals, avoiding reminders of the feticide and LTOP and fears regarding subsequent pregnancies. One participant described feeling as though she was “going mad”, while, in contrast, a number of women related their experiences of “growth” following these experiences.

1. Self-Silencing

Women described different reasons for self-silencing during their recovery from the feticide and LTOP procedures. Guilt feelings emerged as a significant deterrent to discussing these experiences with others.

Extract 181

Janet (W8 private): Obviously, it's the guilt feelings (.) that's what I must say (.) for me it would have been (.) if I don't want to talk about it, it is because I am still too sad. Because I don't want to open up all the old wounds (.) and have all of these memories back and all those things. Then I don't want to talk about it (.) but of course a person doesn't want to [talk about it] because you already feel guilty [and] you don't want to feel judged [pause]. If I had not wanted to talk about it, then it would have been because I don't want to open up all these old wounds (.) and because I

don't know (.) because to talk about it is (.) you must think about everything again (.) and all your feelings come out again and so on.

Extract 182

Fay (W7 private): And in fact most of them [social network] I did not really tell. Most of them (.) I didn't go into detail about what happened exactly or what. They just know I lost a son (.) how, or what or where [they don't know]. The only people I shared the information with was my brother and sisters (.) and then his [husband] brother and sisters and mother. The rest of them they just know that we lost a son (.) but nothing more (.) and the only other person was the pastor (.) because before I went away there [leaving home to travel to undergo the feticide] I had to tell him exactly how I was feeling and why I was doing this.

Janet repeatedly described not wanting to “talk about it” due to feeling “guilty” and as a powerful defensive strategy to avoid feeling “judged” by others. Janet also explained that her reticence to “talk about” these experiences was “because I am still too sad”. Self-silencing appears to be associated with attempts to avoid revisiting the “memories” and opening up “all these old wounds”. Janet noted that talking about it would make her think about the experiences again and then “feelings come out again”, which is what self-silencing attempts to avoid. Self-silencing frequently entailed partial disclosure of the feticide and LTOP during the recovery phase. Fay recounted in the extract above that she “did not *really* tell” (my emphasis) people other than her immediate family what happened. Instead, the termination is constructed as the loss of a child: “we lost a son” and “nothing more”. Fay related a kind of confessional to her pastor, where she told him “exactly how I was feeling” and explained, “why I was doing this”. Silence is employed selectively, as women decide *who* receives *what*

information, and functions to protect the woman (from exposing a potentially judged or stigmatised experience), but also to protect those around her. Disclosing her experiences entails many disturbing descriptions, including fetal abnormality, terminating the pregnancy and the incumbent loss, and may be overwhelming and even shocking to hear. Silence thus serves to protect both the speaker and the listener in these circumstances.

The potential for stigmatisation when silence is broken and people find out is painfully illustrated in Mpho's story below.

Extract 183

Mpho (W5 public): I was told after I was discharged here [tertiary public hospital] after one week [that] I must go to the nearest clinic. I took that paper [referral note] they had given me (.) one of the nurses saw that I didn't accept family planning (.) because now what am I planning? That nurse she broke my heart (.) she told me, "Now you see, you don't want to have family planning then you just go and get another baby, then it is like that [the abnormal fetus she terminated] an abnormal baby" (.) I ask myself: "Is she God or why is she telling me like that?" I felt SO bad (.) and sometimes I ask myself: "Why didn't I talk to that nurse?" I just kept quiet. "Why did I not confront that nurse?" Because I could have helped many people (.) maybe they come to her and she just [says things] to break their hearts because [at] that time I needed someone to tell me: "Don't worry".

During the recovery phase, women in the public healthcare system were advised to follow up at various providers, as Mpho explained in the excerpt above. Women in private healthcare would follow up with their obstetrician-gynaecologist at six weeks and their further

reproductive health would be managed by this specialist. Women in the public healthcare system are required to follow up at six weeks and may be seen by a different obstetrician-gynaecologist, depending on who is available that day. Following this appointment, they are “down” referred to their local primary healthcare clinic. One week after discharge, Mpho had to report to her “nearest clinic” and she did not elaborate as to why she had been required to attend this appointment; however, it appears that the appointment had been made for contraceptive healthcare. She indicated that she did not “accept family planning” during this consultation, and the nursing sister berated her for this, and blamed her for having “an abnormal baby”. Mpho experienced this interaction as making her feel “so bad” and she disclosed self-reproach for having “kept quiet” and not confronting the nurse for her lack of sensitivity. However, this kind of silencing in the face of healthcare provider insensitivity is common, with those confronting providers being the exception within the healthcare provider: patient hierarchy. Significantly, Mpho was not only upset that she did not stand up for herself, but also that having addressed the offensive interaction, she could have “helped many people”.

2. Stressful Partner Relationships

During the recovery period, women recounted difficulty in communicating with their partners – this was a dominant theme. Silencing infiltrated these relationships following the feticide and LTOP procedures. Melissa described her fiancée as “very private” and “not one to talk about his emotions” or things that “are bothering” him. She went on to recount her attempts to “talk if something is bothering you”, but she added that she had learnt to “leave him” if she noticed something “bothering him”. Communication appears to take place according to unspoken rules, where certain ‘sensitive’ topics were to be avoided, while practicalities

related to burial etc. were permitted. Men determine what may be discussed and what should be avoided, even though women construct communicating about emotions and grief as topics that *should* be shared.

Extract 184

Wilna (W11 public): It's something we don't talk about anymore. There are many things that we don't talk about anymore (.) we really don't talk about this at all anymore. The other day he [husband] said I must go and put up the tombstone [for the baby's grave]. That is all (.) we have never really spoken.

Extract 185

Lelanie (W12 public): My husband (.) it's not that he is not interested (.) it's just that he said that I was doing it for myself. So I don't know what to say to you (.) because, for me it went about my child. I need to grieve (.) I must get it off myself (.) because it will bother me the whole time (.) and for him it was different. I can't tell you if it was a big deal for him or not (.) I really can't say because he doesn't show me anything.

Wilna noted, "we really don't talk about this at all". She described that their only interaction regarding their lost baby was related to practicalities such as putting up "the tombstone". The implied disappointment and frustration at their partner's lack of emotional and communicative engagement during their recovery permeates Wilna's and Lelanie's excerpts. The primary obstacle to communication was constructed as being due to gendered differences in how men and women experience and express their emotions. Lelanie and Wilna described feeling lonely in their grief, as their partners avoided the emotional intimacy that sharing

grief requires. During Lelanie's interview, she defended her husband by stating that "it's not that he is not interested"; however, she then added his accusation that she was "doing it for myself" when she decided to terminate the pregnancy. What is significant is that women describe themselves as having been changed and greatly affected by the feticide and LTOP experiences, whereas their partners had either not changed or been affected, or had kept these changes hidden. Men appear to be utilising silencing as a defence against displaying vulnerable emotions such as sadness and grief.

Melissa described the same lack of communication, but also that she confronted her partner about this.

Extract 186

Melissa (W6 public): He's [partner] not one to talk about his emotions (.) and he is very, very private (.) and doesn't easily talk about whatever is bothering him. He will keep it in and keep it in and then when the bomb bursts, then I want to run away (.) but luckily it happens very seldom. I told him: "Don't try to bury this (.) don't do what I did in my younger days. I kept it [emotions] in and kept it in and kept it in and then when it exploded (.) it was ugly." I told him: "Please talk if something is bothering you." And it is going better. [He] doesn't talk about everything that bothers him and I have also learnt to leave him (.) if I see something is bothering him then I leave him.

In this extract, Melissa initially positioned her partner within the "stoic masculinity". For things to get to the stage of "going better", she needed to do the emotional labour of asking him not to "bury this". While things did improve it seems, she still takes on the emotional

responsibility of checking if “something is bothering him”, at which stage she leaves him alone. Jasmine’s account of her recovery was underpinned by ongoing abuse.

Extract 187

Jasmine (W4 public): Everyone told me my boyfriend would change once he has his own son. He hasn’t changed (.) I kept on [stayed in the relationship] I kept on coming back. I started thinking maybe something’s wrong with me because I keep on coming back even though I know I get treated like dirt...

It is apparent that emotional disconnection occurs between the partners; however, Jasmine described her relationship with her boyfriend as abusive. Following the feticide and LTOP she gave birth to a healthy son, which she had hoped would “change” her boyfriend. Her statement that “I kept on coming back” suggests self-reproach for not leaving him even though she was “treated like dirt” by him. Melissa notes that when her partner does express his emotions, it is explosive and possibly scary to witness (“I want to run away”), while Jasmine described her boyfriend as overtly abusive. These constructions depict women experiencing male emotion as either absent, detached or volatile and dangerous. A striking point is that Jasmine blames herself for “coming back” rather than taking the viewpoint that her boyfriend is inherently abusive and obviously to blame, instead she seems to continue to hope that he would change.

3. Navigating a Lack of Understanding

Women presented experiences related to “being misunderstood” during their recovery. The lack of understanding toward their personal and collective experiences as women emerged as a significant source of stress.

Extract 188

Emma (W9 private): You know for me this is why this world is ruled by men (.) because we lose power. There are so many quiet suffering women. It's suffering! How are we going to do it [change things]? I don't know how we're gonna make it? You lose power. Total power (.) because people don't listen to you when you're crazy like that. You're mad (.) you're hysterical. Yeah. You shouldn't complain (.) [shouldn't] think about it.

Emma verbalised her frustration at the world being “ruled by men” causing women to “lose power” during their recovery from late pregnancy loss and LTOP. She referred to the silencing women experience “so many quiet suffering women” and expressed her hopelessness about changing these gendered experiences – “How are we going to do it?” Emma had attained the highest tertiary education among the women participants and was employed within the antenatal healthcare sector. Consequently, she was more vocal and comfortable in commenting on structural and gendered inequality within society than women who had not been exposed to these viewpoints. She went on to describe her experience of losing “total power” due to being ignored, “people don't listen to you”, when women express their experiences in manners that society constructs as “crazy”, “mad” and “hysterical”. She concluded by noting that women are taught not to “complain” and not to “think about it”.

Emma's excerpt below is a powerful statement, speaking to the gendered nature of the recovery process and how women are easily depicted as overly emotional and hysterical.

Emma went on in the second extract below to reflect on the six-week routine follow up appointment with treating providers as being too soon for most women to be referred for psychological intervention: "it's too early".

Extract 189

Emma (W9 private): They [women in the pregnancy loss (including LTOP) support group] go through the social worker/psychologist and there is a six-week appointment post loss. And at that six-week appointment it might be where you already want to [receive] support, but I found that it's too early. Six weeks (.) six months is still early (.) and a year was (.) "I don't know what I'm gonna do with myself now!" I remember how I felt: "I'm a danger to my life, because I'm so desperate. And I don't wanna go and tell it to a psychologist." So I'd lock myself in my car or wherever I knew that nobody could hear me and I would scream and cry and tell things and say horrible things. It's very lonely. Yes (.) that's it. Lonely.

Emma went as far as stating that even "six months is still early" and indicated that she had only felt ready for psychological support "at a year". Emma described her emotions at one year following the "loss" as "desperate" and "a danger to my life". It is significant that she also stated that she did not want to consult with a psychologist. Instead, she would "lock myself in my car" and "scream and cry" in a space where she was actually still silent – alone where "nobody could hear me". Unsurprisingly she described this time as "very lonely".

Once again, Emma expressed a lack of understanding of women's experiences during recovery on behalf of providers as well as women's support structure.

This lack of understanding extended to women's family members as well.

Extract 190

Patricia (W2 public): My mom explained to them [her other two daughters] but she didn't tell them what are the reasons [for the pregnancy ending]. I don't think they are going to understand.

Patricia explained that she had not disclosed to her other daughters the reasons that her pregnancy had ended, as she felt that they would not "understand". Women dealing with this "disenfranchised grief", where, due to stigma attached to abortion and disability along with their having "chosen" to end their pregnancy, appear to have nowhere to go with their emotions. Even their own existing children may not understand why they had decided to terminate their pregnancy. This experience of having their emotions invalidated or even ignored may cause women to question their own sanity – whether their perceptions of what they were experiencing were even true. The "hysterical woman" is usually blamed for her circumstances and reactions, shunned for them and in turn ignored or banished until she is "calm". Consequently, it is understandable that women would hide their strong emotional responses and fear "going mad" as well as choosing to keep the source of their distress secret.

4. Needing Distraction

In order to manage ruminating about the feticide and LTOP, women described preferring distraction to being booked off work for extensive periods of time.

Extract 191

Melissa (W6 public): I was booked off until the 16th of September. [crying] On the 8th I phoned my boss and told him that I cannot sit at home anymore. They brought all my files to my house (.) then I crawled around on my knees [working] (.) then he [employer] told me that I could go back [to work] on one condition: “You are not allowed to carry anything”. And this that they [providers] book you off for so long as well (.) that makes you crazy.

Extract 192

Patricia (W2 public): I was supposed to take four months [leave] but because the baby was not alive (.) I only took a month. I also wanted to go to work because I [did not want to] be alone at home [because] it was stressing me (.) so I wanted to [be] with people. I was thinking about the process [feticide and LTOP] that we went through.

Melissa reported that she had requested to resume work earlier, because being booked off “for so long” had made her “crazy”. Patricia similarly experienced wanting to return to work earlier, following the procedures, in order to avoid being alone and “thinking about the process”. Wanting to “go with people” emerged as important for assisting women in being distracted from their thoughts and emotions. Women were able to “forget” about their

experiences when they returned to routine and normalcy at work, among colleagues who mostly were unaware of their experiences. This affords women space to avoid the confronting thoughts and emotions following feticide and LTOP, and in this sense, the “silence” of their experiences being unacknowledged or ignored and normal work duties continuing, affords women breathing space during their recovery.

5. Getting on with Life

In line with needing distraction, women described life continuing following the procedures.

Extract 193

Fezile (W10 public): That’s not the end of the world [the feticide and LTOP] (.) now I think I’m fine.

Extract 194

Lelanie (W12 public): I just wanted it over and done with.

Importantly, here, however, they spoke of needing to take moments where they could spend time grieving for their lost child.

Extract 195

Janet (W8 private): But to be alone and grieve a little or whatever (.) because your whole day is so busy and a person also has to go on [with life]. I can’t be sad all day. I have a child to think of (.) I must (.) life goes on (.) I have to get up and go on. It’s not nice if someone is depressed the whole time and cries and carries on [cries]. The

people around them (.) eventually you think: “Really?” ((questioning why the person is still actively grieving)). People don’t want to be around you anymore.

Janet described taking time to “be alone” and “grieve a little”. She noted that her “whole day is so busy”, referring to the demands the other people and components of her life placed on her (“I have a child to think of [existing child]”). Women recounted feeling unable or not allowed to “be sad” as “life goes on” and being “depressed the whole time” would result in being isolated by her social circle, as they “don’t want to be around you anymore”. Women were expected to continue with the daily duties and relationships for which they were responsible, without much space for their emotional or other reactions. Consequently, women were prone to minimise their grief reactions during their recovery. The burden of childcare and household chores, along with work duties, leaves little room for women to take up the space in their own lives in which to mourn and “indulge” in grief-related activities. There is also a sense that their support network would quite quickly become annoyed with these expressions of grief. Although women serve and sacrifice in order to carry the many burdens of care they carry, there is little reciprocal emotional and practical support provided them.

6. Performing Rituals

During their recovery, women often reported finding value in holding a ritual in order to symbolise and concretise their grief and loss.

Extract 196

Lelanie (W12 public): I did my own memorial service on my own, for myself. I felt much better afterwards (.) I had my own ceremony in my bedroom for her. I lit candles (.) I put rose petals all around (.) I opened the Bible on Psalm 23, with a cross in the middle and then I played that song by [the well-known singer] ‘Amazing Grace’ (.) and then I prayed and then I spoke with her [terminated fetus] and stuff. And then I was finished and I felt better.

Extract 197

Patricia (W2 public): It was a small gathering for the family. We did things differently because she arrived at home around two o’clock and in our culture (.) we didn’t take her to a mortuary. We bought a casket for her and then we took her to the graves. It was only family [who attended] (.) from my husband’s side and at home. She was young [and] in our culture she wasn’t known (.) actually I believe in Ancestors (.) we are a very cultural people at home [laughs]. We do make the feast (.) we’ll slaughter chickens [and] the sheep to please our ancestors (.) I’ll go to her [demised fetus] grave and talk to her.

Extract 198

Wilna (W11 public): I still think about the child a lot, but we buried the child, he lies in the graveyard.

Extract 199

Janet (W8 private): Well they asked me if I wanted to bury her and they kept her for me, so that was amazing for me...

Angie: Do you ever go to the grave?

Janet (W8 private): Yes, I, (.) it is so, it is actually very close to our house and so on, so yes, (.) but I prefer to go alone. I don't want to take along other people and so on. It is a bit... But, yes. I just sit there and think to myself about things.

Lelanie recalled holding a memorial service “for myself” and she felt “much better afterwards”. Symbolic objects such as “candles”, “rose petals”, “the Bible”, “a cross” and a specially chosen song facilitated these rituals. She included religious beliefs and rituals as she “prayed” and then also communicated with the lost child, “I spoke with her”. Similarly, Patricia found value in holding a small burial and “cultural” rituals such as the “slaughter” of “chickens” and “sheep” in order to “please our ancestors”. Patricia explained that in her “culture”, they did not take the baby to the mortuary, but instead buried her themselves with only a small gathering of family, due to her having been “young” and not “known” by the community. She also described her beliefs that her baby was now an Ancestor and how she found having a grave or burial place helpful for her to visit and “talk to her”. Rituals which include “cultural” and religious enactments and symbols were constructed as providing women with a sense of closure and facilitated their being able to maintain a “relationship” and talk to the lost child. Lelanie’s ritual, however, is a lonely one, while Patricia is able to draw on social symbolism and to share the ritual with others.

7. Avoiding Reminders/Keeping Reminders

During the course of an advanced pregnancy, multiple assumptions, plans and constructions related to the potential child are formed. During the recovery phase, women are confronted with a multitude of reminders of the life they had anticipated and lost. Certain women

regarded mementoes as comforting, while other women reported experiencing distress at (and “triggering” by) reminders of the procedures.

Extract 200

Fay (W7 private): And whenever I walk around, I always have the sonar [of the demised fetus] [printout]. I always have it with me wherever I go (.) it’s always in my bag.

Extract 201

Fezile (W10 public): I even took some pictures (.) which I deleted I think two years back. I decided I can let go of it now.

Fay spoke of keeping the sonar image in an intimate space (her bag) that goes everywhere with her. Fezile similarly kept pictures, but expressed not needing them anymore. In contrast, Melissa found reminders distressing.

Extract 202

Melissa (W6 public): I had a very unpleasant experience [the wound is like] a shop hook (.) all crooked [and] not nicely next to the other scars [previous caesarean section scars]. The first two are exactly basically over one another (.) this one comes here [showing on her body] sort of past it. I try not to look at my stomach (.) it reminds me of it [the feticide and LTOP].

Extract 203

Melissa (W6 public): And it was very difficult for me to walk into a shop (.) I hated going to the clothing stores because the baby things are always right in front of you. I could not handle it. When I walked in there, I would automatically start to cry. (.) the tears flowed. Sometimes I'd walk in (.) start to cry and walk out.

Certain reminders would trigger “difficult” and upsetting reactions from some women. Melissa expressed even avoiding viewing her own stomach in order to avoid seeing the scar left by the LTOP. She also described being upset by seeing “baby things” in clothing stores. She would understandably then remove herself from the reminders, “I'd walk in, start to cry and walk out”. The embodied reminder is, however, impossible to walk away from, and requires active “not looking”.

8. Fear of Repetition

Due to the distress women endured throughout the various phases of the feticide and LTOP experiences, significant fear regarding future pregnancies was expressed. Women who did not already have children feared not being able to have a healthy child, while all women shared and expressed intense fear at having to go through another pregnancy of this nature again.

Extract 204

Wilna (W11 public): I told her [gynaecologist] to snip me [sterilise] then she said: “What if you meet someone else and he wants a child?” Then I told her: “I am not

going to have another child again because I don't want to go through this drama again."

Extract 205

Lelanie (W12 public): I'd like to try again [another pregnancy] (.) but at the moment I'm not allowed to become pregnant with the operation and stuff [having benign tumour removed]. I told my husband: "Let's first see how I progress and if I get healthy and if everything is alright then a person can try again (.) but while I drink this medication (.) I don't see myself going through this again, having another child like this (.) I'm sorry. It's not about just the child, it's about the situation that the child suffers. I don't want to go through that ever again." I said to him [her husband]: "I want to be healthy (.) everything must be removed [tumour] I must be totally 100% healthy again before making decisions like that."

Wilna recounted a provider being resistant to her request for sterilisation due to a potential future partner's desires. She demanded to be sterilised because she did not want to "have another child again" because she did not "want to go through this drama again". Lelanie explained that she was "sorry" but that she could not go "through that ever again". She placed this boundary when discussing future pregnancies with her husband and clearly stated that she would only consider another pregnancy if she was "totally 100% healthy". Lelanie clearly regarded the decision regarding future pregnancies as hers to make – "before making decisions like that". Both women set clear boundaries in order to push back at and resist the social imperative to keep trying to produce a "successful" pregnancy or to fulfil the procreation needs of future and current partners.

9. Longing for the Same Child

In conjunction with the fear of recurrence of fetal abnormality, women also expressed an intense longing for not just another pregnancy or child, but the same baby that they lost.

Extract 206

Janet (W8 private): I want HER (.) and it must just be a little girl. It's a difficult one.
It wouldn't be the same again (.) it can't be.

Extract 207

Odwa (W1 public): I'd like to have one [baby]. If God will let me have my baby boy again (.) three [children] is OK for me. I want that baby back. [crying].

Extract 208

Emma (W9 private): I had started craving this baby. I was really mad (.) I was mad (.) you go mad (.) you know you really want (.) and it's a funny one that you want the baby again (.) you want the same soul again.

Janet emphasised her longing for that specific child that she lost, "I want HER" and then submitted to the reality that "it wouldn't be the same again". Similarly, Odwa related that she wanted "that baby back", her "baby boy". Emma stated that she had experienced feeling "mad" with "craving" for "the same soul". This is an important aspect to note during women's recovery. Whereas providers focus on the next pregnancy somehow being able to compensate for this loss, women constructed the feticide and LTOP loss as distinctive and the

pregnancy as ‘unfinished’. That specific child they had constructed would never be replaced by subsequent pregnancies.

10. Going Mad

Two of the women who participated in this research explained that they had experienced feeling as though they were “going mad” during their recovery.

Extract 209

Emma (W9 private): I could see that very often I would lose my mind. And I would scream and shout. Particularly when I was driving because I had to find a safe space for this (.) because I couldn’t share all the layers of events with many people. But actually (.) many people go through this [late pregnancy loss/LTOP] (.) but there’s nowhere where you can actually talk about it.

Extract 210

Jasmine (W4 public): With this pregnancy [subsequent pregnancy] I was put on medication to really calm me and take the [mental] pain away (.) and basically those things are the only things that kept me [alive] because he [her boyfriend] would [inaudible]. But I feel like that again where I feel I could just sit in a corner and just scream (.) like go crazy [crying] no one cares [crying].

Emma stated that she “often” would “lose my mind”, particularly when she was alone, in “a safe space”. These expressions of screaming and shouting would assist in expressing “all the layers of events”, which she felt unable to share with “many people”. The experience of

feeling mad or “crazy” was also expressed by Jasmine when she explained that she felt like she could “just sit in a corner and scream” because she felt like “no one cares”. Jasmine had been placed on “medication” to “calm” her and take her “pain away”. This experience of feeling “mad” relates to the description of women as “hysterical”, as was discussed already in this chapter. What is significant here is the reaction toward women’s “madness” or emotional distress, which includes medicating and biologically “calming” Jasmine. Emma touches on how women, when emotionally distraught, have nowhere to go with these emotions, particularly when this distress relates to reproductive health experiences. It is noteworthy that Emma found a space for women to share their experiences of LTOP and pregnancy loss in a primary healthcare (public) hospital support group, which she would go on to run.

11. Growing

For many women, recovery represented the transformation of trauma, loss and pain into strength and resilience. They had survived something that brought death into their body and grief into their lives. And yet these women persist.

Extract 211

Fay (W7 private): Then there came a time where I made peace with it (.) what I went through. It was a very, very difficult situation I went through (.) but then emotionally (.) it made me stronger (.) and I think it’s also made my faith stronger (.) I think for me it was painful (.) but it was also a blessing (.) because I have learnt a lot of things from the process that I’m going through.

Fay regarded her experiences of feticide and LTOP as “difficult”, in fact, “very, very difficult”; however, she also regarded these experiences as having made her “stronger” “emotionally”. Having made “peace” with the experiences served to make her “faith stronger”. She speaks to both internal processes – learning – and external processes – a “blessing” (one assumes from God).

One woman, Emma, joined a local support group for late pregnancy loss, which included women who had undergone feticide and LTOP, and was asked to run the group sessions soon after joining. Emma recounted the group sessions as “incredible”.

Extract 212

Emma (W9 private): I basically ran a support group meeting [for late pregnancy loss and LTOP] for about a year and a half (.) and that was incredible. I was like this listener (.) or sometimes I would share a bit of my story again. And I noticed how every time I told the story, I told a different part of it (.) and [found] a different meaning to it (.) and just by telling it and by having other women going [agreement] you know? Mother-to-mother kind [of interaction] you know? Because it was dealing with those mothers who get a little bit spat out of the system (.) because when you are in this state [pregnancy loss] you know you don't have a baby, so what? Off are you. Fall pregnant again. You're not a mum, or you can't be a mum. It really helped me with something. It put a bit of the grief somewhere (.) or released it (.) I mean it takes a lot of talking. It's a very visual trauma, a very visceral trauma. This is what I remember encouraging the ladies to talk about [their experiences]. What colour was this baby of yours? Was it smelly? You know all these horrible things that stick in your mind. You remember blotches (.) you remember death really. You know death is

such an ugly face (.) unless you're a lovely old person (.) you know it shouldn't be a [something] new (.) so it's the shock of what you see (.) and sometimes your ears. But it's more about the eyes. So this is it [women] retelling a story (.) and you're allowed to tell it in any way you like. That helps.

Emma shared parts of her story throughout the sessions, telling “a different part” with a “different meaning” each time. Significantly, she noted that “by telling it” and by having this “mother-to-mother” interaction, a space was created where women who had been “spat out the system” due to not having “a baby” could connect and feel a sense of shared community. The message that women perceive is that they are ejected from the healthcare system until they “fall pregnant again”. Disenfranchised grief may be expressed and validated in these shared spaces between women who regard themselves as mothers, although the healthcare system and society do not. In the excerpt, Emma described “a bit of the grief” being “released” during the support group sessions due to “a lot of talking”. She related the importance of encouraging the women to recount the “visual” and “visceral trauma” that the feticide and LTOP procedures entail. These sessions allowed women to share the “things that stick into your mind” such as the baby being “smelly”, having “blotches”, and the “ugly face” of “death”. The “retelling” of the “story” took place in “any way you like” and Emma regarded this as—helping - “that helps”. The significance of healing being found in using their voices and speaking about their experience cannot be overemphasised, particularly due to the silencing and isolation incumbent on the feticide and LTOP procedures. There is a great deal of power being reclaimed when women are free to talk about even the most ‘shocking’ or ‘disgusting’ aspects of their experiences without the threat of judgement or shame, but instead, by speaking, they encourage other women to speak too.

Providers' Perspectives

Providers described women's recovery from feticide and LTOP procedures in terms of the significance the losses may have for future pregnancies, the lack of familial support the women receive and the lack of institutional support available to women. The paucity of providers' discussion of women's recovery in and of itself is in itself significant and will be discussed in-depth in the final chapter of this thesis. It remains important to bear in mind that providers present their own direct experiences with the women during the procedures, rather than merely presenting their perceptions of women's experiences.

12. Closure and Burial

Women spoke about the process of (not) accessing fetal remains while still in hospital, and some included reference to burial rituals (see Patricia, Wilna and Janet's extracts above). Providers emphasised the importance of women being able to bury their baby, regarding these rituals as beneficial to their psychological "closure" of their grief process.

Extract 213

Xenia (HSP9 public): For anyone that [burial] is a closure process. So there are others that just say: "No, I'm going to bury my baby myself" and they do everything in their ability to get that money together (.) to transport that baby and arrange a funeral.

Extract 214

Zelda (HSP2 public): I mean it [burial] is part of your grieving process. (.) It is part of coping and saying goodbye and closure.

Extract 215

Mathuli (HSP13 public): There's a lot of families [who] want to bury the baby and that always makes me sort of feel like there's closure (.) because they are willing to go through with the burial.

Extract 216

Zelda (HSP2 public): I think in a Black population it is a lot more acceptable to lose a child. There are very few Black patients who have not lost a child. I think their sense of life after death is possibly a lot more established and actually acceptable and we talk about it and we know it is how it is (.) so you are not really losing that spirit [due to some beliefs about Ancestors].

Xenia described arranging “a funeral” as “a closure process” and Zelda (obstetrician-gynaecologist in public healthcare) constructed burial as part of the “grieving process”, assisting women in “coping”, “saying good bye” and experiencing “closure”. Mathuli (obstetrician-gynaecologist in public healthcare) stated that when the families were “willing” to bury the baby, the women experienced “closure” as well. Zelda’s construction of “Black” women being more “used to” their children dying is problematic due to Zelda’s positioning as a White woman. In her view, “very few” Black women had “not lost a child” and were consequently somehow “accepting” of child loss. Zelda explained that, in her perspective, Black people were buffered from the full extent of the loss due to their “sense of life after death” and that they consequently were not “really losing that spirit”. It is true that, due to the racial inequalities and discrimination in South Africa historically, Black children have

certainly been at greater risk of dying due to factors related to poverty, such as disease, malnutrition, crime and neglect. However, what is problematic is that Zelda's construction of Black women negates their individual lived experiences. As indicated in the extracts, however, burial requires both emotional ("willing to go through with the burial") and financial ("get that money together") resources.

13. Implications for Further Pregnancies

Providers emphasised the importance of women being able to experience subsequent safe/normal/healthy pregnancies and for women to retain their reproductive health.

Extract 217

Connie (HSP10 public): We [clinical geneticists] examine the baby after the baby's born to try and determine a diagnosis (.) the aetiology (.) the cause of the problems in order to give the mom closure and also to advise the parents in terms of future risks for [a] next pregnancy and so on.

Extract 218

Hugh (HSP8 public): "So why were you crying?" [during the six-week follow-up appointment with a clinical geneticist]. [Woman] pointed to her suitcase: "I came in expecting to be admitted and sterilised so that I can't have more children" (.) so it was just absolute tears of relief (.) that she came in and she got this totally different message that she wasn't prepared for: "There's help we can give you (.) we can offer you a lot of choices and things like that." And so it's sort of avoidance (.) but it's actually fear.

Extract 219

Amy (HSP5 private): She's going to go through [the] trauma of her second pregnancy (.) in my own mind (.) we [woman and her partner] would have known (.) we would have had closure. We would have had grief (.) we would have been stuck perhaps in some stage of grief. And the second pregnancy would have been perhaps traumatic in certain stages of that second pregnancy (.) but there would be an opportunity to move on.

Connie (clinical geneticist in public healthcare) explained that her role as a clinical geneticist included having to “examine” the baby following birth, in order to confirm the “diagnosis”. She invokes medical expertise as the arbiter of future pregnancies, establishing the “aetiology” and addressing “future risks” with regard to subsequent pregnancies. These “risks” are purely biological, however, with psychological, interpersonal and social risks not being discussed. During the six-week follow-up appointment with the clinical geneticist, Hugh (clinical geneticist in public healthcare) recounted an incident where the woman had expected to be “sterilised” during recovery from the feticide and LTOP. Instead, she received “a lot of choices” with regard to subsequent pregnancies, which brought her “relief”. Hugh presents his hypothesis that women avoid this six-week follow-up appointment due to their fear that the medical system has deemed them unfit to procreate and that they would undergo mandatory sterilisation.

Only one provider, Amy (fetal-maternal specialist in private healthcare), addressed the emotional impact a subsequent pregnancy could have on women who have undergone

feticide and LTOP procedures. The “second pregnancy” was constructed as being “traumatic”, but also assisting women in gaining “closure” following the “grief”. She went on to acknowledge that women may become “stuck” in “some stage of grief”. A subsequent pregnancy is also positioned as being “an opportunity to move on”. Due to the nature of their medical specialisation, it is understandable that obstetrician-gynaecologists focus on the next pregnancy as somehow being able to compensate for the trauma of the pregnancy that ended in feticide and LTOP.

14. Familial (Non) Support

In the absence of institutional follow-ups (beyond the six-week check-in), providers constructed women’s families affecting their experiences of the recovery process from the very beginning. Two themes seemed to recur here in providers’ constructions of post-hospital care, firstly, the involvement of children in the grieving process, and secondly, the negation of family support during out-of-hospital recovery.

Providers spoke of existing children as mitigating the need for the expected baby diagnosed with severe abnormalities or of them providing support in overcoming the grief.

Extract 220

Mathuli (HSP13 public): But of the mothers that feel that “No, I cannot carry this burden of this pregnancy, I already have five children, I cannot have a baby with severe abnormalities (.) I cannot afford this baby”. I have not seen a lot of them that come back with regrets.

Extract 221

Xenia (HSP9 public): I think it is more difficult if they don't already have kids. They will sometimes say: "You know, I have now lost this little one" and they are very sad about it. I mean it's not that they do not acknowledge that loss (.) but then they will say, "But at least I still do have this one and you know they keep me busy." But on the other side what is hard for them is that that little one had also looked forward to the brother or sister to come. So that is now difficult for them. If there is a brother or sister (.) because they had also anticipated [the birth] (.) but it's as though the other children are a sort of buffer. Perhaps a bit of an emotional buffer for them [women].

Extract 222

Maggie (HSP12 private): The one woman did (.) it was terribly beautiful (.) she has two children at home (.) and then this one with the abnormalities [that had been terminated]. Then she also filled in the papers [to have access to fetal remains] and she made a little casket. It was a small baby and the other two children (.) each one in the family put something special in the casket for the baby (.) with the baby and buried it on the farm and held a funeral.

Mathuli (obstetrician-gynaecologist in public healthcare) noted that women with existing children did not "come back with regrets" during their six-week follow-ups. Similarly, Xenia asserted that women who had existing children, although experiencing feticide and LTOP as "difficult", as having an "emotional buffer" due to existing children keeping women "busy". However, Xenia also acknowledged that the existing children would mostly also go through

their own “difficult” grief process. This “buffering” includes not only keeping the women busy, but also actively participating in the healing process. Maggie (nurse in private healthcare) described how some women included their existing children in their burial and rituals with regard to the demised baby. She explained that “each one of the family”, including the “two children”, participated by placing “something special” in the “casket”. The baby was then buried on the family “farm”, where the “funeral” had been held. Such women and their families are able to afford the costs involved with aspects related to this funeral and burial, which is noteworthy as Maggie describes this as the “beautiful” or preferred way to deal with fetal remains. However, women who are unable to even access fetal remains or afford the funeral and burial are no less poignant in their loss; rather they simply do not have the option of performing such a meaningful burial.

Family may comprise a very important source of social support for women during their recovery; however, their support can wane over time. There is little data emanating from the providers’ interviews with regard to family support during women’s out-of-hospital recovery. This may be due to the interactions between women and providers petering out after their hospital discharge, as many women do not attend their follow-up appointments.

Extract 223

Peter (HSP3 private): Especially a little while afterwards [during recovery] (.) initially everyone is (.) your friends and everyone [your family] (.) are with you in the thing. And then their lives go on and I think that (.) I can imagine that it is quite difficult.

Extract 224

Peter (HSP3 private): A person sees the family come back again [with a subsequent pregnancy] and it is going well again. And you can see (.) that scar lies there. I think that also helps (.) it helps me to think that you know what happens now [feticide] is terrible (.) but eventually, in the bigger picture [it gets better].

Peter (fetal specialist in private healthcare) observed that “lives go on” and that “friends and everyone” tend to provide less support as time progressed. Once again, the experience is described as “difficult”. Peter also explained that families do recover from the “terrible” experiences. “The family comes back” although with the “scar”, it usually would be “going well again”. Peter acknowledges the “scar” that stays there – referring to the grief and possibly trauma experiences which change those who experience them, permanently.

15. Institutional (Non) Support

Institutional support during women’s recovery from feticide and LTOP focuses on the six-week follow-up appointment, as well as psychological assistance. It would appear that providers’ interest in women ends at this point, which may be one of the reasons for the paucity of commentary made regarding women’s recovery from feticide and LTOP during provider interviews.

Extract 225

Connie (HSP10 public): On six weeks’ follow-up we usually discuss the findings [with the woman]. The clinical findings (.) the findings of the special investigations (.) and then discuss what we thought the diagnosis is. If we do have one (.) and then we

need a plan if they are going to have more children a plan for future pregnancies. And then usually I just do a quick screen with them with regards to depressive symptoms and then I refer to further psychological therapy if it is necessary (.) I usually then refer further for psychological therapy but it's not the majority [of women].

Extract 226

Xenia (HSP9 public): The services are available but if a person just had more extensive services (.) for example (.) I think it is hard for them [women] sometimes to speak via a translator (.) because there are societal factors that play a role much of the time (.) that causes them to suffer systemically.

Extract 227

Hugh (HSP8 public) A lot of them [women] don't come back to discuss the outcomes or anything like that (.) then they have recurrences. [They say:] "I've got an appointment for next week we'll come and see you and everything" and didn't pitch.

Extract 228

Hugh (HSP8 public): I've always sort of opened the door to say: "Yes please come back, we [are] giving you an appointment to come back" (.) but I've never chased up those [women] that don't come back. If we had more staff (.) or just less load (.) we would probably be able to then make an effort to say: "Hey, why didn't you come back? Are you alright?" And not let them sort of come back two or three years later.

Connie (clinical geneticist in public healthcare) recounted that the six-week follow-up appointment with the clinical geneticist would include a discussion of the fetal remains'

findings, “special investigations” findings and the “diagnosis”. This would also be the space where discussion regarding “future pregnancies” would take place, as well as screening for “depressive symptoms”. Women who required psychological support would then be referred; however, Connie noted that the majority of women would not be referred.

Xenia, as a clinical psychologist in public healthcare who treated the women during their hospitalisation, expressed her frustration at the lack of “available” psychological support services. She touched on the difficulties associated with language barriers and “societal factors” that caused women to “suffer systemically” and not have adequate access to psychological intervention during recovery. Whereas psychological support was regarded as “standard” in private healthcare, in public healthcare psychological support during recovery is challenging to access due to the staffing and resource barriers inherent to the South African healthcare system.

Women commonly defaulted on attendance of their six-week follow-up appointments, and Hugh expressed his frustration in this regard as the women then “have recurrences”. Reasons for poor follow-up will be explored in the concluding chapter; however, it is noteworthy that this occurrence is limited to public healthcare. None of the private healthcare providers described similar difficulties, which may indicate a structural cause for women’s lack of follow-up. Hugh noted that women would agree to attend and then just not “pitch”. He went on to reflect that perhaps some of the fault lay with providers and the system, as there are not enough “staff” and too great a work “load” which prevents providers from adequately following women up, once again indicating the impact of lack of resources on service delivery within the public healthcare system.

16. Conclusion

This chapter presented and described the most prominent findings around women's experiences of their out-of-hospital recovery. During this third phase of their feticide/LTOP experiences, women frequently imposed self-silencing in order to protect themselves from unsupportive reactions, particularly due to stressful partner interactions and the lack of understanding women perceive from those around them. Distraction from revisiting the feticide/LTOP experiences assisted women in managing distressing emotional reactions, as the lives of their family, women's work demands, childcare duties, etc. continue as normal, irrespective of their grief. Performing commemorative rituals, either alone or with family members and keeping reminders of their lost baby assists women in working through their grief, while they may continue to long for that baby. Women may avoid reminders of the feticide/LTOP procedures in order to avoid re-experiencing the trauma reactions associated with these memories and may fear that complications could occur in subsequent pregnancies. Some women felt as though they were losing their sanity during this recovery period, while most women constructed their experiences of undergoing the feticide and LTOP procedures as having stimulated personal growth. The amount and depth of the information women shared was in stark contrast to the paucity of reflection providers recounted regarding women's recovery. This may be largely due to providers' interactions with women tapering down or even ending, following the LTOP procedure. Providers' constructions of women's recovery from feticide and LTOP included emphasising the importance of women burying their baby in order to achieve some psychological closure. Concerns regarding maintaining women's reproductive capacity were prominent among providers, as well as possible implications for future pregnancies. Providers constructed women's family members as

providing inadequate support and women's access to institutional support as minimal at best.

What follows is the final chapter of this thesis, where the emergent theory on women's experiences of feticide and LTOP is discussed and presented.

CHAPTER 8: CONCLUDING DISCUSSION

The preceding three chapters presented the findings of data analysis emergent from interviews with women in order to explore their experiences of feticide and late termination of pregnancy. Providers' perspectives on women's experiences were also included and presented. In order to conclude this thesis, I present my findings as they relate to the research questions I endeavoured to answer. The primary research question for this study was: What are South African women's experiences of feticide and late termination of pregnancy due to the presence of severe fetal abnormality, as related by the women themselves and the health service providers who perform the procedure or provide care? The sub-questions that drove the study were: 1) How do the women relate their experience of the process of coming to the decision, undergoing and recovering from the procedure? and 2) How do health service providers relate the experiences of these women?

The rationale of this study was to add to the literature available in South Africa regarding women's experiences of feticide and LTOP from a feminist perspective, and to include health service providers' perspectives in contextualising the findings. The data included in this study were gathered from women and providers across South Africa and across the private and public healthcare systems. In order to develop a theoretical understanding of women's experiences, a social constructionist grounded theory methodology and theoretical approach was used, and the data viewed through a feminist lens. These data were analysed and presented in the three preceding chapters and divided into three phases as emerged from the data. These phases include phase one, hearing the diagnosis and the decision-making process; phase two, women's experiences of feticide and LTOP procedures and in-hospital recovery; and phase three, women's recovery from these experiences.

The purpose of this chapter is to integrate the analysis chapters (Chapters 5, 6 and 7) into theory that provides an account of South African women's experiences of the decision-making process related to feticide, the feticide and LTOP procedures, and of their recovery. The review of literature presented in Chapter 2 underscored the paucity of research regarding feticide and LTOP and, in particular, the lack of qualitative studies on South African women's experiences in this regard. Chapter 8 seeks to situate the themes that emerged from the interviews in relation to the existing knowledge on women's experiences of feticide and LTOP, and to argue that the theory developed from this study contributes significantly to new understanding of these experiences.

I start the chapter with a brief summary of the findings as presented in the last three chapters. I then move on to an integration of the findings. This integration is guided by the following key questions which provide the foundation for the grounded theory on the impact of structural inequality on women's experiences of feticide and LTOP presented in this chapter: What social issues underpin the women's and providers' narrated experiences of feticide and LTOP? How do these issues intersect to construct different experiences of feticide and LTOP?

What is clear from the accounts presented in this thesis is that there are both similarities and differences in the experiences. The similarities, with no exception, centre on loss and trauma. Loss of a wanted pregnancy and anticipated child was common for all women participants – a loss of which providers are well aware. Trauma centres on the emotional loss, the physical invasion of the body to carry out the feticide and the extraction of the fetal remains. Surrounding this trauma and loss, however, there is no singular story, but multiple ones that

are shot through with different accounts of interactions, structural and social support, assumptions, ideologies and norms. In this integration, I highlight four axes that intersect in framing the experience of feticide and LTOP.

1. Summary of the Phases

The first phase of women's experience of feticide and LTOP starts with women being informed of the fetal abnormality. This study's findings suggest that, upon receiving the fetal diagnosis, women may experience a jarring alteration in their relationship with their pregnancy, akin to "something died inside", which leads to emotional shock and, in some cases, suicidal ideation. Swiss researchers Fleming et al. (2016) affirmed that the fetal abnormality diagnosis once disclosed, caused women and their partners who participated in their study, to experience shock, confusion and helplessness. The findings of my study indicate that these reactions were followed by women constructing explanations for the cause of the diagnosis. These included their own behavioural culpability, such as failing to undergo traditional rituals or being punished for perceived sins, as well as biological culpability, for example being of advanced maternal age. The failure of health service providers to provide antenatal vitamins or to warn against particular medications also featured.

Next, women were confronted with the decision-making process regarding whether or not to terminate their pregnancy. During this phase, women constructed the decision-making process as difficult and conflicted. Essentially, women constructed the decision-making process as entailing no choice at all. "Decision paths" are either made available to women or not, depending on the resources available to them (Mavuso et al., 2020), which includes the desirability of continuing with a pregnancy, the outcome of which would be either a baby

with severe disability and/or an extremely limited lifespan, or one who requires intensive medical and other resources due to severe abnormality. Women constructed providers' and others' input during this phase as either supportive or non-supportive. Support was said to come mostly from women who had gone through the same or similar experience, but for the most part, silence and judgement were expected and experienced. Women responded to these reactions with non-disclosure or partial disclosure and re-storying of their decision. Providers' input during the decision-making phase was perceived as including coercive warnings, denigration as well as supportive content.

Healthcare providers' perspectives on women's experiences during the decision-making phase included women's emotional reactions of anger, denial, threats, as well as ascribing culpability for the fetal abnormality, and a lack of understanding. Providers also regarded relief as a possible reaction that women may experience upon receiving the news of fetal abnormality, particularly in cases where the woman had not been able to access elective abortion during that pregnancy. However, this was not a theme that arose from women's interviews I conducted. In fact, all of the women who participated in this research regarded their pregnancy as wanted, even if it had been unplanned.

Providers constructed the constraints on the decision-making process as including their own recommendations being filtered through legal and constitutional parameters, hospital panels' recommendations, pre-established guidelines, high-level medical teams, as well as providers' own personal ideologies regarding abortion. These panels, teams and guidelines provided some comfort to the providers in the decision to offer feticide and LTOP, but often imposed limits not outlined in the CTOP Act. Time limitations were prescribed upon the decision-making process by the poor antenatal and sonography services available to women in South

Africa within the public healthcare system, as well as women's late presentation for antenatal care, time-consuming diagnostic tests, and gestational limits (imposed by guidelines and panels, not the CTOP Act). Providers judged the wisdom of women's choices as "wise" or "foolish" regarding feticide and LTOP based on providers' personal ideology, the medical and systemic implications of caring for severely disabled children, and the age of the woman.

The second phase of this theory relates to women's experiences of the feticide and LTOP procedures and includes women's experiences of their body being worked on during the feticide procedure and subsequent delivery. The feticide was characterised by grief reactions and embodied stillness. The moment of fetal demise was of particular significance to women and was affected by the woman's preparation for stillbirth. Deciding on the delivery (caesarean section or induction) was constrained by the sector (public or private) within which women received care. Caesarean section (under general anaesthetic) was considered as protecting the women from trauma, while induction conserved their potential future reproductive capacities. Themes related to decisions regarding holding or viewing the fetus included fear, shock, adoration, psychological benefits, performing mothering rituals, and confirming the diagnosis. Naming the baby enabled the ascription of personhood and family belonging. Accessing fetal remains was constrained by mistaken readings of the legislation; some were used for research, while others underwent post-mortem examinations. Women's in-hospital recovery was affected by their experiences of interactions with staff, family and other patients.

The perspectives providers recounted regarding women's experiences of the feticide and LTOP procedures, included working on the women's bodies in performing the feticide procedure. They viewed women as being traumatised by the procedure. Providers' own

experiences of performing the feticide were affected by their religious beliefs, their technical competence, their need for self-preservation from trauma, how the patient behaved, their ability to maintain a “clinical” distance, their level of fatigue and burnout, and peer support. Feticide and LTOP were largely regarded as better than termination upon request, although they did regard performing the procedure as potentially stigmatising. Women’s experiences of the feticide procedure were constructed by providers as being focused on the fetal delivery, dealing with the fetus and then decisions regarding viewing or holding the baby. Women holding or viewing the baby was constructed as assisting women in confirming the diagnosis, while providers also valued providing women with symbolic objects or imprints of fetal feet and hands in order to assist women’s recovery.

Women’s in-hospital recovery entailed providers checking on them and referring them for further assistance, while emphasising the importance of women receiving support during their hospital stay. Providers perceived women’s psychological reactions during their in-hospital recovery as including feelings of guilt, embarrassment and stigmatisation, although providers were prone to emphasise the importance of supporting women’s *partners*.

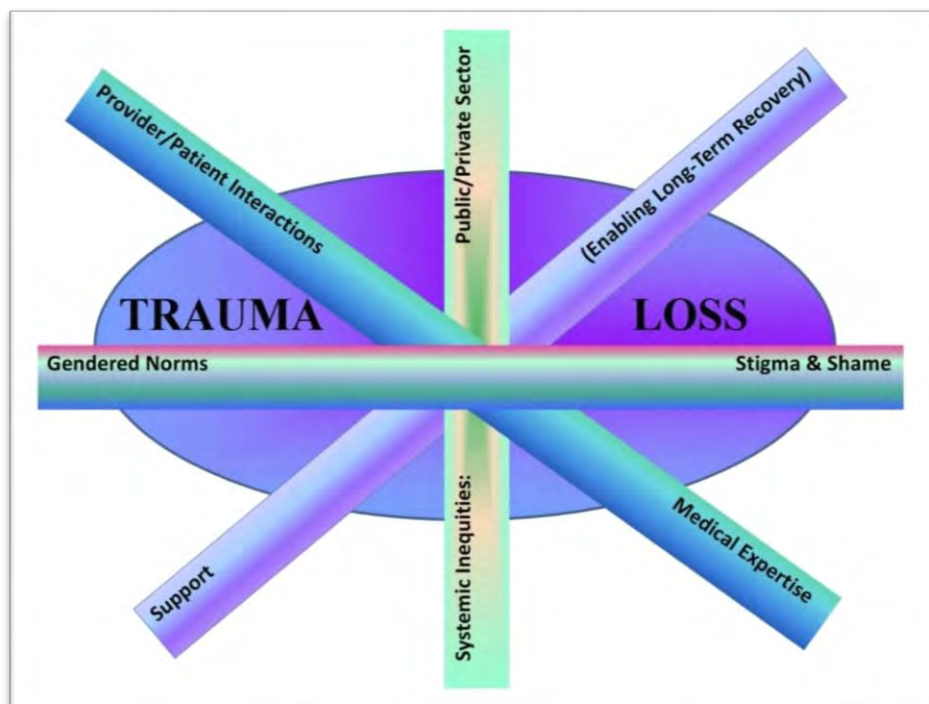
The final phase of this theory relates to women’s out-of-hospital recovery experiences, which include self-silencing, stressful partner relationships, a lack of understanding from those around them, women’s need for distraction, women’s attempts to get on with life and performing commemorative rituals. Emergent themes regarding women avoiding reminders of their experiences, but also keeping mementoes, as well as longing for the lost baby, and fear of going through the same experience again, were prominent. Although the theme of feeling as though women were going mad emerged, so too did the theme of women having experiencing growth from these events. The perspectives providers presented regarding

women's out-of-hospital recovery included valuing fetal burial in order to facilitate closure, contemplating implications for future pregnancies and the familial and institutional support provided to women.

2. Integration of Findings

Trauma and loss sit at the core of the experience of feticide and LTOP of a wanted pregnancy and anticipated new member of the family. These experiences, while being core, are interweaved with a number of underpinning social issues that serve to cement women's experiences in particular ways. Figure 1 below illustrates these issues to which I now turn in this concluding chapter: structural inequities; gendered norms, stigma and shame; and healthcare provider/patient interactions and medical expertise; support enabling long-term recovery. Each is discussed below.

Figure 1 *The Feticide/LTOP Experience*



A study such as this one begs the question of recommendations. Rather than create a separate, disembodied list of recommendations, I interweave possibilities within the discussion below. Overcoming structural inequities clearly requires the infusion of material and human resources into reproductive healthcare – particularly in the public healthcare sector – as well as proper management of these resources. Norms (gendered and medical) are social, but they are also internalised. In this respect, I speak to “voice” and “deep listening”.

2.1 Systemic Inequities: The Public/Private Sector Disjuncture

The significant disjuncture between the public and private healthcare settings in South Africa has been discussed and contextualised in the first chapter of this thesis. Macleod (2019) indicated that the South African healthcare system is deeply bifurcated between the private sector, which is quite high-functioning, yet expensive, and the public system, which serves the majority of the population, while providing under-resourced and overburdened services. Class and racial segregation remain largely evident due to historical inequalities and discrimination ingrained in the South African healthcare system. It is evident that the system in which women experience the feticide and LTOP procedures, either public or private, impacts upon the type of treatment they receive, the timeousness of the service, as well as the manner in which this service is provided.

In the public healthcare system, women receive the diagnosis of severe fetal abnormality significantly later in pregnancy than women in private healthcare, due to “late booking” (in the second or third trimesters of pregnancy) of antenatal care at their local primary healthcare clinics. The South African Department of Health published the statistic that only 47 per cent

of women make use of antenatal care in the first trimester of pregnancy (Statistics South Africa, 2020, March 11). Structural barriers to women accessing early antenatal care in the public system include: the geographical location of the clinics, many of which are inaccessible due to location or cost of transportation; waiting times; the lack of privacy and confidentiality during these visits; and limited resources available in the clinics. These serve to discourage women from attending antenatal healthcare (Jinga et al. 2019). The routine procedure of HIV testing is also a deterrent due to the stigma associated with HIV and discriminatory or stereotyping interactions women report experiencing with nursing staff at clinics (Mthethwa, 2017). Foreign nationals are at particular risk of being refused adequate care and experiencing harassment, embarrassment and discrimination in the public healthcare system (Mthethwa, 2017).

There are a number of more “social” factors that affect South African women’s late accessing of antenatal healthcare: pregnant women preferring to make use of traditional or spiritual healers rather than attending medical facilities; and fears of miscarriage or stillbirth due to witchcraft which, it is believed, may befall women if they do not keep their pregnancy secret until they are visibly pregnant (Kortman, 2020). Consequently, women avoid attending appointments at their antenatal care clinics as this would disclose their pregnancy to their community (Kortman, 2020).

Structural and systemic barriers frequently prevent women from accessing the antenatal vitamins required for healthy pregnancy from their public antenatal healthcare provider (as occurred with one woman in my sample), and many may be malnourished due to poverty. Public healthcare users also may not receive adequate information and counselling regarding the teratogenic risks of certain chronic medications (as occurred with one woman in my

sample). Conradie (2017) identified language barriers, difficulty in communicating complicated terminology and the need for an understanding of the calculation of risk, along with a lack of information about, or knowledge of, the risks associated with teratogenic medication, as affecting women's ability to make agentic reproductive health decisions.

In contrast to these causal factors identified among public healthcare users, none of the private healthcare users who participated in this research indicated that biological culpability had been a factor in causing the fetal abnormality. This may point to the power differentials at play with regard to being “employed” by your patient (private healthcare) versus “receiving” public healthcare. Women who make use of public healthcare, particularly for purposes of reproductive health, are frequently exposed to discrimination and denigration due to factors including their age, nationality, number of existing children they have, and having carried an abnormal fetus. The disparity between public and private healthcare is evident where women who were private healthcare users did not report experiencing discrimination or poor treatment due to their age, nationality or parity (number of previous pregnancies). Rowe and Moodley (2013) explored the construct of South African patients as consumers of healthcare and noted that public healthcare users may be disempowered due to receiving free healthcare and consequently may not feel “entitled” to act as or label themselves as “consumers” and consequently do not complain or resist ill-treatment to the extent that private healthcare users would.

Providers in private healthcare described women and their partners as reacting to the news of the presence of severe fetal abnormality with threats, denial and anger, while none of these reactions were noted by public healthcare providers. This may have something to do with private patients feeling entitled to services as a “consumer”. Public healthcare users, in

contrast, were constructed as being relieved upon receiving the option to terminate, as providers regarded many women as having wanted to terminate the pregnancy anyway, but due to gestational limitations, having missed the opportunity to do so. This is in contrast to my findings with regard to women's constructions of their pregnancies as wanted, even though some of the pregnancies were unplanned. Qin et al. (2019) also found that denial was a prominent response among Chinese women who were informed of severe fetal abnormality.

Private healthcare users have a great deal more choice with regard to which providers and which hospitals they would like to use. Their expectations of service may be much higher than women who use public healthcare services, where their lack of financial resources places them at the mercy of the system (Rowe & Moodley, 2013). Public healthcare users have no choice as to who their doctors are, where they attend appointments, nor how they may respond to receiving bad news, as these interactions take place within a doctor-patient relationship with even greater power differentials than already exist in conventional medical exchanges.

Women making use of the public healthcare system frequently did not understand the technical medical information conveyed to them during interactions with medical specialists and nurses. Data confirm that many women were not sure why they needed to undergo the feticide and LTOP procedures and it was evident that many women were not fully informed about the nature of the injection they received – that it would cause fetal demise. This inadequate communication on behalf of doctors and nurses speaks to the multiple barriers to effectively conveying information which include that the majority of public healthcare patients are poor and of lower educational levels than private healthcare users. Frequently, providers had the expectation that their public healthcare patients simply would not be able to

understand technical information and relayed only the most basic aspects of the medical procedures to them.

Language barriers are a significant challenge to effective communication as South Africa has eleven official languages, and some patients may not be able to speak English well; the language used in most public healthcare settings. Due to the lack of professional interpreters employed within the Department of Health, most translation is performed by anyone who is available and able to do so, including other patients, porters and nursing staff (Van den Berg, 2016). Where doctors are able to communicate in the language of the patient, they may have difficulties translating English technical medical terms into that language. Indeed, the nature of the technical medical information included in these discussions creates interactions between women and providers where miscommunication is very likely, irrespective of additional constraints placed on adequate understanding, as indicated by Asplin et al. (2012), who found that women reported feeling unsure and confused after being informed of the fetal abnormality in their Swedish study. These dynamics speak to the need for deep listening on the part of providers – asking patients to describe what is happening, attending to their accounts carefully, and to gently correct errors where they are made.

The demarcation constructed between the pregnant body and the fetal body allows for reproductive politics to play out in order to preference the fetus, even though severe abnormality had been diagnosed. The fetal body thus becomes the site of social control as it is enacted upon women's bodies and their reproductive agency (Middlemiss, 2022). However, within the public healthcare system, neither the woman's body nor the fetal body enjoy the "importance" placed on the private patient's body. This is evident by the care taken to protect private fetal lives, with fetuses in public healthcare being treated as better off

“disposed of” or parents not having the means to bury them. The majority of public healthcare users are Black and consequently, race emerges as a point of discrimination, where public healthcare users are assumed to be “used to” losing their children and consequently, providers construct LTOP as not as emotionally significant to Black women as it is to other population groups. Unfortunately, it is true that children of colour are more likely to be born into poverty and demise during childhood than White children in South Africa (UNICEF Data, 2022, November 30), pointing once again to the racialised nature of inequality in our country.

The disjunctions between public and private healthcare users’ experiences of the feticide and LTOP procedures include the feticide procedure itself. Public healthcare users spoke about undergoing the feticide procedure without being adequately informed that the injection would serve to directly cause fetal demise. This speaks once again to the lack of agency and autonomy afforded women in the public healthcare system. Women who were not adequately informed of the purpose of the feticide injection (all in public healthcare) experienced the trauma of realising that their fetus had stopped moving or that they were afforded different treatment from that given to the labouring women around them. In these instances, the experience of the birth of their baby is significantly distressing as they had not been prepared for the delivery of a stillborn baby.

A disturbing difference between public and private healthcare included the reported lack of skill many obstetrician-gynaecologists in public healthcare displayed in performing the feticide procedure, which frequently resulted in the procedure having to be repeated or even in failure to ensure fetal demise following LTOP. Providers in public healthcare also displayed discretion in deciding what method to use for the feticide and selected the method

that caused the provider the least distress, but in fact, would cause the patient trauma (e.g., not performing intra-cardiac injection, but rather intra-uterine injection resulting in protracted fetal demise). Private providers ensured their competence at the procedure, if not for their reputation and professional pride, then at least in order to avoid litigation should the procedure fail, and all private providers noted making use of intra-cardiac injection.

Some public healthcare providers indicated that they were not always able to ensure that women's experiences of the feticide procedure are as "bearable" as the procedure is in private healthcare. In certain instances, public health users were required to wait for hours or days before labour would be induced or a caesarean section be performed. This increased the distress women had to endure in knowing that they are carrying a demised fetus, and affected their later interaction with fetal remains, as fetal maceration takes place within a few hours after fetal demise. Viewing and holding a macerated fetus can be exceedingly traumatic and upsetting and rob women of the opportunity to experience "mothering" rituals following delivery.

Public healthcare users were evaluated in terms of their "reliability" should they undergo caesarean section delivery, as the general medical consensus amongst the public healthcare providers was that women should be sterilised following their third caesarean section operation. This "reliability" is determined largely by women's access to structural resources such as transport, and these women would then be the "select" or "special" patients who are "allowed" to continue to retain their reproductive ability. Women who failed to be evaluated as "reliable" would be informed that upon their third caesarean section, it is "standard" and "routine" practice for them to be sterilised. This is particularly disturbing in light of findings, including those of Biler et al. (2017), that indicate no clear difference in morbidity between

women of more than three caesarean sections and those who have undergone fewer. There is thus evidence that women are being erroneously sterilised based on an assumption, rather than verified data.

Private healthcare users were afforded greater autonomy with regard to the method of delivery and were usually presented with the choice between induction of labour or caesarean section under full anaesthetic. In contrast, women making use of public healthcare were very seldom given the option between induction of labour or surgical delivery. Instead, most women using public healthcare endured protracted and unbearably painful induction of labour, which frequently resulted in surgical delivery anyway. In private healthcare, the psychological wellbeing of women was accommodated just as much as their physiological care. This was facilitated by trying to ensure that the delivery would take place in convenient circumstances (e.g., the hospital closest to where the woman resides and in a private room), and taking her requests into account (e.g., not having male providers present during the delivery). In contrast, public healthcare users had no choice with regard to where delivery would take place or in which ward they would stay. These women were then exposed to other labouring women and mothers who had delivered, as well as their babies, which may be extremely upsetting to some women.

Most public healthcare users had to endure these procedures alone due to structural barriers to their support system being present with them throughout the feticide and delivery. These findings are supported by Ndjapa-Ndamkou et al. (2013), who identified a lack of family support during women's public in-hospital stay, following LTOT due to severe fetal abnormalities, as a significant factor affecting South African women's experiences. Private healthcare users, in contrast, were able to have the individuals they prefer to be present with

them during and following the delivery. This lack of support had a significant impact on public healthcare users' in-hospital recovery experiences, as they also lacked proxy voices to advocate for them while they are in physical and psychological distress.

There was little room for women making use of the public healthcare system to personalise their in-hospital recovery experiences, e.g., taking part in mothering rituals such as bathing and dressing their baby. This was simply not offered in public hospitals due to a lack of space, resources and staff, even though the importance of offering rituals which facilitate maternal connection with the baby are experienced as beneficial by many women (Leichtentritt & Mahat-Shamir, 2015). The context in which women undergo the feticide and LTOP procedures evidently affects the extent to which they are able to exert agency and make their own decisions and choices known. Again, nursing staff as well as the medical specialists involved need to apply deep listening and attending to women's voices, even within resource constraints.

The importance of women receiving support from their partner and social network was reinforced by Kamranpour et al. (2019) in their Iranian study, where women's psychological outcomes following termination of pregnancy due to fetal abnormality were significantly improved when they reported receiving sufficient social support (see later discussion). The lack of support South African women experienced following feticide and LTOP, both formal and informal, placed additional pressure on the doctors and nurses caring for their patient, as they felt compelled to compensate for the women's social support, which places greater psychological pressure on the providers. Within private healthcare, however, psychological support was regarded as a routine component of patient care when feticide and LTOP took place. Public healthcare users may be afforded psychological support during their in-hospital

stay, if available; however, these services are also encumbered by the usual barriers within public healthcare, including lack of availability, language barriers and challenges in accessing psychological services.

In private healthcare, women always had access to their fetal remains as most private hospitals included the remains in the documentation related to accessing their placenta. Unfortunately, women in public healthcare were (prior to 2022) subjected to an incorrect interpretation of legislation. Prior to legal interrogation of the interpretation and application of the Births and Deaths Registration Act, 1992 (Act No. 51 of 1992), which took place in 2022, women had been illegally prevented from accessing their fetal remains in the public healthcare system, when the fetus was delivered under 28 weeks of gestation (*The Voice of the Unborn Baby and Another v Minister of Home Affairs and Another* (CCT 120/21) [2022] ZACC 20 (15 June 2022)). This created circumstances where women were denied access to their fetal remains when delivery took place prior to 28 weeks' gestation, exacerbating their distress and grief.

Women may desire access to fetal remains in order to perform burial or rituals congruent with their beliefs; sadly, many women in my sample were not able to afford the burial or cremation costs this involves. Due to these financial constraints, women in the public healthcare system often opted for the hospital to ensure burial or cremation of the fetal remains. In these circumstances they seldom had knowledge of where the grave or remains may be, and consequently experienced further distress. Local municipalities draft their own policies on "indigent" or "pauper" burials, and generally anyone who is unable to pay for private burial or cremation qualify for state burial (Emalahleni Local Municipality indigent and pauper burial policy, Emalahleni Local Municipality, n.d.).

Women within the public healthcare system had high default rates with regard to their six-week follow-up appointments following feticide and LTOP procedures owing to the usual structural barriers – transport and time costs. This places these women at greater risk of recurrences (the same condition occurring in subsequent pregnancies).

Access to ongoing psychological support did not emerge as distinct between private and public healthcare systems. On the one hand, public healthcare users have limited access to ongoing psychological treatment due to the systemic and structural barriers to accessing these services, which are inherent to the public healthcare system. However, private healthcare users are reliant upon their medical insurance to cover psychological treatment, and often these policies and plans do not cover mental health services, or do so with strict limitations to the benefits. It is also worth noting that psychological services are exorbitantly expensive within the private healthcare system and certainly preclude most middle-class South Africans (who are the majority of medical aid members) from making use of these services on a meaningfully long-term basis. This is particularly important, bearing in mind that the women in this study indicated the greatest need for psychological support many months, or even a year following their feticide and LTOP procedures having taken place. Common psychological reactions women displayed following TOP due to fetal abnormality in a Turkish study included depression, trauma and complicated grief (Turkyilmaz et al., 2021), which are psychiatrically significant diagnoses requiring mental health intervention (psychotherapy and pharmacotherapy) on a long-term basis.

This study focussed on the experiences of women who have undergone feticide and the renditions of these experiences, as told by providers. The focus was not on providers per se.

However, due to the resource and structural inadequacies inherent to South Africa's public healthcare system, not only do the patients suffer, but the providers who are employed in this system are also exposed to frustration, pressure and trauma. The lack of structural support and, in particular, the lack of psychological care and support provided to doctors and nursing staff in the public healthcare system, not only affects their own psychological wellbeing, but in turn, serves to have a detrimental effect on their ability to provide sensitive patient care. Medical doctors' high rates of depression and burnout is an international issue that affects South African doctors significantly, and most especially if they work in the under-resourced public healthcare system (Naidoo et al., 2020). While many try to provide as quality service as they can within restrained resources and work overload (Loni, who works in both sectors, states, "even though we do it in public healthcare with what we have as bearable as possible for everyone"), they will also deploy various strategies to survive (Feltham-King & Macleod, 2020). These may include foreclosing dialogue and deciding for patients.

Providers expressed frustration with women who cause *them* distress or discomfort when women become upset during the feticide and LTOP procedures. It is significant to bear in mind that providers' voices also go unheard or unacknowledged by medical systems and, in particular, the South African public healthcare system, which contributes to the lack of psychological support provided to nursing, allied and medical staff. Arnold and Lewinsohn (2010) noted that the working conditions in public hospitals in South Africa were one of the driving factors behind the significant amount of qualified medical doctors choosing to emigrate.

Abortion providers may also be subjected to silencing within the South African healthcare system due to the high levels of conscientious objection among nursing and medical staff

(Harries et al., 2014). Providers, particularly nurses and medical doctors who are pro-choice, tend to self-silence in order to avoid the stigmatisation and prejudice they experience from their social networks and colleagues. Self-censoring, or selective disclosure of their involvement in provision of the feticide procedure and LTOP, is also a common occurrence among providers in the UK (Fay et al., 2016).

2.2 Gendered Norms, Stigma and Shame

Nandy (2017), in her book *Motherhood and Choice: Uncommon mothers, Childfree Women*, describes mater-normativity as the body of gendered norms that assume women to be mothers or mothers-to-be, with all the cultural expectations that go with this role (including being “naturally” able to mother, and self-sacrifice in the face of children’s various needs). These norms are internalised and form part of how women understand themselves and their actions.

The manner in which women in this study sought to explain the diagnosis through personal culpability – both biological and behavioural – points to the operation of mater-normativity. Somehow, it seemed to them, they must have failed in their duties to “naturally” be a mother to a healthy, non-disabled infant or to engage in behaviours that ensured fetal normality. That this ascription of self-culpability was confirmed by providers points to its entrenchment.

In constructing their understanding of the reasons behind, or causal factors of, the fetal abnormality, women expressed concerns that their own behaviour had somehow made them culpable in causing the abnormality. These constructions include being bewitched due to non-adherence to cultural or spiritual rituals, being taught a lesson for transgression against a

deity or spiritual force, or being brought closer to God after sinning (many public healthcare users ascribe to both “modern” medical care and traditional African healthcare (Mofokeng, 2003) and present some conflict in their adherence to both, somewhat contradictory viewpoints). These women are not alone. Maguire et al. (2015) described self-blame and guilt as prominent themes during the process of North American women making meaning of the diagnosis of fetal abnormality.

Wilpers et al. (2021) noted the significant positive impact providers (specifically the medical specialists involved) can have on women if, when they convey the fetal abnormality, they normalise women’s emotional and cognitive responses. This requires deep and non-judgemental listening. Creating a space where women are encouraged to voice their fears and concerns, no matter how “traditional” or “irrational” they may be, would be exceedingly helpful in providers’ better understanding of women’s constructions of causes of fetal abnormality. In turn, this would assist providers in addressing distressing constructions of causal factors that women may hold. This involves deep listening and reassuring women when their construction of the anomaly (e.g., caused by their behaviour) is not accurate.

The women in this study constructed the decision to undergo a feticide and LTOP as their own. This may be seen as empowering; however, this sole-burden of choice also places all accountability and responsibility upon them. The findings of my research indicate that partners tend to defer the decision to women. This may be due to feeling that they do not have a legitimate voice as their bodies are not involved. But it could be to avoid moral accountability, or, as Werner-Lin et al. (2016) explained in a North American study, owing to a lack of communication or feelings of helplessness.

Women regarded informing their partner about the fetal abnormality as important and valid, but they did not regard their partner as having the same level of authority over the decision as they did, due to bodily autonomy. Husbands, rather than boyfriends or casual partners, were regarded as enjoying greater legitimacy in having an input in the decision-making process, whereas casual partners and boyfriends were constructed as having very little, if any, say. This speaks to the influence of conjugal power, where husbands are traditionally regarded as being “in charge” of their wife, according to conservative, patriarchal perspectives.

Women’s spectrum of choice is greatly limited by the burden of care placed on mothers. Public healthcare users, in particular, have limited access to the resources a special needs child would require. Women experience this lack of choice largely due to deeply ingrained social inequalities related to gender, race and class (Shefer & Munt, 2019), and disability, particularly within the South African context of racially based historical inequality. Women in my study spoke to the lack of finances and the “negatives” related to caring for a severely disabled child.

DiClemente-Bosco et al. (2022) described the resources necessary to provide women with true choice. These include an environment that supports women, women having the ability to control these physical and social resources when they are available, and to use their agency in achieving what they choose. Choice consequently includes both having the resources, as well as the power to exert decision-making and achieving the desired outcome (DiClemente-Bosco et al., 2022). True choice for South African women deciding whether or not to terminate their pregnancy, when severe fetal abnormality has been diagnosed, would consequently entail women receiving structural, social and systemic support in all contexts of

their lives, not only during the decision-making process, and the absence of stigmatisation of the enactment of reproductive choice.

The findings of my research indicate that women who undergo feticide and LTOP construct the decision to terminate, and procedures themselves, as stigmatising, although the language they use to describe this experience usually relates to being judged or shamed. Erving Goffman (1963) defined the term stigma as any attribute or characteristic that causes the bearer to be discredited. He regarded stigma as leading to “spoiled identity” – in this case of the failed mother (to-be). As such, stigma works to identify individuals who do not meet with the criteria of “the norm” (or mater-normativity). From this viewpoint, women may experience stigma and “spoiled identity” based not only on their fetus being diagnosed as “disabled” or severely abnormal, but also due to their failure to attain the social constructions of “selfless motherhood”. Stigma associated with abortion is extended not only to the women who have them, but also to healthcare providers involved with terminations of pregnancy, according to Norris et al. (2011), which is also the finding of my research.

Women in this study spoke repeatedly about their fear of being judged. They indicated that this was the reason they were highly selective about whom they told. This is in line with the Task Force on Mental Health and Abortion (American Psychological Association, 2008), which indicated that women who underwent abortion and felt stigmatised experienced the need to keep the procedure a secret and anticipated a low level of social support. The abortion stigma experienced by women who have undergone feticide/LTOP may not be directly comparable to that of women who undergo elective first or second trimester abortions due to the decision-making involved and the wantedness of the pregnancy; however, it is clear from my findings that the women did internalise stigma and frequently anticipated being

stigmatised even before it was enacted upon them. These women experienced felt stigma as they anticipated negative social outcomes, such as judgement, rejection or discrimination, due to prejudicial attitudes toward termination of pregnancy held within their community or society at large. This was the motivation behind the silencing, non-disclosure of partial disclosure of their decision to terminate the pregnancy.

To mitigate or manage stigma and the associated negative emotions, people engage in the number of behaviours, including managing the damaged self, maintaining a good reputation and managing a damaged reputation (Cockrill & Nack, 2013). Women in my study spent inordinate energy on maintaining a good reputation. For example, the ‘secretive’ behaviour exhibited by women can be seen as attempts to regain personal power and control their social identity. As indicated by Scharp et al. (2022), these women are contemplating ending their pregnancy while being visibly and, for the most part, publicly pregnant. To openly admit to failing biologically to grow a healthy fetus, and further to decide to terminate the pregnancy invites (as indicated by my participants) judgement and leads to a loss of social status.

However, silence as form of maintaining a good reputation could also be viewed, as argued by Fivush (2010), as a form of resistance. Here silence is constructed as one resource marginalised groups can utilise in maintaining or regaining their power and would be referred to as being silent, rather than being silenced. Fivush (2010) regarded being silent as a powerful source of resistance to stigma and shame when it is mobilised to refuse to explain or justify oneself. With regard to feticide and LTOP, women may choose to be silent, particularly when they anticipate that the audience would find what they have to say difficult to hear. In a sense it may be a way to protect the listener, rather than themselves. Women would then be both self-silencing in order to maintain their interpersonal relationships and

simultaneously be silenced by others who are unable to hear their experiences without reacting negatively. It may also be possible that the silencing women present may be associated with their wanting to distance themselves from their own experiences and memories of these experiences due to the traumatic nature of the feticide and LTOP procedures.

Fivush (2010) explained that loss of voice and being silenced or self-silencing are interlinked with the process of remembering experiences, speaking about these experiences and deciding not to do so, with an audience that is either able to hear the message, or incapable of receiving it as intended. The findings from my research indicate that both women and providers censored themselves to adapt to their audience in order to reduce the likelihood of being stigmatised or shamed. This silencing and selective sharing was evidenced in my difficulty in finding participants and their taking time to consider the participation request.

Apart from being highly selective about whom they told, some women claimed to have suffered a late miscarriage instead of admitting to a late termination of pregnancy. In this way, they re-storied the process, not only for others, but also for themselves. Women who could rationalise their decision to abort the pregnancy for the benefit of pre-existing children could story their decision as not based on their own needs, but rather their adhering to constructions of motherhood that favour selflessness and service. This could be read as managing a damaged reputation. One tried to normalise the experience and counteract expressed stigma, by providing support to women in similar circumstances. This could be seen as managing the damaged self. Participating in this research and being able to tell their stories in their way may also have been an opportunity to manage the damaged self.

While strategies used by the women may have helped them avoid being socially stigmatised, O'Donnell et al. (2018) argued that much of the psychological distress experienced by women is likely to be due to fear of stigmatisation, rather than regret concerning the decision to terminate the pregnancy. Silencing also prevents women from accessing needed resources which includes receiving information, social support, healthcare services and financial support (Hardon & Posel, 2012).

2.3 *Healthcare Provider/Patient Interactions and Medical Expertise*

I decided, from the outset of this study, to include healthcare providers' perspectives on women's experiences of feticide and LTOP on the understanding that the healthcare provider/patient interaction would be key to how the process unfolded. How "doctor-patient" communication is conducted has been a focus of research for some time, and is described as the "heart and art of medicine and a central component in the delivery of health care" (Fong & Longnecker, 2010, p. 38).

Although most providers (irrespective of the system in which they are employed) constructed their interactions with women as being neutral and non-directional, women, in fact, experienced these discussions as including a great deal of coercive information. Coercive interactions included: descriptions of women being unable to manage continuing with the pregnancy or caring for a child with special needs, dire threats to women's physical and reproductive health should they continue with the pregnancy, as well as condemnation for becoming pregnant in instances where women were of an advanced age (older than 35 years).

Decision-making concerning treatment is a key component of the interaction between healthcare provider and patient. Chapter 5 of this thesis presented findings indicating that healthcare providers regarded women as enjoying full autonomy within the healthcare encounter (not necessarily the home – see later discussion) in making the decision with regard to terminating their pregnancy once fetal abnormality had been diagnosed. Women, in stark contrast, constructed their decision-making process as entailing effectively no choice. Part of this “no-choice” narrative had to do with women’s personal circumstances and their judgement concerning their emotional and/or financial resources to cope with a child with severe disabilities and with a possibly short life span. Nevertheless, how the choice (or no-choice) was put to them in the consulting room may also have affected their sense of “no-choice”. While I cannot know exactly how the encounters played out, the fact that providers consistently constructed the decision to terminate the pregnancy as the “wise” choice, particularly with regard to public healthcare patients, speaks to the possibility of subtle persuasion with the healthcare encounter (Wilbraham, 2009). Indeed, some of the women spoke to the warnings provided by the doctors should they continue with the pregnancy, while others felt denigrated for being in the position of having to make the decision at all (e.g., for having “rotten eggs”). Lelanie stated outright that the “decision is made for you”.

Consent and Coercion. Providers tended to regard women as being coerced by their partners and family members into taking the decision to terminate. Consequently, providers viewed women as being persuaded into choosing to terminate and doing so under duress. Providers also tended to overemphasise the importance of including the partner or extended family in the decision-making process, and may, in fact, have unintentionally invalidated women’s autonomy and agency by doing so. In contrast, the women regarded the decision as being theirs alone to take, and emphasised the importance of making a choice that is congruent with

their values and needs. Family support in making the decision may be helpful, although partners and family members' opinions were not necessarily regarded as such by women. Consequently, providers should *ask* women if they require their partner or support structure to be involved in the decision-making process, rather than just assuming that this is their preference. And they should listen carefully to how women construct their answers to such questions.

Certain providers acknowledged not providing all of the necessary information to women, e.g., they failed to explain that the injection would serve to cause fetal demise and ensure stillbirth. This may be due to this disclosure proving too emotionally uncomfortable or distressing not only for their patient, but for the providers themselves. The feticide procedure was regarded by providers as mandatory once fetal viability had been achieved. However, women were mostly unaware that there are different methods available with which to perform the feticide. This prevented women from being able to participate in the decision-making process regarding the feticide procedure. Instead of informing women of the different feticide methods available to them, providers made use of their preferred method. Listening to women includes presenting them with the option of either undergoing the feticide where fetal demise would take place immediately, or to choose the less "invasive" procedure where the fetus is not directly injected, but instead demises slowly over a number of hours. It would be exceedingly helpful for women to be at least included in the method decision-making process, as they would then be fully informed about the procedure and would be able to mentally prepare themselves for either immediate or protracted fetal demise. It is essential that the providers who perform the feticide procedure should be adequately trained and competent in intra-cardiac injection as well as intra-umbilical injection.

This lack of effective communication goes beyond creating an environment in which women do not entirely understand the diagnosis of the fetus, the causes thereof, nor their options available to them or the procedures they are to undergo, but essentially erodes any true informed consent from having taken place. This constitutes a direct violation of ethical, professional and legal prerequisites for patient care. The issue of providers failing to obtain “competent” consent from public healthcare patients within the South African healthcare system was discussed by Rowe and Moodley (2013), who identified the extreme burden of care, the paternalistic model followed by this healthcare system, and the perspective that poor patients are “incompetent” or unable to make their own healthcare-related decisions, as barriers to true informed consent taking place. It is necessary to note that choice, such as that made during informed consent, is directly affected by structural inequalities and consequently also by the healthcare system of which women makes use.

Fetal specialists, obstetrician-gynaecologists and clinical geneticists usually consulted with one another and formed multi-disciplinary teams in order to determine whether to offer women the option of termination. During their decision-making process, these providers relied upon their interpretations of the CTOP Act as well as the guidelines set by hospital ethics panels. Providers’ own personal viewpoints with regard to termination of pregnancy and reproductive rights affected how they interpreted the legal, ethical and multi-disciplinary teams’ input. These layers of gatekeeping affected women in private healthcare a great deal more than they influenced those who made use of public healthcare. This is due, paradoxically, to the failures of the public healthcare system to provide adequate and timely antenatal care, which results in fetal abnormalities being detected much later than they are identified in private healthcare. In order to compensate for this structural negligence, providers felt pressure to extend the option of termination far beyond what is regarded as

acceptable within private healthcare. Indeed, three of the women who participated in my research study were beyond 38 weeks' gestation at the time of undergoing the feticide and LTOP procedures. This flexibility with regard to the application of gestational limits poses the question as to the significance and necessity of these limits, irrespective of the nature of the healthcare system in which the procedures take place. If the procedure can take place a few days before the pregnancy is due in one healthcare system, why could this not apply to all women? The answer may lie in "poor" lives being constructed as "expendable" and of "less value" than those of "valuable members of society" and consequently, it may be less morally upsetting for public healthcare users to undergo feticide and LTOP far beyond what is regarded as acceptable for private healthcare patients.

Some providers differentiated between abortion on request (wrong), and abortion based on fetal abnormality (right, if recommended by doctors – preferably a panel or team). Providers' personal perspectives with regard to abortion affected their construction of women's decision to terminate as either "wise" (based on providers' medical opinion of a disabled life not worth living) or "foolish" (based on the woman's decision regarding her bodily autonomy and integrity). In a North American study, providers' attitudes toward abortion were found to affect the manner in which they discussed (or omitted to discuss) termination as an option for women in their second trimester of pregnancy where fetal abnormality had been diagnosed (Kerns et al., 2020). In a different North American study, when women made a decision that they suspected was contrary to their providers' preferred decision for them, they experienced a distancing and change in behaviour on behalf of the providers (Redlinger-Grosse et al., 2002).

Providers regarded women using the public healthcare sector as being unable to adequately care for a special needs child due to the resources this would require, and the additional burden of care such a child places on the woman's family, as well as the greater community. The additional strain that a special needs child places on the public healthcare system was also regarded as significant and, in a sense, "futile" due to the poor prognosis most of these babies have. This speaks to prejudice held against disabled people, and particularly those who are born into poverty, with these patients themselves being regarded as a "burden". Graham (2018) explored the differences between those who are disabled, and those who are not, in South Africa and determined that significant employment and income bifurcations exist between these two groups, where those who are disabled are unlikely to escape poverty. Women in private healthcare were also usually encouraged to terminate their pregnancy in the presence of severe fetal abnormality, due to constructions of disabled people as "undesirable" and in order for women to move on to producing a "healthy" child in a subsequent pregnancy.

The issue of choice with regard to LTOP method, either induction of labour or surgical delivery, has been explored in the discussion on public versus private experiences and will not be repeated here. However, it is important to note that this significant experience frequently took place without providers consulting with women in deciding how to deliver the fetus. In addition, surgical delivery is less favoured in the public healthcare system, in order to reduce the costs involved with delivery, and demands placed on theatre time, as well as in-hospital recovery time, which serve to increase the financial toll taken on the public healthcare system. Women delivering stillborn fetuses in their second trimester of pregnancy in the UK are also seldom included in the decision-making process regarding method of fetal delivery (Middlemiss, 2021). However, the RCOG (2010a) explicitly recommended that

women should be provided with choice with regard to the method of pregnancy termination and Kerns et al. (2012) also found that it is helpful for women to be included in the decision-making process with regard to how delivery would take place. The findings of Leichtentritt and Kurnik (2020) speak to the importance of including women in the medical decisions related to the feticide procedure, such as if they would prefer to be sedated, and if so, to what extent.

When women did communicate their needs or concerns, they were met, at times, with nurses and doctors who ignored them or invalidated their expressions of pain. Women experienced induction of labour as excruciatingly painful and their pain management as inadequate or absent. Some women were even left to labour alone without any assistance, even though they begged for help, which constitutes obstetric violence. These findings are similar to those found in other research, such as the study of women and second trimester pregnancy loss in the UK undertaken by Middlemiss (2021), where she found that most of the participants were required to undergo labour induction and these women found this shocking, disruptive and completely unanticipated. Fisher and Lafarge (2015) commented on the lack of sufficient and appropriate pain management that women who undergo TOP due to fetal abnormality experience in the UK and how this affects their experiences of physiological pain as well as emotional distress during the labour.

Women experienced the process of delivering a demised baby as much more physically painful than when they laboured to deliver a live baby. The extent of their physical and emotional suffering during the labour process was directly affected by the wantedness of the pregnancy as well as the knowledge that their baby would be born demised. Popoola et al.

(2022) explored Nigerian women's experiences of stillbirth and found that women reported stillbirth as a distinctly painful mingling of emotional and physical suffering.

Women's requests for sterilisation or hysterectomy during the caesarean-section were also often ignored, or disregarded, in both private and public healthcare systems. One woman participant of my study was still unsure at the time of the interview, if she had in fact been sterilised as she had requested, or not. I could not find any literature on this aspect of the feticide/LTOP experiences. The heteronormative reproduction-destiny narrative permeated much of the coercive guidance provided by doctors who emphasised reproductive capacity as vital to women's wellbeing and even in ensuring that their partners would stay with them. In this way, women's value and desirability are directly equated to their ability to reproduce healthy offspring.

Lack of choice extends to once the baby has been delivered, as providers were adamant that women must at least view, or hold their baby, once delivery was complete. There was little consideration given to women's personal preference and choice in this regard, as viewing and holding the baby were regarded by providers as essential to women fully accepting and understanding the fetal abnormality and finding some sense of closure in the process. Women's accounts, however, indicated that decisions to view or hold the baby should be regarded as highly individualistic, and certainly women should be enabled to make their own decisions in this regard, without coercion. An underlying motivation in providers encouraging women to view or hold their baby may refer to their own need to "justify" their advice and diagnosis, thus convincing women that the providers had been correct in suggesting that they should terminate. A Canadian study reinforced the importance of

encouraging women to make their own decision with regard to viewing the fetal remains, as the outcomes in terms of bereavement did not differ between women who viewed the fetus and those who did not (Sénéchal et al., 2022). The RCOG (2010a) published their Green-top Guideline No. 55 in October of 2010 and advised providers not to try to persuade women to view or hold their stillborn baby if they are hesitant to do so. These guidelines set by the RCOG are generally adhered to, or recognised, by obstetrician gynaecologists in South Africa, even though they are not legislative in nature, but serve as international professional guidelines.

Fisher and Lafarge (2015) emphasised the importance of including women in relation to terms used to describe their “fetus” or “baby” and “termination”, “abortion”, “stillbirth”, “miscarriage” or “pregnancy loss”. Providing choice allows women to exert some control over what is happening to their bodies at a time when they frequently feel out of control, unheard and invalidated. During their interactions with women, it is recommended that providers should adapt the terms used to refer to the fetus/baby according to the constructions presented by each woman (Fisher & Lafarge, 2015). Certain women in my study referred to their “fetus”, while most referred to their “baby”. It is noteworthy, however, that providers tended to use the word “baby”, assuming that this is what women would prefer. This may, however, establish a situation where women feel compelled to use this word.

At the beginning of this thesis, I problematised the word “feticide” but continued to use it as it is the one referred to in the medical literature. Here I argue that in order to address the stigma associated with the term “feticide”, it is necessary to replace it with a description that removes the implication of “killing” a fetus and the concomitant moral condemnation this term may elicit. The findings of this study indicated that women who undergo feticide and

LTOP procedures due to the presence of severe fetal abnormality do construct their fetus as a “baby” and ascribe personhood to the fetus. Consequently, it would be meaningful to both acknowledge these constructions, as well as to describe fetal demise in a manner that would engender compassion, rather than brutality. To this end, I propose that the term “feticide” be replaced with “fetal euthanasia”, where euthanasia is defined as “the hastening of death of a patient to prevent further sufferings” (Annadurai et al., 2014, p. 477) and this would then be classified as “active” euthanasia (deliberate action taken to end the life of a terminally or incurably ill patient, usually via administration of a lethal substance). Chervenak and McCullough (2017) studied the clinical management of pregnancies where severe fetal abnormality had been diagnosed and indicated that many clinicians construct these fetuses as “dying patients” (p. 6). The significance of replacing “feticide” with a less confronting and moralistic description would support providers in describing the procedure to women, as well as facilitate women in speaking about their experiences.

Women who are required to attend follow-up appointments at their local primary healthcare clinics (public healthcare system) reported being confronted with derogatory and discriminatory responses, particularly from nurses who blamed women for the fetal abnormality and admonished them to refrain from becoming pregnant again. During these experiences women reported self-silencing and not voicing their being offended or even defending themselves due to the expectation that they would just be further marginalised, abused or denied adequate treatment and care, should they do so. These findings are similar to those from Kruger and Schoombee (2010) who reflected on obstetric violence being partially caused by the nurses themselves feeling unheard and marginalised. Judgemental and unsupportive interactions were reported by many British women who underwent TOP due to fetal abnormality where they commented on rudeness on behalf of nurses in particular (Fisher

& Lafarge, 2015). It is consequently unsurprising that women who have undergone feticide and LTOP present with poor attendance at their six-week follow-up appointments. Another factor related to poor attendance of follow-up appointments may be due to the avoidance of reminders of these potentially traumatic experiences, as was found by Pitt et al. (2016) in their Australian study of pregnancy termination due to fetal abnormality.

Medical specialists place great emphasis on the importance of terminating the pregnancy as soon as possible following diagnosis as discussed above. It is thus significant that the British Medical Association (2020) recommended that women should not be rushed during the decision-making process due to the complexity of the choice and in most cases, the wantedness of the pregnancy. Women should be provided enough time to process the diagnosis before placing pressure on them to take a time-limited decision (Qin et al., 2019), particularly bearing in mind that, in fact, there is no upper limit to LTOP in South Africa. It is evident that the myth of time pressure in the decision-making process regarding LTOP is an artificial construct created by pro-life narratives, rather than being based upon legislation and in fact serves to place unnecessary strain on women and healthcare providers, as well as curtailing application of the CTOP Act.

The CTOP Act notes that pregnancies over 20 weeks' gestation may be terminated if continuing with the pregnancy would pose significant risk to the woman or the fetus, or if severe fetal malformation is present (National Department of Health, 2021) with no upper limit or any other reference to the type of abnormality or gestation of pregnancy being made. In order to apply the law to each woman's situation, medical specialists also rely on multi-disciplinary teams to guide decision-making regarding when to offer LTOP to women. This is determined by the nature of fetal abnormality, fetal prognosis and gestational age. Frequently

such teams make use of the above-mentioned policy guidelines in order to guide their decisions. Lotto et al. (2017) described these ethics committees and multi-disciplinary teams as being a “corporate” method of dealing with the interpretation of legislation that is open to medical specialists’ interpretation and discretion. This group approach to the decision-making process removes the individual responsibility and instead spreads it across a number of people. The manner in which providers interpret guidelines, policies and legislation, and consequently convey these interpretations to women, is influenced by providers’ personal ideologies with regard to abortion. Those who are pro-choice are frequently frustrated by the lack of agency afforded women’s opinions with regard to LTOP and feticide, and their own discretion is impeded by having to abide by team, hospital and policy guidelines.

Lotto et al. (2017) referred to the impact of such guidelines, which determine what conditions would be eligible for LTOP up to certain gestational periods, and raised concerns that such arbitrary cut-off points may undermine providers’ ability to take the variability of diagnoses and other relevant factors into account. Lotto et al. (2017) went so far as to comment that due to the influence of societal attitudes towards abortion, there should be mechanisms put in place to separate personal perspectives from the law, and thereby protect against interpretations of legislation being coloured by providers’ beliefs regarding reproductive rights. This is my opinion as well.

2.3 Support (Enabling Long-Term Recovery)

International literature suggests that women seek psychological and social support from online groups, mental healthcare providers or their community during the decision-making process related to termination of pregnancy when the fetus is diagnosed as abnormal

(Hammond et al., 2020). However, the findings of my study indicate that South African women are very unlikely to seek help from support groups, mental health providers or their communities during the decision-making phase of the experience. Instead, women are likely to only disclose their situation to those in their inner circle who absolutely have to be informed, and those who are their trusted sources of support. Fleming et al. (2016) found similar outcomes in that Swiss women may avoid reaching out to their support network due to the stigmatised nature of, firstly, carrying a severely abnormal fetus, and secondly, due to their consideration of terminating the pregnancy.

A significant relationship where women report feeling unable to speak up is in their interpersonal relationships with their partner. There are a number of factors which may contribute to the breakdown of communication between women and their partners during recovery from feticide and LTOP. These include that partners may be avoiding triggering memories and emotions, or that women's partners may have emotionally abandoned them during the process and, in fact, have not fully shared the experiences with these women. With regard to avoiding triggers or reminders, women tend to avoid reminders such as their purchased baby items, or the baby isles in shopping centres in order to protect themselves from the strong emotional responses these may elicit. Maguire et al. (2015) reported similar findings among women recovering from second trimester termination due to fetal abnormality in the United States, who reported experiencing grief responses being triggered up to a year following the procedures and women actively avoiding being exposed to such reminders. Women frequently feel responsible for facilitating communication in their relationships and endeavour to use various strategies to encourage their partner to speak about their loss and report that their partners avoid doing so. This may point to their partners also attempting to avoid reminders of their traumatic experiences shared with the women.

Tragically some women remain in partner relationships where they are emotionally isolated with regard to their LTOP experiences or even worse, blamed for having “failed” to produce a healthy baby or emotionally and physically abused. Here the partner either withholds their voice, as a form of punishment or perhaps self-protection against distressing emotions, or uses their voice (and in certain instances, physical violence) to further berate and degrade the woman.

Recovering from such a highly stigmatised and “sensitive” procedure leaves many women silently grieving among their family and their community members while the rest of their social network carries on with life. Malacrida (2015) explored parents’ grief reactions following perinatal death in Canada and indicated that the factors which compounded their grief was the lack of social recognition of their loss, which was associated with decreased social support. Due to the isolation and silencing of women grieving a feticide and LTOP, they may experience complicated grief reactions in light of their lack of support and social acknowledgement of their loss and status as “grieving”. The lack of social “sanctioning” of their loss, along with the silence surrounding their grief frequently leads to a grieving process best described as “disenfranchised” (Lafarge et al., 2014). Disenfranchised grief is common among parents who have experienced perinatal loss, as was confirmed by Lang et al. (2011) in their Canadian study, where disenfranchised grief is defined as loss or bereavement that is “not openly acknowledged, publicly mourned or socially supported” (Doka, 1989, p. 4).

Due to women’s burden of care with regard to childcare and maintaining their household etc. few women feel that they are given the physical and psychological time and space in which to grieve for as long, and to the extent that they would have preferred. Existing children may

also require their mother's comfort as they too grieve the loss of the anticipated sibling, which may place additional emotional burdens on the already burdened women. Consequently, these silent griever go about their day and chores and try to create pockets of time and space where they "spend time with" their deceased baby and allow themselves moments of grief.

Some women describe times during their recovery where they felt like they were "going mad" with longing, grief, anger and frustration and during these times they seldom wanted to consult with a mental healthcare professional. Other researchers found similar and significant psychological outcomes, such as Kamranpour et al. (2020) who studied the psychological experiences of women who terminated their pregnancy due to the presence of fetal abnormality in Iran and found that some participants presented with symptoms of severe depression, felt worthless and experienced difficulty in performing their daily activities. Significant psychological distress was recorded between one to seven years following termination of pregnancy due to fetal abnormality in a German study conducted by Hanschmidt et al. (2018).

Women benefit greatly from peer support groups, either in-person or online, where they are able to speak about their experiences among other women who truly understand, in a space free from judgement. This is a space where they can express and explore their experiences of disenfranchised grief and safely acknowledge the intense longing they have for that particular "soul", along with their fears of recurrence should they become pregnant again. Maguire et al. (2015) found similar outcomes in their study on women's grief following second-trimester termination due to fetal abnormality, where participants reported feeling unable to talk about

their loss within their support network, but instead indicated their need for interactions with support groups targeting their particular experiences.

The post-traumatic growth that most women report experiencing during their recovery, such as feeling proud of how strong they were to endure this, the lessons they learned and their emotional growth, can also be voiced in these spaces. The concept of post-traumatic growth was developed by Tedeschi and Calhaun (2004, p. 1), who described it as “the experience of positive change that occurs as a result of the struggle with highly challenging life crises”. It is not always socially sanctioned to speak about abortion without expressing trauma and regret, and instead expressing feelings of relief that it is over and even gratitude for the experiences may be suppressed. Macleod (2019) emphasised that women seldom describe their abortion experiences as dichotomously either positive or negative, but rather as complex and a conflicting process, which may include relief.

The fear of recurrence is buffered by the longing for the child that had been constructed throughout their pregnancy, and Maguire et al. (2015) found similar outcomes in their sample group, where women indicated that future pregnancy, although anxiety provoking, would relieve their grief. Carlsson et al. (2016) confirmed that women report longing for another pregnancy, while harbouring anxiety of fetal abnormality recurrence, in their Swedish study.

None of the relevant literature noted women feeling suicidal upon receiving the news of the fetal diagnosis; however, Denney-Koelsch et al. (2015) identified grief reactions and depression among women reacting to news of fetal abnormality. Feeling suicidal is in itself an extremely stigmatised emotional response, with a noteworthy bidirectional influence. Kučukalić and Kučukalić (2017) indicated that suicidality causes feelings of stigmatisation;

however, feeling stigmatised may also lead to feeling suicidal. As a clinical psychologist, this finding is significant, particularly as *none* of the providers made reference to concerns about women's risk for self-harm or suicidal ideation. This may indicate that providers underestimate the severity of emotional distress that women experience when they are informed of the fetal diagnosis. It would be meaningful to provide women with psychological support as early in the process as when they are informed of the fetal abnormality, in order to address possible suicidal thoughts.

Women may feel ready to explore their experiences of feticide and LTOP only months or even a year or more following the procedures. However, this is counterintuitive to most healthcare providers who underestimate the long-term impact of these procedures on women's wellbeing, and regard immediate in-hospital psychological support as adequate for resolution of the trauma women experienced. In addition, most providers regard the six-week follow-up appointment as the last time that women would be assessed and referred for psychological treatment following the LTOP. This lack of understanding of the emotional recovery process women endure may result in a lack of awareness that women may continue to present with significant psychological distress many months or even years following the procedures, leaving women to endure grief, depression and trauma alone without adequate detection or intervention. Ongoing support and care is needed and to this end, it would be beneficial to provide relevant training to the doctors, nursing and allied staff who are involved in the care of patients undergoing feticide and LTOP, in order to sensitise them to this distinctive grief process.

It is noteworthy that the avoidance of follow-up appointments among North American women who had terminated due to fetal abnormality may be due to women avoiding

triggering reminders of the feticide and LTOP experience (Ramdaney et al., 2015). With regard to psychological support, it is advisable to encourage pregnancy loss and LTOP support groups and encourage women to attend these from the point of making the decision to terminate in order to provide accessible and safe spaces in which to speak and ask their questions. Ramdaney et al. (2015) suggested that online support groups may be an easily accessible and private method for North American women who had undergone terminations due to fetal abnormality, to connect with one another. These interventions may serve to address and improve women's attendance at their follow-up appointments. The use of digital platforms to improve maternal health is increasing in South Africa, and could be extended to this area.

3. Final Reflections and Future Research

As noted at the start of this thesis, there is very little research on feticide and LTOP in South Africa and elsewhere. This study has shown that it is possible to undertake research on this sensitive topic and to do so from a feminist perspective in the South African context. The importance of research of this nature lies in the pivotal themes emergent from this study, which include the divide between public and private healthcare in South Africa and how this affects women's experiences of feticide and LTOP, as well as the impact of gendered, racial and structural inequality on women's agency in decision-making. The use of the FSCGT methodology proved to be pivotal in bringing women and providers' voices to the fore, while facilitating these constructions being viewed through a critical lens. GT studies are particularly helpful in exploring fields such as feticide and LTOP, where there is little known in South Africa about these women's experiences of these procedures, and much reticence to talking about them. This study and others like it endeavour to counter the silencing of

women's (and pro-choice providers') voices and provide a space for their words to be acknowledged and their experiences validated.

The process of gathering data proved to be even more challenging than I had anticipated and caused the data gathering to extend over a number of years. Access to private healthcare users proved to be the most arduous process due to providers' reticence to become involved in this research, as well as due to the significantly lower incidence of feticide and LTOP in private healthcare in South Africa. I would have preferred to include more than one nurse and one nurses' aid in this study, due to their hands-on interaction with women during their procedures and in-hospital recovery; however, access to public healthcare nursing staff proved impossible, due to their fears of speaking out against the faults in the system. Organisational silencing is a common occurrence not only in South Africa, but also internationally (Seren et al., 2018). Public healthcare staff, in particular nursing staff, indicated that their reason for declining participation was due to concerns that they may face disciplinary action for sharing negative views on the South African healthcare system. The fact that I was able to access sufficient participants from both the women's population as well as the healthcare providers' population bodes well for future studies of this nature and on this topic. Although I would caution all researchers not to underestimate the time it takes to make contact with and interview these participants due to the highly sensitive nature of the topic.

The impact that participation had on the women as well as providers indicates that research of this nature is welcomed and, in fact, beneficial to these populations, as long as it is undertaken from a pro-choice, non-judgemental and empathetic approach. Similarly, Lafarge et al. (2013) found that their participants in the UK reported benefits from having participated in their research, such as being able to tell their story and help other women.

On a personal level, this research challenged me more than I could have anticipated. It asked more of me than I felt willing or able to give at times, and it was in these moments when the only force keeping me going was the women whom I knew were waiting for me to finish. This work has become far more to me than a thesis or a degree. It became a challenge of perseverance and commitment to honour my participants' voices: to ensure that they will not be ignored or silenced once again.

My own psychological health was severely affected by this study and the vicarious trauma I experienced from interacting with women and participants and their own trauma and grief. Being in my own therapeutic process has been exceedingly helpful in working through my own reactions to this study. I would recommend that all researchers who undertake studies on topics of this nature should make use of psychological support in order to manage their own trauma responses, which frequently includes behaviours related to the avoidance of triggers (which becomes the research itself).

In addition to my emotional and psychological health having been affected, this research also served to challenge my own perceptions and beliefs regarding abortion, disability, social injustice and gendered experiences of the South African healthcare system. Publicly aligning myself with feminism, critical health research and pro-choice perspectives affected my professional and private lives, as people (colleagues, friends, family members and patients) reacted to my positioning in powerful, and unfortunately, mostly negative ways due to their own anti-choice beliefs.

Finally, and most significantly, I was confronted with the lived experience of being a woman, mother, wife and employed clinical psychologist trying to complete a PhD thesis. When I wrote about the unequal distribution of the burden of childcare and housekeeping, I was not only providing an academic viewpoint, but also a personal, lived one. I started this thesis with small children and I am ending it with pre-teens. I felt guilty and selfish at times for taking space and time and financial resources away from my family in order to complete this research. And I could not help but observe that my male colleagues do not struggle with as much “juggling” of roles as I have had to do during this process.

In concluding my personal reflection on this study, I would warn other researchers who are interested in the topics of pregnancy loss, late termination of pregnancy and feticide to be aware of the struggles ahead. You will be challenged and changed by this experience. It will be painful, and it may feel impossible to survive at times. But just like the women who so courageously participated in this study, you too must persevere, and you too must not lose your voice in the process.

For those brave enough to tackle such studies, recommendations for future research include:

- greater inclusion of nursing staff in the providers’ sample in order to ascertain their experiences as well;
- a particular focus on how to provide greater psychological support to providers involved in these procedures, and taking into account the distinct differences in support and training required by different providers, e.g., nurses, allied providers (psychologists, counsellors etc.) and medical doctors and specialists;
- women’s experiences when they decided against LTOP to shed light on the difference in outcomes based on women’s decisions;

- a focus on psychological interventions and support structures for women and their families from the first phase of the feticide and LTOP process;
- the experiences of partners and their families, including support that they may need, particularly case studies may be helpful in exploring the different scenarios and contexts in which feticide and LTOP take place;
- social understandings and attitudes towards feticide and LTOP (separate from understandings of abortion in broad terms); and
- the possibilities and functioning of peer support networks.

Irrespective of the approach research may take with regard to the topic of severe fetal abnormality, feticide or LTOP, it is essential that the women whose bodies carry the fetus, are prioritised and their voices listened to.

Policy and procedural recommendations will be compiled into a document for distribution to the South African Department of Health and include feedback and suggested changes to procedures regarding consent, choice, physical care and psychological care of pregnant people who are diagnosed with a fetal abnormality and provided with the option to terminate. In addition, a document providing psychoeducational information in lay terms is to be compiled in order to provide women with information on the “expected” reactions, or experiences prior to, during, and following the feticide and LTOP procedures, and provide information on resources and support networks they can make use of during these critical periods. It is my hope that this thesis will serve as the foundation for the practical, enacted improvement of service delivery, the creation of greater awareness of women’s experiences of feticide/LTOP from an understanding and supportive perspective and the establishment of virtual and physical spaces of safety for their stories to be shared.

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APPENDICES

APPENDIX A: CONSENT FORM FOR PARTICIPATION (WOMEN)

RHODES UNIVERSITY - DEPARTMENT OF PSYCHOLOGY

AGREEMENT BETWEEN STUDENT RESEARCHER AND RESEARCH PARTICIPANT

I _____ (your name) agree to participate in the research project of Angela (Angie) Carol Vorster on South African women's experiences of late termination of pregnancy due to fetal abnormality (involving the feticide procedure) and including the process of decision-making, the experience of undergoing the procedure as well as the recovery process.

I understand that:

1. The researcher is a Clinical Psychologist doing the research as part of her Doctoral degree at Rhodes University. The researcher may be contacted on 082 462 4062 or angiev@telkomsa.net. The research project has been approved by the relevant ethics committee, and is under the supervision of Prof Catriona Macleod, and co-supervision of Prof Lindy Wilbraham, in the Psychology Department at Rhodes University, who may be contacted on 046 603-7328 or C.Macleod@ru.ac.za.

2. My participation will involve one or more interviews with Angie (Angela) Vorster over a period of weeks or months. I may be asked to answer questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to talk

about. My name will be protected throughout the project and I will be given a pseudonym (fake name). The interview/s will only take place when I feel ready to talk about what happened. All information and documents (both hard copy and electronic form) will be stored according to HPCSA guidelines in order to protect my confidentiality (keeping all of my information private).

3. I am aware that the interviews are audio-taped and that these recordings are stored in the same way as all research documentation, so as to protect my confidentiality and privacy.

4. I agree to the presence of a translator if my language of choice is Sesotho and I understand that the translator is a registered nursing sister and consequently professionally bound to maintain the confidentiality of my information.

5. I can tell Angie if I have any problems about my being in the study, or consequences I may experience because of this. If I feel unwell or upset by what we talk about I will inform Angie of this and she will refer me to the nearest counselling centre or psychologist in my area. Should I experience an emergency I can phone The South African Depression and Anxiety Group on 011 234 4837 or 0800 20 50 26 and speak to a trained counsellor. Or I will report to my nearest hospital's casualties unit, where the psychiatrist on call will assist me.

6. I am free to withdraw from the study at any time. However, I commit myself to full participation unless some unusual circumstances occur, or I have concerns about my participation which I did not think may happen.

7. The report on the project may contain information about my personal experiences, attitudes and behaviours, but that the report will be written in such a way that it will not be possible for me to be identified by the general reader.

8. I am aware that Angie is a Clinical Psychologist; however I understand that our relationship will be research based and not for psychotherapy.

9. All information will be used to better understand women's experiences of feticide and to develop theories surrounding their experiences. This will be compiled as a PhD thesis and articles based on this thesis may be published nationally or internationally. This thesis may also be submitted to national bodies such as the Department of Health in order to assist in improving procedures and care provided to women who experience feticide in South Africa.

10. I hereby provide consent that Angie may access my patient file regarding my late termination of pregnancy and realise that this information is regarded as private and confidential and will be managed as such.

11. I understand that I will not be paid to participate in this research, but that my transportation costs will be reimbursed where needed. Choosing to participate, or not participate, will in no way affect my health care service provision.

Signed on (Date): _____

Participant Name and Surname: _____

Signature: _____

APPENDIX B: CONSENT FORM FOR PARTICIPATION (Provider)

RHODES UNIVERSITY - DEPARTMENT OF PSYCHOLOGY

AGREEMENT BETWEEN RESEARCHER AND RESEARCH PARTICIPANT

I _____ (participant's name) agree to participate in the research project of Angela Carol Vorster on South African women's experiences of late termination of pregnancy due to fetal abnormality (involving the fetal injection of potassium-chloride or lignocaine) and including the process of decision-making, the experience of undergoing the procedure as well as the recovery process.

I understand that:

1. The researcher is a Clinical Psychologist conducting the research as part of the requirements for a PhD degree at Rhodes University. The researcher may be contacted on 082 462 4062 or angiev@telkomsa.net. The research project has been approved by the relevant ethics committee, and is under the supervision of Prof Catriona Macleod, and co-supervision of Prof Lindy Wilbraham, in the Psychology Department at Rhodes University, who may be contacted on 046 603-7328 or C.Macleod@ru.ac.za.

2. The researcher is interested in exploring how health service providers reflect on women's experiences of late termination of pregnancy due to fetal abnormality, and specifically when 'feticide' or fetal termination takes place prior to pregnancy termination. The focus of this research is on the women's experience of these medical procedures, but not an evaluation of the health care service or providers' performance.

3. My participation will involve one or more interviews conducted by Angie Vorster over a period of weeks or months. I may be asked to answer questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to disclose. My anonymity will be protected throughout the project and I will be given a pseudonym. Electronic and hard copy data will be stored in such a manner as to protect the confidential nature thereof.

4. I am invited to voice to the researcher any concerns I have about my participation in the study, or consequences I may experience as a result of my participation, and to have these addressed to my satisfaction. If I feel unwell or upset by the content of our discussions I will inform Angie of this and she will refer me to the nearest counselling centre or psychologist in my area.

5. I am free to withdraw from the study at any time. However, I commit myself to full participation unless some unusual circumstances occur, or I have concerns about my participation which I did not originally anticipate.

6. The report on the project may contain information about my personal experiences, attitudes and behaviours, but that the report will be designed in such a way that it will not be possible to be identified by the general reader.

7. I am aware that Angie is a Clinical Psychologist; however I understand that our interactions are research based and not therapeutic in nature.

8. All information will be used to better understand women's experiences with regard to the research topic and to develop theories surrounding their experiences. This will be compiled as a PhD thesis and articles based on this thesis may be published nationally or internationally. This thesis may also be submitted to national bodies such as the Department of Health in order to assist in improving procedures and care provided to women who experience feticide in South Africa.

9. I understand that my participation in this research will not result in remuneration of any kind, nor will I incur costs due to my participation.

Signed on (Date): _____

Participant Name and Surname: _____

Signature _____

APPENDIX C: LETTER FOR THE PROVINCIAL DEPARTMENT OF HEALTH

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN HOSPITALS

My name is Angie Vorster, and I am a PhD in Psychology candidate at Rhodes University in Grahamstown. The research I wish to conduct for my doctorate involves studying women's experiences of feticide and late termination of pregnancy due to the presence of fetal abnormality. This project will be conducted under the supervision of Professor Catriona Macleod (RU, South Africa) and Professor Lindy Wilbraham (RU, South Africa, co-promoter).

I am hereby seeking your consent to conduct interviews with women who have experienced late termination of pregnancy due to the presence of fetal abnormality, where feticide took place as part of the termination of pregnancy. Due to the tertiary nature of this medical intervention, most of the women would have received treatment at (XX) Academic Hospital, or at private hospitals in (XX). I would also like to interview healthcare providers who are involved with feticide procedures in order to gain their insights regarding women's experiences in this regard.

I am a Clinical Psychologist and have extensive experience in treating conditions related to trauma and am able to contain whatever emotional distress may arise during these interviews. I have also made provision for appropriate private and public healthcare referrals should participants require further psychotherapy. Previous research has found that women find the opportunity to engage in research interviews as helpful in dealing with their experiences and the interviews themselves serve as an opportunity to debrief. It is important for research on

this sensitive topic to include the voices of South African women and add their experiences to the body of international knowledge in this area.

I have provided you with a copy of my proposal which includes copies of the consent and assent forms to be used in the research process, as well as a copy of the approval letter which I received from the Rhodes University Research Ethics Committee. Should I receive permission to conduct this research, I would first request permission to do so at each separate medical institution as well.

Upon completion of the study, I undertake to provide the Department of Health with a bound copy of the full research report and make myself available for personal feedback, or policy recommendations, should you require. My goal is to be able to make a meaningful contribution to service delivery in this area. If you need any further information, please do not hesitate to contact me on 082 462 4062, angiev@telkomsa.net. Thank you for your time and consideration in this matter.

Yours sincerely,

Angie Vorster

APPENDIX D: LETTER FOR PRIVATE PROVIDERS

Dear Colleague

I am currently busy with my PhD (under the supervision of Prof Catriona Macleod at Rhodes University) studying women's experiences of late TOP and feticide, including health care providers' experiences in this regard. Due to the sensitive nature of the topic I am struggling terribly to find participants willing to be interviewed for my qualitative data gathering. I have all the necessary ethical and research clearance as well as permission from the (XX) DoH to access their patients and staff, however I would like to include **private** patients and physicians from across the country, so as not to limit my data just to public healthcare services.

I am able to travel throughout SA in order to interview participants (women and health care providers) and am not just interviewing physicians who have performed feticides, but all doctors, nurses or genetic counsellors who are involved in the process, from diagnosis of abnormality through the procedure and afterward. Any feedback or assistance would be immensely helpful.

Warm regards

Angie Vorster

APPENDIX E: REQUEST FOR PARTICIPATION

RHODES UNIVERSITY – DEPARTMENT OF PSYCHOLOGY

Research Project: Consent to be Contacted by Researcher

My name is Angie Vorster and I have asked your doctor to give you this letter to tell you about the research that I am doing. It may be possible that you would like to add your voice to this research. I am interested in talking with you about your experience of ending your pregnancy.

This research project has been approved by the relevant ethics committees, and is under the supervision of Prof Catriona Macleod (with Prof Lindy Wilbraham as co-supervisor) in the Psychology Department at Rhodes University, who may be contacted on 046 603-7328 or C.Macleod@ru.ac.za.

I would like to arrange one or more interviews with you where we discuss your personal experiences of ending your pregnancy. Your real name will not be used and I will make sure that no one is able to recognise you through the information you give me. Your privacy will be protected at all times. Interviews will take place at a time and place that suits you and only once you feel ready to talk about your experience.

If at any point during the research you feel upset or unwell, I will refer you to psychological service providers nearest to your residence. I am a clinical psychologist but in my role as

researcher, I will not be able to provide psychotherapy as this would cause dual role conflicts.

You are free to withdraw from the study at any time up to publication of the research and participation is completely voluntary.

All information will be used to better understand women's experiences of terminating their pregnancy in the circumstances where fetal abnormality has been diagnosed and to develop theories about their experiences. This will be compiled as a PhD thesis; articles based on this thesis may be published nationally or internationally. This research may also be submitted to national bodies such as the Department of Health in order to assist in improving procedures and care provided to women who experience late termination of pregnancy in South Africa; we will also provide recommendations to our government information regarding how changes could be made to their legal policies.

You will not be paid to participate in this research; however, your transport costs will be reimbursed if necessary. Women in similar circumstances have welcomed the opportunity to tell their stories in a confidential space, and your participation may help other women in future.

By signing this form you are agreeing to allow your health care provider, Dr to disclose your personal contact information including your cell phone number and/or e-mail address to the researcher, Mrs Angie Vorster, and for me to contact you in order to discuss the research further and to talk about arranging an interview. I can be contacted on 082 462 4062 or angiev@telkomsa.net for information.

Participant name and surname in print _____

Signature _____

Date _____

Cell phone number _____

Email address _____

APPENDIX F: LETTER OF APPROVAL FROM RHODES ETHICS COMMITTEE

Rhodes University Ethical Standards Committee, Rhodes University, P O Box 94, Grahamstown, 6140 Tel: +27 46 603 7366. Fax: +27 46 603 8934. Email: ethics-committee@ru.ac.za

04-Mar-2016

Dear Angela Vorster

Ethics Clearance: South African Women's Experience of the Decision, Procedure and Recovery from 'Feticide' and Late Termination of Pregnancy due to the Presence of Severe Fetal Abnormality: Women's and Health Service Providers' Perspectives.

Principal Investigator: Angela Vorster

This letter confirms that a research proposal with tracking number: RU-HSD-16-01-0011 and title: **South African Women's Experience of the Decision, Procedure and Recovery from 'Feticide' and Late Termination of Pregnancy due to the Presence of Severe Fetal Abnormality: Women's and Health Service Providers' Perspectives.** was given ethics clearance by the Rhodes University Ethical Standards Committee.

According to reviewers, all aspects of the very sensitive nature of this study have been taken into account by the researcher. The committee is convinced by the documentation submitted that the researcher has the capacity to provide a containing environment for participants and

to take action should any participant need to exit the study or become distressed by participating in the study. The committee also realizes that such a study has important knowledge benefits for South African women and the health profession and that the participants themselves might gain some positive benefit from talking through their experiences with someone who is trained to listen (even if operating as a researcher in this instance).

Please ensure that the ethical standards committee is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on completion of the research. The purpose of this report is to indicate whether or not the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the ethical standards committee should be aware of. If a thesis or dissertation arising from this research is submitted to the library's electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloguing number allocated.

Yours Sincerely,

Dr J. Marx: Chairperson RUEESC.

Note:

1. This clearance is valid from the date on this letter to the time of completion of data collection.
2. The ethics committee cannot grant retrospective ethics clearance.
3. Progress reports should be submitted annually unless otherwise specified.

**APPENDIX G: LETTER OF APPROVAL FROM PROVINCIAL DEPARTMENT OF
HEALTH**

National Health Research Database: Important Information

NHRD Support (DO NOT REPLY) <nhrd@hst.org.za>

Tue 2016-06-21 12:21 PM

To: Angela Vorster <VorsterAC@ufs.ac.za>

Dear Angela,

This email confirms that we have received your application (*FS_2016RP7_49*). The status of your application has changed.

The new status is: “**Approved**”.

APPENDIX H: SEMI-STRUCTURED INTERVIEWS FOR PARTICIPANTS (WOMEN)

INTERVIEW SCHEDULE WOMEN WHO HAVE EXPERIENCED LATE TERMINATION OF PREGNANCY AND FETAL INJECTION OF LIGNOCAINE/POTASSIUM CHLORIDE

Introduction

Introduce some background to myself, the research and motivation for the interview. Introduce translator if required. Discuss all documentation and allow time for participant to complete all documents. This aspect may take some time, however it is an essential step in the interviewing process. Establish rapport by obtaining relevant background and demographic information.

Body

Tell me the story of ending your pregnancy. Start from the beginning when you realised that you were pregnant, to the present. Take as long as you want to. I will listen and not interrupt. (open-ended and allows participant to start at any point of her story)

Aspects that require exploration if they are not addressed by participant:

Her experiences of the pregnancy prior to diagnosis of fetal abnormality (contextual, interpersonal and systemic factors).

Her experience of the diagnosis of the fetal abnormality.

Her experience of the decision-making process.

Her experience of medical consultations throughout the pregnancy (and diagnosis and decision-making).

Her experience of the procedure.

Her experience of adjustment following the procedure.

Her experience of the support received following the procedure?

Her experience of the terms and language used by the health care providers and others.

As these interviews are only semi-structured, it may be possible that not all of the information required is covered during the first interview. Consequently, successive interviews may be required. As far as possible, follow-up interviews will be scheduled in order to explore questions that arise from initial transcription and analysis of the previous interview material (in terms of grounded theory method).

Closing

Contain emotions and assess and discuss need for debriefing or psychotherapy referral.

Express gratitude for willingness to participate and validate participant's voice.

Discuss follow-up interviews and future contact.

Ensure participant has researcher contact details.

APPENDIX I: SEMI-STRUCTURE INTERVIEWS FOR PARTICIPANTS (PROVIDERS)

INTERVIEW SCHEDULE HEALTH SERVICE PROVIDERS INVOLVED IN LATE TERMINATION OF PREGNANCY AND FETICIDE

Introduction

Introduce some background to myself, the research and motivation for the interview. Introduce translator if required. Discuss all documentation and allow time for participant to complete all documents. This aspect may take some time. However, it is an essential step in the interviewing process. Establish rapport by obtaining relevant background and demographic information.

Body

Drawing on your experience, please tell me everything you know about how women experience ending their pregnancy as a result of fetal abnormality, from when they receive the diagnosis, to making the decision, undergoing the procedure and recovering after the procedure. Tell me everything that you think is relevant and I will simply listen. How do you think patients experience late termination of pregnancy? (Open-ended and allows participant to start at any point)

Aspects that require exploration if they are not addressed by participant:

How do you think patients experience fetal termination? Feticide.

What aspects affect how women experience these procedures? (Contextual, interpersonal and systemic factors).

Please talk to me about the patient's experience of the diagnosis of the fetal abnormality.

Tell me about patients' experiences of the decision-making process.

How do you think patients experience medical consultations throughout the pregnancy (and diagnosis and decision-making).

Tell me about patients' experiences of the procedure.

How do you think patients adjust following the procedure?

What are your perceptions regarding the support patients receive following the procedure?

Please tell me about any 'difficult' cases you found hard to deal with?

Tell me about cases that you think went well?

What do you do to help patients to understand the diagnosis and medical procedure?

What is your role in the patient's decision-making process?

How do you try to ease patient discomfort?

Please reflect on the language we use to talk about these patients and procedures.

As these interviews are only semi-structured, it may be possible that not all of the information required is covered during the first interview. Consequently successive interviews may be required. As far as possible, follow-up interviews will be scheduled in order to explore questions that arise from initial transcription and analysis of the previous interview material (in terms of grounded theory method).

Closing

Contain emotions and assess and discuss need for debriefing or psychotherapy referral.

Express gratitude for willingness to participate and validate participant's voice.

Discuss follow-up interviews and future contact.

Ensure participant has researcher contact details.

APPENDIX J: CONFIDENTIALITY AGREEMENT TRANSLATOR

CONFIDENTIALITY AGREEMENT:

Translator

I, _____, (name of translator) agree to maintain full confidentiality in regards to any and all interviews conducted with participants of Angie Vorster's research study on women's experiences of feticide and late termination of pregnancy due to severe fetal abnormality.

Furthermore, I agree:

To hold in strictest confidence the identification of all individuals participating in interviews.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information obtained during interviews.

Translator name (printed)

Translator signature _____

Date _____