Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy

Kay Jones

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ABSTRACT

This thesis calls attention to women having a termination of pregnancy for fetal abnormality by highlighting their lived experiences and the meanings they attribute to these experiences.

Phenomenological material was gathered from four women using semi-structured interviews. A post-intentional phenomenological design was used, along with theoretical models of existential phenomenology and The Meaning-Centred Grief Model. The women's narratives lent themselves to the development of crafted stories that allowed for the uncovering of what had previously been hidden.

Women felt a deep sense of being alone during their experience that represented more than a lack of physical 'thereness' of others. They realised that they were existentially alone giving birth to their babies, even when surrounded by people who cared for them. Through social stigma, being overwhelmed and devastated for making the decision to end their pregnancies, they felt silenced in their grief. A sense of unpreparedness left the women with feelings of uncertainty and not being ready for the reality of what was happening. The women shared a vulnerability that reflected a place of fear, shame, guilt and judgement from others. This place allowed for the possibility of holistic harm that for some of the women, they felt they deserved. Women desperately wanted connection, acknowledgement and compassionate support as they went through the loss of their babies. They needed time and breathing space to make sense of what was happening and come to terms with the reality.

The findings of this work offered a deeper understanding of women's unspoken embodied experiences of ending their pregnancies. This insight supports health care providers to see each woman as unique in both her needs and her ways of finding meaning in the loss of her baby. It encourages the use of woman/family-centered bereavement care planning that reflects what is important to them in the context of a termination of pregnancy. These findings re-focuses care that allows the woman, her family and her caregivers to connect in a more intimate way that offers a sense of holistic safety, interrelatedness and of being on a shared journey. This work encourages caregivers to walk closely beside the women and their families to nurture this humanistic relationship and to bring a sense of togetherness.

This work puts a spotlight on bereavement care and the need for it to be prioritized in maternity care provision. Midwifery education is needed, at both undergraduate and post graduate levels, that is consistent, contemporary and supportive of this level of care. Caregivers are encouraged to acknowledge the journey of women having a termination of pregnancy is a complex, entangled and context-driven experience that deserves the utmost consideration and attention.

The findings reflect a body of evidence that acknowledges the devastating experience of terminating a pregnancy for fetal abnormality and prompts caregivers to approach this care with the woman and her family firmly at the center of the care.

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ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed

Dated 28th June 2024

ACKNOWLEDGEMENTS

In this acknowledgement section, I extend my deepest gratitude to all who have walked with me on this challenging but fulfilling journey.

This research project started a few years ago and was, at first, a journey I was unsure I wanted to make. I was unsure of how I would ever get to the end. The hurdles seemed to be unsurmountable, and I doubted my every step. Then I returned home to New Zealand and my passion for this topic was renewed. I could not stop pondering the experiences of women and how they coped ending their pregnancies.

As this research developed, I became increasingly committed to hearing women's stories and trying to understand what women went through and how my midwifery care might impact on these experiences. Without the women I have met during my midwifery career and the four women I have interviewed for this research I would not have received the gift of understanding, of appreciation for what it is like to lose a baby through terminating a pregnancy. For this I am forever grateful. This gratitude is beyond measure and is so deeply felt that I am at times overwhelmed with these feelings. I would like to express my gratefulness and deep regard for all these women. My promise is to show this gratitude every day, with every woman I provide midwifery care to, regardless of their own story. Midwifery, the women I meet and the work I do provides me with the chance to be thankful every day.

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"Let us be grateful to the people who make us happy: they are the charming gardeners who make our souls blossom"

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My colleagues have stood beside me literally and figuratively as I have taken each step. They have trusted my determination to see midwifery bereavement care be the very best it can be and have encouraged me to keep going in this quest. There have been so many times that we have shared stories, experiences and feelings and together we have tried to figure out how we can do better. Midwives are an astounding group anyway, but this work has highlighted the deep commitment midwives have to caring for all women with compassion and kindness. There are many midwives who have an intuitive knowing and I have learnt so much from them. My colleagues are incredibly special to me, and I thank each and every one of them.

"At times, our own light goes out and is rekindled by a spark from another person. Each of us has cause to think with deep gratitude of those who have lighted the flame within us"

Dedication

This work is dedicated to all the women who have lost a baby and to their stories of vulnerability and pain. Also, to all the babies that have come and gone in a heartbeat. Rest in peace little ones.

CHAPTER ONE: ORIENTATION TO THE STUDY

Introduction

This first chapter introduces this study and gives an orientation to the overall research context. The focus and aim of the research are discussed and the research question offered. It shows the justification for the study and describes how this study came about. It states why this research is important and, in support, provides stories from my own practice. It then details the context of the study by discussing what brings a woman to the experience of having a termination of pregnancy for fetal abnormality. Several related concepts are analysed and discussed to provide an explanatory background to the study. Finally, a content overview of the thesis is provided.

"I will love the light as it shows me the way, Yet I will endure the darkness as it shows me the stars." **Og Madino (1923-1996)**

I have spent a lot of time trying to understand the experience of loss in pregnancy and it is uncertain if my understandings will ever be complete. How could they be, as every story of loss is unique and as individual as those living the experience. While I deeply appreciate the light that shines on my path as I walk alongside those who have lost a baby, it is indeed the darkness that highlights the beautiful moments that appear amid the gloom. The wonder and reverence I feel when a baby is born, regardless of the baby's life story, is always a time of thanksgiving. However, I remain curious about how the experience is for the baby's mother. It is the stories from the mothers that I so desperately want to hear, immerse myself in, and try to understand, so that I can gain a deeper appreciation for what it is to lose a baby in the context of a termination of pregnancy (TOP) because of fetal abnormalities. This research offers a 'looking in from the outside' perspective of the narratives of four women who, after been given the diagnosis of their baby having a serious condition, made the decision to end their pregnancies.

Research Approach

The methodology of post-intentional phenomenology (PIP) was chosen to support the exploration of the lived experiences of the women from their own remembering's. The intention of this inquiry was to find meaning in their narratives, contemplate the re-telling of their stories, and highlight their experiences of experiencing. By using a qualitative research methodology, there is the possibility of bringing to light the experience of TOP within social, spiritual, experiential, linguistic, emotional, and cultural contexts (Munhall, 1989). Bleiker et al (2019) reiterate that qualitative methodology can put forward a richness and depth of understanding that offers insights into how a person interprets and makes sense and meaning of their experiences. In addition to these notions, PIP offers an even more intimate and devoted journey towards understanding what it is to be human (Vagle, 2018). PIP allows for the belief that there is not necessarily a single reality, and therefore the analysis of data reflects the multitude of truths within a single phenomenon. The relevance of this statement acknowledges that each woman who experiences a TOP has a unique 'truth', and her story is seen from her own unique perspective. The phenomenon of having a TOP is often veiled in secrecy so this current research is compelled to uncover these 'truths' to enlighten others of the woman's lived reality (Jones, et al., 2017b).

Kadyschuk (2023) stated that any analysis or interpretation of data is interrelated to the understandings brought forward by the researcher. Therefore, my own experiences of caring for women who are going through a TOP were produced and provoked alongside the women's own interpretation and meaning making (Vagle, 2018). My own assumptions were brought forward, challenged and then pushed back, forcing me to ponder how my own thoughts relate to what the women experienced. PIP sat me in a space of 'uncovering' possibilities, venturing further than the words alone and placing me firmly in the women's stories.

PIP allowed me to enter the lived experiences of women having a TOP by giving me the means to explore their narratives and their ways of being in the world. My own beliefs were suspended and other ways of knowing appeared. As Vagle (2018) states, PIP acknowledges the ebb and flow of the context or social complexities of a phenomenon and how the entanglement is, in fact, part of the phenomenon. While utilising the PIP philosophy of multiplicities, the women's stories presented alternative ways of thinking, seeing and finding meaning (Vagle, 2018).

While qualitative data and interpretation of that data is frequently used in the investigation of health research, the methodology of PIP is not as common (Miles et al., 2013a). Vagle (2019) states the difference between traditional phenomenological methodology and PIP is the production and generation of a "cacophony of philosophies/theories/ideas that accomplishes something(s) that these same individual philosophies/theories/ideas may not be able to do" (p. 1). This implies that according to PIP, a phenomenon is seen as having a contextual identity and therefore shows the possibility of facilitating social change dependent on that context. The experience for a woman having a TOP is highly impactful on a personal level and PIP allows for this experience to be understood by others (Jones et al., 2017b). The research question seeks this understanding and along with the acknowledgement of the experience of having a TOP, comes empathy and compassion.

Research Question

The research question asked was: *What are women's experiences of having a termination of pregnancy for a fetal abnormality in the second trimester of pregnancy?*

Research Aim

The aim of this research is to hear and understand the experiences of women having a TOP for fetal abnormality so that what has often remained unsaid and, therefore, unheard, may be expressed and brought to the fore. Women's voices may provide a deeper understanding and appreciation of what they went through. It is acknowledged that for women going through a TOP the experience is undeniably complex. However, it is in the retelling of their stories that the unpacking of these complexities is made possible. Instead of merely reading these stories, this research aims to experience the flowing, expanding, fleeting, and even transient remembering's of the women.

The women's narratives may support and influence maternity care provision, and impact those receiving the care as well as those providing the care. The potential for new understandings from this research offers a deeper, richer, more humanistic approach to caring for women going through what has been described as a deeply traumatic experience (Jones, et al., 2017b). Gaining practice insights will enable current midwifery bereavement care to be contemporised to ensure the most current and appropriate care standards are incorporated into practice.

Justification for the Study

There is an increasing body of literature on women's experience of miscarriage and stillbirth. Most of the research on pregnancy loss has been directed towards either investigating pregnancy loss because of miscarriage in the first trimester or a stillbirth in the third trimester (Burden et al., 2016; Cacciatore et al., 2008; Farren et al., 2018; Smith et al., 2020). The over-arching findings of the already undertaken research confirms that the loss of a baby, no matter what gestation, is hugely impactful on women and their family's health and well-being.

There is also extensive research and knowledge on decision making around fetal abnormalities and the impact of such decisions (Blakeley et al., 2019; Lafarge et al., 2014; Marc-Aurele., 2020). Women and their families are faced with trying to make sense of this actuality and, subsequently, navigating their way through the experience. They are required to make profoundly difficult decisions regarding the continuation of their pregnancy or having a medical TOP, knowing that the outcome will still mean the loss of their baby (Blakeley et al., 2019).

Although the aforementioned research supports knowledge of some contexts of the loss of a baby, there remains a significant gap in knowledge around women's experiences of birthing when having a TOP for fetal abnormality. The overt responses to losing a baby can be justified and anticipated but what about, what is *not* visible, or what is n*ot* spoken of?

The advances in diagnostic technologies in maternity care have enabled women to be informed of any serious abnormalities found in their unborn child (Kamranpour et al., 2021). Thus, there is the possibility of more women being placed in a position of making the choice of continuing or ending their pregnancies. Along with these technological advances, there has been, globally, an overwhelming trend towards the liberalisation of abortion laws (Center for Reproductive Rights [CRR], 1992-2023). This trend equates to more women, worldwide, accessing TOPs as part of their human rights. There have been, however, four countries that have made their abortion laws even more restricted (CRR, 1992-2023). More liberal international abortion laws support the need to gain further understanding of the experiences of women ending their pregnancy in the context of women been given a poor prenatal diagnosis. Holistically, there is also the need to understand how women make meaning of their labour and birth within the context of having a TOP. It should be noted that for some, the terms termination of pregnancy and abortion are interchangeable. Kavanagh et al, (2018), suggest that the use of the phrase 'termination of pregnancy' refers to the ending of a pregnancy after a prenatal diagnosis. Whereas the term 'abortion' is often associated and stigmatised as the ending of an *unwanted* pregnancy. The phrase 'termination of pregnancy' is therefore used in this thesis. New knowledge will enhance care provision and, therefore, the lived experiences of women going through the loss of their baby in the context of a termination of their pregnancy in the second trimester.

What Drew Me to the Research Question

I have been conscious of women's experiences of having a baby who has abnormalities even as a student midwife in the 1990s. These experiences often felt empty, bleak, and seemed to happen in a single heartbeat. The diagnosis made and the woman informed, the birth arranged and dealt with. It seemed that the sooner it was over the sooner everyone could forget it had ever happened.

The sadness and anguish described by women who have found themselves in this situation seemed to go unheard. Their voices were lost in the uncomfortableness of the moment. Yes, they cried and were offered sympathy. Yes, they were treated with a special reverence bestowed on those who have 'lost'; still, their true lived experience seemed to be overlooked. This was not because of disregard or lack of care but appeared to be more about clinically managing the situation rather than truly, holistically, considering the experience.

My role as both a private and employed midwife has given me a familiarity with women and their experiences of pregnancy loss. Through either providing the midwifery care or supporting others who provide that care, I understood the clinical care to be based on the policies and guidelines of the birthing facility. This understanding is not a judgement of that care; rather, a statement of the reality of the care provided. While each woman's experience and the circumstances around her loss were unique, there seemed to be a recurring sense of hush or, even, muteness about how they felt having lost a baby regardless of when the baby died—before birth, soon after the birth, or because of the birth (TOP).

When a woman was experiencing a TOP, there was a prickly discomfort that was felt but never acknowledged. There seemed to be an incongruence between normal birthing and the reality of these birthing situations. A feeling of apprehension and grimness often sat within the birthing room and all those who entered. The end of a life before it had begun was so difficult to comprehend, as was the inhumanity of the situation, or perhaps, even more poignantly, the humanity of what was happening.

However, the lived experiences of women who labour and birth in these situations could be considered, by many, to be a mystery. Commonly, the social constructs of the loss of a baby may be visible and consist of the expected responses; the sadness, the grief, the guilt, and even the relief (Jones, et al., 2017b). The unspoken of, the embodiment of the experience, the deeply felt impressions held by the woman; all of these remain covered to many, often including the woman, herself. To know how to truly 'be with' the woman and provide situation-sensitive and compassionate care is what drives the current research. Not just the type of care that clinical guidelines suggest or what 'I think' is appropriate care. Instead, care that is meaningful and significant to the woman's whole experience.

Why Does the Research Matter?

Midwifery represents 'being with women'; a concept familiar to and accepted by those in the midwifery profession (Bradford et al., 2019). However, the depth a midwife might commit to going to while putting this concept into practice is uncertain, especially in the context of the loss of a baby. It is not a criticism of midwives; rather, an acknowledgement that this care is challenging and not every midwife feels comfortable 'going there'. This research goes beyond the 'knownness' of such care and allows the midwife to embrace her intuitive and vulnerable self, all the while walking beside the woman in a way that is meaningful. Ultimately, doing so will enable the woman and the midwife to come together in a shared experience that matters to both parties. The potential for a positive impact on both the woman and midwife during this care is evident and seen as important.

For a woman to experience a TOP, she is likely to be taken to a nightmarish place of loss. If, at least for some of the journey, she is accompanied by a midwife who is 'with' her, then perhaps some of the nightmare can be alleviated. For the midwife to meet the woman 'where she is', rather than assuming the woman will follow the midwife, represents unconditional and wholehearted support. Every woman deserves this commitment to care but not every midwife knows how to provide it.

For so long, terminating a pregnancy has been cloaked in a blanket of disguise; leaving women alone in their experiences and silenced into a place of unimaginable grief and sadness. This research matters because women matter and their experiences of the loss of a baby through a TOP matter.

A Story From My Practice

This story recalls my first experience of providing midwifery care to a woman having a TOP. It serves as a starting point in my learning about how to 'be with' a woman who is ending her pregnancy. It also made me reflect deeply on what I had witnessed, how it affected me and how the woman responded to what happened to her. My assumptions were put on notice, and I began to see how a woman may experience a TOP.

Sally unexpectedly found out she was having her first baby when she was 15 or so weeks pregnant. She attended her first scan at 18 weeks gestation not really knowing what to expect. The scan revealed that her baby had a fatal congenital condition, anencephaly (Medline Plus, 2019). Sally was offered a TOP which would be carried out in the medical ward of the local hospital. The termination proceeded but, as it was not progressing as expected, the nursing staff requested that a midwife attend Sally to assess what was happening. I attended her as I was on shift in the hospital birthing suite. What I found was a distressed young woman, by herself, lying flat on a bed in a single room. She was inhaling nitrous oxide from a small cylinder next to her. She appeared to be semi-conscious but still crying out in pain and distress. Sally's nurse entered the room and exclaimed that she had a heavy patient load and unfortunately could not spend much time with Sally. She then left the room, leaving me with Sally. I found a bed pan beside the bed, so I put an incontinence sheet in it and placed it on the chair next to the bed. I sat down on the bed next to Sally and gently removed the gas mouthpiece from her mouth. When Sally came around, I introduced myself to her and said that I was there to support her. When she was able, I helped her sit up and asked if she was able to sit on the chair. As she sat down on the bed pan, I reassured her that I had put a soft lining in the pan, just in case her baby arrived and that I would not leave her. Sally's demeanour began to change, and she appeared to be close to birthing her baby. Only a short time passed, and she did, in fact, give birth. She birthed silently with her eyes closed, as if in deep concentration about what she was feeling, both physically and emotionally.

Afterwards, Sally held her baby son for a short time and before long she got off the bed, got dressed, packed her things, and indicated that she was ready to leave the hospital. I asked her if she would like to take her baby boy home or would she rather that he stayed at the hospital. She sadly stated that her home was full of extended family, and it felt disrespectful to take him home to such a noisy environment. She felt that he would have more peace and privacy in the hospital than at home.

She gave her son one last stroke on his chest and left the room.

This all happened so quickly and without any hesitation. I found myself standing alone in an unfamiliar hospital room holding a tiny Moses basket with a tiny, disfigured, dead baby. How could a mother just walk away from her baby without a backward glance? She had just given birth but to the outside world she would appear as a young woman walking down a hospital corridor. My thoughts soon shifted to Sally's lived experience. She was either the bravest woman I had ever met, or the most detached women, or perhaps something much less obvious. Was I making assumptions about her own unique lived experience? Her response was so unexpected as she seemed to be content with both her experience and her decision. But how would I know? Does a lack of an expected response equate to her being content with what had just occurred? Does silence equal acceptance? Perhaps it was not contentment at all; rather, behaviour that reflected the consequence of fate or bad luck. Did she feel a sense of 'inescapableness'; was she incapable of escaping the reality or ignoring the truth? If this was so, then what choice did she have but to walk away?

Sally's story opened my heart and eyes to a woman's experience of terminating a pregnancy. I reflected on the scenario for many months and concluded that Sally did what she felt she needed to do. I could account for the clinical aspects of the experience; the use of nitrous oxide, the physiology of birth, the immediate post birth care, but, in the end, I had more questions than answers. I did not understand what Sally had experienced or how her care had impacted her, holistically. What would the days and months ahead be like for Sally and what were the consequences of her experience?

I had feelings of ineptness when thinking of what Sally had gone through and how I had cared for her. Not through clinical incompetence but a sense of inexperience in caring for a bereaved woman. I wanted, no, needed, to understand this experience at a deeper level so I could 'be with' a woman in a more humanistic way. To do so, I needed to delve under the obvious, behind the assumptions, and beyond myself to get to a place of tender-heartedness to be able to fully appreciate a woman's journey of loss.

It has taken many years of deeply reflecting on each woman I have cared for to get to a point of commitment to this research. Each woman I meet touches those tender spots of self-doubt about how they perceive my care. I know that I cannot solve or set right what they have gone through, but I am desperate to open a place of knowing that will allow me to step into their world of loss, if they let me.

As a result of all the women I have met, the losses I have witnessed, and the heartfelt experiences I have had, I have leaned into learning more about the loss of a baby through a TOP because of fetal abnormalities. Unbeknown to me, my PhD journey started way back when I met Sally.

Study Context

Definition of Terms

See Appendix A.

Antenatal Screening and Testing: What Brings a Woman to This Experience

For many women and their families, expecting a baby is a time of hopes and dreams. The arrival of a healthy baby is looked forward to and anticipated. For most women, this prospect is not farfetched or unrealistic, in fact, it is almost assumed. This 'taken-for-grantedness' is a socially constructed concept that abides with the notion of normality (Misztal, 2015). Therefore, many women see prenatal screening as normative behaviour that offers certainty rather than it being seen as delving into the unknown (Heise & Manji, 2016).

Stapleton (2017) described the utilisation of prenatal screening as "enabling individual pregnant women (and their partners) to make meaningful reproductive choices with regard to having or not having a child with a serious disorder or disability" (p. 202). From a philosophical perspective, Stapleton suggested three potential rationales for prenatal screening for abnormalities in the fetus. Firstly, for the avoidance of physical and psychological suffering for the future child that may be related to some inherited or congenital abnormalities. Secondly, consideration for the potential psychological suffering of prospective parents and their family because of the grief and anguish they feel when witnessing their child's suffering that cannot be remedied or prevented. The last rationale is that screening for abnormalities that provides parents with the choice of continuing with the pregnancy or ending it may lessen the overall burden of disease on society. These rationales for prenatal screening are seen as contentious by many and highlight the complexity surrounding the making of reproductive choices.

Contrastingly, the rationales for not screening are based on fetal rights, feminist advocacy, and disability rights perspectives (Stapleton, 2017). As prenatal screening is used to make reproductive choices, it is seen as opening the door to accessing abortion, and many fundamentally believe this to be an immoral use of such information. Wertz et al., (1993) suggested that prenatal screening for genetic or congenital abnormalities is like a "search and destroy mission" (p. 541) to eliminate a fetus with a disability.

From a feminist perspective, prenatal screening may jeopardize a woman's reproductive autonomy related to terminating a pregnancy, especially if she is encouraged by others to partake in screening to avoid the birth of an affected child. The decisions a woman makes regarding screening or not, ending a pregnancy if the baby has an abnormality or not, reflects the ultimate argument that a woman is the only person who can make these decisions (Nardi, 2019). Regarding disability rights, screening for abnormalities is seen as potentially stigmatising those who will be born with a disability. It relates to the discrimination and societal exclusion of both the future child as well as their family (Garcia et al., 2011).

The worldwide use and development of prenatal screening and testing has seen an increasing ability for clinicians to diagnose fetal abnormalities (Kamranpour et al., 2021; World Health Organization [WHO], 2023). In resource rich countries, like Aotearoa New Zealand, these are now routinely offered to all pregnant women regardless of risk factors or status (Royal Australian and New Zealand College of Obstetricians and Gynaecologists [RANZCOG], 2018). However, access to prenatal screening is not as easy in some countries and depends on the health care system adopted by the country; the resources available; and the country's current laws on fetal rights, disability, and abortion (Ravitsky et al., 2021).

Screening and testing can consist of maternal blood tests, ultrasound, and/or chromosomal analysis, and these are used to either identify risk or diagnose genetic or congenital abnormalities in the fetus (National Screening Unit [NSU], 2023; RANZCOG, 2018). Ironically, although antenatal testing can indicate a multitude of very serious disorders, viable treatment is available for only a few affected babies (Whitworth et al., 2015).

Towards the end of the first trimester of pregnancy (0-13 weeks) women are routinely offered a variety of screening investigations, the first being an ultrasound examination, including Nuchal Translucency (NT) screening. In conjunction, women are offered a blood test referred to as a maternal serum screen. Biochemical markers that are evident with chromosomal abnormalities are screened for and the combination of these two screening tests increases diagnostic accuracy. For example, when both tests are carried out together, 85-90% of babies who have Down syndrome will be detected, compared to 70% or less using NT screening alone (Ministry of Health [MoH], 2023c). Non-invasive Prenatal Screening (NIPS), a maternal blood test that looks at all 23 pairs of the fetus' chromosomes from 10 weeks of pregnancy onwards, is available in over 60 countries worldwide (Ravitsky et al., 2021). It can indicate if there is an increased chance that the baby will have a chromosome related condition (NSU, 2023).

Women who are subsequently found to be at increased risk of having a baby affected by a chromosomal abnormality are then offered further prenatal diagnostic testing—either Chorionic Villus Sampling (CVS) or an Amniocentesis. CVS involves removing and testing a sample of chorionic villus (pre-placental tissue). The examination is conducted between 11 and 13 weeks gestation and can definitively diagnose chromosomally abnormal pregnancies (NSU, 2023). Amniocentesis is performed at a slightly later gestation, usually from 15 weeks gestation, and involves the removal and testing of amniotic fluid cells. This test can diagnose, with 100% accuracy, a baby that has either Down syndrome or another chromosomal abnormality (NSU, 2023).

Women who have not accessed the first trimester screening are able to access second trimester maternal serum screening (14-20 weeks gestation) (NSU, 2023). This is a maternal blood test only and can provide either a low risk or increased risk result. If an increased risk result is returned, then the woman is offered an amniocentesis (as above) as a diagnostic test (NSU, 2023). Additionally, in the second trimester of pregnancy (13-27 weeks), most women have a comprehensive anatomy or morphology ultrasound scan. Routinely, this is conducted between 18 and 22 weeks gestation, and aims to detect gross anatomical abnormalities in the fetus. Although not able to positively detect chromosomal abnormalities there may be inconsistencies in the anatomy that are visualised and raise subsequent concerns (MoH, 2023c; NSU, 2023).

TOP (Medical)

When a woman is offered and consents to a medical termination of her pregnancy, the pregnancy has continued until the diagnosis can be confirmed. The pregnancy then ends with the induction of labour resulting in the birth of the baby (RANZCOG, 2018). The definition of a medical TOP is a medical procedure to end a pregnancy that involves use of medicines to remove the embryo or fetus and placenta from the uterus (RANZCOG, 2018). It is described as an induction of labour, typically using the drugs Mifepristone and Misoprostol to induce uterine contractions and cause the passage of the fetus and placenta (Abortion Services in NZ, n.d.). The Mifepristone is administered 48 hours before admission, and the induction can take up to 24 hours. There is a possibility that further surgery to remove retained tissue may be required. The procedure usually takes place on a birthing suite or a surgical/gynaecological ward (RANZCOG, 2010). In some countries a surgical termination of pregnancy can be performed but the current study focuses on the induction of labour as a form of TOP (Te Whatu Ora, 2021). For this study, the definition of the second trimester is the pregnancy interval between 13 and 27 weeks gestation (Healthify, 2022).

The care provided to a woman undergoing a TOP is pivotal to the woman's experience and long-term memories of this time in her life (Kamranpour et al., 2021). Health care providers (HCPs), including midwives, doctors, and allied staff, often sit in a place of uncertainty and professional concern regarding the care they provide (Armour, 2018). There does not appear to be a 'how-to' book on providing situation-sensitive and holistic care to a woman when her baby is diagnosed with an abnormality and the decision to end the pregnancy has been made. There are guidelines and protocols on clinical practice, but these often do not discuss the more subtle nuances that reflect each woman's unique experience.

Statistics

The Perinatal and Maternal Mortality Review Committee report (PMMRC, 2022) shows the rate of TOPs in Aotearoa New Zealand in 2020 was 3.01:1000 births; in total, 179 pregnancies. These data relate only to pregnancies that were over 20 weeks gestation or the baby weighed over 400g if the gestation was not known. It does not include any pregnancies that were terminated between 13 weeks -19 weeks +6 days as these data are not collected. Also, these data do not provide all the reasons for the TOPs except to state that 62.6% of terminations (over 20 weeks gestation or over 400g in weight) were for congenital abnormalities.

International literature states the main fetal congenital conditions that lead to the TOP are neural tube defects (including anencephaly, hydrocephalus, and spina bifida); cardiac abnormalities; and other organ abnormalities (including kidney and abdominal abnormalities) (Hern, 2014; Kose et al., 2015; Royal College of Obstetricians and Gynaecologists [RCOG], 2010). The genetic abnormalities most commonly cited for a TOP include; Trisomy 21, 18, & 13 and Turner's Syndrome, along with a myriad of syndromes and single gene disorders (Hern, 2014; Kose et al., 2015; RCOG, 2010). These data are from international studies from developed countries and could justifiably reflect Aotearoa New Zealand statistics. It should be noted that while some of these conditions are not considered fatal, some could be considered life-threatening or life-limiting.

Overseas studies from other developed countries recognise that between 80 and 95% of women whose unborn baby is given a diagnosis of a serious condition, choose to end the pregnancy (de Crespigney & Savulescu, 2008; Kose et al., 2015; Lie et al., 2023). It is unclear how many women in Aotearoa New Zealand decline a TOP for fetal abnormalities as these data are not collected.

Analysis of international statistics is challenging as the inconsistent collection of data on gestation and reason for terminations are, at best, vague and, at worst, entirely non-existent (Sullivan & de Faoite, 2017). In fact, in some countries there is no collection of data on any pregnancy losses, regardless of gestation (Sullivan & de Faoite, 2017). It is also apparent that the laws related to TOP vary greatly from country to country.

Literature also suggests that a second trimester termination of pregnancy may be offered when the continuation of the pregnancy will put the mother at risk of serious harm. For example, maternal cancer, advanced pre-eclampsia, sepsis, cardiac disorders, placental abruption, and severe psychiatric illness (van Eerden et al., 2014). The current study does not investigate the situation of potential maternal harm from the continuation of a pregnancy; rather, the focus is the TOP because of fetal abnormalities. TOP was specifically examined because it involved the loss of a baby that would likely be affected by its condition throughout its life rather than the termination of an otherwise well baby.

Legal Considerations

In Aotearoa New Zealand, the new Abortion Legislation Act (AL Act, 2020) enables women to access TOP without restriction within the first 20 weeks of pregnancy. After 20 weeks gestation, women seeking a termination must consult a qualified health practitioner who will assess her physical health, mental health, and well-being (NZ Govt., 2020). The health practitioner is then able to state if they believe a TOP is “clinically appropriate” in the circumstances (Section 11). The health practitioner, themselves, are required to consult with at least one other health practitioner before consenting to the TOP and consider all relevant legal, professional and ethical standards, including the MoH’s Interim Standards for Abortion Services (NZ Govt. 2020). The AL Act (2020) replaces the previous law that considered having or performing a TOP a criminal act.

It should be acknowledged that all health practitioners are bound to adhere to thorough regulatory frameworks, standards, and guidelines from their respective professional bodies (AL Act, 2020). The health practitioners who may be involved in termination services are nurses, doctors, and midwives. Additionally, health practitioners are not able to prescribe medications used for medical terminations unless:

- it is a health service permitted within their scope of practice
- the practitioner holds a current practicing certificate
- the practitioner has the necessary qualifications, prescribing rights, skills, competency and resources to provide abortion services. (MoH, 2023b)

While it may be suggested that changes in the law will spark an increase in requests for TOP after 20 weeks gestation, for what some may consider random reasons, there is still the requirement for women to consult with a health professional prior to any termination after this gestation. This requirement implies that both the woman and the health professional will have a detailed conversation regarding her options and then she will be assessed, holistically. If a termination is seen as "clinically appropriate" she will then be able to make an informed decision regarding either the termination or continuation of her pregnancy (AL Act, 2020 Section 11).

The legality of a woman being able to access a TOP is paramount for supporting her to make reproductive decisions regarding her own body. The law reflects the uniqueness and individuality of each woman and her childbearing journey. With the decriminalisation of TOPs women can have autonomy over their own body. The current study sits in this space of reproductive choice and enables HCPs to understand the embodied experiences of women who go through a TOP for fetal abnormality.

Supporting Concepts

The following five concepts—loss versus death, gendered language, trust, pain, and holistic care—have had an impact on the research, in addition to the development of understandings gained from the women's narratives. Either there has been some troubled pondering of their meaning or place in the study, or there has been some exchange of ideas with my mentors about constructs of these concepts. To this end, I have offered some unpacking of these concepts in relation to this thesis with the aim of giving clarity alongside the research findings.

Loss Versus Death

The question arises regarding the use and appropriateness of the word 'loss', compared to the words, 'death, dead, die, dying, or stillbirth', in the context of this research. Although the baby is not 'lost', in one sense of the word 'lost' could mean "taken away or beyond reach" (Merriam-Webster Dictionary, n.d.). This implies a physical distancing but, from a spiritual context, does not necessarily describe a separation. In the context of death, 'lost' is said to be defined as the state or feeling grief when deprived of someone or something of value (Oxford Languages, 2023). In contrast, loss is also defined as forgetting, overlooking, or misplacing (Oxford Languages, 2023). With these different definitions, the conundrum becomes about context and interpretation. The problem becomes about the different connotations of the word loss and the alternative meanings the word has.

When using the words lost or loss to describe the death of a baby or the ending of a pregnancy, the emotions, ideas, and experiences of the bereaved family must be taken into consideration. This is also related to the holistic aspects of culture, spirituality and how death is contextualised by the family. Alternatively, for some, the words death, dead, or dying may be seen as unemotive or impersonal. Gustafsson (2007) suggested that these softer terms (lost/loss) are often deployed to avoid direct reference to death or dying as many consider this a taboo subject. Barlet et al. (2022) considered the language used between clinicians and parents and found that the words *die, dead, death, dying,* or *stillborn* were rarely used. They found family members used colloquial euphemisms like *passed away* or *not make it.* Clinicians used medical jargon when referring to the death of the baby; for example, *ultimately fatal* or *poor prognosis* which merely implied the death of the baby.

For both families and clinicians alike, using language that acknowledges the baby's death as well as soothes the often-feared experience of death, a linguistic delicacy is offered. The use of these euphemisms (lost/loss) to explain the ending of a pregnancy or death of a baby may be seen as protective language to allay discomfort for both the family and the HCPs. Also, it minimises the risk of being offensive or too blunt, especially when there is uncertainty of the wider meaning the family have given to the death. However, this rationale confines the experience to a euphemistic expression that may not hold the true meaning of what has happened.

Again, the challenge remains with the holistic interpretation of the language used around the death of a baby. Meaning is not fixed by linguistics alone; instead, the complexities of spiritual connotations, social identity, cultural influences, and personal choice play an important role in the language used. The use of any one word or phrase, in this context, is problematic as the sharing of meaning cannot be assumed. Along with the recognition of the diversity and complexity of the experience of TOP, the aim is to capture the experience linguistically, and to, indeed, find a shared meaning. The intertwining of the meaning attached to words is influenced by a multitude of factors, some known and acknowledged and some hidden and unconsciously used. The wide range of cultures, communities, religions, and philosophical standpoints; along with the specificity of personal experience, pain, suffering, and bereavement, will dictate the words used and the meaning attributed to these words.

One of the discourses regarding the words 'loss or lost' when describing the death of a baby is seen as the connotation that the baby has "metaphysically been relocated to another place", whether this place is identified (Wright, 2020, p. 111). It does not reflect the interpretation of many women as they feel their baby has not been *lost* or sent to another place; rather, they feel the baby is still with them, still in their lives. They feel a deep attachment to their baby and their relationship with their baby continues. They identify as the baby's mother and the baby as their son or daughter, regardless of whether their baby is physically with them or not. The concept of having lost their baby also potentially diminishes the women's attachment to their own identity as a mother. If their baby has been *lost,* then their role or sense of self-hood is also potentially *lost.* For women who have experienced a TOP, their sense of *loss* may stem from the intangible, the shattering of their dreams, hopes and desires rather than the physical *loss* of their baby.

“E kore ahau e ngaro, he kãkano ahau I ruia mai I Rangiãtea”
“I will never be lost, for I am a seed sown in the heavens of Rangiatea”
(Barrett, 2023)

In contemporary literature, lost/loss are commonly used as words that co-exist with the death of a baby or pregnancy. Shannon and Wilkinson (2020) used the word loss when discussing grief counselling for bereaved families. Similarly, Flach et al. (2022) used the phrase “women who have lost a baby” in their consideration of the concept of complicated grief. The term ‘loss' is used regardless of the moment or context of the death of the baby. The Perinatal Society of Australia and New Zealand (PSANZ), in the Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (Flenady et al., 2020) use the word death/dying in the recommendations for clinical practice. However, in the recommendations for perinatal bereavement care (Section 3), which includes care for bereaved families, the word loss is used. These practice guidelines are endorsed by numerous clinical and social support networks, including Sands and Stillbirth Foundation Australia. One of PSANZ’s mission statements is that the Society “fosters communication and collaboration between all those involved in perinatal research and in the care of the mother and baby during pregnancy, birth and the postnatal period and offers professional, political, administrative and educational advice" (PSANZ, n.d.). The Society fosters collaboration between all relevant professions and organisations; therefore, could be considered representative of best practice in bereavement care.

Recent research that reflects the grief related to perinatal death, supports the use of the words ‘lost/loss’ to describe the death of a baby or ending of a pregnancy. Lang et al., (2011) described parental grief associated with perinatal loss; while Kurz (2020) used the term “pregnancy loss”, which could describe either the death of a baby or the ending of a pregnancy. Additionally, Fernandez-Basanta et al., (2020a) investigated parental coping strategies when a perinatal loss is experienced. Guidance should be sought from the bereaved families, themselves, as their interpretation of the impact of the language used is pivotal to the experience. Baby Loss New Zealand, (2014), an on-line support group for bereaved parents, uses the word ‘loss’ in their title. However, Sands NZ (2023), also a support network for bereaved whānau, interchange the word death and loss, in their online information. Furthermore, current literature considers the words ‘lost/loss’ when considering the lived experiences of women who have miscarried or had a stillbirth. Kirui and Lister (2021), in their research, use these words consistently when analysing the data collected from interviews from women.

Trying to find a word that is appropriate for all women is a linguistic challenge. The words death versus lost seem to be at opposite ends of the turn of phrase spectrum. The incorrect choice of words used will potentially cause further trauma to the woman going through a TOP.

The women in this research all used the terms loss, death, died, and passed away to describe the death of their babies. The phrases used seemed to be interchangeable and all were explicit in their meaning. It was unclear why particular words were used for specific points in their stories; there did not seem to be any rhyme or reason for their word selection. The variety of words could be used as a guide for those caring for bereaved women regarding suitable language. The mirroring of the women's choice of words may be interpreted as reflecting what they feel comfortable with. If in doubt, a conversation about what words they would prefer to be used when referring to their baby, could offer clarification.

In summary, the terms used to describe the death/loss of their baby should be at the discretion of the woman, herself. How she sees herself and the meaning she has placed on her experience, her holistic view of what has happened, and how she sees the world are all used to inform the language used. There is no justification to not use the language that reflects the woman’s own interpretation. There should be no singularity in the way the death/loss of a baby is put into words as there is a multiplicity of contextual ways of looking at this experience. To assume the appropriate words that should be used, risks the women’s experiences being depersonalised and standardised. Every woman’s story is unique, as is the way she sees herself in the world. The language she chooses reflects this uniqueness.

Gendered Language

The loss of a baby is not specific to women or people who are heterosexual, as it can happen to any pregnant person. It is acknowledged that individuals can have diverse gender identities, while the maternity experience historically has been a heteronormative and an exclusively gendered space (Barros-Lees, 2021). Language used regarding the loss of a baby/pregnancy has routinely been cis-woman centred and did not offer room for those who consider their gender to be fluid. It is recognised that identifying as female is not a pre-requisite to pregnancy and birth. Birthing people who identify as transgender or non-binary are not immune to experiencing the loss of a pregnancy and/or baby. Many members of the LGBTIQA+ community wish to build a family and the risk of losing a baby because of fetal abnormalities is as much a reality as for any expectant parent. Many agree that the loss of a pregnancy/baby is one of the most devastating events a person can experience, regardless of how they identify (Furtado-Eraso et al., 2021; Hendson & Davies, 2018; Riggs et al., 2020).

Although the terms ‘woman’, ‘mother’, and ‘maternity’ are used throughout this research, it is not intended to exclude those who give birth and do not identify as a woman. All four of the participants in this research identified as women; therefore, gender-based language is used to represent their identities.

Trust

To me, trust means that both the birthing woman and the midwife recognise the reliability, truth, and ability of each other. Trust is also commonly understood to be the belief that someone is good and honest and will not harm you, or that something is safe (Merriam-Webster, 2023). However, trust might mean something quite different to the woman who is receiving the care. Trust is determined by cultural or social factors, past experiences, or personal values. Trust may be reliant on the perceived intentions of the carer and that the care is focused on the woman rather than the midwife or the institution. Further, feelings of anxiety brought on by the environment, the people in that environment, and the trustworthiness of those people will all impact on the woman's feelings of trust. When a midwife approaches a woman with true regard and compassion, then feelings of trust are likely to be enhanced. Trust could be seen as the social super glue of modern society, without trust, fear rules.

To measure or assess whether the woman feels that she can trust the midwife could be considered a difficult concept to quantify. Even though there are scales for measuring trust, these may not be relevant as trust is dependent on the woman’s interpretation related to her experience. Lewis (2019) suggested that the trust between a woman and her health care provider develops over time, through their interactions, and as if using building blocks of trust. Initially, the woman has an expectation that she can trust the health care provider because of an assumed competence but then, as their ‘knownness’ of each other grows, so too their trust grows. As Lewis stated, development of trust results in the woman having a sense of agency or self-determination and includes the health care provider trusting the woman.

Along with the trusting relationship nurtured between the woman and her health care provider, the concept of a woman’s self-trust must be acknowledged. It is especially important in the situation of a TOP as the consequences of the decision-making process for woman influences this self-perception. The concept of self-trust in the context of a TOP is already in jeopardy for many women as having made the decision to end their pregnancy has the potential to diminish their belief in themselves anyway (Jones, et al., 2017b). Women’s ability to trust themselves is often determined by the trust others have in them which, in turn, is determined by how the health care provider interprets the woman’s role in the care provision. By paying particular attention to what the woman is saying (or not saying), by using curiosity while listening, and the raising of compassionate questions, the woman's own decisions can be confirmed and incorporated into her care planning.

Pain

I presuppose that the emotional pain women may experience is greater than the physical pain, as supported by Jones, et al. (2017b). In practice, I would believe this to be true. While the midwife can offer alternatives to manage the physical pain, there is no cure or anecdote for emotional pain. There is no 'making it better or making it right'. The midwife can, however, bear witness to the woman's pain, both emotional and physical. Research suggests that both sources of pain should be considered as being on the broader spectrum of pain. Rather than being either physical or emotional pain, these pain sensations sit somewhere in the middle (Hartney, 2022)., which may indicate why this 'pain' is so difficult to manage or cope with as it is in the wilderness, the 'no-mans-land' of pain.

It is only when we accept the woman as we find her that we can truly acknowledge without prejudice what she is experiencing. Our own perceptions of expected pain tolerance, causes of pain, the rationale for feeling pain, and expression of the pain being felt are often based on our own inherent belief system around the relationship between suffering and pain. Ours is not to wonder why or what; instead, to wonder how we can support the person who is in pain or is suffering. If we can see ourselves in them, we might have taken the first step towards compassionate, empathetic, and sensitive care.

Holistic Care

As suggested in the above concept, a woman is more than the sum of her parts. From my midwifery lens, I see holistic care as seeing the woman as being complete, rather than being parts that somehow do not inter-relate or connect to each other. The holistic nature of care implies that all aspects of the woman are intermingled and inter-dependent. To provide holistic care to a woman experiencing a TOP requires careful and sensitive acknowledgement and consideration of all aspects of her 'being'.

It could be anticipated that for some women, during a TOP, the labour and birth are seen as a moment in time to be compartmentalised into 'then' and not brought into their present. Understandably, this may 'protect' them from the anguish and rawness of what they are going through. To see a woman holistically, enables both the woman and the midwife to navigate the ups and downs of the termination by accepting that some issues come to the surface while others disappear for a time.

As a way of declaring my pre-assumptions on the lived experience of women who have terminated their pregnancy because of a diagnosis of a fatal abnormality of their baby, I have written the following poem. While I acknowledge that I have not personally experienced the loss of a baby, I have witnessed many women who have. The use of poetry is a way to help decipher my thoughts and try and always view the death of a baby from the woman's perspective.

The days are long and so is the road towards surviving this nightmare
Our family doesn't deserve to suffer like this
We embraced our love and saw the future for our family
Sadness and emptiness were not part of our dreams
Some things are just too hard for a heart to cope with.
The pain of it breaking shoots needles of grief all the way through it
The tears that flow do nothing to wash away this pain
They just empty more of my soul- dripping to the floor
If only the pain would stop and give me a chance to breath
It feels like the next beat of my heart will be its last
Its vibration rattles my mind like a ticking bomb
There is no release only brokenness that hurts too much
Help these feelings go away before I fall to my knees and never get up
My baby, my body, my heart, all falling apart.
How will I survive this?
Do I want to survive this?
I need to feel a different pain so this feeling can hide inside it.
Disguised and ignored, forgotten for now
I am shaking with the pain as if trying to rattle it into submission
Controlling the volcano of grief that is ready to spill out of me.
Please make it stop, make it go away, have mercy on me before I can't go on… help me.

Thesis Structure

This thesis consists of 11 chapters.

Chapter One has provided an orientation to the study. It has included the research question along with the focus, aim, and justification for the research. In included a discussion of what drew me, personally, to this topic and why the research matters; a story from my practice supports this discussion. Finally, the context of this research was offered and included antenatal screening and testing, the TOP procedure, the statistics of TOP, and the legal considerations of a TOP.

Chapter Two provides a literature review that considered international and contemporary research on women’s experiences of having a TOP. The review used a hermeneutic approach to the findings of the research.

Chapter Three focuses on the methodology of post-intentional phenomenology (PIP) as used in this research. It considers the theory and practicalities of PIP, as well as rationale for using PIP as a research methodology.

Chapter Four considers the methods used in this research. It includes participant recruitment, collection of the research data, as well as the preservation of the participants rights.

Chapter Five introduces the post-intentional phenomenological concept of Tentative Manifestations and Moments. The chapter offers practice reflections to support these notions.

Chapters Six to Nine belong to the participants. Chapter Six introduces Katie’s story. It includes her crafted story, interpretations within her story, and moments from her story.

Chapter Seven introduces Paige’s story, including her crafted story, interpretations within her story, and moments from her story.

Chapter Eight introduces Tui’s story. It includes her crafted story, interpretations within her story, and moments from her story.

Chapter Nine introduces Ursula's story, including her crafted story, interpretations within her story, and moments from her story.

Chapter Ten provides an exploration of the findings identified within the narratives of Katie, Paige, Tui, and Ursula.

Chapter Eleven offers a discussion on the findings as identified in Chapter Ten.

Finally, Chapter Twelve provides an in-depth discussion of the overview of the research including a discussion of findings in relation to literature, recommendations, and concluding thoughts.

Chapter Summary

The current chapter has offered an overview of the thesis and the context of the research. It provided personal reflections from practice that gave a wider lens to this study as related to the research aim and justification for this research. Associated conceptual discussion on various, related notions that support this research was offered. The next chapter provides a contemporary literature review that investigates what is already known about the phenomenon of TOP for fetal abnormality.

CHAPTER TWO: LITERATURE REVIEW

Introduction

Aim

The aim of this hermeneutic literature review was to consider contemporary literature around women's experience of a TOP for fetal abnormalities in the second trimester of pregnancy. With immersion into the data of the selected articles, the phenomenon of having a TOP will be revealed from a hermeneutic viewpoint or an interpretative perspective. Along with the investigation into related literature, any gaps in research into the experience of TOP will be identified. This review will first present the findings and follow on with the synthesis of these data.

Background

The rationale for undertaking this literature review was to collect relevant, timely research on women's experiences of having a TOP, and synthesise it into a cohesive summary of existing knowledge in the field. The process allowed for a contemplative approach to my own research focus to address any gaps in current literature and enabled the research study to be unique and specifically focused on exploring identified gaps. Although I have a good amount of clinical experience in caring for women having a TOP, I was compelled to deepen my understanding of what current literature can add to my knowledge. The literature review also enabled an understanding of the theories underpinning the experience of TOP; thus, allowing the development of the context related to the study topic. Along with a deeper understanding of the experience of TOP, this literature review enabled me to assess the significance of my own findings.

With the rapid development of more sophisticated prenatal screening and testing techniques, pregnant women now have higher levels of awareness of their unborn baby's health (Blakely et al., 2019). Women can be informed of structural abnormalities, genetic diseases, and pregnancy-related conditions that are affecting their baby. Such diagnoses may have a serious impact on the outcome of their pregnancy (Wang et al.,2022). If a poor diagnosis is made, women can potentially be offered prenatal treatment, palliative care once the baby is born, or a TOP.
There is also worldwide liberalisation of abortion laws as abortion rights are becoming recognised as fundamental human rights for millions of people globally. Over the past 30 years, more than 60 countries have liberalised their abortion laws (Center for Reproductive Rights [CRR], 2021) which implies that potentially more women will be able to access safe and legal

abortion care as part of their reproductive health care. Therefore, HCPs require a holistic and humanistic understanding of what it is like to go through a TOP for fetal abnormalities.

Overview of Literature Review

While considering what framework might be suitable for this literature review, it became obvious that a large part of the immersion in the selected literature involved reading and re-reading the articles, going back and forth, around and around, diving deeper into the literature each time they were read (Stanford Encyclopedia of Philosophy, 2020, Section 1.3). The understanding of the meaningfulness of these works began to expand and mature and, in turn, the critique of the selected articles developed. This process resembled the hermeneutic circle that suggests that there is a "circularity to understanding" (Stanford Encyclopedia of Philosophy, 2020, Section 1.3).

Hermeneutics is the study of interpretation and provides a framework for describing literature reviews (Stanford Encyclopedia of Philosophy, 2020). Modern hermeneutics, as developed by Heidegger and Gadamer, is based on the notion of human understanding gained through interpretation. The process is impacted by a person's self-understanding and of their place in the world. This includes how language is understood, considering the context, and culture surrounding the interpretation (Boell et al., 2010).

Hermeneutics is connected to the process of creating interpretative understanding of each individual article and its text that progresses to enhance understanding of other related articles. This, in turn, brings parts of literature into a whole body of literature. As Heidegger stated, the review of literature using hermeneutics requires the fusion of the reader's own "fore-having" (one's own experiences) and the 'object' (the text) (Bramer et al, 2018 p. 184). The potentiality of new understanding comes through renewed interpretive attention to and reflection on any pre-understandings. As discussed by Boell et al., (2010), the concept of the hermeneutic circle is most suitable for literature reviews in humanities and social sciences as these generally focus on what it is to be human. They argued that this analytical framework (the hermeneutic circle) gives a continuing, open-ended process that affords an increase in understanding in research on "the lived experience" (Stanford Encyclopedia of Philosophy, 2020 Section 2.2) and an opportunity for re-interpretation of contemporary literature.

The current literature review considers previous research by Jones et al., (2017b) and Lafarge et al., (2014), that explored experiences of women having a TOP. Taking these investigations into account, this literature review seeks to consider what is still unseen or concealed in research of women's experiences and does so through utilising a hermeneutic review methodology to go beyond what is obvious in the data provided in the aforementioned articles.

Rather than following traditional rules commonly used to guide literature reviews, hermeneutics requires that the reader attunes or places themselves in a responsive frame of mind to see beyond the expected critique. Part of the hermeneutic review process involves allowing the questions that surface to interact with dialogue. What is still unknown, still covered, is potentially exposed and inclines the reader to question the knownness of the literature (Crowther et al., 2014). From this point, new understandings are possible as the review uncovers yet to be discovered nuances of the research.

MacLeod et al. (2023), used a hermeneutics literature review methodology to consider "the messiness of everyday experience and human interaction" (p. 1) when reviewing literature on the process of implementing health programmes, services, and practices. In their literature review they found that much of what HCPs do "including when implementing evidence into practice requires well-conducted and well-timed, clinically relevant conversations that include the patient's values, context, concerns, and priorities and may require a shift from one's original position or agenda" (2023, p. 2). This conclusion reflects the tension between the humanness of the HCPs as well as patients and shows that both are in a state of 'being-in-the-world' and all the nuances of that concept (MacLeod et al., 2023).

Crowther et al. (2014) employed an interpretative hermeneutic review process when considering the concept of joy in birth as described in literature. They saw the possibility of revealing what was concealed and unsaid within and between the words of the literature. The hermeneutic review of the selected articles showed the gaps or 'spaces in-between' the scientific literature and the interpretation or concept of joy (Crowther et al., 2014). Kusnanto et al. (2018), used hermeneutics to support their literature review of the biopsychosocial model of illnesses in primary care (MacLeod et al., 2023). The use of hermeneutics to guide their review provided an increased understanding and insight regarding the primary care model. They found that the understanding gained was directly influenced by other relevant articles and contributed to the 'wholeness' of their knowledge. With the constant and circular motion of interpretation and re-interpretation of the literature, critical assessment was enabled. These provide examples of a change of understanding, via reviews of literature, using a hermeneutic methodology that expand the body of knowledge of the human experience in different contexts.

A hermeneutic literature review considers the process of creating an interpretative understanding of each selected article and its text that, in turn, informs the interpretation of the next article. The next article is interpreted in context of the previous articles read and the articles yet to be read. From a hermeneutic standpoint, the understanding of the 'parts' (text) enhances the understanding of ‘the whole’ (article) and this toing and froing describes the hermeneutic circle (Boell et al., 2010).

This concept of an ‘unfolding and developing’ understanding offered by using a hermeneutic circle for this literature review enables the deep dive into the experiences of women who have had a TOP due to fetal abnormality and, therefore, is a justifiable literature review method. The interpretive journey allows for the discovery of midwifery practice recommendations that will support both the bereaved woman and the midwife. By concentrating on the narratives from the women, the women’s voices will be heard, their experiences acknowledged, and valued.

Search Methods to Identify Studies

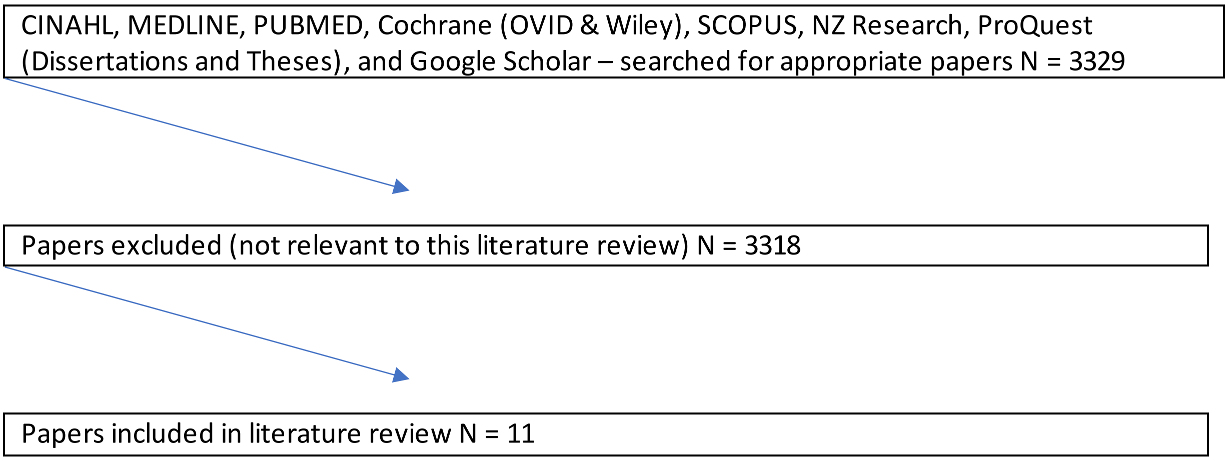
While this literature review uses a hermeneutic mirror to evaluate the most contemporary literature, a more traditional literature search approach is used which enabled an “efficient and complete” search process (Stanford Encyclopedia of Philosophy, 2020, p. 531). It does not diminish the hermeneutic philosophy used in the review of the literature; instead, it supports the determination of appropriate literature to review.

The keywords/phrases used in an electronic search were “termination of pregnancy” AND “fetal abnormality” AND “women's experiences” OR “lived experiences”. These keywords/phrases were tested several times to make sure that they were effectively locating literature for the purpose of the review. The judgement for inclusion was based on the title, abstract, year of publication, and ethical approval process.

An electronic search was undertaken of the following databases; CINAHL, MEDLINE, PUBMED, Cochrane (OVID & Wiley), SCOPUS, NZ Research, ProQuest (Dissertations and Theses), and Google Scholar. To increase the likelihood of identifying all relevant studies, the reference lists of all retrieved articles were also hand searched. The search terms were tested to check that they effectively located the types of articles that were consistent with the inclusion criteria prior to conducting the search in all engines (see Table 1).

Table 1

Search Outcome Process



CINAHL, MEDLINE, PUBMED, Cochrane (OVID & Wiley), SCOPUS, NZ Research, ProQuest (Dissertations and Theses), and Google Scholar – searched for appropriate papers N = 3329

Papers excluded (not relevant to this literature review) N = 3318

Papers included in literature review N = 11

Criteria for Including Studies in the Review

All relevant studies on the topic area were included to enable a comprehensive overview of published literature relating to women's experience when terminating their pregnancy for fetal abnormalities in the second trimester of pregnancy. The search was limited to articles published between 2019 and 2022. Jones et al. (2017b) completed a literature review that considered literature before 2017 so literature before this year was not considered. Another rationale for only including the years 2019-2022 was the desire to investigate changes or developments in knowledge in the level of clinical care that may have impacted women's experiences. Over these years there has been a development of perinatal bereavement care training programmes that acknowledge the potential impact. For example, Qian et al. (2022), reported the development and evaluation of such a programme for nurses and midwives in China. In 2022, The National Bereavement Care Pathway was developed in England to provide a consistent and improved bereavement care to families who have experienced baby loss through a TOP for fetal abnormalities (n.d.). Susanne Armour (2018) wrote her doctoral thesis on 'The lived experience of midwives caring for women facing TOP in the late second and third trimester'. Although her study did not specifically investigate TOP for fetal abnormality, it nevertheless offered insight into how midwives experience caring for women having a TOP; thus, providing another viewpoint of this level of care.

While only literature written in English were included, it did not exclude women giving birth in different cultural or geographic contexts. The search included literature that had been peer-reviewed and the full text was available to view. Previously published literature reviews and systematic reviews were excluded. Only original research findings that used qualitative methodology and represented the labour and birth experience of women having a TOP for fetal abnormality in the second trimester were included. The accepted clinical timeframe was from either the time of feticide, if this occurred; the time of diagnosis that included the induction of labour; or the start of medication to induce the labour. The end timeframe was either within days of the birth or after the deposition of the baby's body. These determined timeframes allowed a focused study of the actual labour and birth experience and the immediate time before or after the birth.

Figure 1

An Overview of the Steps Used in This Literature Review for Literature Searching. This process can start at any point of the circle. The circular process not only acknowledges the constant production and provocation of understandings but also sits with the ebb and flow of material analysis seen in PIP.

Search Outcome

Of the 3,329 papers identified from the initial search, 11 papers met the inclusion criteria and the literature review aim (as stated above). A manual search provided no further papers. These final studies represented 202 women who had experienced a TOP for fetal abnormality in the second trimester of pregnancy (see Table 2).

Each paper was assigned a number to facilitate ease of identification. Five studies were underpinned by phenomenology (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Hendriks et al., 2022; Lafarge et al., 2019; Patricio et al., 2019) one ethnography (Middlemiss, 2021), one grounded theory (Qin et al., 2019). The remaining four studies used a qualitative methodology, thematic analysis (Guy, 2019; Hammond et al., 2020; Irani et al., 2019; Kamranpour et al., 2021) one of which used a mixed methods approach (Kamranpour et al., 2021). The 11 studies reached across nine different countries (details in Table 2). Studies originated from the fields of midwifery, nursing, neonatology, anthropology, bioethics, and obstetrics. The lead researchers of the 11 papers were either nurses or midwives, other HCPs, psychologists, or sociologists.

Table 2

The Process of Selecting Each Study Included in the Literature Review

Title	Publication	Participants	Data collection	Methodology	Summary/ themes	Study strengths	Study weaknesses
1. Perinatal loss and parental loneliness: Narratives of later termination of pregnancy	2022 Hendriks, M.J., & Abraham, A. on behalf of the Swiss Neonatal End-of-Life Study Group Switzerland	3 women	Semi-structured interviews Observation	Hermeneutic phenomenology	**-Decisional loneliness/support** **-Perceived pressure of time** **-Fragmented care** **-Role of midwives** **-Lack of standardised bereavement care**	Offers some useful clinical recommendations	Acknowledges small sample size Minimal discussion of hermeneutic phenomenological philosophy
2. 'My biggest fear is that people will forget about him': Mothers' emotional transitions after terminating their pregnancy for medical reasons	2022 Gonzalez-Ramos, Z., Zuriguel-Perez, E., Collado-Palmares, A., & Casado-Marin, L. Spain	15 women	Semi-structured interviews Focus groups Field diary	Phenomenology	**-Emotional journey** Representation and desire to be a mother Main concerns Impact of the news Decision-making Emotional responses before and after the termination	Termination happened within 2 years	Minimal discussion on relevance of findings to clinical practice
3. Too big, too young, too risky:	2021 Middlemiss, A.I.	10 white heterosexual women.	Ethnographic interviewing	Ethnography	**-The fetal body as too big: Labour & birth because of fetal size**	The concept of 'consequences of consequence' was	Data to support this study are not available to the

Title	Publication	Participants	Data collection	Methodology	Summary/ themes	Study strengths	Study weaknesses
How diagnosis of the fetal body determines trajectories of care for the pregnant woman in pre-viability second trimester pregnancy loss	UK	Data included narratives from 24 women who experienced fetal loss from either premature birth or fetal death (in utero)			**-The fetal body as too young: Labour & birth because of non-viability** **-The fetal body as risky: Limiting choice around feticide in the second trimester**	unique to this study ‘Trajectories of care’ is considered a useful care concept Based on a sociological framework	public due to ethical concerns Excluded women who do not engage in social media Diversity of participants is limited
4. Termination of pregnancy for fetal anomalies: A quantitative study of the informational and educational needs of women	2021 Kamranpour, B., Noroozi, M., & Bahrami, M. Iran	25 women	Semi-structured interviews and field notes	Mixed methods Qualitative content analysis	**- Receiving information tailored to the client's circumstances** **- Learning life skills to cope** **- Getting prepared for the next pregnancy**	Number of study participants ensure a wide range of data	Acknowledges the unique cultural context but does not unpack this No clear guidance on what information/ educational information may be useful
5. Parental experiences of uncertainty	2020 Hammond, J., Klapwijk, J. E., Hill, M., Lou, S.,	15 women (8 in UK & 7 in Netherlands)	Semi-structured interviews	Thematic analysis	-**Sources of uncertainty** Probability Ambiguity Complexity	Useful practice recommendations offered	Time since pregnancy loss was variable and

Title	Publication	Participants	Data collection	Methodology	Summary/ themes	Study strengths	Study weaknesses
following an abnormal fetal anomaly scan: Insights using Han's taxonomy of uncertainty	Ormand, K. E., Diderich, K. E. M., Riedijk, S., & Lewis, C. London, UK, and Netherlands				**-Issues related to uncertainty** Scientific Personal Practical **-Managing uncertainty.** Parent strategies External coping resources Internal emotion coping resources Role of health professionals	Focusing on 'uncertainty' in this context is unique to this study Although analysis of data was based on two different maternity health systems (UK & Netherlands) this study showed commonality of experiences	may have impacted recall All participants were highly educated. Less educated participants may interpret uncertainty differently
6. Pregnancy termination for fetal abnormality: Ambivalence at the heart of women's experiences	2019 Lafarge, C., Rosman, S., & Ville, I. England and France	27 women (England) 17 women (France)	Qualitative questionnaires (England) Interviews (France)	Interpretative phenomenological analysis (England) Mixed methods (France)	**-Hope and despair** **-A choice but no choice** **-Standing still and rushing** **-Bonding and detaching** **-Trauma and peace** **-Disclosure and secrecy** **-Bridging past and future** **-Individual and societal experience**	Wide range of data collection techniques provided wide ranging data Collaborated data analysis	Discussion on methodology was covered in previous publications

Title	Publication	Participants	Data collection	Methodology	Summary/ themes	Study strengths	Study weaknesses
7. Cognition, emotion and behaviour in women undergoing pregnancy termination for fetal anomaly: A grounded theory analysis	2019 Qin, C., Chen, W-T., Deng, Y., Li, Y., Mi, C., Sun, L., & Tang., S. China	41 women	In-depth interviews	Grounded theory	**-Denial phase** My baby is fine-how can it be abnormal Heartbreak Denial and doubting the diagnosis **-Confirmation phase** Is my baby really abnormal? Is this an incorrect diagnosis? Mythic expectation. Researching information, reassessing **Decision-making phase** My baby is abnormal What should I do? Gathering pros & cons, decision making Anguished **Recovery phase**	Some cultural context acknowledged	First limitation noted in article is somewhat abstract
8. Emotional and cognitive experiences of pregnant women following prenatal	2018 Irani, M.,Khadivzadeh, T., Asghari Nekah, S.M., Ebrahimipour. H., & Tara, F.	7 women with diagnosis of fetal anomaly	Semi-structured interviews	Content analysis	-**Grief reactions during the time of diagnosis:** Shocked and panicked Distressed and disbelieved	Directly considers each women's story/text as source of data Clear indication of trustworthiness	Does not fully consider the context that informs the data Acknowledges the unique cultural context

Title	Publication	Participants	Data collection	Methodology	Summary/ themes	Study strengths	Study weaknesses
diagnosis of fetal anomalies: A qualitative study in Iran	Iran				-**Perinatal loss through a pregnancy termination** Guilt and shame Loss of their expected child Suffering and emotional distress process Unmet needs by health professionals -**Fears of recurrence in future pregnancies** Worried about inadequate prenatal care and abnormal fetus in next pregnancy -**A dilemma: hope and worries** Hope for normality. Worried about future		but does not unpack this
9. Experiences and outcomes following diagnosis of congenital fetal anomaly and medical	2019 Atienza-Carrasco, J., Linares-Abad, M., Padilla-Rulz, M., & Morales-Gill, I. M. Spain	27 women	Non-participant observation and semi-structured interviews	Phenomenology	-**Communication of the diagnosis** Clinical relationship Environmental Diagnosis report -**Emotional impact** Reactions to the news Treatment possibilities	Consideration of research rigour Broad demographic information provided	Unclear if descriptive or interpretative phenomenology

Title	Publication	Participants	Data collection	Methodology	Summary/ themes	Study strengths	Study weaknesses
termination of pregnancy: A phenomenological study					Time for reflection Social representation of motherhood **-Termination of the pregnancy** Decision-making Reasons for termination Patient's experience Grief **-Psychosocial support** Perceptions of help & support Future expectations	Useful clinical recommendations offered	
10. I poems on abortion: Women's experiences with terminating their pregnancies for medical reasons	2019 Guy, B. US	6 women All white, heterosexual, aged 25-38 years	Self-written narratives	Listening guide- a feminist data analysis method	The emotional journey: - excitement - shock - devastation - compassionate choice - gratitude	Creative use of women's narratives Offers the reader the ability for further interpretation of data	Small sample size Lack of diversity in participant Methodology is intended to use oral rather than written narratives
11. Fetal abnormality with possibility of legal	2019 Patricio, S. S., Gregorio, V. R. P.,	8 women	Semi-structured interviews	Hermeneutic phenomenology	**-Diagnosis of fetal abnormality incompatible with life**		Themes were ambiguous

Title	Publication	Participants	Data collection	Methodology	Summary/ themes	Study strengths	Study weaknesses
terminations: Maternal dilemmas	Pereira, S. M., & Costa, R. Brazil				**-Possibility of either terminating or not with the gestation** **-Judicial authorisation request for legal termination** **-Pregnancy termination** **-Assistance from the multiprofessional health team**		

Quality Appraisal

As suggested by Kable et al. (2012) the appraisal tool known as CASP (Critical Appraisal Skills Programme, 2024) was used as a framework to critically evaluate the studies selected for the literature review. The tool requires the researcher to assess the appropriateness of each study using a qualitative methodology for their research topic (validity, ethical considerations, data analysis, and explicit findings). Using this method, all but one paper was assessed positively against all criteria of the CASP tool. One paper (Lafarge et al., 2019), failed to meet the criteria regarding ethical considerations or provide confirmation that ethical approval was obtained. However, the authors did refer to the original research completed in 2013 and this documentation stated the ethical issues addressed and that ethical approval was received. When the research techniques used to obtain data generate an emotional response, ethics committees act as gatekeepers and protect the participants from harm (McCosker et al., 2001). The safety of all involved in a research project is of paramount importance and the submission of a research proposal for ethical approval to an ethics committee encourages consideration of this issue. Finally, all 11 studies were included based on the CASP criterion (See Table 3).

Table 3

Quality Appraisal of Included Literature

Author	Title	Subject	Argument	Evaluation
1. Hendriks, M.J., & Abraham, A. on behalf of the Swiss Neonatal End-of-Life Study Group. (2022) Switzerland	Perinatal loss and parental loneliness: Narratives of later termination of pregnancy.	The views of parents (3 women) and 5 HCPs regarding late termination of pregnancy at ≥20 weeks gestation. Focused on their decision to discontinue their pregnancy.	**Research conducted by End-of-Life practitioners.** The decision to terminate a pregnancy ≥20 weeks gestation poses unique ethical challenges. Little is known about this experience in Switzerland, but late TOP is known to be highly stigmatised with women reporting social and/or self-judgment. How best to support women is of main importance to HCPs working in the field of later TOP.	Provided validation of known experiences of women in this context. Offers useful clinical insight into an overall theme of continuity of care both before, during, and especially after the TOP. This should include emotional and clinical support. For this literature review, 3 women were interviewed, along with fathers and HCPs. This may have diluted the in-depth analysis and description of the experiences of the women. Appropriate methodology used as research focuses on the narrative of participants.

Author	Title	Subject	Argument	Evaluation
2. Gonzalez-Ramos, Z., Zuriguel-Perez, E., Collado-Palmares, A., & Casado-Marin, L. (2022) Spain	'My biggest fear is that people will forget about him': Mothers' emotional transitions after terminating their pregnancy for medical reasons.	To explore women's emotional responses throughout the process of terminating a pregnancy for medical reasons.	**Research conducted by a nurse and a midwife.** There are predominant emotions that HCPs need to be aware of to help women work through them and lessen the impact of TOP on their mental health. Highlights the role of the HCP in this context.	Covers a wide range of experiences throughout the experience of TOP. The term 'for medical reasons' may be misleading as it may imply maternal or fetal medical reasons. No women who had a TOP for maternal medical reasons were included so it should have been indicated in the title of the study. Validation of finding are stated clearly. Appropriate methodology used as research focuses on the narrative of participants.
3. Middlemiss, A.I. (2021) UK	Too big, too young, too risky: How diagnosis of the fetal body determines trajectories of care for the pregnant woman in pre-viability second trimester pregnancy loss.	Diagnostic activities on the second trimester fetal body in relation to gestational timeframes, legal time thresholds, and its eligibility for TOP for reasons of fetal abnormality results in specific 'trajectories of care'.	**Research conducted by sociologist.** The determining factor affecting care trajectories for the pregnant body is the biomedically diagnosed status of the fetal body. These include:	Conceptualises the differing pregnancy loss experiences for women that are determined by the fetus, alone. Considers the concept of 'consequences of consequences'.

Author	Title	Subject	Argument	Evaluation
			fetal size, non-viability and the potential for a live birth during a TOP. These issues structure the healthcare options and medical care offered to women facing pregnancy loss in the second trimester.	Suggests that the women's agency or the ability for women to make choices, autonomously and act on them, is reduced because of the focus is primarily on the fetus and not women. Shows the allocation and availability of resources depends on the different diagnoses and, in turn, impacts on the women's agency. Politically astute discussion. Does not offer any recommendations.
4. Kamranpour, B., Noroozi, M., & Bahrami, M. (2021) Iran	Termination of pregnancy for fetal anomalies: A quantitative study of the informational and educational needs of women.	Exploration of the informational and educational needs of women who have experienced a TOP because of fetal abnormalities.	**Research conducted by midwives and nurses.** One of the most important responsibilities of HCPs is to clearly explain and provide information for facilitating informed decision making.	Does not offer in-depth analysis of the experience of TOP. Findings appear rather superficial as they are based on only 3 main findings which do not represent the holistic impact of the experience.

Author	Title	Subject	Argument	Evaluation
				However, the findings are useful when HCPs consider the needs of women experiencing a TOP. Findings are validated by other studies.
5. Hammond, J., Klapwijk, J. E., Hill, M., Lou, S., Ormand, K. E., Diderich, K. E. M., Riedijk, S., & Lewis, C. (2020) UK and Netherlands	Parental experiences of uncertainty following an abnormal fetal anomaly scan: Insights using Han's taxonomy of uncertainty.	To understand how parents perceive and manage uncertainty after being confronted with a structural anomaly during routine ultrasound.	**Research conducted by clinical psychologists and geneticists.** Sources of uncertainty included receiving ambiguous information or the information was complex and challenging to understand. The emotional and personal aspects of uncertainty had negative impacts on the women. The uncertainty related to the TOP process and the practical aspects of care were identified as problematic.	Included women from both the UK and the Netherlands. Some use of narratives. Clear analysis of the role uncertainty plays in women's experiences of TOP and how this may impact on the experience. Although narratives from both parents were included, it was clear who the dialogue was from (mother or father). Some clinical recommendations.

Author	Title	Subject	Argument	Evaluation
6. Lafarge, C., Rosman, S., & Ville, I. (2019) England and France	Pregnancy termination for fetal abnormality: Ambivalence at the heart of women's experiences.	To determine the centrality of ambivalence in women's experiences of TOP for fetal abnormality.	**Research conducted by clinical psychologist.** Ambivalence or uncertainty is experienced by many women going through a TOP. Women's perceptions of and engagement with the world are impacted by experiencing a TOP. Women are likely to experience social and personal stigma related to the TOP.	Validation of finding provided. The use of opposing language poignantly highlighted the themes (disclosure and secrecy). Insightful use of narratives to support analysis. Suggesting that there are no normative responses to TOP is clinically significant. Highlights the incongruency of the rationale for prenatal diagnosis and the place people with disabilities hold in society. Does not offer substantial clinical/practice recommendations. Failed to meet the criteria regarding ethical considerations or provide confirmation that ethical approval was obtained.

Author	Title	Subject	Argument	Evaluation
7. Qin, C., Chen, W-T., Deng, Y., Li, Y., Mi, C., Sun, L., & Tang., S. (2019) China	Cognition, emotion and behavior in women undergoing pregnancy termination for fetal anomaly: A grounded theory analysis.	To understand the cognition, emotions and behavior of women who have undergone a TOP because of fetal abnormality.	**Research conducted by nurses.** Mental distress after a TOP is a serious issue. With increasing detection rates of fetal abnormalities comes an increase in women experiencing TOP. Effective intervention for women undergoing a TOP for fetal abnormality is urgently needed and crucial in easing the women's mental suffering.	Development of a cognitive-behavioral framework that includes; -Denial phase -Confirmation phase -Decision-making phase -Recovery phase. This is based on the timeline from diagnosis to post TOP. Some practice recommendations are offered. Unclear how the framework may be used in practice.
8. Irani, M.,Khadivzadeh, T., Asghari Nekah, S. M., Ebrahimipour, H., & Tara, F. (2018) Iran	Emotional and cognitive experiences of pregnant women following prenatal diagnosis of fetal anomalies: A qualitative study in Iran.	To explore the emotional and cognitive experiences of pregnant women following prenatal diagnosis of fetal abnormalities.	**Research conducted by midwife.** Pregnant women are often ill-prepared for abnormal findings related to their unborn baby. When women terminate their pregnancy because of fetal abnormality, they often experience depression,	While the cultural aspects of women in Iran was stated as being reflected in this study there is no in-depth discussion provided regarding these cultural nuances. Some clinical recommendations offered.

Author	Title	Subject	Argument	Evaluation
			anxiety, grief, and post-traumatic stress disorder.	
9. Atienza-Carrasco, J., Linares-Abad, M., Padilla-Rulz, M., & Morales-Gill, I.M. (2019) Spain	Experiences and outcomes following diagnosis of congenital fetal anomaly and medical termination of pregnancy: A phenomenological study.	To determine and describe the experiences of pregnant women who decide to terminate their pregnancies because of fetal abnormality.	**Research conducted by nurses.** The concept of 'frustrated motherhood' is proposed. The psychological consequences of a TOP will depend on the care and support provided by HCPs. 'Patient-centered' communication helps understanding, influences adaptation and ensures sufficient autonomy is provided.	Useful and relevant clinical recommendations are offered. The use of narratives adds to the analysis of data. A wide and relevant range of time frames and experiences are included in the analysis.
10. Guy, B. (2019) US	'I poems' on abortion: Women's experiences with terminating their pregnancies for medical reasons.	To highlight the individual voices of women who terminate their pregnancies for medical reasons.	**Research conducted by psychology doctoral student.** Strict laws and policies in the US influence accessibility to TOP.	The use of the Listening Guide is unique and allows the women's voices to stand out in the analysis. Some clinical recommendations offered.

Author	Title	Subject	Argument	Evaluation
			Limited access to health care makes it difficult for women to terminate their pregnancies. All the TOP were related to fetal medical conditions only. Because women often experience 'unscripted emotional work' when going through a TOP, many are left to cope on their own.	The concept of ‘abortion doulas’ is unique and possibly highly impactful on women’s experiences. In the Aotearoa New Zealand context, midwives often fulfill this role.
11. Patricio, S. S., Gregorio, V. R. P., Pereira, S. M., & Costa, R. Brazil	Fetal abnormality with possibility of legal terminations: Maternal dilemmas.	To identify maternal dilemmas about the diagnosis of fetal abnormality incompatible with life.	**Research conducted by an obstetric nurse.** The diagnosis of a fetal condition that is incompatible with life poses a unique range of emotions for pregnant women. Women’s decision making was influenced by information given, knowledge of the condition, religion, family, and moral factors.	Discussion regarding the cultural aspects of abortion/TOP in Brazil is offered. Narratives are used to good effect in analysis. Some clinical recommendations are provided.

Author	Title	Subject	Argument	Evaluation
			Women commonly carried the responsibility during the process which reflects strong gender roles and gender-based traditions. In Brazil, abortion is considered a crime against life. Permission to abort is by judicial approval. Permission does not mean an exception to the criminal act but is seen as an acquittal.	

Analysis Framework

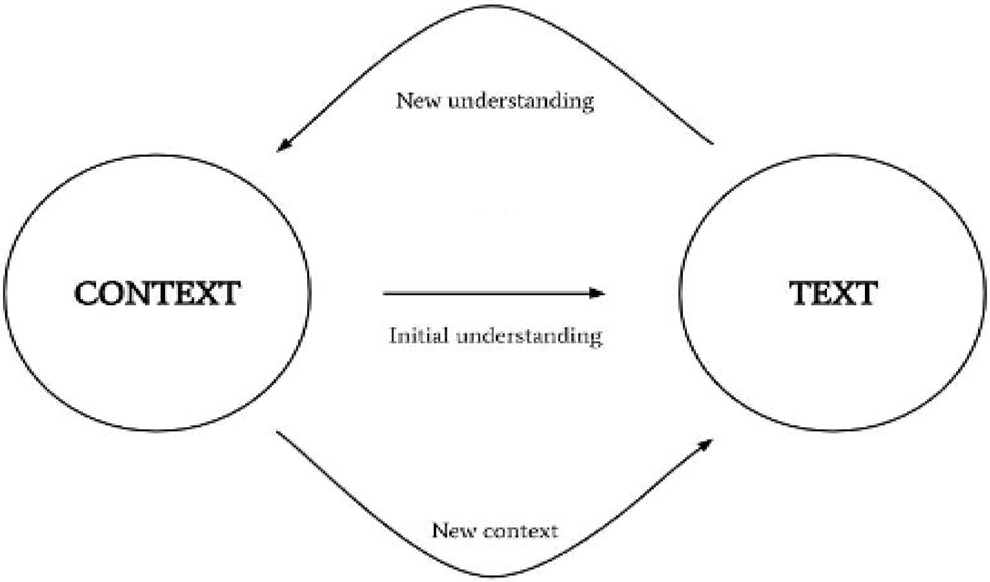
The justification for taking a hermeneutic circle approach lies in the suggestion that human experience research involves the experience of 'knowing' (Vagle, 2018). To 'know' the phenomenon of having a TOP is to have an encounter that is deeply felt, "etched into the memory, the body, the being and the identity" (Vagle, 2018, p. xii) of the person having the experience. In addition, this analytic notion has the potential for seeing and understanding *things* in a new way. What historically was thought to have a certain meaning may, in fact, have a multitude of 'yet-to-be-discovered' meaning. The framework enables a search of the text for what is often not seen, heard, or noticed (Vagle, 2018).

This journey of interpretation allowed for the review of the literature from an in-depth perspective that delved more deeply into the articles than a traditional literature review. The review enhances understanding of the phenomenon and, therefore, the literature is, itself, reviewed for authenticity and rigour.

In Figure 2 below, Le Cunff's (2022) version of the hermeneutic circle related to critical reading illustrates the journey of interpretation of both text and context. As initial understandings are tested by the text, the new understandings gained comes back to the context and so on. These 'parts' of the analysis make up the 'whole' of the phenomenon (Le Cunff, 2022).

Figure 2

Hermeneutic Cycle (Le Cunff, 2022)



Synthesis and Analysis

The 11 studies that met the literature review criteria included the experiences of 202 women. All 11 papers were read multiple times, which initiated a sense of immersion into the text. During the reading process, notes were made that promoted continued questioning of what was being read and interpreted. This act is aligned with Crowther et al., (2014) who reiterated the notion of unpacking or uncovering what is said by being open to the questions that develop from the reading and re-reading of the text. As each word was read, the text unfolded, and was applied to the whole meaning of the sentence. As the process repeated itself, new understandings gained from the text were checked with previous understandings to look for tension or confirmation of those interpretations, as well as existing beliefs or knowledge (Le Cunff, 2022). The graphic illustration of this process is reflected in Figure 2, above. Subsequently, the narratives of women's experiences within the context of a TOP for fetal abnormality in the second trimester of pregnancy were extracted and reviewed.

Findings

Analysis of the 11 articles found during the literature search demonstrated four main themes;

1. Communication, connection, and certainty.
2. Sense of self; self-worth, self-image, self-awareness.
3. At the mercy of their emotions.
4. The embodied experience of labour and birth.

Aspects of these themes are summarised in Table 4 and elaborated on in the following sections.

Table 4

Emergent Themes

Table 4 illustrates the beginnings of the interpretation process. As the interview transcripts were read and re-read, words, phrases, responses leapt out and became visible. They seemed to carry a common thread of meaning. These were jotted down, and it soon became clear that these were all somehow connected. From this table, further meaning-making and connections were developed.

CARE PROVIDERS (Communication, connection, & certainty)
Assistance from the multi professional health team (Patricio et al., 2019)
Role of the midwives (Hendriks et al., 2022)
Bereavement care (Hendriks et al., 2022)
Fragmented care (Hendriks et al., 2022)
Receiving information tailored to the client's circumstances (Kamranpour et al., 2021)
Role of health professionals-managing uncertainty (Hammond et al., 2020)
Time for reflection (Atienza-Carrasco et al., 2019)
Reaction provoked by the news (Atienza-Carrasco et al., 2019)
Unmet needs by health professionals. (Irani et al., 2019)
Issues related to uncertainty (Hammond et al., 2020)

Scientific
Personal
Practical
Sources of uncertainty (Hammond et al., 2020)
Probability
Ambiguity
Complexity
Confirmation phase (Qin et al., 2019)
Is my baby really abnormal? Is this an incorrect diagnosis?
Mythic expectation.
Researching information, reassessing.

SOCIAL (Sense of self; self-worth, self-image, self-awareness)
Psychosocial support (Atienza-Carrasco et al., 2019)
Perceptions of help & support (Atienza-Carrasco et al., 2019)
Individual and societal experience (Lafarge et al., 2019)
Social representation of motherhood (Atienza-Carrasco et al., 2019)
Guilt and shame (Irani et al., 2019)
Loss of their expected child (Irani et al., 2019)
Managing uncertainty (Hammond et al., 2020)
Parent strategies (Hammond et al., 2020)
Perceived pressure of time (Hendriks et al.,2022)
Representation and desire to be a mother (Gonzalez-Ramos et al., 2022)

EMOTIONS (At the mercy of their emotions)
Emotional responses before the termination (Gonzalez-Ramos et al., 2022)
Emotional responses after the termination (Gonzalez-Ramos et al., 2022)
Impact of the news (Gonzalez-Ramos et al., 2022)
Hope and despair (Lafarge et al., 2019)
-A choice but no choice
-Standing still and rushing
-Bonding and detaching
-Trauma and peace
-Disclosure and secrecy
The emotional journey: (Gonzalez-Ramos et al., 2022; Guy, 2018)
- excitement
- shock
- devastation
- compassionate choice
- gratitude (Guy, 2018)

Grief (Atienza-Carrasco et al., 2019)
Suffering and emotional distress process (Irani et al., 2019)
Denial phase (Qin et al., 2019)
My baby is fine-how can it be abnormal
Heartbreak
Denial and doubting the diagnosis
Anguished (Qin et al., 2019) (Decision making phase)

CLINICAL LABOUR & BIRTH (The embodied experience of labour and birth)
Pregnancy termination (Patricio et al., 2019)
The fetal body as too big: Labour & birth because of fetal size (Middlemiss, 2021)
The fetal body as too young: Labour & birth because of non-viability
The fetal body as risky: Limiting choice around feticide in the second trimester

Reasons for TOP (Atienza-Carrasco et al., 2019) Patient's experience (Atienza-Carrasco et al., 2019)

Communication, Connection, and Certainty

The experience of terminating a pregnancy may be considered a relatively normal clinical event for HCPs, but to women this experience is unexpected, scary, and often unfamiliar to them.

> *For the doctor at the hospital, it is so normal to meet people with problems*. (Patricio et al., 2019, p. 128)
>
> *They spoke to me with a language I did not know*. (Patricio et al., 2019, p. 128)

Women reflected that the communication between the HCP and themselves needed to be tailored to the woman herself, rather than condensed down to a brief summary of the facts. Information sharing was particularly important. Patricio et al. (2019) found that the quality of the communication between the woman and her caregivers was vital in making the woman feel welcomed, respected, and cared for. Quality communication would be seen as relevant for all women seeking maternity care but even more so when coping with the loss of their baby. Women sought relevant and clinically correct information that would give them a reassuring perception that they were being cared for by experts (Hammond et al., 2020; Hendriks et al., 2021; Middlemiss, 2021; Patricio et al., 2019). Women stated that they not only wanted but desperately needed to be able to talk to their caregivers about what was happening, about the baby, and about what troubled them. Women sought a sense of connectedness with those around them as they journeyed through an unknown experience. They reported that they were desperate for information about their baby's condition and turned to the internet or friends and family for help (Hammond et al., 2020). One woman described how the HCP offered information on a support website for others in the same situation. She found this useful and stated: "*I found articles and real-life stories that helped me understand everything I've been through and realize that I am not alone*" (Atienza-Carrasco et al., 2019, p. 1229).

However, for others, the feeling of being overwhelmed was silencing, halting their ability to take it all in (Atienza-Carrasco et al., 2019; Hammond et al., 2020). Emotional numbing was frequently reported and represented a feeling of shock, a sense of unreality, or being disconnected. These feelings left the women unable to comprehend what was happening (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Hammond et al., 2020; Kamranpour et al., 2021; Qin et al., 2019). "*There was a moment I stopped hearing what they were saying…I couldn't say a word*" (Atienza-Carrasco et al., 2019, p. 1228).

Some women felt as if many of their questions were left unanswered (Kamranpour et al., 2021). They felt there was the need for one dedicated person that they could turn to for answers to these questions, to offer some continuity of both information and care (Hammond et al., 2020; Hendriks et al., 2022). This would offer a common thread or continuity of information regarding what will happen next, what is involved and who they could rely on.

> *I needed a spiritual caregiver, an ethicist, a philosopher, just somebody to talk to about what is right. I wanted to do the right thing, but I had nobody to talk to*. (Hendriks et al., 2022, p. 1493)

Several women remembered the inconsistencies in inter-professional communication that resulted in inappropriate care discussions (offering newborn screening options, asking if they were excited to meet their baby) (Hendriks et al., 2022). However, many women had positive experiences of the way HCPs communicated information with them (Hammond et al., 2020). They found that when the HCP slowed their discussions down and did not rush through the explanations, they felt well informed and more at ease (Hammond et al., 2020).

One woman described the termination as a ‘disaster’ with stressed and unprofessional staff (Irani et al., 2018). Some women believed that their dissatisfaction of their care was not because of clinical incompetence; rather, the perceived lack of emotional involvement by those caring for them (Atienza-Carrasco et al., 2019; Hendriks et al., 2022). Hendriks et al. (2022) considered the notion that HCPs walk a thin line between perceived over involvement and detached care provision. They stated that previous research suggests that the emotional input of the HCP may well influence the woman’s decision making and, for that reason alone, HCPs are notoriously mindful of not getting too emotionally involved. For many women, they were unclear on who would provide their care, the time frame involved with the termination, the possible consequences, or even the actual termination procedure (Kamranpour et al., 2021).

> *How am I supposed to have a vaginal delivery after my first baby was born by caesarian section? How am I meant to tolerate this? What if my uterus ruptures? I have so many questions*. (Kamranpour et al., 2021, p. 100)

Many women felt that once they were informed of what to expect they felt calmer, more prepared and less anxious (Patricio et al., 2019). They appreciated a sensitive, unrushed explanation and many felt that once their care was handed over to a midwife, they felt reassured and well cared for (Hendriks et al., 2022). Often the women reported feeling supported by the midwives and appreciated their empathy and understanding of what they were going through (Hendriks et al., 2021): *“she took my hand... I was very nervous and was glad of her company”* (Atienza-Carrasco et al., 2019, p. 1227).

Qin et al. (2019) and Hammond et al. (2020) described the uncertainty many women felt regarding the diagnosis and searched for a glimmer of hope that someone had made a mistake. "*I find it difficult to give up my expectations... maybe they (the HCP) gave me the results of another pregnant woman*" (Qin et al., 2019, p. 88).). This sense of confusion and unsureness was perceived by many women in all 11 studies and represented both a scientific and personal framework as well as practical issues (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). From a scientific point of view, many women felt uncertain of the reliability or 'truth' of the diagnosis and tried to manage this feeling by discussing the situation with HCP, friends and family as well as the internet.

> *I tried the internet...I ended up disappointed and overwhelmed when I realized that what I was really looking for was a miracle and what I found was far from that.* (Atienza-Carrasco et al., 2019, p. 1229).

Participants researched, discussed, and searched for more information on their baby's condition. As a way of 'buying time' before the reality set in, the women wanted time to find out more, talk more, and learn more about what was wrong with their baby. "*One more time to check, one more time to make an effort, trying my hardest until the day I can do nothing more*". (Qin et al., 2019, p. 88) They searched for answers to perhaps unanswerable questions such as 'what is the truth about my baby and what hope is there?'

This level of uncertainty was not helped by inconsistencies in communications with HCPs. Many women asked if their baby really was abnormal, and whether the diagnosis was correct (Qin et al., 2019). They asked if the skill of the HCPs were high enough and if the medical equipment was advanced enough. How could they feel reassured that the results were correct? Women wanted reassurance and sought it from the HCPs. They were hanging on to hope that they had, in fact, made a mistake and their babies were 'normal'. The women were often given numerical probabilities of the severity of their baby's condition but for many this did not offer certainty. Often, they asked for a second opinion and wanted to consult with other HCPs (Atienza-Carrasco et al., 2019; Hammond et al., 2020; Irani et al., 2019; Kamranpour et al., 2021; Qin et al., 2019). Kamranpour et al. (2021), discussed the impact of lack of information or, more precisely, the lack of answers to the many questions women had regarding the health of their babies and suggested that it is likely to lead to a disruption in the process of mourning.

Sense of Self; Self-worth, Self-image, Self-awareness (Connection, certainty)

Several of the studies indicated that the women had a perceived image of themselves as mothers-to-be and held onto this image with a vehement determination (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Hammond et al., 2020; Irani et al., 2019; Lafarge et al., 2019). Pregnancy and motherhood were seen as important milestones in their lives, and they saw these 'rites of passage' as part of being a woman (Gonzalez-Ramos et al., 2022). To become a mother was seen as a 'beautiful process full of optimism' but because of experiencing the termination of their pregnancy, they felt 'a loss of innocence' (Gonzalez-Ramos et al., 2022).

> *It was a weird sensation. Being happy, being sad, trying to feel all the little joys. I hummed, I listened to music, as if he was going to live, as if I was going to welcome him. It was weird. At the same time, I was crying and explaining to him what was going to happen*. (Lafarge et al., 2019, p. 47)
>
> *It's very hard to accept that in losing this pregnancy I've also lost the last chance to live my dream*. (Atienza-Carrasco et al., 2019, p. 1230)

Perhaps the most powerful, poignant, and paradoxical reality for women, as mothers, was their desire to protect their baby within the context of also having to actively participate in the termination of their own pregnancy; the killing of their child (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Qin et al., 2019). Nearly all the reviewed studies indicated this reality to be the case.

The social concepts of guilt and shame invaded the women's thoughts because of the decisions they made to terminate their pregnancies (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). Shame was felt personally and was seen as a reflection of themselves as a mother; whereas guilt was founded in the actions or decisions they made (Selva, 2018). Any decision they made had the potential for judgement and regret from others and, even more poignantly, from themselves. Irani et al., (2019) stated in their study of the emotional and cognitive experiences of women going through a TOP, women commonly experience emotional shock when they realise that their baby is very unwell. They suggested that considerate and non-judgmental care is imperative to protect the woman's emotional well-being. Women's sense of self is permanently changed because of the loss of their babies and this intimate, personal, and deeply impactful experience is now reflected in how they are in the world (Guy, 2019; Lafarge et al., 2019).

> *I had always thought that termination, in whatever circumstances, was completely wrong. Now I had to face the fact that I'd had one*. (Lafarge et al., 2019, p. 46)

> *I have played God and killed my baby, but it was for the right reasons. It just does not ever feel right*. (Lafarge et al., 2019, p. 46)

This internal conflict bound these women to a place of "a choice but no choice" (Lafarge et al., 2019, p. 46). The chasm between doing what they considered was the right thing and terminating the life of their baby was a matter of personal torment. *"I ended the life of my baby, and I wanted him so much"*. (Lafarge et al, 2019, p. 46)

Many women described the situation as being between a "terrible and horrible scenario" (Lafarge et al., 2019, p. 46). The dilemma was protecting their baby from suffering but that also meant ending the life of their much-loved baby.

> *There comes a point where there is no hope of recovery, no hope of anything approaching a normal life, no hope of progress. Then it is probably the kindest thing to turn off the machine. That's what I did for my baby, in a way – I turned off the life support that was my pregnancy.* (Lafarge et al., 2019, p. 46)

Some women experienced 'time' as a foe, something that was always sitting with them during their experience of terminating their pregnancy. Either time went too swiftly and left them confused and overwhelmed or time went slowly, and they wished for the time to pass. Some of this time pressure was a perceived timeframe that related to what was expected of them or of the situation. From learning of their baby's diagnosis, trying to find information to support their decision making, and awaiting the termination of their pregnancy, time was always on their minds. As Lafarge et al. (2019) suggested, time appears to be either static or hurried with women wishing to speed up or slow down the process. Even during the labour and birth, time was pivotal in their experience. Time dragged on as they tried to cope with both their emotional and physical pain; alternatively, the birth happened before they were ready and came as a shocking experience (Atienza-Carrasco et al., 2019; Guy, 2019; Hammond et al., 2020; Irani et al., 2019; Lafarge et al., 2019; Qin et al., 2019). These experiences of time are related strongly to the women's own self-awareness or a sense of them 'being-in' time, entangled in a movement beyond their control.

> *Too many hours for such a sad and painful end*. (Atienza-Carrasco et al., 2019, p. 1231)

> *The whole process was fast and cold. I only have vague memories because I was sedated.* (Atienza-Carrasco et al., 2019, p. 1231)

> *I wasn't psychologically ready. The physical pain has gone, but the pain in the soul lasts much longer.* (Atienza-Carrasco et al., 2019, p. 1231)

Many of the women felt psychologically unsupported at their time of greatest need. It was not only how much support they were offered but also what type of support and when the support was offered that played a role in this perception (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2022; Kamranpour et al., 2021).

"S*ometimes I just wanted to lock myself in at home so as to not hear anyone commenting on what happened. Instead of helping, they ended up making me even more worried*" (Atienza-Carrasco et al, 2019, p. 1232).

The psychological support experienced by many women seemed to be either minimal or inappropriate (Atienza-Carrasco et al, 2019; Hammond et al, 2020; Hendriks et al, 2022). They often reported lack of information on the support available to them or the support offered tried to normalise their experience (Guy, 2019; Kamranpour et al, 2021: Lafarge et al, 2019) which downplayed what they had been through and inclined women to silence the grief they felt. This response led to feeling disenfranchised and stigmatised about their experience (Atienza-Carrasco et al, 2019; Gonzalez-Ramos et al, 2022; Irani et al, 2019; Kamranpour et al, 2021; Lafarge et al, 2019; Patricio et al, 2019; Qin et al, 2019).

> *With people close to me I find it difficult to behave naturally... all my friends are pregnant or are already mothers. I don't know how to deal with this.* (Atienza-Carrasco et al, 2019, p. 1232)

The sense of uncertainty from a personal standpoint reflected an even more intimate and heart-felt experience. For many women, the meaning of life, death, and the role they played in this process was at the soul of this precarious feeling. This existential loneliness was reported by many of the women in these studies and many found the path through this extremely difficult and sat heavily on their shoulders (Atienza-Carrasco et al. 2019; Gonzalez-Ramos et al. 2022; Guy, 2019; Hammond et al. 2020; Hendriks et al. 2021; Irani et al. 2019; Kamranpour et al. 2021; Lafarge et al. 2019; Middlemiss, 2021; Patricio et al. 2019; Qin et al. 2019).

I felt very alone when I had to make the decision about my pregnancy… I had a lot of doubts" *(*Atienza-Carrasco et al. 2019, p. 1230).

For many women, they were unsure of what the next step was. They felt in limbo without certainty of what would happen next. The emotional shock and bewilderment of their situation extenuated these feelings of uncertainty and they felt vulnerable and scared. Inconsistent information, along with having to deal with multiple different HCPs, did not alleviate these feelings of uncertainty (Atienza-Carrasco et al. 2019; Gonzalez-Ramos et al. 2022; Hammond et al. 2020; Hendriks et al. 2021; Kamranpour et al. 2021; Lafarge et al. 2019; Middlemiss, 2021; Patricio et al. 2019)

For many women, experiencing the termination of their pregnancy was a situation that they did not expect, and they did not know how to navigate the myriad of heart-breaking issues they faced. While many of the women described the experience as stressful and overwhelming, only a few of them felt that they already possessed the appropriate coping skills (Atienza-Carrasco et al. 2019; Gonzalez-Ramos et al. 2022; Hammond et al. 2020; Hendriks et al. 2021; Irani et al. 2019; Kamranpour et al. 2021; Lafarge et al. 2019; Qin et al. 2019).

The complexity of the experience often made finding methods of coping difficult and another source of anxiety and self-doubt. Many women searched the internet for advice on how to manage both their physical and emotional concerns. While it would seem natural for women to reach out to family and friends for support, many women reported that they felt unable to do this because of the stigma attached to ‘choosing to terminate their pregnancy’. It implies that they felt as if they had done something wrong or at least not something ‘a good mother’ would do to their child.

> *It’s also a matter of having to cope with facing people. Termination is a taboo subject, and unless you have yourself in this situation, people are quite unaware*. (Lafarge et al, 2019, p. 48)
>
> *I’ve had lots of arguments with my partner because I need to vent, and his elusive attitude annoys me. He thinks I’m just hurting and he’s afraid I’ll become obsessed.* (Atienza-Carrasco et al, 2019, p. 1232)
>
> *My family avoids talking about it in front of me... they think that makes me suffer less, but really talking about it, too, helps me get over it.* (Atienza-Carrasco et al, 2019, p. 1231)

However, for some, those closest to them did offer valuable and needed support.

> *We have had a lot of support from family and friends. They made it clear to us that they were there and wanted to help.* (Hammond et al, 2020, p. 204).

Some women coped with the intensity of the situation by using avoidance. They deferred thinking about the future and only focused on the ‘here and now’. This way they were able to not feel so overwhelmed with what they were about to go through (Hammond et al. 2020). To keep them going they often hung onto a sense of hope, regardless of their certainty of the diagnosis and planned interventions.

> *I tried to say to myself: that's it, I don't love him anymore, I have to stop loving him. And then I think he never moved more than that night. And then I said to myself: no, it's not possible, I still have 1% chance that he has nothing wrong.* (Lafarge et al. 2019, p. 47)

The possibility of their baby being 'normal' made them cling onto a sense of hope even though the odds were minute. To take this feeling of hope from them would signify the final outcome, which was too painful to bear.

At the Mercy of Their Emotions

Once women had been given the diagnosis of fetal abnormality, they often felt overwhelmed with such intense emotions. The predominant emotion, at this point was shock, sadness and utter confusion (Atienza-Carrasco et al. 2019; Gonzalez-Ramos et al. 2022; Guy, 2019; Hammond et al. 2020; Hendriks et al. 2021; Irani et al. 2019; Kamranpour et al. 2021; Lafarge et al. 2019; Middlemiss, 2021; Patricio et al. 2019; Qin et al. 2019).

*I couldn't stop crying... basically I was asking myself, why me? Why me? And what had happened to him. I would go over every day what I had done. And I couldn't find anything (*Gonzalez-Ramos et al., 2022, p. 8).

Many women reported feeling fearful of the birth, and especially fearful that their baby would suffer during the birth or afterwards. Women reported feeling overwhelmed by a myriad of emotions creating chaotic cycles of confusion, hopelessness, and uncertainty (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). The internal dialogue that tormented women was obvious throughout the 11 studies and highlighted the intense emotional hardship that was shared by the women in these circumstances (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019).

Lafarge et al. (2019) presented evidence of the conflicting emotions of wanting to bond with their unborn baby; yet, to protect themselves, emotionally detach from their baby. The conflict between "*giving life while thinking about taking it*" (Lafarge et al., 2019, p. 47), was frequently described by women and caused them immense emotional reactions of guilt and deep sadness (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). Women experienced feeling devastation and agony have been described in the articles and these emotions were often reported as leading to 'emotional exhaustion'.

> *The period of time between learning our diagnosis and ending her suffering was agonizing. Each movement of my baby-movement that for months had brought me such joy-now brought only unbearable heartache. Looking down at my full pregnant belly knowing how sick my daughter was and knowing that she would not live was horrendous.* (Guy, 2019, p. 273)

The intensity of the experience is reflected in the language used by the women to describe the experience and was symbolic of both the intense physicality of the event and the overwhelming feelings of loss binding them to the experience; highlighted with the women's use of raw, brutally honest and uncensored narratives. The words used by women to describe some of the emotions they felt included "*I feel like the sky is falling*" (Qin et al., 2019, p. 87); "*The pain of the body has never achieved the pain of the mind*" (Qin et al., 2019, p. 88); "*I don't want to see or hear anything...please don't let me know anything about it*" (Atienza-Carrasco et al., 2019, p. 1231); and "*asking for the baby's forgiveness*" (Gonzalez-Ramos et al., 2022, p. 8).

The statement from one woman; "*My world stopped, there were no birds, nothing in the sky and the trees did not even seem to be moving... I remember looking at the world and thinking how dare the world carry on as if nothing has happened*" (Lafarge et al, 2019, p. 46) offers insight into the inexplicable language of heartache that she used to describe her feelings.

In the context of having to make decisions about termination, many women felt that "*you are damned whatever you do*" (Lafarge et al., 2019, p. 46). Analysis of all 11 papers revealed that terminating a wanted pregnancy was a dilemma that contravened a woman's personal moral compass (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). As Lafarge et al. (2019) suggested, the grief felt by women after the termination of their pregnancy is bound to the often-chosen path of secrecy. The internal conflict of whether to disclose what they have been through, compared to keeping their grief private, was seen as an almost unanswerable dilemma for many women (Hendriks et al., 2021; Kamranpour et al., 2021; Lafarge et al, 2019). However, several women chose to purposefully not discuss the termination as a way of recovering from their loss (Atienza-Carrasco et al., 2019; Qin et al., 2019). By not thinking about it they felt they were able to put the experience behind them.

It was reported that those around the women were often hesitant to talk about the loss for fear of exacerbating the women's distress. This hesitancy, in fact only increased the women's feelings of loneliness and isolation (Atienza-Carrasco et al., 2019; Hammond et al., 2020). As Gonzalez-Ramos (2022) stated, women often reported feeling great sadness after the termination that heightened their feelings of emptiness and loss. As part of their grief, many women were fearful that their baby would be forgotten or not acknowledged as ever existing (Gonzalez-Ramos et al., 2022, Hammond et al., 2020). Their memories were all they had to remember their baby by and once these faded, so did the significance of their loss.

The Embodied Experience of Labour and Birth

The reality of how the termination of their pregnancy would be managed, what would happen at the time, and who would care for them, was also spoken of by the women (Atienza-Carrasco et al., 2019; Hammond et al, 2020; Gonzalez-Ramos et al., 2022; Middlemiss, 2021). These issues left women feeling apprehensive about what was ahead of them. For many of the women, the reality of having to labour and give birth to their baby was unexpected and frightening (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Hammond et al., 2020; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019). Many presumed they would be sedated or put to sleep for the termination, or the procedure would be quick and straight-forward, not involving any great amount of discomfort. For many of the women, the reality of the experience was a long and painful process and they found it traumatic (Atienza-Carrasco et al., 2019; Irani et al., 2019; Middlemiss, 2021; Lafarge et al., 2019).

> *The realization that I would have to go through childbirth was such a shock. I'd have to deliver. It just had never crossed my mind. I just thought that they would put me to sleep, deal with it and then I would wake up and it would all be gone, sort of thing.* (Middlemiss, 2021, p. 88)
>
> *I was scared like when I was a kid, scared of the unknown.* (Lafarge et al., 2019, p. 48)
>
> *Not knowing what to do when the baby comes out. Not knowing if I should look or not. I did not prepare myself for that.* (Patricio et al., 2019, p. 128)

The experience of giving birth was emotionally challenging with some women describing it as "horrible" (Middlemiss, 2021 p. 92), "being torn apart" (Atienza-Carrasco et al., 2019, p. 1231), and "shocking" (Middlemiss, 2021, p. 87). The notion of 'unpreparedness' that many women felt, led to not being aware of the possible complications. For those women whose birth did not follow the predicted trajectory, the consequences were profound and seriously impacted the women's physical and emotional health (Atienza-Carrasco et al., 2019, p. 88). For most women, the experience of labour and birth involved considerable pain and distress (Atienza-Carrasco et al., 2019; Irani et al., 2019; Middlemiss, 2021).

> *I had really bad hemorrhaging and it was really traumatic.* (Middlemiss, 2021, p. 88)

> *The moment of delivery was very painful; my husband and I cried a lot.* (Irani et al., 2019, p. 26)
>
> *I can't forget that moment that I realized I was ejecting him.* (Atienza-Carrasco et al., 2019, p. 1231)

However, another woman described the birth as being "peaceful, gentle and having a sense of marvel" (Lafarge et al., 2019, p. 48). For some women, the birth of their baby was considered a beautiful moment and one that soothed their soul.

Women reported being very aware that the medication they were taking was going to end their baby's life. The inevitability of what they had 'chosen' to do was now a reality and they had a sense of finality.

> *Taking the abortion pills was very hard, lots of very negative thoughts came into my mind.* (Atienza-Carrasco et al., 2019, p. 1231)
>
> *I just took the tablets and was sent on my way to carry my dead son around in my tummy for two days until I had the termination.* (Lafarge et al., 2019, p. 47)
>
> *I kept life and death in my belly for two days... it was the most traumatic period.* (Lafarge et al., 2019, p. 47)

Women who experienced a feticide (fetal heart is stopped before birth), described it as the worst part of the process (Atienza-Carrasco et al., 2019; Hendriks et al., 2022; Lafarge et al, 2019; Middlemiss, 2021). While women who went through a feticide knew what was involved, some were overwhelmed with the actual process of stopping the baby's heart before birth (Middlemiss, 2021). They were aware that their baby's gestational age meant that without this procedure their baby would be born alive, which would potentially add to their trauma.

> *They just said that's what they did once the baby got to that gestation. I was probably in shock at the time and I just kind of went with what they said"* (Middlemiss, 2021, p. 91)
>
> *That was almost the hardest bit really. You just lie there while they do it.* (Middlemiss, 2021, p. 92)

Middlemiss (2021) suggested that women often find themselves in a place with no exit. The woman can accept or decline this procedure but, for many, a feticide is recommended to alleviate the risk of distress and trauma around the time of birth. While the thought of 'knowing' the exact time of their baby's death is likely to overwhelm them, the alternative of birthing a baby that will inevitably die may be even more distressing for some women. However, for some women, seeing their baby born alive may reflect the realness of their baby's birth, regardless of when their baby died.

To cope with the holistic experience of labouring and giving birth, women utilised various coping skills. These included needing to "Be on my own" (Atienza-Carrasco et al., 2019, p. 1231); "not wanting to see or hear anything" (Atienza-Carrasco et al., 2019, p. 1231); "talking about it" (Atienza-Carrasco et al., 2019, p. 1231); "encouragement from my family and friends" (Atienza-Carrasco et al., 2019, p. 1232); "going back to work" (Atienza-Carrasco et al., 2019, p. 1232): "asking for social support" (Qin et al., 2019, p. 89); "avoiding any related event" (Qin et al., 2019, p. 89); "sharing with other parents who had the same experience" (Hammond et al., 2020, p. 204); and "trying to stop loving my baby" (Lafarge et al., 2019, p. 47). These narratives imply women are attempting to divert away from the situation and the myriad of emotions that accompany it. At the same time, they are seeking comfort from those who know them well and can understand what they are going through.

Discussion

This hermeneutic literature review explored contemporary international literature on women's experiences of terminating their pregnancy because of fetal abnormalities. While others reviewed the evidence concerning these experiences (Jones et al., 2017b; Lefarge et al., 2014), the current review focused on literature published after 2019 to enable an investigation of the most recent lived experiences and research on this phenomenon. Using a hermeneutic mirror to unpack the findings, analysis aimed to illuminate what the women experienced; what was not previously understood; what was unsaid, unheard, and unknown, to potentially enhance knowledge and understanding of such experiences.

Chang et al. (2018) stated that women-practitioner communication should be a priority with all pregnant women but even more so when the information given is likely to produce profoundly intense reactions. Most women were not expecting such dire news and felt so overwhelmed by the events that they often were unable to comprehend what they were being told. Considering this emotional response, the women required the information to be repeated, time and time again (Turner et al., 2022). The perceived lack of nurturant communication had the potential to not only add to the women's distress but, as suggested in many of the reviewed papers, add to the women's sense of mistrust of both the communicator and the information given (Turner et al., 2022). Communication is transmitted both verbally and non-verbally and the women's narratives in the reviewed papers frequently revealed that the women had a sense of intended meaning (good or bad) by using both methods of communication (Toller, 2011). These miscommunication issues are also seen in historical research findings, so this more contemporary review reiterates these conclusions and indicates the ongoing impact of communication between the women and the HCP, in this context.

For many of the women in the reviewed papers, the connectedness between themselves and those providing their care was considered a pivotal point in their experience. Whether the care was perceived as compassionate and kind, or cold and distracted, the impact of how their care was interpreted was the foundation of how women navigated their way through their experience. They reportedly found clarity and a way forward when they felt a connection or 'an ease of being with' the HCP. Conversely, they felt stalled by their anxiety and distress when they did not feel this connection. The level of care was able to generate feelings of connectedness and support at a time when many women felt lost and confused. Alternatively, when these feelings were not nurtured, the women remained in a place that lacked connection with those around them (Fernández-Basanta et al, 2020). Women desired care that respected and acknowledged the reality of what they were going through. Care that demonstrated compassion in all interactions whether that was with communication, clinical care, or care that offered support and conveyed that the woman was not alone (Heaney et al, 2022). The desire for connection is seen frequently in maternity care research and portrays the need for women to feel connected and in a trusting and respectful relationship with those providing their care (O'Brien et al, 2021). The literature adds to this notion from a contemporary research standpoint.

For many women, a consistent person, whether they be a HCP or not, was seen as an ideal conduit between them and 'the process'. A feeling of continuity of care and information was considered a way of trusting the bigger picture that, to many, was fraught with inconsistencies and, therefore, a source of anxiety. This level of uncertainty was reported as being consistently high amongst all the women interviewed and stemmed from inconsistent processes, people, and information provided throughout the whole experience. Without factual and reliable information, many women felt in a precarious position, both emotionally and physically. The need for continuity of care and/or carer is well documented in midwifery literature and forms a cornerstone of midwifery care in many countries, including Aotearoa New Zealand (Perriman et al., 2018). The women's narratives in the current review reiterate the philosophy of continuity of care which seems highly influential in how each woman experiences a TOP. Therefore, consistency in care validates findings in this literature review as well as historic TOP research (Jones et al., 2017b; Lefarge et al., 2014).

The notion of certainty, or rather uncertainty, had a strong influence on the women's experiences. The feeling permeated the event from the starting point right through to post TOP. Lack of clarity regarding the diagnosis plagued many women because of the huge implications of an incorrect or incomplete diagnosis (Frederico et al., 2018). Many felt unsure of the competency of those providing the diagnosis, not because they believed they were clinically incompetent but because of their inappropriate communication styles and the environment in which the news was given. The women often reported that the news came as such a surprise that they found it difficult to believe those giving it. Gendler et al. (2022) described the concept of vigilance in decision making that reflects a cautious yet proactive process that women often demonstrated. This process involves confirmation, collaboration, discussion, and assimilation of information that ultimately leads to a final decision being made. Without certainty, however, the process was problematic as the women needed to feel that this process was trustworthy, robust, and reflected their own values. Conversely, some women in the reviewed papers were unable to cope with feelings of uncertainty which added to their sense of confusion and anxiety.

The desperate need for women to gather information about their baby's condition, the possible outcomes of that condition, and the potential implications for the baby was clearly stated in all the papers reviewed (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). From this research, many women felt the information they required was either not forthcoming or unintelligible to them. The time spent explaining what was happening and likely to happen was often seen as scant, and women resorted to searching the internet or asking friends and family for their input. For some women, engaging in online social forums (Facebook, bereavement support groups) was a welcome source of both information and support (Klarare et al., 2020).

The findings of this literature review also support the idea, as McCoyd (2009) has previously stated, that there are no written scripts for normal emotions to inform women's experiences. Women are forced to adapt to a space both physically and emotionally when their expectations around the process of terminating a pregnancy are unclear or unknown (Carlsson et al. 2016; Lotto et al, 2016). Women struggle to find guidance to support their feelings and experiences. McCoyd (2009), introduced the concept of "feeling rules" (p. 442) or the socially constructed and accepted way of feeling and how these 'rules' relate to women who are terminating their pregnancies. For women in the reviewed literature, not only were they unprepared for their baby's diagnosis but they were also unprepared for the intensity of their situation. Both circumstances left them unaware of what they should feel, what they should do, and how they should cope with what was happening. This tenuous emotion path is summarised in previous literature and is reiterated in the current literature review (Jones et al., 2017b; Lafarge et al., 2014).

The findings of this literature review illustrate that the experience surrounding the TOP due to fetal abnormality was a profoundly traumatic experience that caused emotional turmoil. Women experienced a myriad of highly charged emotions that range from devastation to sorrow and from fearfulness to guilt (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). The feelings of grief and raw emotion were frequently overwhelming for the women and commonly created a sense of confusion, hopelessness, and uncertainty. While these findings are also evident in earlier research conducted by Lafarge et al. (2014) and Jones et al. (2017b), this literature review places a spotlight on current clinical care experiences and the implications of these on women who have been through the termination process. These findings reiterate that the impact of terminating a pregnancy remains intense and profound.

The feelings of shame and guilt were frequently expressed in the data. Many of the women's narratives reflected the idea that their babies had the right to live but not at the risk of the baby's suffering. They now found themselves having to make these life and death decisions. They felt devastated and wracked with shame and guilt. For some women these feelings came from their belief that somehow, they caused the abnormality in their baby (Maguire et al., 2015). Others felt responsible for judging or not accepting the baby's abnormalities by deeming their baby as 'imperfect'. Many women were reluctant to discuss the termination with friends and family because of the potential of reliving their trauma or even worse, hearing the judgement of others (Roseth et al., 2022). The perceived stigma of terminating a pregnancy was felt by many women, as such they felt alone in their grief (Maguire et al., 2015). These conclusions are validated by what is already known about the possible psychological implications of having a TOP but what is not as clear is how to reduce the impact or occurrence of these psychological impacts. Further, the wider concept of psychosocial impact is evidenced in this literature review and the findings validate further consideration of these impacts.

Women's common narrative of 'pain' could be their only way of making some sense of meaning regarding what was happening to them in the absence of other 'feeling rules'. The physical pain of labour became intertwined with the emotional pain of having to give birth to a baby they had 'chosen' to terminate. At least their pain, whether emotional and/or physical pain, was real; whereas their spiritual pain remained unfamiliar to them. From a phenomenological perspective, Walsh (2022), reflected on Heidegger's concept of pain and suggested that the perception of pain is unique to the individual experiencing it; therefore, others cannot truly feel that person's pain. For example, while others may empathise or have felt the pain of childbirth themselves, they cannot feel her pain. As Walsh (2022) argued, the immense range of pain is, however, regarded as 'pain', irrelevant of the source, the intensity or the perception. In reviewing the literature, it could be argued that the reality of women's sensation of pain was often concealed to others. Their lived or embodied experiences left the women reportedly 'lost for words', rendering them voiceless. Reflecting on the women's narratives of the papers reviewed, for many women the experience seemed to have 'taken their voice'. This sensation is believed to be in response to the unpreparedness and helplessness that many women felt during this time. Whether the women's 'silence' was through being overwhelmed with the sensations or not having the words to express what they are feeling is reflective of the intensity of their experience. This sensation easily translates to an overall sense of unsureness or even unpreparedness around the termination process. For women to be unaware or not cognisant of what was about to happen indicated a lack of preparatory information and support offered to women (Georgsson et al, 2019).

The concept of self-image as a mother was discussed widely in the reviewed literature. The maintenance of the women's identity was pivotal to what happened to their babies; and for many, the threat to their own sense of self was real. The common thought was a sense of needing to protect their babies from suffering and/or harm. Warland et al. (2010) proposed that it is normal for parents to protect their young from danger and this understanding was portrayed in many of the women's narratives when deciding to terminate their pregnancies. Societal constructions of motherhood imply that a woman nurtures her child and to be seen as 'a perfect mother' she must protect her child (Delgado-Perez et al, 2019). As reflected in all the reviewed literature, the tension between the woman's self-image of being a perfect mother and ending her pregnancy is one peppered with doubt, guilt, and shame.

The concept of time passing is stated to be a perception based on the relationship between things (Standford Encyclopedia of Philosophy, 2019). In the context of this literature review, the passing of time is seen as the relationship between the woman experiencing a termination of her pregnancy and those around her and the unfolding process. It is 'measured' by the changes that occur. For example; the toing and froing while making the decision to terminate the pregnancy, the length of the labour and birth, the aftermath or recovery after the birth/death of their baby. The literature reveals that the women experienced time as passing either too quickly or too slowly, depending on the circumstances. When they needed to make decisions and comprehend how that decision would impact on their lives, time moved too quickly. Whereas, when they were physically and emotionally experiencing the termination, time moved too slowly, for many of the women. Time passed is also said to be only measured in our memory; how long an event took, how suddenly an event happened (Stanford Encyclopedia of Philosophy, 2019). It implies that the women's embodied experience of terminating their pregnancies involved their memory of what happened and influenced how they felt time had passed. Their perception of events is etched into their memories and influences their recall of events.

The sense of unpreparedness for what was about to happen during the termination of pregnancy was seen in many of the women's narratives. Whether the women used a sense of denial to not think about what was to come or they were innocent to the process, they commonly reported feeling shocked and overwhelmed by what lay ahead. The idea of giving birth terrified many of them as it would mean coming face to face with their baby and the consequence of their decision. What was only considered in an abstract way would now confront them directly and there was no hiding from what had happened. The labour and birth would represent a continuation of the crisis they experienced with the diagnosis, then the decision making, and then, finally, the birth (Gendler et al, 2022). Many believed that the pregnancy would be terminated while they were asleep or sedated, leaving them oblivious to the physical reality of ending their pregnancies (Georgsson et al, 2019). Many of them felt intense feelings of concern about the termination process as well as their physical and emotional reactions to the experience. The likelihood of actual harm to themselves or the inability to cope with the process was often mentioned as being of utmost concern. Some of the women remarked that their concern for their baby was now replaced with the fear for their own well-being as the outcome for the baby was a fait accompli.

The women who went through a feticide as part of the termination of their pregnancies recalled the overwhelming helplessness and sadness of experience. To know what the procedure was for left the women knowing exactly the time of their baby's death. One the one hand, the women understood why a feticide was needed; on the other hand, the harsh reality was that this choice was the ending of their baby's life. As Leichtentritt et al. (2017) stated, feticide represents "maintaining a post death relationship with a child they did not know, whose death they chose and witnessed, within a social context that ignores their loss and forces them to silence their grief" (p. 665). Literature that examines the procedure of feticide validate the women's experiences found in this review but still the unspokenness of what the women went through remains unknown (Leichtentritt et al, 2017).

Implications for Practice

This literature review offers further insight into the holistic practice implications of obstetric care for women undergoing a TOP because of fetal abnormalities. While clinical competence in the skills involved in managing a TOP are critical to the overall outcome of the procedure, it is suggested that more humanistic issues are at stake. The women's narratives in the 11 papers reviewed all reflected the priority they placed on the concept of human connection. That is to suggest that the woman feels that those caring for her have a caring relationship with her. That she is valued and acknowledged and that she is in a judgment free space (Stiles, 2021).

The inter-relatedness of communication that revolved around feeling heard; being involved in the conversation rather that spoken 'at'; and the transferring of information that was relevant, sensitive, and personalised, all resonated with the women interviewed. Women required information that answered their own specific questions, and, at times, they needed this information repeated or in a 'take home' format. They appreciated having time to digest what they were being told and to ask questions as they arose. The timing of this information gathering varied with each woman but, generally, they felt too overwhelmed to make sense of what was shared and wanted to slow down in this communication experience. The use of medical jargon was often foreign and alienating for the women and its use increased their confusion and anxiety. Lay language that was more reflective of how the woman herself might describe the situation was required.

For many women, the availability of a 'go-to' person would have allayed some of their fears and given them consistency of information and support. The use and development of a birth plan that is facilitated by the continuity provider, in collaboration with the woman, may solidify these feelings of dependability in the process. Birth plans have, in the past, been used extensively in many countries and, while some believe these to be outdated and ineffectual, they may be seen as a way of starting discussions between HCPs and women (Kaufman, 2007). Rather than being a finite and inflexible list of 'wants', they could be seen as an initiator of a discussion on expectations and understandings of different aspects of the termination. These could be used as a tool to define what is important to the woman and those supporting her, as well as fine tuning her comprehension of what may be involved in the experience. As suggested by Kaufman; "A birth plan is an approach to labour, rather than a term for a specific kind of outcome" (Kaufman, 2007, p. 48).

The need for a more holistic and thorough preparation for the termination is required by the HCP. Time spent explaining what to expect, who will be involved, the possible complications that may occur, and what precautions are in place, as well as the possible timeline of events may be useful. This information may be better in written form with the use of discussion to answer any questions the woman may have bearing in mind the potential comprehension issues women who are already distressed and afraid may have receiving this information. Individualised and case-specific information should be offered in a sensitive and comfortable manner.

Many women in the reviewed papers found being offered information on support groups and on-line information useful and enabled them to access these in their own time frame. Up to date resource lists should be offered to women to support them as they move through this experience and beyond (Alqassim et al, 2022; Georgsson et al., 2019). Alqassim et al. (2022) suggested a 'circle of care' approach for any pregnancy loss experience that involves HCPs, allied health workers, family, friends, as well as support from others who have also experienced pregnancy loss. This concept could include appropriate and individualised follow-up from HCPs experienced in pregnancy loss care.

This literature review supports the notion of specific educational requirements for HCPs who provide TOP care. Both undergraduate and postgraduate education on what is required for the appropriate and situation-sensitive care of women experiencing a TOP is pivotal for the HCP to be able to meet the women's holistic needs. Armour (2018) stated that targeted education for midwives in this level of midwifery care is not optimal and consideration is needed for on-going educational resources to be developed to facilitate this education. Armour goes on to suggest that many midwives feel unprepared for the complex midwifery work involved in providing holistic and appropriate care, in these circumstances (2018).

Limitations

The number of participants in each article were relatively small but, as Malterud et al. suggested, the number of participants should be "sufficiently large and varied to elucidate the aim of the study" (2015, p. 1753). This assessment of sample size is dependent on the findings and depth of analysis of the research data. It is suggested that although the data are highly reflective of the participants' experiences, the wide time frame of those experiences (from diagnosis through to months or years after the TOP) may have diluted the depth of the data. In other words, often data analysed covered many parts of the experience rather than focusing on one or two specific moments in the experience of TOP.

One study by Hammond et al. (2021), used two sets of participants (groups from UK and Netherland) but it was unclear why these two groups were used. The data analysis showed minimal comparing and contrasting of the differences and biases between each group. These differences may have been influential in the experiences of each group from a cultural and health care perspective. Therefore, drawing conclusions from the data analysis may be misconstrued or overly generalised.

While many of the reviewed papers concluded that HCPs should be educated or supported to be better communicators and provide better resources for women going through a TOP, many do not give specifics of how this might come about. If this suggestion would potentially positively impact on the women's experience, then targeted practice or educational points should be made clear and be shown to be achievable.

All the studies indicated that ethics approval had been obtained for each research project. However, very few papers discussed the specifics of the uniquely vulnerable participants in these studies and how their ethical approvals were of high importance to the well-being of those participants. As Gordon (2020) reminded us, many research participants have multiple vulnerabilities over and above those identified in the research ethics statement. He stated that the concept of vulnerability remains elusive and, although researchers consider the obvious vulnerable points (emotional and physical), there are areas of participant vulnerability that maybe overlooked (Qian et al., 2022). Areas of institutional vulnerability, economic and medical vulnerability, as well as differential vulnerability, are also areas of susceptibility for the women participants (Gordon, 2020).

Gaps in the Literature

While all 11 papers represented women's experiences from a global perspective, there was minimal inclusion of the cultural nuances in each geo cultural area of research. Cultural practices in relation to motherhood, birth, and death vary widely throughout the world and while some of the reviewed articles briefly mentioned the cultural aspects of the TOP experience, many did not. The current research also does not address the wider cultural nuances of the TOP experience as the recruited participants do not reflect women of minority cultural groups of Aotearoa New Zealand. Although every attempt was made to gain participants that reflected a wider cultural representation of Aotearoa, New Zealand, this was not achieved. As Boules stated in a resource for culturally and linguistically diverse (CALD) populations "Childbearing is a biosocial event marked both by the universality of the biological process and uniqueness of each social and cultural environment within which it occurs" (2020, p. 6). Therefore, the cultural context of TOPs and how women's experiences may be impacted by these would be worthy of research in the future.

All the articles reviewed took a wide lens approach to the experience of TOP. The experiential timeframe was often cited as being during the diagnosis and continued through until well after the TOP. This wide perspective, while allowing for a broader discussion of the TOP experience, did not focus on the pinnacle of the experience—the labour and birth. This conclusion comes from the in-depth review of the narratives from the women interviewed in the included articles (Atienza-Carrasco et al., 2019; Gonzalez-Ramos et al., 2022; Guy, 2019; Hammond et al., 2020; Hendriks et al., 2021; Irani et al., 2019; Kamranpour et al., 2021; Lafarge et al., 2019; Middlemiss, 2021; Patricio et al., 2019; Qin et al., 2019). It is not to assume that other times during their TOP experiences were not impactful; rather, amongst the intensity of the whole experience, the labour and birth of their babies stood out as having the greatest impact of all the events surrounding their TOP. This current research allows for the labour and birth experience to be heard and acknowledged and consequently, a deeper understanding of how women find meaning in this part of the TOP is highlighted. Without this current research, these often silenced and invisible encounters with the loss of their babies would remain unknown to others.

The articles reviewed indicated that the age of the participants was not specifically considered, other than being considered of adult age. This leads to the question of whether women of different ages, specifically younger/teenage women, experience a TOP differently to women of different ages. It would certainly be a topic for future research as statistics indicate that women under the age of 20 have higher incidences of fetal abnormalities (Chen et al., 2007; Chen et al., 2022; Sirakov, 2012).

Notwithstanding the already identified gaps in current literature, the current research is vital to identify the contemporary experiences of women going through a TOP. Since 2000, 38 countries have changed their abortion laws which must surely have had an influence of the theoretical accessibility of abortion services for women worldwide (Council on Foreign Relations, 2023). Practice insight and guidance needs to be as contemporary as possible to enable HCPs to provide women with 'situation-sensitive' care that reflects the holistic needs of women. It is no longer acceptable that women experience standardised and routine TOP care because of lack of understanding of the lived experience of women. Nor is it acceptable that the impact on women going through a TOP is forgotten, ignored or silenced. With an increase in comprehension from HCPs on the realities women face when having a TOP, the possibility of woman/family centred care can be provided.

Although all the papers reviewed identify the immeasurable and devastating impact women experience when going through a TOP, they did not descend deeply into the existential reality of the experience. The current research surrenders to the multitude of truths regarding the experience and reflects how women *exist* within it. This research considered the covered over, hidden, unspokenness of what women go through and provided a lens into the self-constructed, contextual reality that only the women themselves could speak of. Without the current research that searched for what is not obvious, women were bound to remain in the space of *other-ness,* of their lived experience being foreign to others. This current research provided clarity to what HCPs have previously only assumed that women experience during a TOP. It shows the experience for what it truly is, and the meaning women place on the experience.

Conclusion

The findings of this literature review acknowledge the often overwhelming and traumatic nature of going through a TOP for fetal abnormality. The contemporary research reviewed here validates previous research done in this field. It can be restated that for many women going through a TOP their lives are forever changed. It is agreed that having a TOP has the potential to substantially impact a woman's mental health, especially if she already has mental health issues.

The experience of having a TOP for fetal abnormality is related to the widest possible demographics so the experience could be considered universal. Regardless of maternal age, marital status, number of previous children, and contraception used, a woman's ethnicity or religious beliefs, women, worldwide, can find themselves considering a TOP for fetal abnormality. The addition of advances in screening and diagnosing technology means even more women will find themselves in the situation of needing to decide whether or not to terminate their pregnancy. For HCPs who care for women experiencing this scenario, a deeper and more reflective approach is required to be able to meet the holistic needs of women. Through further education and resources, HCPs will be able to recognise the embodied experience of having a TOP and the impact their care has on this experience. Compassionate and situation-sensitive obstetric care is imperative in the support of women who go through this experience and such care should be valued, prioritised, and held to the highest standards.

CHAPTER THREE: METHODOLOGY

Introduction

The philosophical framework and methodology that informed the research will be discussed in this chapter. The principles and main points of the methodology of (PIP) using Vagle's work will be considered, along with the rationale for using this methodology will be highlighted. Vagle's (2018) five component methodological processes that have scaffolded this inquiry will be explored. These processes were complex in nature, as was the finding of meaning amongst the data, so the use of PIP was informed by theoretical frameworks of the Meaning-Centred Grief Model (Dezelic et al., 2014; Wong, 2008) and an existential-phenomenological approach to understanding grief (Claspell, 1984; Madison, 2005). These frameworks added to the meanings gained from the experience of terminating a pregnancy due to fetal abnormalities.

The Concept of Phenomenology

The word phenomenology, translated from Greek, means 'to bring in the light' (Cavalier, n.d.). Illuminating what is often in the shadows of the human experience is the underlying philosophy of this qualitative methodology (Heidegger, 1996). Many researchers have tried to place phenomenology into a 'box' that defines what phenomenological research methodology and philosophy is; however, as Vagle (2018) contended, "phenomenology is not a singular, unified philosophy or methodology" (p. xiv). It is suggested that there are many vantage points to view and 'see' phenomenology, but all agree that this methodology sits in the realm of 'the experience' (also known as, 'lived experience') (Heidegger, 1996; Vagle, 2018; van Manen, 2014). Therefore, phenomenology does not represent the theory or the measurement of experience but the lived, embraced, embodied experience of a phenomena.

Phenomenology offers a method of entering another's world; metaphorically 'lighting' the experience for others to see more clearly. The interpretation involved with this methodology requires deconstructing and reconstructing the experience or phenomena, thereby enabling the meaning of being human to be illuminated (Miles et al., 2013a).

Phenomenology is considered particularly useful when seeking to investigate how a specific group of people make meaning of a particular experience, and how they organise and understand their worlds based on their interpretation of that meaning (Merriam, 2009). As van Manen (2017) wrote, researchers using phenomenology "investigate the primal, eidetic, or inceptual meanings that are passed over in everyday life" (p. 812). Van Manen (1984) also wrote, phenomenological research, “makes us thoughtfully aware of the consequential in the inconsequential, the significant in the taken-for-granted” (p. 36).

Historical Background of Phenomenology

When using a phenomenological approach, it is important to provide an historical outline of the development of phenomenology as both a philosophy and a research methodology. Doing so acknowledges that this methodology has been used for centuries, essentially studying experiences or consciousness of experiences. However, it became more recognised as a method of research in the early 20th century in the works of Husserl, Heidegger, Sartre, Merleau-Ponty, and others (Stanford Encyclopedia of Philosophy, 2021). As a philosophical movement, phenomenology has its origins in ancient Greek philosophy but has more recently been used as a structured approach to research inquiry (Churchill & Wertz, 2015). It is agreed that the German philosopher Husserl (1859-1938) is considered the founder of the 20th century phenomenological movement and developed the concept of descriptive or transcendental phenomenology. He believed that human beings were subjects in a world of objects, and it was the study of the consciousness of those objects that he called phenomenology. Husserl assumed that all truths cannot be measured by a mathematical formula or tool without considering the subjective or personal experience (Hassan, 2015). He asked the question ‘What do we know?’ and, was able to describe a phenomenon as it was experienced. Husserl claimed that by describing how we perceive the world through our conscious awareness we can give meaning to our lived world experiences (Churchill & Wertz, 2015).

Husserl’s student, Martin Heidegger (1889-1976), also a German philosopher, differed philosophically from Husserl and developed a second philosophical stance of hermeneutic or interpretive phenomenology. Husserl subscribed to phenomenology being able to describe a phenomenon, while Heidegger believed that the aim of phenomenology was to uncover and understand the state of existence or the experience of being, rather than a mere description of a phenomenon. Heideggerian phenomenology, concerns itself with understanding meaning that is often hidden and, in doing so, uncovering the experience of *Being* or presence in the world (van Manen, 1990a). Although Heidegger (1962) stated that the concept of ‘Being’ is undefinable, he suggested a focus on everyday existence of people is necessary to explore the nature or meaning of a phenomenon. Heidegger was concerned from an ontological perspective with understanding how someone or something is situated in the world (Churchill & Wertz, 2015). That is, being mindful of where a person positions themselves in their world and how it is related to their understanding of their existence and human experiences or ‘being-in-the-world’ (Heidegger, 1962). It is this relationship between ‘being-in-the-world’ and our expression and interpretation of that experience that is central to Heidegger's thoughts on phenomenological inquiry (Hassan, 2015).

For Heidegger, the concept of 'being' is the state of existence or a state of *being in the experience.* By using the concept of '*being-with*' or '*being-alongside-the story*', interpretation is gained from not only the words spoken but also the silence, the deep sighs or the laughter (Horrigan-Kelly et al., 2016). According to Heidegger's (1962) interpretive phenomenological methodology of inquiry, the lived experience can be interpreted and explained when the *meaning* of the experience has been identified. This type of inquiry slows the researcher down and holds their gaze on the phenomenon itself.

Introduction to PIP

PIP sits comfortably beside phenomenology as a research methodology but is positioned slightly to one side of phenomenology. While PIP shares a lot of phenomenological philosophy, this methodology embraces and acknowledges the myriad of truths and the back and forward motion of being in the story. To ensure that one voice does not override any other voice, a deeply contemplative approach and a wide-lens view is required. As Vagle (2018) suggested, PIP represents the contextual, incomplete, and malleable truths of a phenomena that are in a constant state of becoming, production, and provocation. The interpretation of this statement suggests the meanings of a phenomena are divulged as material moves through the investigation process. The challenge lies in the need to be constantly reflexive of my own positionality (how I position myself in the world), perspectives, and insights (Vagle, 2018) which requires "the reflexive monitoring of the text in its production" (Macbeth, 2001, p. 43); or, in other words, as the meanings of the phenomena are turned into text, one must always be alert to changes, possibilities, and alternatives.

The notion that "phenomenology is a craft" (Vagle, 2018, p. xii-xiii), represents a further challenge of sitting in the PIP research space. To hone a craft takes trust, effort, dedication, and, most importantly, time. Vagle (2018) suggested that the crafting of post-intentional text and material will show a different perspective/shape/form with each rendition of the text, which implies that there is no checklist or 'how-to' manual for PIP; rather, a desperate need to "turn yourself over to the craft and see what comes of it" (Vagle, 2018, p. xiv). This is a challenge as it requires surrendering and, therefore, trusting in a process that seems to have no set path. It encourages me to step forward into something, not knowing what the something is or when I will arrive.

It could be assumed by this conjecture that PIP never eventuates in 'an answer' to the research question. If the end of a journey is not apparent, then how will I know when I have arrived? PIP encourages the researcher to sit in a place of ambiguity, suspending hard findings and solid truths (Vagle, 2018). This enigmatic sense allows reflection, self-critique, and vulnerability that enables the 'answer' to be found. The 'answer' is likely to be different every time it is sought and is dependent on who is seeking it and the context of the search. The end of the discovery journey is when the researcher (or other) catches a glimpse of meaning, purpose, and a sense of becoming more fully human (Vagle, 2018). Therefore, PIP offers a launchpad for the personal interpretation of the phenomenon. No prescribed or pre-determined ultimatum of what the correct answer is can be offered; rather, the potential for an individual to find their own revelations, their own 'knowing'. As van Manen (2001) suggested, "It is impossible… to construct a full interpretive description of some aspect of the lifeworld, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal" (p. 18).

While the theory of interpretative phenomenology has been used as 'scaffolding' for the current research, Mark Vagle, an American professor and researcher, takes phenomenology to a level that offers an even more insightful and reflexive space. Initially, Vagle based his work on phenomenological philosophers such as Husserl, Heidegger, and Merleau-Ponty, to name a few; and, more recently, notes the phenomenological ideas of van Manen. However, he believed that there was a need to expand these philosophies and methodologies to reflect a more fluid, contemplative, and open way of thinking. For instance, instead of using the word 'data' Vagle (2021) proposed the term 'PIP material' as this terminology reflects our ability to think very broadly and creatively about what constitutes the 'material' we work with in our inquiries. Whereas many phenomenological philosophers discuss the notion of bracketing as a way of checking the validity of the research (consciously separating the thoughts and assumptions of the researcher to sit outside the data [Janak, 2018]), Vagle (2018) viewed these concepts as lacking the acknowledgement of the 'knowing' of the researcher. By using post-reflexivity, the researcher's own thoughts and assumptions can add to the multiplicity of truths, remembering that this notion takes reflexivity to a more entangled and intertwined state. Reflexivity represents looking backward and deeply into what was/is in a phenomenon; whereas post reflexivity represents looking under, over, in-between, and around a phenomenon (Vagle, 2016). As Vagle (2018) suggested, this acknowledgement enables a more dynamic production of PIP material. It implies that seeing the 'truth' of this material is fluid and forever changing rather than only existing in the moment of interpretation. Vagle (2009) contended that it is in the researcher's intentional relationship with the phenomenon – not simply in the researcher, participants, text, in their power positions – but in the dynamic intentional relationships that tie participants, the researcher, the produced text, and their positionality together (2009).

Vagle (2018) recognised the commonly held view amongst many phenomenologists that the art of data interpretation lies in the "of-ness or in-ness" (p. 43) of that data. That is to state, that interpretation is reflective 'of-the-data' or the data 'sits-in-the-phenomenon', which implies that any interpretation of the data reflects the phenomena as described by the participants. Vagle, however, stated that the notion of 'through-ness' is more relevant to PIP, as reiterated by his philosophy of moving through the material as it ebbs and flows, as it shifts and changes, and reflects the ever-changing context. It is akin to seeing the material from the beginning perspective of analysis and then seeing it morph *through analysis.* As Vagle stated, this "signifies some salient, partial, fleeting, temporary, unstable intentional meanings that are constantly in states of production and provocation" (p. 45). The lived experience is highly relevant, but Vagle suggested that this is more static material whereas the phenomenon changes with any given context, cultural concept, or re-telling. This notion alludes to Vagle's suggestion that the phenomenon, itself, is in a constant state of becoming.

His conception of PIP takes the researcher into a space that shows "the dynamic intentional relationship that ties participants, the researcher, the context, broader social issues and matters, the produced texts and their positionalities together" (Vagle, 2018, p. 32). Remembering that intentionality is based on the relational space between people and is often considered something that cannot always be seen but may be able to be felt or sensed (Mulcahy, 2019). As PIP is inspired by post-structuralism (discards the idea of interpreting the world or a phenomenon within pre-established, socially constructed structures [Bensmaïa, 2005]), it breaks down powerful hierarchies and structures that have been constructed as conventions in qualitative research (Hong, 2019). As Hong (2019) noted, "this empowers researchers to explore and initiate discussions about phenomena, and especially those which have been restricted by research traditions and procedures researchers have felt methodologically constrained to follow" (p. 1). It implies that we purposefully and mindfully try *not* to reconcile the edges and margins of the theories that we use to support our interpretation (Vagle, 2018), which shows PIP's acceptance of conflicting and contradictory aspects in the dialogue and the interpretation, itself. The mismatching of these edges and margins is seen as a space for unrestricted questioning and pondering to flourish rather than avoiding these risks or forcing equality among different philosophies, theories, and ideas.

Vagle stated that PIP stands apart from other forms of phenomenology to include the social construction of phenomenon and recognises the influence of culture on experiencing and interpretation of phenomenon (Jones & Vagle, 2013). Previously, phenomenology was based on either an interpretation or a description of a particular phenomenon (Matua et al., 2015). Vagle (2019) suggested that the study of any chosen phenomena should be placed in the context that it is lived in, furthering stating that experiences are both personal and social; that is, phenomena are lived by the individual person.

The Journey Towards the Methodology

This study was guided by the methodology of PIP (Vagle, 2018). PIP reflects what has perhaps been hidden or forgotten and is only revealed to others in the re-telling. By weaving the context, memories, nuances, and meanings gained into a crafted story, a representation of each woman's journey of terminating her baby is presented.

As the researcher, intertwining includes my own lived experiences of caring for women during their termination. Together, the connections between researcher and the participant, or how we "find-ourselves-being-in-relation-with-others" (Vagle, 2018, p. 20), probes into what may not have yet been thought. This theoretical framework acknowledges and balances on the edge of the phenomenon's contextuality, multiplicity, and fluidity. PIP goes beneath what is obvious, looking for the experience of experiencing (de Mul, 2014).

Originally, the methodology of interpretative phenomenology was selected to be the foundation for this research. I felt that this methodology offered all the key elements of hearing the women's stories, making meaning of their experiences as well as being a reflexive modality. As a midwife caring for women having a TOP, it was of the utmost importance to be able to deeply immerse myself into the lived experiences of the women and see or even *see through* the story from their narratives. I have provided midwifery care to many families who have experienced the loss of their baby and I have witnessed their journeys of grief. Caring for them during these times has developed in me a deep appreciation for the unimaginable sorrow they feel when they greet and, at the same time, farewell their babies. I felt I needed to delve deeper into their experiences so I could 'be with' them in a more meaningful way and in a way that both honoured and respected them and their babies. There is the anticipation that midwives and other HCPs will also gain an understanding of this provision of care and the practice nuances that are involved.

To this end, the concept of an interpretative qualitative methodology was seen as an ideal conduit in the context of this research (Delve & Limpaecher, 2020). However, through discussion and guidance from my supervisors, the methodology of PIP was introduced. The desire to discover and appreciate the unfolding, the flowing, and the contextual movement of the phenomenological material was at the forefront of the rationale for selecting PIP as a methodology. In the context of PIP, phenomenological material is that which offers the researcher access to the phenomenon such as interviews, observations, anecdotes, historical analyses, and writings (Vagle, 2022). PIP reflects the direct inter-relatedness of the phenomena and the ever-changing context in which it sits and enables the flexibility of possibility.

However, at first, my loyalty lay with the familiarity and known-ness of interpretative phenomenology. The language spoken in interpretative phenomenology resonated with me and seemed to fit with my vision for the investigation of this research question. It felt comfortable, ‘known’, like an old friend. As with any introduction to ‘newness’, I pondered the possibilities for some time, reading, reflecting, talking, and delving within my own researcher’s heart. I was torn between staying with the familiar or stepping out into the wild blue yonder of research methodologies. I had witnessed bereaved families being ‘brave’ while enduring the loss of their babies, so I felt compelled to follow their lead. Perhaps the place that reflects bravery is also the place where their ‘truth’ resides. If I wanted to experience and understand their stories at a deeper level, then I needed to go to that place with faith and a deep sense of ‘trusting the process’.

My appreciation for the ability to situate the phenomenon of experiencing a TOP because of fetal abnormality into a contemporary context and align it with the social issues of lived experience, also guided me towards PIP. The social reality of this phenomena is seen as a vital component of PIP which is intent on looking at the social complexities, construction, and implications; and how these are reflected in society. As Vagle (2019) stated there is a fundamental assumption that PIP acknowledges that all phenomena are both personal and socially constructed. That is, phenomena are lived by individuals and are in a constant state of production through social interactions and relationships. This notion reflects the conscious or unconscious ‘entangled complexities’ of the lived, produced, and provoked experiences that the women in this research represent. The realisation of the potential of this methodology to lay bare this phenomenon offered such an intense opportunity of discovery that the decision was made to wholeheartedly commit to PIP.

As part of the methodological premise of PIP, the unsaid, unseen, and the even inconspicuous moments in the experiences are where the light of the phenomena resides. Vagle (2018) named this notion of ‘space’ as the ‘tentative manifestations’ of the PIP material. The in-between space of the narratives is where I can go beyond the given, beyond what is obvious, and where the jewels of understanding lie. PIP enabled me to move through the PIP phenomenological material towards a more insightful comprehension of what it is to have a TOP. The interpretation of the in-betweenness of meaning related to this methodology reflects Vagle’s (2018) concept of ‘tentative manifestations'. That looking for moments of surprise, of unexpectedness, of a misplaced statement, or even a time of revelation, reflects the concept of tentative manifestations. These could trigger a sense of concealment or what is truly felt or perceived is kept hidden.

Additionally, from a methodology perspective, the notion of 'tentative manifestations' (Vagle, 2018) as related to relationships or connectedness that are constantly able to change and morph into different versions of themselves, sparked my inquisitiveness. The possibility that 'truths' are fleeting, expanding, and able to entwine back on themselves, making new meanings as they flow is reflective of how Vagle (2018) described phenomenological research: "it is in a constant state of becoming" (p. 11). The implication is that the concept of truths or the taleteller's (the participant's) account of their experience can change or grow as it is investigated and there are likely to be multiple explanations or interpretations of their stories. PIP does not profess be able to identify the one and only truth of the women's stories'; rather, it assists in the understanding of the nuances of the story that presents itself in the here and now.

I wrote the following poem to explain how I approached the analysis of the phenomenological material:

How do I know that of another when I am the other?
Do I see their pain?
Do I feel their despair?
Do I hear their heartbreak?
Do I smell their anguish?
Do I taste their grief?
I imagine, I suppose, I venture, I explore.
I peel away and submerge myself into the gaps
I can fancy that I know, ponder what it means
Conjure up a feeling, get a sense of how it is
I succumb to the sensation, surrender as I must
Listening for what is not said, willing the words to let me in
Somewhere in the middlemost lies the possibility of knowing
The story is not mine, but I am desperate to follow
But I cannot know it all because I am the other

This poem gave rise to a visceral appreciation of the possibilities of PIP. Further reading and talking with other researchers who have utilised this methodology provided me with real resonance, and I found myself doing the 'phenomenological nod' as described by Nelms (2015). Recognition involved a suspension of disbelief of what the phenomenological material might be showing. It relates to the feeling of 'known-ness' with what has been written or spoken of. What I was hearing and reading 'rang-true' to me and gave me a sense of familiarity. It helped confirm the connection between what I thought I knew and what the theory of PIP research was implying.

Munhall (1994) suggested that phenomenological research methodologies provide a richness that reveals a full, embodied, multifaceted, multilayered, thoughtful, and sensitive insight into human experience. Additionally, it offers the possibility of moving those who consider research findings and enables them to release previously held preconceptions.

PIP showed relevance to the research question which related to 'the experience of women having a TOP'; so, the quest was to explore, uncover, and consider the 'becoming' of the experience and how it was interrelated to the women's meaning of the experience. Thus, the implication that the experience and the women's meaning of the experience are intimately interconnected.

Another concept that guides PIP centres around the researcher's post-reflexivity which involves the researcher regularly considering how they are positioned within the phenomena (Vagle, 2018). It requires that the researcher keeps looking inwards to keep sight of their own perspectives and insights, and their background regarding the phenomena. It should be acknowledged that the researcher's position or lens into the phenomena is highly contextual and for-ever-changing. Vagle (2018) goes further in the explanation of post-reflexivity by encouraging the researcher to "see what frames their seeing" (p. 15) or to reflect on how they see what they see.

Vagle (2018) stated the importance of this viewing of the phenomena by being constantly aware of the moments that we see; that is, those times that make us feel connected or disconnected or even shocked by what we observe. Further, the need to keep in our mind's eye, our beliefs, perceptions, perspectives, and opinions that we hold onto through our own experiences and thoughts. Finally, Vagle advised us to be aware and cognisant of our assumptions of normality, what we see as 'every-day-ness'. It "presses us to question our understandings, the traditions we are operating within, and the history we are launching from – while carefully examining the participant's experiences, the theories we chose to think with and the contexts at play" (Vagle, 2018, p. 155). This notion does not exclude the researcher's thoughts, experiences, or perceptions; instead, encourages these to be embraced, considered, reflected upon, and incorporated as part of the phenomena.

This approach towards the multiplicity of possibilities of PIP methodology and the material gathered sits squarely with me as I feel compelled to reflect on my own experiences of caring for women who have terminated their pregnancies. The need to be reflective, denotes a cornerstone of PIP and contributes to the inter-relatedness between the women's experiences and my own experiences as a midwife.

The concept of the 'fusion of horizons' reflects this *togetherness within the data* (Vagle, 2018). It is described as each person having their own horizon or view of an experience. In the context of the current study, the woman and myself, the researcher, have our own horizons or interpretation of an event. As a way of trying to understand another's experience of a phenomenon, we extend our own horizons to join or fuse with another. Our understandings or 'horizons' come together and rather than just one person 'knowing' a phenomenon, the insight is shared. In describing the fusion of horizons, Clark (2008) added,

> Understanding is the fusion of our past and present horizon. Indeed, the present cannot be formed without the past. Past and present cannot exist without each other, and understanding is always the fusion of these horizons supposedly existing by themselves. (pp. 58-59).

From a methodological construct, phenomenological researchers employ bracketing (deliberate putting aside one's own belief about the phenomenon under investigation or what one already knows about the subject [Chan et al., 2013]), but this seemed to miss the point of the intentionality of PIP. These experiences are what have fuelled my moving forward with this research. To have to completely side-line my own thoughts and feelings of this phenomena, would have potentially lost a side of the phenomena that helps me 'see' how it is for women, the embodiment of their experiences. PIP appeared to be an even better fit and it felt rich with possibility that would also enable me to reflect on my perceived known-ness and personally challenge my presumptions. Without this reflexivity, sitting within the women's narratives would, potentially, be less intimate and the 'unseen' may remain covered.

As part of my own journey toward PIP as a research methodology, I spent time remembering and reflecting on my own experiences caring for women who have experienced a TOP. Rather than dismissing these prior knowledge, assumptions, and beliefs, I was encouraged to "see what frames our seeing" (Vagle, 2018, p. 153). Doing so enabled me to recognise my assumptions rather than have them covertly direct me during the research. Thus, I could identify what I thought I knew already and what might, in fact, be yet revealed.

Bearing Witness as Part of PIP

The phrase ‘bearing witness’ seemed apt to describe my memories as well as a foundation of PIP. Bearing witness refers to sharing our experiences with others, most notably in the communication to others of traumatic experiences (Pikiewicz, 2013). Arman (2007) offered a similar notion that to be a witness is to “dare to meet the situation, to see and encounter the person, to confront the pain and to remain with it” (p. 89). Witnessing is seen as a concept and phenomenon that is connected to caring sciences and includes a human way of relating, a way of existing and a way of ‘being’ in the world (Bunkers, 2014; Heidegger, 1996). It involves listening to, writing about, and speaking of the stories heard, as if becoming a testament to another’s truth.

Arman (2007) suggested that bearing witness involves seeing suffering as a human experience and becoming aware of that person’s deepest needs and desires. Similarly, to bear witness could be seen as “standing in front of the other and saying, ‘here I am’” (Levinas & Nemo, 1985, p. 195); and, in doing so, seeing their vulnerability. Seeing and not avoiding the vulnerability of another, and being fully cognisant of the circumstances, could be acknowledged as a fundamental aspect of witnessing (Arman, 2007; Cody, 2001). Knowing and being with another person during times of challenge or suffering could be seen as a combination of both closeness and respect and, as Naef (2006) suggested, there is the opportunity for both to experience something beyond the experience, whatever that may be. This ‘something beyond’ could illuminate the phenomenological concept of intersubjective reflection or reflexivity that regards our vulnerability to the experiences of others by allowing us to move outside of ourselves into their world (Carter, 2014). This experience continues by turning back upon itself; thereby, enriching our encounter with the world.

Tait (2011) takes this point of view even further, suggesting that bearing witness is not the same as seeing something; it exceeds it. Carter (2014) expressed it as giving the witness a self-understanding that is, ironically, fraught with meaning; or, in other words, ‘thick with meaning’. The possibilities of bearing witness include a deeply personal yet shared experience of gained understanding and meaning that reflects “opening a window on the unknown” (Arman, 2007, p. 90). Parse (1998) proposed that *to witness* equates to a true presence; a notion enhanced by Raholm and Eriksson (2001) who illustrated that witnessing could enable the witness to be sensitive to the unspoken in encounters.

Sharing ourselves and our stories with others opens a place that may not have been previously recognised or experienced. It may involve facing the truth of the situation—its secrets, uncertainty and possibilities. While some stories are rawer than others, we all long for the benefit and necessity of a witness, for a witness assures us that our stories are heard, regarded, and contained. As Maya Angelou (2014), an American poet, suggested, “There is no greater agony as bearing an untold story inside of you”.

For women experiencing labour and birth when having a TOP for fetal abnormality, to have someone validate what happened, to also ‘see’ what they saw, and to attest to what they went through, is intimately associated with bearing witness. To witness the experience of being human *with* another could be seen as witnessing a phenomenon being ‘brought into the light’ (Heidegger, 1982). As the women experience the time before, during, and after the birth of their babies, they remember the moments—the deep sighs, the silences, the catching of the breath, the calling out—all testaments to their lived experiences. Dawes (2010) reflected on this experience as the ‘penetrating silence’ that is part of bearing witness. It implies that it is in the moments of silence, and in what is not said or ignored, that the meaning sits. What may be seen as indescribable or beyond words is now consciously seen, felt, and sensed. By acknowledging the fundamental human connections of *being with* and linking this relationship to bearing witness, those who witness can immerse themselves in the women’s experiences and offer new significance and meaning. This study considers the researcher’s immersion into the women’s stories that remain unwitnessed and not acknowledged.

Personal Reflection

This reflection speaks to the personal 'space' I find myself in when caring for a woman having a TOP. I offer this as a way of sharing my thoughts with the hope that other HCPs may recognise this.

From my experiences of caring for women who have terminated their pregnancies, I remember being in what felt like a ‘sacred bubble’; that is to say that I felt entwined in the woman’s world, a world that felt deeply attuned to ‘another place'. I was always conscious of the context of my midwifery clinical role, but this space felt different and somewhat hushed—not from a noise point of view but from an other-worldly sense. I struggle to describe what I feel is unnameable.

With the joining of both interpretative, qualitative phenomenological methodology and the nuances of PIP, a research pathway was established. In anticipation of hearing the stories that would be shared with me, combined with my lived experiences of caring for women who were having a TOP, this methodology would be able to meld these two sides of the phenomena into a deeper understanding of what it is to terminate a pregnancy because of fetal abnormalities.

Working with Supportive Theories

Along with the use of PIP as the research methodology, the current study was informed by the theoretical frameworks of the Meaning-Centred Grief Model (Dezelic et al., 2014; Wong, 2008), and an existential-phenomenological approach to understanding grief (Claspell, 1984; Madison, 2005). These added to the meaning-making of the research and supported the significance of the research material by offering a contextual path to understanding.

The Meaning-Centred Grief model can be seen as a way of discovering meaning in the moments that reflect the human experiences of despair, grief, trauma, tragedies, and difficulties (Dezelic et al., 2014). Having a framework that represents the ability to cope with difficult life situations, allowed for the theoretical consideration of the embodied existence of body, mind, and spirit. Wong (2008) stated that this meaning-centred model explores the deep structure of personal meanings that may be consciously or unconsciously recognised but are often difficult to verbalise. The model allows the phenomenological approach towards the lived experience to find the meanings attached to experiences consistent with the person's own perceptions, the context of the experience, and the memory journey of those experiences. While being immersed in the four women's narratives, the theory of the Meaning-Centred Grief model gives attention to the meaning the women place on their experience, as well as the researcher's own analysis.

Clapsell (1984), when considering the existential-phenomenological approach to research, stated that all experiences are interrelated and do not happen in isolation. That is to imply that we must strive to 'see' an experience as it presents itself rather than interpret an experience with rigidity and sharp edges. Reality sits within a complex web of variables, including, the environment (social, physical, cultural, emotional, spiritual); the memory of the experience; and the intimate interpretation of the experience by the one having the experience. Existential-phenomenological concepts often defy reason; instead, they consider the existence of possibility and what is seen rather than constructed through analysis (Embree, 1998). This implies that the methodology seeks to reveal the central meaning of what is being studied rather than the development of vague and nebulous notions regarding the phenomenon. Madison (2005) concluded that existentialism involves the embodiment or the interaction between the body and the experience that can either be consciously or unconsciously 'felt'. In other words, the atmosphere of the environment, rather than just the location, is *felt*. When others walk into a room their presence is *felt* often before they are even seen. Life's experiences are often sensed rather than concrete sensations like touch, sight, or sound. Existentialism offers an anchor to attach meaning, to give it a steady platform, and to offer purpose to experiences. This research is supported by these concepts and allows a deep and intimate understanding to 'being in the world'.

Methodology Rationale Related to Midwifery

Midwifery is underpinned by similar philosophical notions of PIP regarding shared experiences and ‘being-with’ women and their childbearing experiences (Miles et al., 2013a & b). This methodology, therefore, aligns well with midwifery, as well as other maternity services providers, as care provision involves a process of relating to and engaging with women. Midwifery and other maternity services are also based on the philosophy of care which involves the care provider being concerned with how the woman lives, her world, and those around her.

There is limited understanding of women’s experiences of ending their pregnancy because of fetal abnormality and how they find meaning of this lived experience. Given the dearth of understanding, using PIP is justified. Wilding and Whiteford (2005) suggested using a phenomenological research design can highlight “something that has received little attention and about which little is understood” (p. 100). Vagle (2018) supported this notion with the use of PIP and asks the question “What is it like to experience this phenomenon?” (p. 63).

As Parse (1998) suggested, human phenomena often share universal lived experiences such as joy, hope, sorrow, contentment, grieving, and suffering. To this end, Vagle (2018) reiterated that PIP is contemplative, endeavouring to capture the in-between-the-lines understandings of the experience of being human. Both the women’s and the researcher’s experiences do not occur in isolation but are intertwined into the humanness of each other’s lives. By accepting the fundamental human connections of being-in-the-world, I, the researcher, immerse myself in the women’s experiences so that I recognise that I am part of, not apart from, the women’s world or reality. The shared knowledge and experience between myself and the participants support Parse’s thoughts of ‘abiding with’ the participant and brings shared feelings and experiences to life.

As PIP attempts to understand aspects of a phenomenon as related to those who are likely to experience that phenomenon, then the experience of giving birth and midwifery have a likely connection. The shared knowledge and understanding gained from using PIP can help maternity health care workers (midwives, obstetricians, allied health practitioners) to improve practice and thus facilitate the needs of women experiencing this situation.

When asking women about their experience of giving birth during a TOP, the experiences of the women will be heard as their perception of the phenomenon and their awareness of what it felt like to be *them* during this time. In this study, the women’s personal and intimate embodied experience is sought.

PIP strives to ‘see’ something, even fleetingly as it recognises the exquisitely unique and sensitive experiences of the women. PIP is expected to be cognisant of the often hidden and subtle nuances of narrative, the explicit nature of a woman’s lifeworld, and the intensely personal meaning construction given to an experience. The significance of her ‘lived world’; the events, thoughts, memories, emotions, bodily awareness, embodied action, flow of time, the self, and relationships with others is discovered.

The method involves staying close to the women’s stories and staying true to the material “because it is the nearest you can get to the thing itself” (Miles et al., 2013b, p. 413). However, Willis (2001) suggested that things are not simply things; instead, they become things in the act of perception and naming. By naming or calling the experience ‘something’, the interpretation is again formed by all manner of influences like culture, social context, and even the memory of the experience.

PIP embraces the philosophy of interpretative phenomenology but elevates this methodology by acknowledging that the interpretative process is a never-ending or finalised process. PIP illustrates the fluctuation and fluidity of the interpretation of any material and allows both the participants and the researcher to capture their ‘truth’ in any given moment. The combination of meaning-making through the material, along with the multitude of realities or truths, is furnished by PIP in this study.

Besides the rationale for using PIP, the use of qualitative methodology is supported when describing the human experience from an individual’s viewpoint, and so is considered appropriate for this study (Mapp, 2008). Miles et al. (2013a) stated that qualitative research methodologies are increasingly being used to research midwifery practice and related topics. They suggested that this methodological paradigm gives maternity care providers insight into the stories of the women for who they provide maternity care and enables a more humanistic approach to that care provision. Also, given the scarcity of existing understanding and the deeply personal nature of the phenomenon of terminating a pregnancy for fetal abnormality, a qualitative methodology was proposed. The lens of this methodology is focused on finding deep meaning and understanding of the phenomenon as determined by those experiencing it.

Intentionality in Relation to PIP

While the word intentionality is explained as the plan or purpose for doing something, in the context of PIP, intentionality relates to the connection, relationship, or bond between things. It refers to the interconnectedness between human beings and their lifeworld where their attention and thought (consciousness) is always directed towards something (Matthews, 2006).

When considering 'consciousness' or 'to be in an experience', it is not related to how the world is objectively viewed but how the world is experienced and what that experience means (de-Vitry Smith, 2013). That is, by definition, related to the feature of consciousness, implying that a person is conscious 'of something'; and for us, as humans, that consciousness is of the world (Nelms, 2015).

Further, the concept of intentionality and how it relates to "how people are connected meaningfully with the things of the world" (Vagle, 2018, p. 28) resonated with me. Intentionality is seen as the connection between us and others in the world (Vagle et al., 2016) This concept of 'being-in-the-world' spoke to me about interconnectedness and the shared meanings of experiences.

Intentionality is both an epistemological and an ontological concept found in PIP methodology (Vagle, 2016). The place of intentionality lies in the interconnectedness between the material that represents the participant's knowing and the researcher's own knowing. It acknowledges the assumed reality of the researcher and the actual reality the participant. It is the relationship between *beings and be-ing* and how these interrelate to each other (Stainton-Rogers, 2006). According to Bryman (2008), epistemology is based on a theory or the nature of knowledge and what constitutes acceptable knowledge in a particular discipline. The woman's knowledge of the phenomenon is pivotal, and the researcher's knowledge adds to the combined knowing and understanding. Knowledge-as-understanding signifies knowing that comes with meaning-finding and is a result of reflective practice and an interconnectedness between the experience and the embodied understanding of that experience. Further, knowledge-as-being results after reflexivity and deep consideration of the gained knowledge. This knowledge enhances perceptiveness and provides pathic forms of understanding.

Lines of Flight

In conducting qualitative research, researchers are accepting of the idea of multiple realities instead of a single reality (Cresswell et al, 2007). Multiplicities within phenomena are connected while being moveable and dynamic; a meaning that originally is seen as a truth becomes open and contemplative with multiple connotations. Thus, instead of the embodied experience of a phenomena being bound, restrained, or having only one definitive meaning, there is the potential of multiple meanings. Vagle (2015) strongly endorsed the notion of the multiplicity of realities or meanings which he conceptualised as "lines of flight" (p. 604) or the dynamic and constantly "fleeing, eluding, flowing and leaking" (p. 604) of the stories and the meaning or 'truths' belonging to the stories. By these definitions, Vagle (2018) suggested that the intensities or complexities of phenomena are likely to "become, in and through phenomena" (p. 128). A line of flight implies phenomena are capable of “flowing and swelling” (Vagle, 2018, p. 129), indicating an ever-changing landscape of meaning. As Merleau-Ponty (1962) suggested meanings associated with phenomena are constantly being constructed, de-constructed, blurred, and disrupted. Again, the intentionality or interconnectedness of the stories is reflected in this notion.

Van Manen (1990a) also stated that intentionality is the “inseparable connectedness of the human being to the world” (p. 181). Even more pertinent, in relation to the current study, is Heidegger’s (1982) description of intentionality as being an embodied experience that is consciously related to a subject. Therefore, intentionality is not focused on the person experiencing the phenomena nor the experience; rather, the relationship between the two.

By entering into the middle of things, the multitude of layers of the phenomena and how things connect, rather than a superficial layer that defines only the ‘what things appear to be’, can be seen. PIP invites the researcher into the depths of things and enhances consciousness of the complexity of the phenomenon. In this way, intentionality means those in-between spaces where individuals find themselves-intentionally-in relations with others in the world. However, these in-between spaces are not objects that can be poked and prodded, nor can they be observed in the traditional sense. They must be philosophised—conceptualised, discussed, opened-up, and contemplated (Freeman & Vagle, 2013).

Considering the many definitions and understandings of ‘intentionality’, the possibility of gaining a deeper level of insight into the lived experiences of women terminating a pregnancy, has the potential to touch and transform both the woman telling her story and the person hearing or bearing witness to her story.

The Methodological Process of PIP

Component 1: Identify a PIP Phenomenon in Context(s) Around a Social Issue

To study an event in a woman’s life that has historically been silenced or hidden for generations (Jones et al., 2017) requires a deep level of immersion to be able to appreciate how the phenomenon manifests and appears in the ‘lifeworld’ or the world of human experience. As Todres et al (2007), suggest, "how we live in relation to time, space, body, others and mood is fundamental to describing the holistic context in which being human makes sense" (p. 60). To this end, the experience of terminating a pregnancy because of fetal abnormality sits immersed in the woman’s lifeworld.

To instil a deeper social acknowledgement of the phenomena of terminating a pregnancy, witnessing the unpacking of the deeply internalised and personal journey women have taken has the potential for social acceptance. As Brene Brown (2021) surmised, to help shame survive "it needs three things to grow exponentially: secrecy, silence and judgment" (p. 137).

Component 2: Devise a Clear Yet Feasible Process for Gathering Phenomenological Material

To gain an understanding of women's experiences of terminating a pregnancy because of fetal abnormalities using a PIP methodology, I needed to hear the stories from the women themselves. To this end, I interviewed women who had lived the experience, which offered me the women's own version of what happened using her words, memories, and interpretations. These one-on-one semi-structured interviews became the material from which the phenomena could be unpacked, uncovered, and understood.

Component 3: Make a Post Reflexion Plan

As Vagle (2018) suggested, exploring my own assumptions, thoughts, and reflections as I moved through the analytical process, added to the understanding of the phenomenon. By reflecting on both the women's experiences and my own clinical experiences, the overlaying of meaning became apparent. By superimposing both perspectives, the commonalities and, conversely, the unknown-ness of the experiences, were brought into focus. This reflective action happened before, during, and after the collection of the material and became a part of the analysis. I used a journal style of writing to capture what intrigued me, what made me stop and ponder, and undoubtably what made me challenge my previous thoughts. I frequently found myself re-reading what I had previously written and discovered a degree of superficialness in my insight. This realisation forced me to go back into the material, switch off my 'looking' brain and activate my 'knowing or feeling' brain. As Socrates said, "The only true wisdom is in knowing you know nothing" (www.goodreads.com, 2022).

Component 4: Explore the PIP Phenomenon Using Theory, Phenomenological Material and Post Reflexions

To obtain understanding and true insight implies that a deep appreciation of the nature and context of the phenomenon has been gained. While textbooks may provide a conceptual view of the experience of terminating a pregnancy, a deeper, holistic level of understanding required that I utilised an immersive approach. A woman having a TOP for fetal abnormalities in the second trimester of pregnancy has traditionally been cloistered away, both clinically and socially (Jones et al., 2017). To be able to understand this hiddenness, I was required to metaphorically walk amongst these women who have had the experience, to catch sight of what is seen, through their eyes; to hear the language used and to comprehend what is witnessed. Understanding this phenomenon also required seeking the unspoken, the covered up, and the in-betweenness of their experiences. The concept of in-betweenness describes the space between what the women openly talk about and what is implied but not directly stated. It offers parts of their stories that are uncovered, covered, and recovered, suggesting a toing and froing of meaning making within their stories (Sarroub, 2002). Together, the spoken and the implied meanings of the women's experiences offer a deeper, more rounded appreciation and understanding of the phenomenon. As suggested by Riegner (2014), regarding the in-between-space, "Just as in the structure of a musical melody, the intervals are equally as important as the notes" (p. 3).

Sitting with the theories that scaffold the analysis added to the clarity of the embodied experiences of the women. Along with post reflexions, the unfolding of the material into meaningful interpretations of the experience of terminating a pregnancy because of fetal abnormalities showed themselves.

Component 5: Craft a Text That Engages the Production and Provocations of the PIP in Context(s) Around a Social Issue

The crafting of the text was a culmination of the material collected from the interviews, my reflexive journals, as well as the foundational theories used. I incorporated a variety of text formats including an individual crafted story for each woman that was based on her verbatim interview transcript. It also included 'moments' and their interpretations that highlighted small, yet significant and meaningful, times within the women's stories that stood out. These were small verbal vignettes that provoked me to 'stop' in the text. My interpretations were based on my own understanding of what the woman was experiencing and focused on reading between the lines of the material. Finally, text that combined common pathways of meaning and involved bringing theories into play were produced.

Challenges Encountered Using PIP

As with any research methodology that is unfamiliar, it takes a considerable time of immersion to gain an in-depth understanding of its nuances and philosophical stance. It could be compared to walking into a darkened room, stepping cautiously with few points of reference. It has its benefits and challenges, as with anything that is, at first, unknown. Ironically, my understanding of PIP increased as I progressed into this darkened space, and it was because of the unknown that the known became visible.

The incorporation and reflexivity of my own knowing, as well as the women's experiences regarding the phenomena, has been a two-edged sword. These conjoined experiences became intertwined, inter-related, and enabled the 'seeing' of other's experiences along with my own, as if adding to the phenomena and the consciousness of the experience. Rather than my experiences (as the researcher) being the authoritative voice, this methodology encompassed both experiences and showed varying perspectives of the same phenomena. As Soule and Freeman (2019) suggested, "it is in this interconnectedness that the phenomenon appears" (p. 859). The experiences are shared from different perspectives that potentially enhance the meaning-making. However, the balancing of both my own and the women's stories often felt as if meaning and assumptions could have been muddled. My truth was based on my experiences, insights, and assumptions but do these sit alongside the women's experiences with a sense of reciprocity? If so, how do I know this? Vagle (2018) described phenomenology as "an encounter" (p. xii); one that may be barely noticeable or, conversely, deeply felt. He suggested that some "encounters are etched into our memories, our bodies, our beings, and our identities" (Vagle, 2018, p. xii) which resonated deeply for me and, perhaps, brought some reassurance that my own personal stories related to this phenomenon comfortably sat alongside the women's own stories. Not overshadowing them or being more relevant but a shared encounter that has been viewed from different perspectives.

Another challenge of using PIP as a research methodology sits with the notion that phenomenological understandings are elusive and abstract, forever changing, unfolding, and twisting. It infers that there is no 'real or final answer' to the research question that originated at the beginning of the journey. The challenge here reflects a seemingly never-ending piece of work, which I certainly experienced when sitting with the material. It was unclear where the 'end' of my interpretation lay. There were many times that I felt I had delved deeply into the narratives but equally as many times I felt that I had not even scratched the surface of meaning finding. Again, as Vagle (2018) reminded, "phenomenological research is in a constant state of becoming" (p. 11). The end is perhaps anywhere one wants it to be and to find the end is, itself, part of becoming.

The phenomenon of experiencing a TOP relates to "the ways in which we find ourselves being in relation to the world through our day-to-day living" (Vagle, 2014, p. 20). It implies that the same phenomena can impact differently on those who experience it. Part of the challenge of PIP was in the exploring of how each woman's experiences were different from my own or from the other women's experiences. The purpose of seeking out these differences was to more fully explore the phenomenon, to challenge my own biases and assumptions. However, while searching and exploring these depths, the challenge lay in the 'truth'. PIP states that there is more than one truth; therefore, when and how does the myriad of 'truths' reveal themselves? In other words, what is real and what is imagined or assumed? The concept of truth or the multitude of truths is seen as one of the more abstract challenges of PIP.

Chapter Summary

This chapter reviewed the broader research methodology of phenomenology and its foundation in this study, and considered both the theory of PIP, as it sits within phenomenological research methodologies, as well as how PIP sits within the phenomenon of a woman terminating her pregnancy because of fetal abnormality. It described the scaffolding of this research as well as the rationale for using PIP as the most appropriate methodology to answer the research question. A description of how PIP evolved into the chosen methodology for the research was offered. Details related to the theoretical frameworks that supported the study were outlined. Further, the methodological process of PIP was presented, as were PIP concepts that scaffolded the research methodology. The following chapter explicates the methods used in the study.

CHAPTER FOUR: METHODS

Introduction

This chapter describes the research methods employed to reveal the experiences of women who have had a TOP because of a diagnosis of fetal abnormality. First, the consultation process and engagement with advisors will be discussed. Second, the ethical considerations of the research will be discussed. Following, the details of the participants/women and their involvement in this research is provided and includes the measures used to preserve the rights of the participants, this research involves those who are considered vulnerable (Shaw et al., 2019). The process of collecting phenomenological material will be presented as well as information on the analysis of the material using Vagle's (2018) whole-part-whole method. This method is informed by Vagle's (2018) five-step process of material analysis. The concept of tentative manifestations (the inbetweenness in the data) will be represented, as well as the development of crafted stories. To complete this chapter, the challenges encountered are explored.

Consultation and Engagement

To ensure that the research participants were holistically considered and at the forefront of the study, advisors, who may be considered stakeholders, were approached. These advisors were independent of, but had an interest in, the aim of the research. Advisors were invited through networking, word-of-mouth, or professional networks. Each person was asked if they would agree to provide feedback on the research proposal, including the methods to be employed. They were also sent both the participants information sheet and the consent form (APPENDIX B & C). They responded individually about their thoughts and suggestions. The consultation process was carried out to ensure that I had covered all aspects of the issues related to preserving the rights of the participants and was initiated as soon as the participant documents were developed.

The consultation with the advisors positively impacted how I communicated with the women I interviewed in a culturally appropriate manner. Discussion with the advisors reinforced that the greatest sign of respect is to show a sincere interest in what is being said and to reflect generative listening skills. Midwifery demands this level of communication skills and being reminded by my peers helped me reflect on and evaluate my own skills which required a mindfulness and commitment to the aim of the research. This was a task I was ready for, and I was prepared to totally immerse myself in hearing the women's stories.

There was an appreciation from all advisors regarding the interview process as they felt it reflected a woman centred approach. This approach was seen in the focus given to meeting the woman’s needs, her expectations and her aspirations (Fahy, 2012). Additionally, all advisors agreed on the importance of seeing and hearing each woman as being unique. The gathering of material was seen as a chance for the women’s stories to be heard and honoured (Crepinsek et al., 2023). The advisors all believed that women having the ability to share their stories would be both empowering and woman centred; that is, to support the notion of the women owning their own narratives within the act of sharing their stories. It was suggested that the acknowledgment of each woman’s own knowing would enhance their sense of inclusion, connection and representation (Rezvani & Gordon, 2021). The following advisors offered their input:

- Māori Lead Maternity Carer (midwife) (Bay of Plenty)
- Māori research leader (Counties Manukau District Health Board)
- Māori midwifery Clinical Director (Counties Manukau District Health Board)
- Sands (NZ) Representative (past president & bereaved parent)
- Tauiwi (someone who does not identify as Māori; Moorfield, 2003-2022b) core and Lead Maternity Care midwives

The generosity of the advisors was appreciated, and their feedback deeply impacted the research. As examples of their feedback, the advisors acknowledged that, from their perspective, there was scant understanding of the topic. Their feedback encouraged me to stay committed to the research and to be resolute in the aims of the study. They also reiterated the vulnerability of the women and measures to be put in place to acknowledge their mana (defined as prestige, authority, control, status, spiritual power; Moorfield, 2003-2022a), and to also honour their stories. These comments resonated with me, and I reassessed the measures put in place to ensure that no harm would come to the women. These actions are expanded in the ethical considerations. While there was the possibility of emotional distress on the re-telling of their stories, I reviewed how I would respond and show support and empathy to the women if this were to occur.

Initially it was planned that the woman would be interviewed alone as it was presumed that having someone else present might alter their story, a notion supported by Taylor et al. (2021). Taylor's research into participant alone versus accompanied participant during the interview process revealed that having someone else accompany the person being interviewed may result in the interviewee being hesitant to disclose difficult feelings, emotions, and memories. It was suggested that interviewees may be concerned about upsetting those who attend the interview with them (Taylor et al., 2021). However, after discussion with the advisors, it was suggested that women may feel less vulnerable if they had the option of being accompanied by a known support person with them during the interview. If their stories were potentially altered, then these were still their stories and should be seen as valid and relevant as any other version of their story. This notion was particularly supported by the Māori advisors and was seen as reflecting a culturally safe approach. From this suggestion, the women were reassured that they were welcome to have a support person attend, if preferred.

Researcher's Reflection

This reflection developed from sitting in the space of my own worldview. It is through the process of reflection that I evaluated my own concept of how stories are owned and told.

My assumptions regarding the possible impact of participants having someone accompany them during the interviews (or not) could be seen as, initially, a euro-centric view of sharing a story. My unintentional but naive rationale was that I did not want their stories to be watered down or even 'contaminated' by others being present. The focus was on a somewhat narrow-minded overview of the story being told by not acknowledging that the woman telling the story had complete ownership of what she said and how she said it. The woman's interpretation of what she experienced was of the highest importance and whether she described it this way or that, then so be it. It is her remembering that I was keen to capture, not my version of her story (alone in her telling without any outside influences). I also reflected that each time a woman shares her story the content is likely to change over time and with each re-telling. These changes do not undermine her story but reflect the ebb and flow of her thoughts and memories of what she experienced. What comes to her mind during her recounting her story is as important as any other time she tells it. The authenticity of their stories remains solid because *it is her story.*

Ethical Considerations

Ethics approval for the research (21/102) was granted by Auckland University of Technology Ethics Committee (AUTEC) on 14th June 2021.

Selection of Participants

Although the experience of a TOP involves other family members, the embodied and experience of women was seen as the critical issue in this study.

The loss of a baby is not specific to women or people who are heterosexual as it can happen to any pregnant person. It is recognised that identifying as female is not a pre-requisite to pregnancy and birth. Birthing people who identify as transgender or non-binary are not immune to experiencing the loss of a pregnancy and/or baby. Many agree that the loss of a pregnancy/baby is one of the most devastating events a person can experience (Furtado-Eraso et al., 2021; Jones et al., 2017b; Riggs et al., 2020). The participants were not asked to identify their gender during the selection process.

Additionally, while the data were to reflect the women's stories, the accounts and findings of this study are likely to impact on partners and other family members of women experiencing a

TOP. It is also likely that this study may inform and guide future studies of partners and other family members.

Originally, the participant sample size was fluid, depending on the number of people who came forward to be included in this study. The number of women who were willing to partake was small. In total, four women were recruited. All women meet the inclusion criteria, except for one who was pregnant at the planned time of the interview. Following discussion with the woman and my supervisors, the exclusion criteria was re-considered and altered. The woman herself was keen to be interviewed and stated that remembering the loss of her baby would not cause her undue distress. She also stated that she was very keen to share her story to add to the knowledge of the experience of terminating a pregnancy as she felt her experience was veiled in silence and taboo.

Recruitment Numbers and Justification for Sample Size

Although the final number of participants was small in quantity, the data collected were in-depth, reflective of their experiences and offered intense insights into their terminations. Malterud et al. (2015) commented on sample sizes for qualitative research and suggested the number of participants should be reflected in the aim of the study which was to provide a greater understanding of the experiences of women terminating their pregnancy in the second trimester for fetal abnormality. However, the final number of participants was limited to the number of women who chose to participate. On reflection, the highly sensitive and personal experiences of women who have had a TOP may have hindered them feeling comfortable reliving and sharing their experiences. Deeply unpacking the small quantity of rich material would meet the aim of the research.

As every woman’s experience was unique, I was mindful of how many women would be considered the ‘correct’ number of participants. Malterud et al. (2015) stated that the “data quality and variability of relevant events are often more important than the number of participants” (p. 1759). Again, the four women who were interviewed in this study provided such detailed and unique stories, they enabled me to gain a greater understanding of the experience. Malterud et al. (2015), presented using the concept of “information power” (p. 1753) as a guide to the appropriate sample size. It implies that the more information the sample holds, relevant for the actual study, the lower number of participants is needed. In other words, the richness of the data was more relevant than the number of participants. Reflecting on this notion, I concluded that the depth and relevance of the material collected during the interviews would equate to the concept of information power. As Malterud et al. (2015), reiterated, if the participants are highly specific for the research aim, the aim is supported by contemporary theory, if the interview dialogue is comprehensive, and there is in-depth exploration of the narratives, then the number of participants can legitimately be small. These four particulars have been reflected in the study, making meaningful engagement with the data possible. Participant recruitment was initially planned through networking with other bereavement midwives throughout Aotearoa New Zealand and word-of-mouth. Interestingly, one bereavement midwife asked if the midwife involved in the women's care would be identified in the study, highlighting the possibility that the midwives may be somewhat reserved in referring women to the study as it may appear to involve evaluation of their practice as the known midwife (Armour et al., [2018], Armour et al., [2020]. It was explained to the midwife that no details of the clinical team would be collected, documented, or named. It was reiterated that geographical location of the termination or the birthing facility that the woman attended would not be identified. This comment, however, did cause me to pause and reflect on how I had worded my approach to them.

Participant Recruitment

Contact was made with office holders at the Pregnancy, Baby and Infant Loss Support Group (formerly known as Stillbirth and Newborn Death Support [Sands NZ]). The recruitment announcement was discussed, and Sands (NZ) felt comfortable writing a statement for their social media platform that included a summary of the study and my email address so women who may be interested in participating could contact me (see Appendix B). Consequently, four women approached me, interested in participating in the study. Two other women emailed me stating that they were interested in finding out more about participating but did not reply to my return emails, so no further contact was made with them. It was important to enable the women to lead any contact with me as I was conscious of the sensitivity of them sharing their stories with me.

Once contact with each woman had been made (by the woman, herself), there was a discussion that included the aims of the study, the inclusion and exclusion criteria, the woman's right to withdraw at any time, the confidentiality measures, the data collection method, and answering any questions she may have. Then, with their agreement, the Participant Information Sheet and the Participant Consent (APPENDIX B & C) forms were sent to them electronically. A tentative date was suggested by the women based on their availability. Once they felt they had had enough time to read and consider the documents I had sent them, we confirmed the interview date, and I answered any further questions they may have had. Each woman completed the consent form and emailed it back to me, prior to the interview. Immediately before the interview took place, consent was verbally obtained, adding to the written consent that had been completed prior to the interview.

Overview of Participants

Participants were women aged 20 years or older. The age inclusion criterion was guided by studies that suggest that women younger than 20 years of age may have a different perception of their lived experience of and response to the loss of a baby through a TOP, than those of older women (Czukas, 2020; Webb, 2017). It is suggested that there are a multitude of age-specific challenges that are unique to younger women. This notion, however, leads to the importance of understanding the meaning of the loss of a baby via termination of pregnancy for younger women under the age of 20 years; an area of research that should be considered.

Women were invited to be included in the current study if they had experienced their TOP within the last 5-years. In recent years the increased awareness of holistic impact of terminating a pregnancy because of fetal abnormalities has become apparent (Heaney et al., 2022; Jones et al., 2017b). There is greater acknowledgement of women's lived experiences of this phenomena, internationally, and it is suggested that regardless of a woman's birth experience she is likely to retain a very vivid and accurate remembering of the experience (Jones et al., 2017a). Also, women who experienced the loss of their baby in the more distant past are more likely to have experienced a different maternity environment than those of more recent times (Ngan, 2017).

Study participants were required to be fluent in English to ensure that the context and meaning of their stories were reflected accurately as the data were analysed. French philosopher Ricoeur (1913-2005) stated, "whatever understanding comes to us it comes in and through our use of language to talk about our lived experience" (Pellauer & Dauenhauer, 2022). While this inclusion criterion may have excluded important multi-cultural perspectives, the risk of misinterpretation that could lead to misrepresentation of the woman's story was of importance. Also, understanding the informed decision and consent giving aspects of this research was considered pivotal in the preservation of the rights of any potential participant, especially considering the sensitive nature of the research. Although these ethical processes were offered in both verbal and written form, it was critical that the woman was fully cognisant of what she was embarking on. While translators may have been a possibility, I felt that the nuances of the woman's story may be missed or misconstrued via translation.

Part of the participant profile was that the woman lived in Aotearoa New Zealand, and she had the TOP in this country. Aotearoa New Zealand has a unique maternity care model relative to many models of maternity care throughout the world (Dawson et al., 2019; Grigg & Tracy, 2013). The cornerstone of this model of care is the concept of continuity of care/carer which allows for the care by a known midwife. This level of partnership between the woman and her caregiver reflects a woman/whānau-centred approach that is recognised as being the gold standard of maternity care around the world (Dawson et al., 2019) and implies that the maternity outcomes for women are better holistically rather than just clinically (Dawson et al., 2019). Considering these issues, this study was designed to consider women's experiences in an Aotearoa New Zealand context of care. However, future comparative studies may highlight the impact of different care models for women while having a TOP.

The gestational age of the woman's pregnancy was seen as an important aspect of the participant criteria and the guide age was between 14 and 28 weeks gestation (second trimester). This gestational range is the more common time that a woman is offered a TOP because of fetal abnormality (Abortion Services in New Zealand, n.d.). Firstly, the diagnosis of fetal abnormality is often only known from 12 weeks of pregnancy and, secondly, in Aotearoa New Zealand, a medical abortion (termination) involves the induction of labour and consequent birth of the fetus. This clinical issue is specifically relevant to the current research.

All four recruited women appeared to identify as cis-gendered, although this was not confirmed by the participants.

At the beginning of the research, it was anticipated that recruitment would include women from a wide range of ethnic and cultural backgrounds. As it transpired, all the women who were recruited identified themselves as Aotearoa New Zealand European, so the participants did not represent a cross-section of women living in Aotearoa New Zealand. It would have been ideal to be able to recruit women from other backgrounds to gain a wider, cultural perspective but that may be the focus of future research. It can only be assumed that women from other ethnic groups either did not feel comfortable sharing their stories or the recruitment process (via Sands NZ) did not reach women of a wider cultural background. There is also the possibility that recruiting midwives felt unsure of approaching some women because of an assumed cultural inappropriateness regarding discussing their loss (Cronin et al, 2018). See Appendix D for the full participant inclusion and exclusion criteria.

Preserving the Rights of Participants and Creating a Safe Space

Preserving the rights of the women was ethically important to ensure those who were most vulnerable were respected, acknowledged, and felt safe to participate (Shaw et al., 2019). My supervisors discussed, guided, and confirmed the appropriateness of the details of my research project, especially regarding the participation information sheet (Appendix B) and the participant consent form (Appendix C). Guidance on preserving the rights of the participants was also gained from Auckland University of Technology's (AUT) research policies (AUT, n.d.) As per research protocol, all documents were submitted to the AUT Ethics Committee during the ethics approval process. Ethics approval number 21/102 (See APPENDIX F).

Clarifying continuing consent and the option for the woman to halt any involvement in the research process added to a sense of trust. I always behaved in a professional and respectful manner which supported the women's confidence. Partnership was acknowledged and by respectful agreement of location and timing of interview and the woman's comfort in sharing her story.

Six issues were considered to ensure the preserving of participants' rights. These were: emotional, spiritual, cultural issues; as well as protection from deceit, harm and coercion, confidentiality and privacy.

Emotional.

When a research participant is required to recall or remember a sensitive or emotionally sensitive topic, they are particularly vulnerable (Seedat et al, 2004). The women took an emotional risk remembering the loss of their baby. Their experiences and memories were likely to be emotionally laden and reignite feelings of sadness, grief and loss. It was anticipated that the experience of being interviewed would offer the women a sense of being heard rather than opening old wounds (Seedat et al., 2004). Supporting the women to be self-determined regarding what they disclosed during the interview reduced the emotional risk associated with reliving the experience and memories and was discussed at the very first contact with the women as well as at the beginning of the interview process. Each woman was asked if she felt comfortable sharing her story and was encouraged to only share what she felt happy doing so. Some women stated that they had not shared their experience with anyone else other than those who supported them through the labour and birth. The risk of being stigmatised or even rejected or condemned by their friends and families was very real, as was the associated risk of being exposed. A deep sense of trust that no identifying information would be divulged was paramount in the participant-researcher relationship (Newton, 2016).

To safeguard the women every precaution was taken to preserve their rights and welfare. I was aware that if the interview process became too onerous for the women they would be supported to choose to pause or cease the interview or remove themselves from the research. This did not occur with any of the women. Often the women shed tears during their interviews as they recalled their experiences, and I offered a moment of remembrance and a pause in the conversation. All the women seemed comfortable to share their emotions and appeared to appreciate a pause for reflection.

It was important not to assume a woman's potential vulnerability as this could only be measured by the women, themselves. Assuming vulnerability may have undermined the women's autonomy and diminish her authentic self. A safe and private environment for the interview to take place was determined by each woman. During the interviews, no overly intrusive line of questioning or insensitive probing was utilised. To minimise the risk of emotional harm, the interviews were conducted by myself, an experienced bereavement midwife. My midwifery experience hopefully offered an unspoken 'comfort' to the participants as I was cognisant of and familiar with the clinical aspects of the women's stories, as well as the expression of grief that often accompanies the re-living of such experiences. Further emotional support or reduction of the risk of emotional harm, both the inclusion and exclusion criteria, were enacted as these specifically related to the potential participants' vulnerabilities. The women may have felt at risk of being morally judged for their decision to end their pregnancy. This issue was addressed on the participants information sheet and reflected my non-judgemental attitude.

As all the women expressed their sadness and remembered feelings of their terminations I enquired about their emotional well-being during and after the interviews. All the women reported that they felt comfortable recalling their experiences.

To acknowledge and safeguard any potential vulnerability of the women, they were offered post-interview support through recognised support agencies in the community, namely, Sands (NZ) and Perinatal Anxiety & Depression Aotearoa (PADA). The four women who consented to participating in this research, were all part of the bereaved parents support group Sands (NZ), therefore had this support service known and available to them.

Spiritual.

By reconnecting with their memories of loss, the women were likely to re-join their own personal journey of finding meaning in their experiences (Neimeyer, 2011). For some, this may have offered them further self-discovery or growth; while for others, their grief may have been re-ignited. To support women spirituality, it was important to support the use karakia, prayer, lighting of a candle, or some other spiritual ritual to acknowledge and support the recounting of their stories. The specific action was determined by the women and whole-heartedly supported by me. Adequate time to acknowledge and respect these special moments was a high priority during the interview process. All four women chose to quietly remember their babies and bring their memories to the front of their minds. It was apparent by their tone of voice and demeanour that they were very mindful of their babies as we began the interviews.

Cultural.

Prior to the interview taking place, the women were asked if there were any cultural considerations that should be acknowledged regarding the interview process. For example, each woman was asked if there were any rituals or ceremonies they would like to uphold. Each woman chose to orientate their baby into the context of their current lives as a way of setting the scene for the conversation that was to follow. For all the women, this was represented by them introducing their baby by name and telling me how long ago their baby had died; followed by stating where in the family their baby fitted by describing any siblings born prior or after their baby's death.

The social context of the participants was acknowledged and respected. For example, the location of the woman at the time of the interview (e.g., at home in the lounge), what was happening in her life on that day, and how it was for her to feel 'ready' to talk with me.

Cultural discomfort was possible especially for women whose cultural norms did not necessarily support sharing experiences of death or dying. There was the potential for the women to feel a sense of cultural shame for making the decision to end their pregnancy (Jones et al., 2017a). However, the act of telling their stories, allowed for connection between the woman and myself. Stories convey the culture, history, and values that unite people and potentially brings new meaning to the storyteller and deeper insight to the listener (Stevenson, 2018). There was immense possibility for this connection and engagement in another's lived experience to reflect the concept of mutual respect, autonomy, and ownership of the story. This possibility was seen as reflecting a culturally sensitive approach to what may have been a vulnerable experience for the women. The women were reminded that they were able to have a support person with them during their storytelling. Also, the appropriateness of the location/timing of the interview was paramount and based on each woman's choice.

The participants were treated with the utmost dignity and their cultural comfort was attended to. Each woman's unique way of reflecting her own cultural norms was highly valued and acknowledged. The women selected the location of their interviews, reflecting of her feelings of cultural safety.

Harm and coercion.

Regarding the issue of harm, a comprehensive participant information sheet that outlined the rationale and the process of collecting and analysing data was provided. The women's privacy was protected by formal confidentiality agreements for transcriptionists (Appendix F), thus ensuring any breaches of privacy were avoided. The risk of harm was also avoided by ensuring that the data would only be accessible by those directly connected with the data (researcher, researcher supervisors). The facilitation of ample time to answer any questions the women may have had and the accompanying discussion regarding the research would also avoid any risk of harm or coercion as all communication was clear, truthful, and unbiased. Each woman was informed that they could withdraw from participation without consequence up until analysis of data commenced. This meant that the voluntary nature of the study was emphasised and addressed any possible coercion experienced by the women.

To acknowledge the potential for psychological harm, the women were offered contact details and resources to access psychological support as required. They were offered 'breathing space' or the opportunity to have a break during the interview if they felt that they would benefit from a pause in the interview. To address any possible on-going distress experienced by the women, they were offered the cessation of the interview if seen as appropriate. It was acknowledged and expected that the nature of the interview topic and the associated questions would potentially pre-dispose the women to a level of emotional distress. The experiences and memories of the women were likely to be emotionally ladened and to inspire feelings of sadness, grief, and loss. However, any existing and/or acute emotional vulnerabilities were considered a risk of putting the participant in harm's way. To support each woman's autonomy and self-determination, if the potential risk of harm was identified, it would have been discussed with the woman and we would then have come to an appropriate decision regarding risk-management. This was not the case with any of the women.

Another plan for the reduction in the risk of coercion of any potential participant, was that I would not make the initial contact, but contact would be initiated by any woman via the Sands (NZ) Facebook page that provided my contact details. It was important that there was careful consideration of ethical principles that govern properly conducted research when researching a potentially vulnerable participant group.

The interviews prompted women to relive and remember the loss of their baby. Therefore, my relationship with the participant needed to be trusting and as comfortable as possible. I tried to put the women at ease by reassuring them of my role and the intention of the interview. By showing continued empathy for their loss, I endeavoured to develop a deeper level of rapport with the women.

Confidentiality.

The stories the women shared reflected the notion of trust and confidentiality between the two of us. Sharing was guided by mutual respect, the intention of the research, and the dignity of both the woman and me, as well as the woman's story. I acknowledged the uniqueness of each woman and her personal story. Honouring the diversity of both the woman and the researcher is a priority in the researcher-participant relationship (Newton, 2016). The women were supported to act in an autonomous manner and have self-determination with what they chose to share with me.

By adhering to the strict management of data and identification of each woman, any potential risk of breaching confidentiality or privacy was managed. These protocols addressed any potential harm to the women through disclosure or personal identification. (See APPENDIX G)

Privacy.

By coming together in a safe and impartial environment, the women were able to share their memories of their labour and birth. It was an uninterrupted and respectful situation facilitated by both the woman and me. The interviews took place in a private venue that allowed freedom of expression. All interviews were conducted during the daytime and the women were in their own homes. By meeting in a location that feels safe for the participant, trust and positive regard can be shared between participant and researcher (Newton, 2016).

Privacy (about the woman) included:

- Use of pseudonyms to protect the woman's (and her baby's) identity. Only one woman requested the use of a pseudonym. The other three women chose to use their own names and the names of their babies.
- Signed agreement by transcriptionist of interviews to not disclose any information gathered from transcribing the interviews was completed and the document stored securely. The transcriptionist was very experienced and aware of the need for strict privacy (APPENDIX E).
- The timing of the interviews and the location was determined by the women to ensure their availability did not compromise their privacy. All the women chose to do their interviews during the day.
- The recruitment process meant that any potential participant determined the initiation of contact with me, therefore, ensuring no invasion of privacy. My contact details were published on the Sands (NZ) Facebook page.
- During the interviews no overly intrusive line of questioning or insensitive probing was utilised to ensure that the women had ultimate control over what they chose to share.

Confidentiality (about the data):

- The only personal data that were collected was to ensure the inclusion/exclusion criteria were met and transcripts could be returned to the participant, if required.
- Confidentiality was addressed with the women during the initial contact, prior to the interview, and again after the interview as appropriate.
- Confidentiality was addressed during 'data cleaning'. To ensure a clean data set, I removed any identifying information (e.g., age, geographical location, names, etc.)

- To reduce the risk of deductive disclosure, the analysis of the material and final findings of the research has no identifiable context (e.g., date of TOP, location of TOP)
- The transcribed interviews and signed consent forms have been stored on a safe storage cloud (Teams). Hard copies of the consent forms have been securely stored in the Midwifery Department, AUT Manukau Campus, Auckland, Aotearoa New Zealand.
- The women were not obliged to answer any question or share any information that may have caused them extreme distress.
- Each woman had access to the transcript of their interview which enabled them to confirm and/or clarify any issues. None of the women requested a copy of their interview transcripts.

Gathering the Phenomenological Material

Once purposive recruitment had taken place to identify women who had experienced a medical TOP and consented to participate, interview times were organised. On the day of each interview, consent was again confirmed with each woman. The interviews were conducted via Zoom as COVID-19 restrictions were still in place and this method of communication was chosen by each woman. It was confirmed with each woman, prior to the interview, that she was familiar with the Zoom platform and that she did not have any accessibility issues with the internet. Each interview was recorded, with the participant's awareness and consent. Introductions were made as this was the first face-to-face (Zoom) meeting between me and the woman. Before the interviews began a welcoming ritual (as determined by the woman) took place to acknowledge their participation, story, and the research aim. For all four women, this ritual consisted of a moment of reflection on their baby, what their baby's name was, how old their baby would be now, and a heart-felt physical description of their baby (e.g., "looked just like his sister, really long feet"). I ensured that each woman felt comfortable with proceeding and that she had everything she needed by asking: "Have you got everything you need with you, or do you need to collect anything?" (e.g., glass of water, etc.).

Only one woman asked to be de-identified and offered a name for herself that she would be comfortable using. She did not feel the need to de-identify her baby. The other three women declined to 're-name' themselves or their babies. As one woman stated, "I want the world to know my story, finally, so I chose to be who I am!" Once each woman indicated that she was ready to start the interview, I asked a broad opening question to elicit the participant's personal narrative (Louw et al., n.d.): "Are you able to tell me about your pregnancy journey that ultimately ended in you experiencing the loss of your baby?" As required, the following question was used to highlight the birthing experience for each woman: "Are you able to tell me about your experience of labour and the birth of your baby?"

Hearing the Women’s Stories

The women were not given any direction as to where they should start their story; rather, it was left to them to start their story where they felt comfortable. Using the word ‘journey’ in the initial question represented this notion of ‘the travelling through her story’ and implied that the journey was indeed ‘hers’. I internally acknowledged that each woman would have pre-thought what she wanted to say prior to the interview, and it was gauged to be ‘what was on top’ for the woman (Louw et al., n.d.). Qualitative researchers have noted that usually very little prompting is required when a participant is asked to recall their own experiences and this certainly was confirmed for the women in the study (Louw et al., n.d.) Occasionally, however, encouraging questions were used, as appropriate, to facilitate clarification of the woman’s story. For example, “Are you able to tell me how that made you feel?” “I wonder if you could possibly expand on that a little more?” “Would you feel comfortable telling me how that was for you?” My responses included affirming sounds, gestures, and comments to offer support and encouragement. This communication was also used to confirm that I was actively listening and engaged in what the woman was saying (Louw et al., n.d.). During each interview I monitored the woman’s emotional responses and well-being. If she showed a sense of becoming overwhelmed with what she was sharing, I encouraged her to take a breather, pause, and gather her thoughts. Once the woman felt able to continue, she did so. In the event of a participant becoming extremely upset (enough to potentially harm herself) I had planned to call 111 to get immediate help. This did not occur, and all women remained emotionally stable throughout the interviews (albeit emotional with the re-telling of their stories).

Once each woman felt she had told her story and had nothing more she would like to add, the interview was concluded. To bring the interview to a natural end, I acknowledged her story and thanked her again for her willingness to share such a personal event in her life. Before ending the Zoom meeting, I enquired about how the woman was feeling and offered her some quiet time while still on the Zoom meeting to ‘come back to the now’ (van Der Kolk, 2015). Each woman was reminded of the on-going support available to her, if required. They were also reminded that they were able to read the transcribed interview, if they would like. The women were also offered a copy of their ‘crafted story’ that I created as part of the thesis. Each woman accepted this offer. A koha or gift of gratitude was sent to each of the woman as an acknowledgement of the gift of their stories.

A reflective journal was used to capture thoughts, concepts that came to me while pondering data, as well as reflecting on the phenomenological process. The journals also recorded my own assumptions and the unfolding ideas around my ‘sitting with the material’. I was able to reflect on my own experiences and challenge myself to see past these or, conversely, see more deeply into my own clinical understandings. Through this reflective process I realised that my experience of this phenomena is one thing, but the depth of understanding or 'wisdom' comes from *reflecting on the experience*. In other words, just having an experience does not imply wisdom but it is the reflective process that is vital for adding to my knowing. As Choi (n.d.), suggested, "keeping reflective journals consciously acknowledges the values and experiences of the researchers rather than attempting to control their values through methods" (p. 1). These data sat beside the narrative material and added to the analytical process. Examples from my reflective journalling are given below:

19 Jan 2022 - After an Interview

I had another interview today. I was less nervous today but had a sense of trepidation that she wouldn't feel comfortable enough to share her story with me. She thought she would find this experience cathartic. She stated that she has not talked to a lot of people about her story as she wondered if others aren't interested or find the discussion as uncomfortable. She wondered if others see her story as something "to get over". She lost her daughter 2 years ago because of a serious and rare heart condition. The look on her face as she recalls the experience is one of real sadness and some self-doubt. There may be some shame in her body language, also. I'm not sure... Her baby would potentially have survived but she made the decision to interrupt the pregnancy. She made the decision based on 3 factors; their daughter and how it may affect her life having a sibling that had chronic health issues, their relationship being put under strain, and the challenges the child may face. All I could see was a woman who decided because of the love of others… not the disappointment or distaste of having a child challenged with its health. This decision wasn't easier or less traumatic but rather was equally as hard as any other TOP decision. She related that there was minimal "guidance", either from the health professionals or literature as the condition was considered rare. Would having more guidance or literature have made the decision easier? She did say that she would have liked someone to tell them what to do but of course, this would never happen. Perhaps this is a tension in the concept of informed decision making as they didn't feel informed but were required to decide anyway. How does that sit within the "*informed*" part of this. How did they make the decision? At the end of the interview, she shared her sense of regret. One thing she said was very interesting: her husband asked her recently if she ever thinks of the baby they lost. She reported that she thinks of her daughter many, many times a day. She wondered why he didn't.

These interviews are confronting - half of me feels sadness and the other half feels excited. Is that bad that I am excited hearing their stories? I think of what they have gone through, but I also think of the data that have been gifted to me and the possible insight it may offer me.

How did she decide what to tell me or how did she decide what *version* of her story she would share? Did she decide in the moment... whatever came to mind, whatever she became aware of as a memory...Did being listened to alter what she said or how she said it or even the words she used in her story telling? What did she choose not to tell me? How did being *heard* feel for her?

11 Jan 2022 - From My Midwifery Practice

I shed a tear today, which is unlike me. This was an induction of labour for fetal abnormality. My tears represented the pain of witnessing such a tragic loss and the indescribable brokenness the parent's felt. How could you not have an emotional response to the father's comments: "This is so crazy, what's happening, are you sure this is real?" The mother told me, before labour began, that she was scared. She was unsure what she feared, but she was physically shaking. Perhaps the "place" these parents landed is a similar place to where all parents who lose a baby "land". A desert of barren lands, desolate and empty. No shelter from the elements, no safe harbour, just mile after mile of stark landscape in front of them. It seems to me that the grief of losing a baby reflects the weight of the world on their shoulders. The parents expressed the same devastation, the same overwhelmed sense of loss, the same disbelief that all bereaved parents express. Why does this happen to some families? How is this fair?

How did I settle her fear? Or even, could I settle her fear? I responded to her statement with "I'm here with you and I am not going anywhere... I've got you, you are safe".

Am I OK? Yes, I am. The tears were in private, and they allowed me to feel the emotions that this experience stirred in me. I am not devoid of emotion, and I am comfortable feeling them. The feelings keep me in a place of empathy with the experience and the family going through this. I can't believe that I get to experience these parents' loss... to witness their raw emotions. I am forever humbled, grateful and in awe of their acceptance of me being with them.

Analysis of the Phenomenological Material

Each recorded transcript was transcribed by a private typist who specialises in doing this work. She signed a confidentiality agreement to ensure strict privacy of the data (Appendix F). Using Vagle's (2018) PIP methodology, data were approached from a "whole-part-whole" standpoint. That is, each interview transcript was deconstructed into parts to be made into a new whole by combining the relevant parts. This process enables a deep analysis of material and a capturing of the entirety of a story. It requires breaking the story into relevant, 'leaping-out' sections and then joining the story into a new or previously unseen way to highlight the phenomena. The following six-step process is supported by Vagle's PIP.

Step One – Holistic Reading of the Entire Text

Reading through each transcript for the first time was like opening a long-awaited present. It was surprising that some of the narrative seemed unfamiliar to me. It was not that the transcripts were incorrect; rather, there were very small pockets of material that I did not clearly remember hearing during the interviews. My attention may have been moved by what the woman had previously said, or a reactive thought had come to mind. These previously un-heard, probably inconsequential moments made me read the transcripts more carefully. I was aware that this first reading was useful to gain an overall sense of what the woman said and, as Vagle (2018) suggested, "spend some time getting reacquainted with the phenomenological material" (p. 110). My aim was not to take notes or make comments but get a re-introduction to the conversation. Van Manen (1990a) talked of that which makes a thing what it is. Therefore, it could be suggested that hearing the story of a woman who has gone through a TOP highlights the wholeness of the experience before others (me) attach meaning to it.

Step Two – First Line-by-Line Reading

This is the first time I slowed my reading down and allowed myself to ponder what I was reading. I highlighted parts of the transcripts that stood out for me because of what was said but even more intriguingly was what was not said. There was a sense that when the woman really was focused on a part of her story all the 'ahs and ums' disappeared. They seemed to have clarity of recall and did not 'think' about what they were saying. In other words, they were recalling a clear memory, thought, or feeling.

For each woman, the highlighted verbatim passages, phrases, or even single words were transferred to a separate document to highlight what leapt out at me or, conversely, left me wondering. My thought process was not finely tuned at this point but based on my spontaneous reaction to what I was reading. I was at the very beginning of becoming aware of meaning behind the words.

Step Three – Follow-Up Questions

While reading the transcripts again, I considered any uncertainties and queries regarding what was being said as well as what was not being said. The following questions seemed to repeat themselves with each transcript:

- What am I feeling when I read these words?
- What is the material telling/showing me?
- How could the meaning, relationship, connection be covered over or be in disguise?
- What lies behind what is said?
- How do these reveal new understanding?

At this point I was not necessarily trying to find a particular answer to these questions, but I was curious to delve even further into the material. The analogy of having a row of closed boxes in front of me and being eager to see what was inside each box, reflected my feelings. The concept of having so many unanswered questions without directly focusing on finding the answers stirred a sense of frustration within me but having learnt to trust the process of analysis, I remained as patient as I could.

Step Four – Second Line-by-Line Reading

As part of the process of 'moving-through' the material, I began to get a sense of 'moments' of possible significance. These appeared out of the material and seemed to protrude into what I was reading. They made me pause, re-read what was said, and sit with the possible meanings attached to these moments. They stood out amongst the words and made me ponder. The concept of 'leaping-out' (mentioned earlier) is also described as "jumping out from a hiding place and surprising someone" (Merriam-Webster.com, 2022a). It describes exactly how it felt. I could *feel* the words rather than just read them; and at times, I felt my breath pause as one does when surprised by something unexpected.

Although this was my third time reading the transcripts, and I was becoming familiar with the words and the flow of the stories, the unexpectedness of what I was reading was perhaps related to this supposed familiarity. With this sense of knowing the material, I was drawn to see 'what I hadn't seen before'. I had a sense of delving into the un-spokenness of the words. This may seem contrary because the words, themselves, *are* the woman's own words; so how could her meaning be unspoken? The truth of the women's narratives represented their own unique expression and, as Fernandez (2013) suggested, enabled a fluid or flexible understanding between the "observed, discoverable reality" and the "private interpreted, lived experiences" (p. 82).

The stories told, while reflecting their memories of the event, may have altered 'during the recalling'. The context of being interviewed, the time passed, the memories that float to the surface, all help construct the woman's story, and may not always represent *all* the experience. As Crowther et al. (2017) suggested "Given the possibility of endless contextual variations, how can one ever judge (and on what basis) that a story shared at a particular time and place as 'true,' complete, or accurate?" (p. 827). Considering this possibility, I found myself looking for the 'concealed', the spaces in-between what was said and what was meant. It made me focus on standout points, comments that have an element of surprise, 'moments' in the text, areas that perhaps seemed to be contradictory or did not fit. Vagle (2015) called these "leaks, flows and intensities of the narrative" (p. 11). This description visually reflects the unseen/unheard meanings of the stories as I was alerted to what leaked out of the words.

Each transcript was kept separate to remain in its own unique story space. The nuances of each story were beginning to show a 'new whole' and the women's true, unconcealed views, memories, and feelings were coming to light.

Step Five – Third Line-by-Line Reading

As each transcript was read through for the third time, my meaning-making of the material increased causing me to check my own assumptions of the meanings gained. My familiarity with each woman's story gave me a false sense of security because I knew that once I felt I 'knew' what was said my own inquiry into the hiddenness, the un-said ness of the words may be taken for granted. As Vagle (2018) suggested, "phenomenological research is in a constant state of becoming" (p. 11), which implies that there is no one meaning and no one truth. As Paulus et al (2008), stated, "the state within which we work(ed) has to be fluid, tolerant of uncertainty and ambiguity, and open to change" (p. 239). I have used these thoughts to keep me in a state of continuing curiosity rather than a more comfortable place of assumptions. With this step, I reflectively considered my own knowledge and meaning making I had from experiences of caring for women who had gone through a TOP.

Step Six – Subsequent Readings

This final step led me to develop broad-stroke understandings. Eventually, each of these were designated into smaller, more specific understandings which were again was set up in a separate document for each story. Each document was headed with a phrase, a word, or a concept that reflected the meaning of each story. Over time these changed and developed into more intimate renditions of 'meaning' that came from the frequent immersion into the data. As Vagle (2018) suggested, this process requires open searching, tinkering, and reshaping of the many layers of 'meaning-finding'. From these understandings, analysis was offered to convey the research meaningfulness that came from the material. It included my own reflections and implications for practice discussion. Finally, the crafting of the individual women's stories was completed.

Bearing Witness as a Form of Analysis

As mentioned in Chapter 3, the concept of 'bearing witness' strongly influenced my overall analysis of the material. Earlier, I described how, during my research journey, I had spent many hours remembering and reflecting on the experiences I have had caring for women who have had a TOP. When considering the definition of this concept offered by Arman (2007), "to dare to meet the situation, to see and encounter the person, to confront the pain and to remain with it" (p. 89), I found myself positioned in a reflective space of trying to see what the woman saw, (metaphorically speaking) even if only through my own view of the world. This is not to imply that I have lived this experience; rather, I can witness the experience from afar and, with empathy, I can chronicle their experiences. If doing so can acknowledge the women's deepest needs and desires when going through a TOP, then the notion of 'bearing witness' may serve its purpose.

During my analysis of the material, I was frequently brought back to the image of walking beside the woman and as I read and re-read their stories and became more engaged in their experiences. I often felt as if I was moving beyond the words into the space 'in-between' or even beyond the experience. This 'somewhere beyond' illuminated the PIP concept of reflexivity that represented the experiences of the women by allowing me to move outside of myself and into their world (Carter, 2014).

As Vagle (2018) suggested, PIP supports the view that "the individual (the woman) is being, becoming and moving through the lifeworld in intersubjective relationships with others" (p.23). My repeated immersion into the women's experiences resonate with this idea of intersubjectivity by acknowledging their journey and me accompanying them as the 'travelled'.

This deeply reflective and introspective journey sits with the method concept of whole-part-whole by indicating the production and provocation of meaning in the material (Vagle, 2018). The back and forward motion of contemplation aligns itself with Vagle's methodological five step process of 'being in the data'.

Focusing on Intentionality

Following on from Vagle's (2018) five step analytical process, each participant's transcript was searched for moments. Merriam-Webster Dictionary (2022b) defines a moment as: "A brief indefinite interval of present time which is of importance, influence or significance. An occasion affording an opportunity". To identify these times of possible importance, the transcripts were read with the thought and openness to 'something is happening that stands out, that has made me pause'. On reflection, I felt a tethering to their stories, as if their words were drawing me into their memories and holding onto my thoughts. As Vagle evocation, I am looking for the participants to bring me to their experiences of the phenomena, resonated with me so clearly, as if I could 'see' myself moving inwards, towards the inner layers of the stories rather than the stories moving towards me. It is me that was being absorbed rather than the stories 'fitting around me'. The stories were not changing but I certainly was.

The analogy of a moment, or a moment in time, could be like a snapshot of what is happening to someone or something. That snapshot represents a compelling point in the event, as if that moment represents the whole experience in a pinpoint of time. It could be identified as 'the experienced moment' or a time that frames our understanding of behaviour, responses, or the subjective experience. The unconsciousness of the instance becomes a conscious recognition of the significance of what happened. The *nowness* or *presentness* is what stays with us after time has passed (Wittmann, 2011). It has the potential for the meaningfulness of the experience to be attached to the moment.

Van Manen (2001) wrote that "reflectively bringing into nearness that which tends to be obscure, that which tends to evade the intelligibility of our natural attitude to everyday life" (p. 32, as cited in Vagle, 2018). These 'moments' seemed to also coincide with a change of energy for the women. There seemed to be a common behaviour in their storytelling that reflected a deeper thoughtfulness as they remembered something important.

By considering the tentative manifestations or 'spaces in between' (in this context, the space in between the words/meanings within the stories), there was the opportunity to focus on the intentionality of the narratives. This could be interpreted as focusing on the relationships or connections between people, the embodiment of the experiences, the multitude of contextual aspects of the stories, and the meanings attached to the stories.
Therefore, to accomplish this level of focus or consideration, the transcripts were considered from a difference vantage point, with a view to identify those 'moments' that stood out. To some degree, the previous read throughs had brought these striking points-in-time to the front of my mind anyway. I felt a deep sense of possibility when I was consciously 'going through' the narratives. With each 'moment' that was identified, I sat with the words, the obvious meanings, and then dived headfirst into the in-between spaces and looked at how the moment related to the woman's relationship or connections with those around her, the baby, the cultural/social context, the internal thoughts that she may be having, and the embodied experience as well. Remembering that the 'inbetween-ness' or the concealed spaces is where I wanted to venture.

As I sat, immersed in the words that I felt stood out as potential moments, I suspended my first reactions to what I was reading. I cleared my mind and invited the meaning of the women's narratives to be provoked and produced, as if I was playing with the words. Vagle (2016) talked of the playfulness in the interpretation of material, the tossing and catching of meaning. This action is not intended to be light-hearted; rather, experimental, exploratory, seeking the entangled multiplicities of meaning.

Finally, when some semblance of meaning appeared from my immersion in the moment, I followed this thought process and, as if beyond the words, came my understanding. All the pieces came together and offered me a sense of knowingness about what the woman had experienced *in that moment* and how it sat within her entire story.

Methods of Analysis Supported with Theory

Meaning-Centred Process for Grieving

To guide and support my analysis of the material I used Wong's (2003) Meaning-Centred Process for Grieving which incorporates many well-known grief theories and reflects the widely held view that memory making, and the experience of loss can enable the bereaved person to 'make sense' of their loss. This concept resonated throughout my analysis and was reflected by the myriad of questions the women had about "Why did this happen to me?" "Why do bad things happen to good people?" "Was it wrong for me to make this decision to protect my baby from suffering?" The women's yearning to find meaning or solace in their loss had an overpowering impact on their grieving. As Wong suggested, "Grief is such an intimate and yet strange wasteland" (p. 1), implying that if grief is a 'wasteland', then any chance of finding meaning in such a barren landscape equates to the eternal search for relief or answers to their questions.

As analysis of the material occurred, the meaning centred process (including meaning-making, acceptance, contemplation, etc.) was highlighted by the phrases, words, and reactions used by the women in their narratives. When sentiments of trying to 'make sense' of their experiences were heard, the analysis method/process gathered these moments and offered a common thread of inquiry. Using Vagle's (2018) phenomenological 'whole-part-whole' analysis process, these moments were separated from each woman's story then conceptually joined to find mutuality of understanding and meaning. This process of narrative reconstruction illustrated the congruence between the women's narratives and experiences and led to the development of shared understandings which became the findings of the research.

Existential Phenomenological Methods

Existential-phenomenological methods related to bereavement were utilised to support the analysis of material (Madison, 2005). This bereavement construct considers the intersubjective and interactional view of human existence in relation to the phenomena of bereavement. Madison (2005) stated that "each human existence essentially is an interaction with the world and with other people" (p. 342). As an example of this construct, although a woman is experiencing the termination of her pregnancy as an embodied experience that only she is experiencing (from a bodily perspective), she is not devoid of the interplay between what and who are around her. As Madison suggested, "even the choice to be alone is within the context of relationships. We are inescapably with-beings, thrown into and responding to specific social and cultural worlds" (p. 343).

Using existential-phenomenological theory as part of the method to conduct this research began with the development of the research question. The question considered the experience of women, a type of enquiry that is an intricate part of existentialism. The concept continued with the collection of the phenomenological material. As a way of highlighting the existential or embodied experience each woman went through, the semi-structured interviews showed the values, goals, ideals, intents, emotions, and relationships of each woman. These were captured amongst the retelling of their story and related to their own interpretation of their experience. This construct reflects the subjectivity of the lived experience that each woman went through which, in turn, highlighted the theory of existentialism in phenomenological research. The methods used to interpret the narratives required a level of introspection and a humanistic approach to the collected material. As the analysis of material is a pivotal point in the research methods, the existential technique of the researcher placing themselves in the experiential context of the person they are trying to understand was used (Pandin & Yanto, 2023). As part of Vagle's (2018) five step phenomenological 'whole-part-whole' analysis process, this existentially led immersion into the material provided a deeper level of analysis and, therefore, more humanistic understandings were gained from the material.

Together, the Meaning-Centred Process for Grieving and the existential-phenomenological theoretical constructs were able to offer a framework for the method of analysis of material that reflected the experiences of the women.

My Own Journey of Post Reflexivity

The concept of post-reflexivity refers to the inward journey I took to consider my positionality within the research (Vagle, 2018). It also indicates that my developing knowledge is in a constant state of flux; it is partial and ever-changing and, thus requires that I "pay careful attention to the complex socially constructed ways in which reality gets framed through one's researching and writing as a qualitative researcher" (Vagle & Hofsess, 2016, p. 337). Another view of post reflexivity is the acknowledgement of my role in the research. It requires that I pay attention to the cultural, political, social, and ideological origins of my own perspective and voice; as well as the perspectives and voices of the women I have interviewed (University of Melbourne, n.d.).

I appreciate and acknowledge that my position or the context of my deliberation has changed immensely, and where I sat before starting this research was vastly different to where I was as I wrote the thesis. The way I saw the world 'pre-research' was based on experiences as a bereavement midwife with many stories to tell. I felt that I had developed a degree of clinical competence and I routinely reflected on what happened during each experience of caring for bereaved parents who had ended their baby's life. My sense of 'normal' was tempered with a deep commitment to the uniqueness of every woman for whom I cared. In other words, there was never a 'normal' (response, situation, experience) and any assumptions I had should be taken with a grain of salt. In fact, I consciously avoided making assumptions as experience told me that what I saw was not necessarily 'the truth'. Rather than listening to any possible assumptions I chose to sit with what Vagle (2018) called pre-understandings. This process required that I search through my own knowledge and how I knew what I knew. With PIP, however, these personal assumptions were as relevant to the research as any other source of knowledge (Vagle, 2018). Rather than dismiss or disregard my assumptions, I explored how they played a part in producing the phenomenon.

I found moments that I instinctively connected with; and, conversely, left alone the times I felt less connected with. Then I:

- Challenged any assumptions of normality
- Reflected on my beliefs, perceptions, perspectives and opinions that framed my own knowing.
- Embraced moments that grabbed my attention or even shocked me.

(Vagle, 2018, p.154)

The above actions assisted with my acceptance and acknowledgement of all the sources of 'truth' and helped me see the previously concealed aspects of this material. While combining the theoretical teachings of pregnancy loss and the intersection of my midwifery experience, I intertwined what the women's narratives (phenomenological material) taught me, along with my own learnings gained from sitting with this material. The merging of these different knowledge tangents allowed me to 'find' a deeper layer of meaning.

Crafting the Stories

With each woman's story, a crafted or bespoke re-write of that story was completed. According to Caelli (2001), the crafting of a story in this research context is about "deriving narratives from transcripts" (p. 276). This crafting would eventually be offered back to each woman as an account of her story, as told to me. The process involved writing without the verbatim comments such as 'um…hey…., you know what I mean?'. While it is truly acknowledged that the stories were, in themselves, extremely powerful, the editing process brought together their narratives into a flowing tribute to their experiences. Occasionally the odd word was changed, or the grammar was considered, but, overall, what resulted was a true rendition of their stories. In the re-writing, the holistic experiences were not changed but enhanced as the process opened the interpretational space and provoked further wandering 'through' the data.

To craft the stories from the transcribed interviews required that I totally immersed myself into the narrative which, in turn, aided my 'being-in' the data. It offered me a chance to become attuned with what had been shared and to 'read between the lines', especially when I remembered those pauses, the sighs, and the tears (Crowther et al., 2017). This process gave rise to even more unanswered questions and made me check in with my own assumptions about my own meaning-making. Many times, I found myself reflecting on other women's responses to the loss of their babies and felt myself give a phenomenological nod to what I was reading, writing, sensing, wondering, and feeling (Nelms et al., 2015). Gadamer (1976) suggested that this is a way of making the story our own. That is not to imply that the woman's ownership of their story is dismissed; rather, that I saw myself in the story and recognised a knowingness or intuitive understanding of the story. The combination of all these factors also uncovered what had *not* been said, what was implied but not verbalised by the women. It reflected what was left unspoken of and where, potentially, the phenomena lay. While understanding the PIP concept of "through-ness" (as in 'passing through'), or the fluidity or the interim nature of the narrative, it is acknowledged that even these crafted stories are only one moment or one version of the stories. As Vagle (2018) suggested, this fluctuating and malleable idea enables the stories to morph into a different interpretation as the context to the story changes over time.

Trustworthiness – Research Rigour

Demonstrating trustworthiness in qualitative studies is essential to evaluate its worth and to ensure the research findings have the integrity to make an impact on practice, policy, or both (Hadi & Jose Closs, 2016). Qualitative research, it is argued, cannot be determined by following prescribed formulas. Instead, the strength of qualitative research lies in the ability of its language to display a picture of the world in which we discover something about ourselves and our common humanity (Buchanan, 1992). Qualitative research requires evidence of detailed attention to the authenticity of the material and the ways in which interpretations are made of the material (Kalu, 2017). The ultimate test of a study's worth is that the findings ring true to the people who read it and the findings reflect the reality of the experience (Kalu, 2017). The reader gains a sense of possibility from what is read, as well as a feeling of confidence in the findings. From a phenomenological standpoint, the reader may indeed offer 'the phenomenological nod' that implies an understanding of what is being read (van Manen, 1990b). Hadi and Jose Closs, (2016) suggested that trustworthiness was related to the accuracy and honesty of the material and should reflect the reality of the experience. The trustworthiness of phenomenological research is critical to both the reader and those who are impacted by the research.

In this research, my own practice confidence allowed me to find a familiarity in the findings according to the many women to who I have provided TOP care. Their stories, while unique, had a sense of known-ness about them that found me giving a phenomenological nod to what they were speaking. Of course, there were many instances of surprise and curiosity in their stories that had me searching for further meaning. Stahl and King (2020) suggested four criteria should be used to determine the trustworthiness of a research project which are then able to generate believability and a sense of truthfulness in the findings; these are: reflexivity, credibility, transferability, and dependability.

Reflexivity

The concept of reflexivity requires the frequent acknowledgement of the researcher's own positionality within the research. That is, my experiences, perceptions, understandings, and any personal influences that will potentially impact on my analysis of the material (Vagle, 2018). Heidegger (1996) suggested that to conduct reflexive research, the researcher's own pre-assumptions cannot be ignored and, in fact, merge with the data and lead to a new understanding of being-in-the-world. The interpretive phenomenology (including PIP) philosophical framework acknowledges that researchers are intricately situated in their own lived experiences; therefore, their thoughts and feelings are used to enhance the interpretative process rather than be hidden or put to one side (Vagle, 2018). Vagle (2018) underscored that in PIP the integration of the researcher's own knowing and the analysis of the collected material is a crucial to the act of reflexivity. It promises "to begin to uncover underlying, shifting changing knowledges that are at work in all intentional relations, and can begin to embrace post-structural arguments such as all-knowing being partial and fleeting" (Vagle, 2018, p. 154).

As a midwife who has cared for women who have had a TOP, I appreciate that to know a phenomenon is to start to understand it. From this starting point I was able to acknowledge my own pre-assumptions and begin to engage with the stories of the women who participated in the research. As van Manen (1990a) suggested "to write means to write myself, in a deep collective sense" (p. 132). The collective and individual voices of the women guided me when I ask myself 'What are the words trying to say?' 'How could it be covered over or be in disguise?' 'What lies behind what is said?' There is always the possibility of other interpretations which may be richer or deeper and Vagle (2018) suggested that there is no single truth; rather, PIP understands that there are many truths.

Reflexivity required that I consider my own values and morality regarding the phenomenon, which enabled me to surrender to total immersion into both the material and the experience. This immersion was critical to the analysis/interpretation of the material and, as Gadamer (1997) suggested, becomes a "fusion of horizons" (p. 302). That is, the viewpoints of both the women and myself merged into new understandings of the women's experience of the phenomenon. This was apparent in both the crafted stories as well as the analysis.

Vagle et al. (2016) talked of the entangled nature of reflexivity, stating that any reflective action is always 'becoming'. In other words, during the process of reflecting, knowing is always partial and ever changing. It is during this act of lingering in the phenomenological material that we hope to find meaning, to unpack our understandings, and ripen the possibilities that the material may offer us. To be a reflexive researcher, I acknowledged that I was part of the experience, context, and culture of what I was trying to understand and interpret. My own pre-assumptions and previous lived experiences gave a framework for the research, along with a generalised context of midwifery practice. My professional position in relation to the phenomenon of TOPs has been discussed in previous chapters and I have described my own practice experiences. Although the overall clinical concept of the TOP remains the same, the uniqueness of each woman's experience guided how I found meaning in the interpretation of their experiences.

Again, comments made by the women who had lost a baby through a TOP, came to mind when sitting with the material before me. Conversations with my supervisors triggered further reflection leading to deeper understanding of the phenomenon. All the while remembering that my interpretation is only one way of describing the phenomenon of TOP for fetal abnormality.

As part of my reflexivity in this research, the use of Vagle's (2018) five-part PIP method of analysis was used to make me stop and think. With each read and re-read of the material I considered if what I was reading was what I *knew* already or was this insight new to me. Did I have a sense of familiarity with what I was reading or was the material proposing something I had not considered before? As I went through these five steps, I jotted down thoughts and feelings that I returned to so I could find meaning or the potential for meaning. I recalled experiences I had had and tried to relate these to what I had read. Had I witnessed others reacting the same way or had I considered these responses as being possible, even predictable? On reflection, could I corelate what I was reading and feeling with the reality of my own witnessing?

Credibility

Credibility is confidence in the 'truth' of the findings (Barrow, 2017). However, in a phenomenological study there is a fundamental notion that there are potentially multiple meanings or truths related to a phenomenon (Vagle 2018). In this study, truth, value, or credibility was obtained from the discovery of experiences as they were lived and perceived by the women. Jorgenson (1989) also stressed the need to demonstrate the perspective of the insider or the women who have lived the experience. By using the same keywords or language and identifying and acknowledging cultural and social frameworks of the women, I was able to gain direct access to "the insider's" world (Jorgenson, 1989, p. 35).

To further demonstrate credibility, the women were asked if they would like copies of their transcripts for comment. None of the woman took up this offer. I can only assume why they declined but I believe that they felt that as the interviews were recorded then they would be a credible representation of what they said during the interviews.

My supervisors were asked to read and provide comment on my writing throughout the process of interpretation. I believe the process of reading, re-reading and writing, re-writing will lead me to a place of 'being-with' the material. My newfound understanding of the phenomenon will come from a place that was not visible to me prior to this study.

Flynn and Korcuska, (2018) suggested that a phenomenological study is credible when it presents such accurate interpretations of human experience that people who also share that experience would immediately recognise it. Those who have experienced giving birth in the context of having a TOP for fetal abnormality or have provided care for a woman who has had this experience, will recognise their own experiences in those described and can feel a commonality of experience. Credibility from this perspective can be seen in international studies that reflect women's experiences of having a TOP but from a wider timeframe. For example, Jones et al. (2017) in a meta synthesis of this phenomenon showed similarities in women's experiences to those seen in the current study. Carlsson et al. (2016) also showed findings that showed likeness to the current findings regarding the intensity of emotional and physical pain felt by women having a TOP.

Transferability

Transferability refers to research findings that have applicability in other similar settings (Burchett et al., 2011) The question that may be asked to determine transferability is, could these findings be applied to a wider population? Although the findings are specific to a relatively small number of women, the overall results will be relevant to other women experiencing a TOP for fetal abnormalities. The contextual factors which surround the TOP may be different (where the woman lives, her cultural practices, availability of services) but transferability is illustrated when others can begin to make connections from the revealed material and can transfer it into their own practice or lived experience (Finlay, 2009). I endeavoured to provide a sufficiently rich description of the phenomenon to allow the reader to gain an understanding of it, thereby enabling them to compare these interpretations and themes with those that they have seen emerge in their own situations.

As I sat with the data, I reflected on how the participants’ stories could sound familiar to other women’s experiences of having a TOP. The process of data analysis highlighted words, phrases, and emotions that are universally recognised as being reflective of the grief felt when a baby dies (Jones et al., 2017b). The reactions and responses have a commonality that would surely resonate with other women.

As part of showing transferability, I viewed the wider community of those having a TOP for fetal abnormality and considered how the women’s narratives could be that of any woman, anywhere. I considered how any other woman may experience a TOP and notwithstanding the varying contexts of the experience, the experience may well be similar. As part of this thesis, I have completed a literature review that shows that regardless of where the woman is, essentially, the embodied experience is similar. That is to suggest that the physicality of the phenomenon is familiar, but this does not imply the contextual (cultural, social, spiritual) considerations are the same.

Chapter Summary

This chapter captured the research methods employed in the study. The representation of the women and the ethical considerations, as well as the data collected were discussed. Included in the discussion were the measures used to preserve the rights of the women as the research involves those who are considered vulnerable. The process of collecting data was stated, as well as information on the analysis of the data using Vagle’s (2018) whole-part-whole method. The concept of tentative manifestations (the inbetweenness in the data) was presented, alongside the development of crafted stories. To complete the chapter, the trustworthiness of the research was presented.

CHAPTER FIVE: TENTATIVE MANIFESTATIONS – MOMENTS IN THE STORIES OF LOSS

Introduction

This chapter offers the context for the next four chapters which provide the description and exploration of both tentative manifestations and the concept of moments within each woman's story. This chapter then explores the PIP concept of tentative manifestations; and to introduce this concept, personal practice reflections are used. Lastly, a reflection of my own thoughts and feelings regarding any pre-assumptions I may have had is offered and how it felt to be starting this journey of understanding into these women's experiences.

Preamble

The following four chapters represent the experiences of each of the four women interviewed regarding terminating their pregnancy because of fetal abnormality. Each chapter is individually dedicated to Tui, Ursula, Katie, and Paige. First, an introduction to each woman is presented. Next, a crafted story is offered that was born from the transcribed interviews. I have done minor editing to help with the flow or readability of each story, being mindful to not alter the soul of their words. Crafting was done after immersing myself in their stories, time and time again. Each time I read the stories, I picked up different moments in time that stood out and spoke to me. I felt my thoughts and reflections moved past just the words and began to intermingle with my memories of these moments in the live interviews. The pauses, the deep sighs, the emotions stirred (or not), as well as the tone and volume of each woman's voice as she told her story.

I then offer a brief interpretation of each story allowing the reader to correlate what each woman has talked of and a reflection of her story. Lastly, each woman's story has been teased out into moments in time. By using the following description of the concept of 'moments', the make-me-stop-and-ponder passages in the interviews are brought into focus. As if seeing these moments through a looking glass, I was able to see past what was perhaps obvious and look more intimately at the experience. The purpose of this submergence into the words is to find the space between the words. As Reigner (2014) suggested, "Just as in the structure of a musical melody the intervals are equally as important as the notes" (p. 3), experiencing betweenness among the parts/words of a story is the key to finding wholeness, or meaning, in the phenomenon. In other words, by using "this phenomenological approach we can attempt to grasp betweenness as a dynamic reality such that all parts become revelations of the whole" (Reigner, 2014, p. 4).

While betweenness describes the relationship between two known things (in this case, words), the concept of in betweenness was also considered at length. The definition of inbetweenness from a phenomenological standpoint is the space that is assumed to be present. It is a construct that speaks to the interpretative process of discovery of meaningfulness (Neubauer et al., 2019). The moments selected from the transcribed interviews were perhaps just a few of the notable moments within each story. From this deeply reflective process further chapters offer a culmination of possible themes or familiar threads interpreted via these moments.

Tentative Manifestations

To be able to delve deeply into a phenomenon that changes as the context changes, as time moves on, and as the interpretation 'becomes', is both a challenge and a journey of potentiality. In this instance, to be immersed in the words, possible meanings and the self-awareness that this involves is part of the phenomenological concept of 'tentative manifestations', as described by Vagle (2018). Instead of describing or developing themes, as commonly found in other forms of qualitative research, tentative manifestations or the uncovering of the discoveries within the data are offered. This collection of assumptions slowly grows as they take shape, and it is acknowledged that the meanings are always in a process of becoming. They are constantly in a state of flux as the context changes and as the story adjusts to the act of remembering. Through a generative process of production and provocation, the meanings multiply, diminish, return, and are re-made (Vagle, 2018).

There is a moving away from 'what' the women were saying to a place of movement or, perhaps, of going with the current of where their words might be traveling. In other words, how things were 'becoming' for them. Instead of the more confining concept of themes, the more immersive action of moments was used to plunge into the women's stories.

The Concept of Tentative Manifestations Shown in Reflections of my Own Practice

The synthesis of tentative manifestations (moments or 'things' uncovered) and PIP methodology reinforces the researcher's own experience or knowledge of the phenomenon that is studied. Vagle (2014) talked of the researcher's own perspective and experience as being valuable guides to the inquiry undertaken. It is suggested that the researcher's education and knowledge base is the likely reason for the investigation of a particular phenomenon in the first place. So instead of denying any bias, Vagle (2014) stated that the researcher should openly acknowledge their preconceptions and reflect on how their subjectivity is part of their analytical process.

The following three practice stories illuminate the concept of tentative manifestations by spotlighting moments in my own practice. While these stories are based on the experiences of bereaved parents, the stories are written from my perspective. That is my 'being' in the story, my own personal interpretation of what I experienced in relation to being in the room with the parents. Vagle (2018) encouraged the researcher to explore these moments and find meaning in them. This gained insight can then filter into my analysis of phenomenological material obtained in this research and aid my understanding.

These stories honor the parents and what they went through, although they remain anonymous. Although they went through something unimaginable, their encounter with death showed me what they experienced, if only from the outside looking in. The tentative manifestations are shown in my reflections as those moments that made me stop, take notice, and pay attention. These moments came and went, were provoked, and produced a response from me that often lingered. Some moments were fleeting, and some were only recognised afterwards, but all impacted me and stirred my awareness. From a standpoint of curiosity, my regard for how I was placed in these experiences offered me a perspective of wonderment. If I felt a particular sense of what was happening, how did this reflect what the parents were feeling? My reflections may not represent how the experience was for the parents. My consciousness of what was happening and what was felt by the parents is merely an assumption on my part. However, these reflections have scaffolded my work and shown me an array of possibilities and 'maybes' that have sparked my curiosity to sit in this phenomenon. Witnessing such profound human emotions never fails to move me. I long to understand, if that is even possible, their journey through this most heart-wrenching experience. I want to "be with them" in a meaningful way and bear witness to what they are going through.

Three Stories From My Practice

"She's Here"

Walking into the room… the room where a baby is going to be born and die in a single heartbeat. Putting my hand on the door as if it is a talisman, I am hoping it will offer me the wisdom I need. I breathe in a calmness, preparing myself for what I am about to bear witness to. I need to clear my mind of the everydayness of my thoughts, steadying myself for the wave of emotions I am about to encounter. I open the door to a dimly lit room and the woman appears in the distant shadows. I cannot see her face, but I can sense her presence. The others in the room seem to be circling her like a planet that is holding them in its orbit. Like invisible threads of concern and uneasiness, such is the intensity of their dedication to her. The room seems to be holding its breath as if anticipating what is about to happen. It is silent except for the occasional deep breathing sounds and the gentle instructions of her partner. "Just breathe… keep going… breathe for me… that's it…". These instructions could well be employed by the room itself and everyone in it, not just the woman. As well as her partner, there is a hospital midwife quietly hovering, watching for signs of progress. The woman has her eyes shut, seemingly concentrating on making it through the next contraction. Scanning the room, I try to absorb what I am sensing, trying to find my place in the room. I feel like an intruder, so to remain inconspicuous I stay silently in the shadows. Before I can be absorbed into this space, I need to attune myself to the already present energy in the room. Like an unwritten script for how to 'be', I try to decipher the code that is unique to this woman and her partner. I cannot help but be hesitant about breaking their bubble so, in my head, I try to justify my presence. My role is not to subtract from the hospital midwife's care; instead, to add layers to the care—layers that offer a depth of holistic support to both the midwife and the couple. Ironically, perhaps the exact opposite is also true; my role may be to help peel back the layers of the experience to help find meaning, to acknowledge, or bear witness, and perhaps to assist the couple "find themselves in the experience".

She appears detached from what is happening in the room but when I make my way to her, she opens her eyes and smiles. All I say to her is "hello", and I touch her hand. She grabs my hand with such firmness, it takes me by surprise. She breathes through another surge of pain, hunching her shoulders as if drawing her body inwards. A deep groan comes from within and as the pain subsides, she shakes her head. I am unsure of what to do next. Should I stay beside her as she holds my hand, or should I move away? I feel frozen to the spot, not knowing if moving will disturb her or if she wants me to stay close. I instinctively stay put, trying to decipher what she wants from me. Standing there for what feels like an eternity, just holding her hand, not saying anything. The stillness is oddly calming; it allows me to merge one step closer into the room. Being right next to her, I can feel my breath becoming shallower, as if I am trying to even breathe quietly. I sense being on high alert, watchful of what she might do next, mindful that I will need to respond to her. In time, I know I will settle my thoughts and meld even further into her space.

The room remains silent, awaiting her next signal. Then, she sighs deeply, opens her eyes, and climbs off the bed. She has broken the spell that we were all under and we all visibly relax. She goes to the bathroom, and we can all hear that the next contraction is a strong one. Her moaning reverberates around the small space, amplifying it. The noise seeps out into the room and I mentally compare this contraction to the previous one. I can feel my heart beating faster, awaiting a sudden sign that she is about to birth. Instead, she steps out of the bright lights of the bathroom back into the darkened birthing area. There is a tangible shift in energy, as if everyone has had a chance to stretch after holding a position for so long.

I have had a chance to read her birthing story so far and estimate she has been in labour for about 4 hours. She is just 22 weeks pregnant, and her baby was seen to have serious heart abnormalities at a recent ultrasound. She and her partner have made the impossible decision to end the pregnancy. This is her third baby but will be her first vaginal birth as her first two births were caesarean sections. My mind systematically considers all the things that could go wrong, none of which help me feel more reassured.

She lies on her side, facing away from me. Her partner pulls up a stool and leans into her, burying his head into her shoulder. They both sob in each other's arms. The reality of what is happening seems to have stirred in their minds like waking up from sleep and realising that the nightmare is real. There are so many emotions going through my mind, while watching them hold each other. It is heart wrenching to hear their combined sobs, like a symphony of desperation and despair. Watching the tenderness of their touch while consoling each other makes me feel like I am trespassing into their private world, and I turn away. A wave of recognition of the depth of their pain washes over me and, for a moment, I have an intense sensation of melancholy. I cannot help but be affected by their sadness and I do not want to ever be immune to feeling this way. While witnessing their hearts breaking, I try to remain focused on assisting her birth their baby. I too, pull up a stool and sit behind her, and find myself unintentionally breathing in unison with her. She moves from one side to another, trying to find a position that gives her some respite from the labour pains. Not surprisingly, she is unable to find any let up so instead just weeps out loud, swaying her bent up knees side to side. Looking at her face, I see almost a blankness, her eyes wide yet unseeing. Almost like an emptiness as her overwhelming emotions cancel each other out and leave her seemingly numb.

In a surprising moment of calm, she turns to me and tells me that she is too scared to see her baby when it is born stating; "I don't think I can see the baby... I don't think I could cope with that". I acknowledge her statement with a silent nod and consider how this might unfold at the birth. The next contraction is long and powerful, and she calls out to anyone listening; "Please, I can't do this, please make it stop, you have to make it stop". I move closer to her, and she takes my hand again. All I can do is acknowledge the hard work she is doing and remind her that this will not last forever. She closes her eyes and very quietly says; "she's here".

I look down the bed and there, between her legs, is the most beautiful sight anyone could possibly see. Her baby is lying on the bed swaddled in a glistening silver shroud of intact membranes with the dark red placenta attached to them. Nobody moves, nobody needs to move; she is indeed, here. While the suddenness of the birth did not surprise me, the silence in which she surrendered her baby to the world, did. She gazed at her partner who looked confused by the sudden activity. He seemed to be hanging back, trying to make sense of what had just happened. When he saw his baby girl, he stepped backwards covering his face with his hands. She reached out her hand to him, saying, “she’s here, she’s here, it’s over”. Remembering that she had told me of her fear of seeing the baby, I moved her daughter to the other side of the room. I opened the amniotic sac and released both the baby and the fluid from the birth cocoon. So many emotions were racing around in my mind as I saw the tiny baby girl in her complete amniotic home. It seemed surreal that she had arrived without a sound from her mother and in such a beautiful ‘bundle’. The relief that the birth was complete was like an appeasement to what may have happened. The cord was clamped and cut, and I wrapped her in a tiny, soft blanket. This brief reprieve allowed me to catch my breath and steal myself for her possible rejection of the baby. I turned to face the woman and her partner, holding their baby but not moving any closer to them. I was waiting for them to guide me, to lead my way to them as I held their tiny daughter. She looked over to me and without saying a word just put her arms out to receive her baby. A wave of relief washed over me, and I let out my held breath. It felt like a million miles between her and her child, as if I could not get this little one to her mother quick enough. She cradled her baby to her chest with her partner standing close beside her. She kissed her baby and told her how much she loved her. She also told her how sorry she was for making her suffer. Saying this out loud made the loss even more real to her and brought another flood of emotion to the surface. This time the sounds were deep and growling, absolutely agonising to hear. I choked back my tears, not because I did not want to show them but to halt the tidal wave of sadness that I knew was tipping over in response to her lament of grief. There would be time enough for me to cry, but not now, not here.

She sat holding and rocking her baby for some time. She appeared to be in a space that any mother would be in after the birth of their baby; relieved, peaceful, and engrossed in her baby. We talked in a hush about the suddenness of the baby’s arrival and how calm she appeared. I wanted desperately to share with her how miraculous the birth seemed; so, when the time felt right, I said, “that was a truly magical birth”. I was not sure how she would respond to my comment as this was only my interpretation and can often be unrelated to the woman’s own experience. She paused, looked at me with such a pleading look and said, “do you think so?” I held her hand and told her that I could not remember a more beautiful sight. I reminded her that her baby was softly embraced by her own placenta and membranes, and she had birthed her so tenderly. I suggested that the birth allowed her little daughter to be born with the utmost dignity and grace. We both sat in silence for some time; remembering, holding space for each other, and making sense of how something so beautiful could have come from something so tragic.

"Oh, My Beautiful Baby"

Jane and Tom were expecting their second child. At Jane's 20-week anatomy scan an unusual tumour was seen on the baby's right leg. Unsure of what it was and what impact it would have on their baby, Jane and Tom were asked to come back in a month for a follow-up scan. By this time the tumour had grown dramatically and now involved all the baby's leg making it appear hugely deformed. It had also completely enveloped the baby's abdomen and was putting pressure on the baby's diaphragm. It was diagnosed as a fast-growing cancer that would ultimately be fatal for the baby.

I meet Jane and Tom on the day they were to birth their baby. Jane is now 28 weeks pregnant and having her labour induced. It had taken them 4 weeks to gain a second opinion regarding their baby's condition and to investigate alternative treatments. Unfortunately, the prognosis of their baby's condition was confirmed, and plans were made for Jane to birth her baby. A feticide had been performed as a live birth would not be appropriate in the circumstances.

When I entered her birth room, I noticed Jane was in established labour and working hard. She did not say or do anything when I approached her, but Tom looked at me with a sunken look in his eyes. I was another person involved in their nightmare and he neither welcomed me nor shunned me. Instead, I felt as if I was to become just another witness to this unperceivably torturous event. There was a tension between being present in the room and absorbed into their grief and staying outside of their experience by remaining a spectator. Part of me wanted to 'do my job' without investing in their story but a bigger part of me pushed me to offer my care and undivided attention to Jane and Tom. I was already part of their story by just entering their room, so felt that I could not be half-hearted about my involvement. Perhaps, as the phrase 'half-hearted' means, caring for Jane and Tom required all my heart, not just part of it. I knew the emotional investment required would be challenging but when would witnessing the birth and death of a baby not be emotionally hard work? For me to prepare for this commitment, I visualised myself walking beside Jane and Tom, not behind them pushing them nor in front of them leading the way. Instead, in step with them on their journey, offering them unconditional support and aroha.

The induction was into its 20th hour, and I got a sense that both Jane and Tom were beyond exhaustion and no doubt close to collapse. I was unsure how I could ease their burden, how I could help carry them for a while, to off-load some of their grief. But I knew that I could not. Despite any attempts I might make to lessen their heartbreak, my role was to support them in their pain, not to take their pain away. Tom hovered over Jane, trying to soothe her with his words, his touch, and his love. Jane appeared to float in and out of awareness as if swimming through huge waves of both physical and emotional pain. She would reach for Tom and cry out weakly at the peak of each contraction, then crumple back into the bed, as it passed.

I wondered how much longer Jane and Tom would have to endure and what would need to change for their baby to be born. There was a sense of this never ending, never being over with. Perhaps it never would be over for them, the memory of the day their baby was born would never be forgotten.

As the baby had obvious abnormalities, I felt anxious about how I might respond seeing the baby for the first time. Wondering if the deformity might impact on the birth, I was also feeling troubled about managing any birth complications. Part of me was impatient for this baby's arrival but part of me was fearful of how gruesome the abnormalities may look. From what the scans indicated, the baby was enveloped in a huge tumour, and I could not picture, in my mind's eye, how this would look. I was conscious of not frantically busying myself with tasks to compensate for the apprehension I was feeling. To remain focused, I reminded myself to respond to what the moment required of me, nothing more, nothing less. To stay present and concentrate on the here and now, rather than try to foresee the outcome.

After another hour or so, Jane's demeanour changed. She became talkative, almost chatty, asking what would happen when her baby was born, when the doctor would be coming to see her, and would she need to change rooms soon. As any midwife knows, when there is a change, any change, it most likely represents a change in the labour. Jane became more focused, and her awareness level heightened. She began describing what she was feeling; "I can feel him on my cervix, he's moving down". This change in energy seemed to shake Tom up, he had been in such a rhythm of each contraction's ebb and flow. He stood still with his hands on his forehead, appearing disorientated. Jane's previous submissive posture changed to a more pronounced position with her legs bent, her arms holding onto them, and her back straight. Her breathing became purposeful and controlled. She made direct eye contact with me and had the look of pure determination on her face. I did not have anything to say to Jane, not because I was dumbstruck but because she had taken full control of what was happening. She was leading the way and I just had to follow her. It seemed as if birth was imminent, but I was unsure if I was ready for this baby to be born.

With the next contraction Jane actively began pushing; long, hard, noisy pushes. No one offered the customary cheer-leader style encouragement; it did not seem necessary or appropriate as Jane was birthing her baby and did not need us to prompt her. Tom stood close to Jane, speechless. His previous composure and calmness now replaced with a sudden jolt of reality. Their baby was coming, now, after waiting so long. He had his head turned away as if he was deliberately focusing on somewhere other than where their baby would be born. Jane was also focused on birthing her baby and with the next contraction her baby's head was born. Knowing the abnormalities this little boy had made welcoming him fraught with apprehension for everyone. What could only be imagined was now going to become clear. There was a tension in the room that reflected this worry but his birth was imminent so there was no shying away from it now. With the next contraction, Jane pushed her son out onto the bed. I felt relief that Jane had birthed her son but also hesitation in discovering the reality of his condition.

Jane had her eyes tightly shut and even covered her eyes with her hands as if to offer double the protection from the reality of her son's birth and death. She was silent and seemed frozen, while Tom let out a gasp and literally clung to Jane. As if time stood still, no one moved, no one spoke, and it seemed that no one even breathed for the longest time. Everyone was inwardly responding to what had just happened. This tiny, lifeless body lay on the bed. The abnormalities were obvious and hard to see; no baby should look like that. His skin was red and raw, and I could imagine the pain he had experienced before he died. I wrapped the baby in a towel and waited, waited for Jane to respond to her son's birth. She opened her eyes and cautiously received her baby into her arms. At first, she just looked at his face. Perfect, tiny and peaceful. She wept with what seemed like a mixture of relief, love, and despair. The sound is not easily described except to say that it touches a spot so deep inside that it is unclear where that spot is. I do remember shivering with the impact of hearing her heartbreak. Her tears landed on her son's face as she let out every possible emotion that had been sitting within her for so long. What she saw was her sweet boy, wrapped in a towel, looking at peace. She had not yet seen the rest of his body and I was hesitant to rush her discovery of this. Without any encouragement from me she unwrapped her son from the towel and saw his misshapen body for the first time. She showed me that a mother's love for her child is beyond physical appearances and surely goes beyond human understanding as when she saw her baby all she said was "oh, my beautiful baby".

"We're Calling Him Daniel"

Sue and Jon were a young couple who lived rurally and were expecting their first baby. Sue's pregnancy was progressing well until her 20-week anatomy scan. This examination indicated that their son had renal agenesis which deemed him unable to survive after his birth. On finding out this devastating news, they decided to terminate the pregnancy. The following week, Sue and Jon presented at birthing suite, prepared for an induction of Sue's labour.

Sue asked me that before we start the labour could they listen to their baby's heartbeat for one last time and have a tracing of it for her memory box. I placed the CTG on Sue's abdomen and we listened to her boy's heartbeat. She cried quietly as the minutes ticked by. Jon sat with his head down, holding on tightly to his own hands as if trying to hold in his emotions. I could not begin to comprehend what emotions Sue and Jon were feeling. Where is the script for how to 'feel' when you are hearing your baby's heartbeat for the last time, knowing that very shortly you would be witnessing his death? I found this time to be one of the most poignant and saddest moments I have had as a midwife. We had not yet begun the induction and already this was overwhelming my heart. Somehow, I felt like the queen's executioner, about to fulfil my duty; but my duty involved facilitating the death of an innocent baby. Logically, I knew this was a purely emotional response but hearing the baby's heartbeat, knowing what was about to happen, touched me like nothing else had. I had a visceral response that made my head spin. I was trying to rationalise why I was sitting on the side of Sue's bed, listening to her baby, about to give her the medication that would be the beginning of the end of her baby's life. It felt like an inner turmoil between the midwife who had a clinical responsibility and a mother who wondered how any parent could survive such an experience.

Sue's labour progressed and within a few hours she was experiencing regular, painful contractions. Jon was rather separate to what was going on. He sat some distance away from Sue and appeared to be engrossed in his computer. Sue was mainly silent except for frequent deep sighs as the contractions intensified. Although they seemed somewhat distant there was a calmness and ease in the room. Initially, I wondered why there seemed to be this gap between them but reflected that my assumptions may be based on my own interpretation of support. At one stage, Jon left the room without explanation. Sue did not seem bothered by this and continued working through her contractions. When Jon returned, he went up to Sue, kissed her lightly on the head and returned to his computer. The silent labour continued for another hour or so until Sue, obviously in strong labour, asked me if it would be much longer as she was reaching her limit. This question remains firmly in the 'unanswerable' category as predicting when a baby will be born is like trying to predict when the wind will stop blowing. She continued her labouring journey, and it was not long after this that Sue expressed a feeling of pressure. She got up to go to the bathroom and, on her return, stated that the pressure was increasing. Jon came over to Sue and sat facing away from the foot of the bed. He held her hand but remained silent. It soon became apparent that the baby would soon arrive and, sure enough, within 10 minutes, Sue birthed her son onto the bed. He was tiny, perfect, pink, and alive! There were obvious signs of life as he opened and closed his mouth. His heart could almost be seen through his chest and was beating strongly. There were some involuntary muscle movements but no noise. Knowing that his time was limited, I paused before clamping his umbilical cord and instead suggested to Sue and Jon that we not cut it yet. A few minutes later Sue birthed her placenta, so I wrapped their son and his placenta in a small, warm cloth and again waited for guidance from his parents. Sue picked up her baby and held him close. Jon cautiously turned towards Sue as she showed him the baby. Jon looked completely distraught and sat there, sobbing. He looked at Sue and said, “But he’s alive”. “I know Jon, hold him while you can,” Sue replied. “I can’t, I might hurt him,” said Jon. “No, no, you won’t hurt him, please hold him, he’s your son,” encouraged Sue. Jon tentatively took his son into his arms, and just wept and wept. Sue lay back on the bed and grabbed her head between her hands, saying; “Oh my god, oh my god, I can’t believe it.” Ten minutes went by, and the baby was still warm and pink. Together Sue and Jon unwrapped their son to see all of him. They grasped his tiny hand and stroked his head as they spoke so gently and lovingly to him. I sat next to Sue’s bed, just breathing in the relief and the joy both Sue and Jon were showing. At one point Jon looked at me and asked; “Is he suffering?” I had no way of knowing but rather than adding to their anguish, I replied, “Jon, look at your son’s face. Does he look peaceful to you?” “He does” replied Jon, and that was all that was said.

Sue and Jon sat together on the bed, taking turns holding their son. They laughed, they cried, they just looked, absorbing every second of their time with their boy. About 2 hours after he was born, Jon said, “I think he’s gone”. Sure enough, his tiny heart was still, and his colour had already changed. “I think you're right Jon. Rest in peace little boy”. This realisation brought a new wave of emotion and both Sue and Jon cried openly for their son’s passing. Jon looked up at me and said, “We are calling him Daniel”.

Afterwards

Remembering these three births brings back both the emotional and the physical memories of what happened. These are intertwined and one thought connects to the next. I find that I cannot separate the midwifery story from the human story. When I think back, the memories and emotions are just under the surface of my mind, and I am thankful for that. I do not want to forget or compartmentalise these as they light the path for the next time by offering me guidance and counsel. For me, there is not a sense of distress when accessing these thoughts; rather, a sense of liberating my emotions and confirming my belief in providence. Each time I bear witness to a family’s tragic loss, the deeper my appreciation of life’s fragility grows. At the same time, the beauty of both birth and death becomes more apparent to me. It would be pointless if my experiences did not expand my vision, did not shatter my once held illusions, and did not drop me to my knees in the honouring of the women and families I have met.

In the beginning of my practice of caring for bereaved families, it seemed as if I was trying to walk on a swing bridge. The foundations under me were constantly moving making me readjust myself to stay upright. Over time, I find that I am still walking on that swing bridge but now I have better balance, greater inner strength, and a deeper trust in the 'ropes that hold me'. I know that when I offer a woman my undivided attention, she responds in a way that ultimately meets her own needs, as if scaffolding her own ability to withstand what she is going through. Together we are navigating the time and space, searching for moments of respite, safety, and hope. I know that being an unwavering witness does not mean having to know what to do ahead of time or making things right; rather, holding that space and trusting how the experience unfolds. I believe focusing on the unknown-ness of what to do amplifies the tension around 'doing or saying the right thing'. The more I over think my care, the more uncomfortable or awkward I become. This thought is related to the emotional work we do with birthing parents, not the clinical care. Having said that, there is a compelling need for both trust in the woman and the process.

My midwifery care often seems to be like working in a void. While the world spins around me, I feel strangely still. I would choose to describe this as a sacred space that relates to both the birthing woman and my own place of meaning. This space is different to any other space as it focuses my thoughts, actions, and connectedness to the woman and what is happening for her. The sacredness allows a level of emotional awareness that is often censored by the busyness of the workplace. For me, each time I enter this dedicated space, I discover my midwifery self, again and again.

The Concept of 'Moments'

Hearing that the baby will not survive once born or swallowing a pill that will stop the pregnancy or giving birth to a stillborn baby all constitutes 'a moment'. A point in time that is defined by an event that cannot be re-written, that cannot be re-played but marks a point of no return, a point of change. Once the moment passes, it is relegated to the past but, nevertheless, it still has the potential to impact the future. The occasion swirls in the minds of those who have lived it, toing and froing between bittersweet memories and anticipation for what is to come.

Heidegger (1992) suggested that there are no 'now-points' in time; rather, the future is the not-yet-now, the past is the no-longer-now, and the present is the now that flows from future to past at each passing moment. While this logically makes sense, the concept of 'a-moment-in-time' can still be seen as relevant in the memories of those who have lived that moment.

The accompanying emotions that sit alongside these points in time are reflective of where those moments may take the person. A moment of discovery may lead to a sense of dread or, conversely, to a place of hopeful anticipation. The feeling of dread may see the desire to slow down the passing of time whereas anticipation may prompt time to speed up.

However, as Heidegger (1992) surmised, “the human is not confined in the present, but always projects towards the future”. While a moment may be one defined point in time, the consequence of that moment potentially impacts memories as well as actions in the future. In fact, the moments that are projected into the future are no doubt compelled by those moments that have passed. This interrelatedness describes the Heideggerian concept of temporality that implies that each timeframe impacts the other with a connectedness that ebbs and flows. It also alludes to those tentative manifestations or connections between the past, the present, and the future (Vagle, 2019). As Heidegger stated (1992), the concept of time or moments-in-time is the unity of these three dimensions of time. Mindfulness author, Amit Ray (2015), suggested, “life is a collection of moments”.

To try to describe ‘a moment’ may be seen as a thankless task with no clear definition. A moment may be perceived as an instance, a single point, or the merest speck of time. What is more, a moment may be over an immeasurable period or even an accumulation of many moments that are stitched together and edited to make what seems to be a mere moment. The in-between spaces are dispatched and, thus, a moment is crafted.

However, the undetermined nature of ‘a moment’ seems to be more a linguistic construct than a physical or perceptual one. The Collins English Dictionary (2014) defines moment as:
“A brief indefinite interval of present time which is of importance, influence or significance. An occasion affording an opportunity”.
The word moment derives from Old French language and is described as a verb—to move. The question that begs to be answered is does a moment have the potential to ‘move’ as in shift something or someone, whether from a physical, spiritual, or emotional point of view? For those experiencing a moment, there seems to be a distinct clarity around it, a focused lens that distinguishes a point within the totality of an experience. It offers a crispness to the experience while the edges surrounding this point remain blurry. Whether the ‘event’ has a single focal point or has a collection of points joined together, moments come and go, forever relegated to the past. Regardless of how a moment is defined or described, the point of this construct is to highlight or illuminate something that has happened, something that has meaning or purpose, something that has changed everything. As poet, Mary Oliver (1935-2019), suggested, “All eternity is in the moment”, implying that a point in time can simply represent all of eternity.

Researcher's Reflections

While moving through this research journey, I have felt the intensity of these women's stories and what stands out within their tales are the moments. These seem to be accentuated within the flow of words and appear to be bigger than the background story. Almost as if a spotlight has been shone on these points and show a particular poignancy. Somehow these focused words give a sense of what is known as the "phenomenological nod" (Nelms, 2015, p. 17), where the reader finds a resonance with the meaning conveyed. In the apparent everydayness of a conversation, I was ready to fall into these stories and find the space in between the words.

There were times when I doubted my understandings but then I was compelled to return to the stories and wait for the voices of the women to re-direct me. Using this connectedness encouraged me to wait, listen, and ponder what was intended to be heard and, even more importantly, what was meant but perhaps not directly said.

Earlier in the research process, I was interviewed by Dr Tania Fleming, one of my supervisors, in a way that enabled me to reflect on my own pre-assumptions and unpack the meaning of my experiences. I believe this process was vital to show me where I was on my own journey. What was uncovered were questions that I had not yet addressed. For example: How would I know what a woman is experiencing during a TOP? How do I 'know' what to do when providing care to a woman? Where does this 'knowing' come from? Is wisdom the same as practice confidence? How do I acknowledge a woman's unique journey of loss? How might my care impact on a woman's experience? Will my pre-assumptions about the experience impact the woman's voice being heard? Through the process of reflective practice, I was able to gain a deeper and more meaningful understanding of where I sit with the phenomenon. To be encouraged to talk about my own experiences was cathartic and the experience gave me a clear slate to work from. From this starting point I could acknowledge my own pre-assumptions and begin to engage with the stories of others, not to compare but to share the commonalities that developed.

Finally, as each perceived 'moment' was contemplated it became apparent that there was no chronological order to these moments. These could jump from the birth of the baby back to the time of diagnosis then moved forward to after the birth. Initially there seemed no rhyme or reason to the flow of these moments. However, upon reflection, these seemingly random points, in fact, were influenced directly by the ebb and flow of the women's stories. This movement in the women's rememberings represent their 'journey of memories' and indicates that the women's recollections were fluid and ever-changing. What they remembered and spoke of was related to the context of the sharing of their stories, the passing of time and what came to mind in that moment of re-telling.

Chapter Summary

This chapter has offered an unpacking of the PIP concept of ‘tentative manifestations’ that affords a deeper and more intimate path into the women’s stories. The chapter also focused on ‘setting-the-scene’ for the next four chapters. Further, an explanation and placement of the concept of ‘moments’ within the women’s narratives were offered. Together, these offered the mapping out of the journey ahead. Finally, I provided a personal reflection of my own passage through the experience and the questions I was encouraged to consider along the way.

CHAPTER SIX: KATIE: BERNARD'S STORY IS NOT A VERY LONG STORY BUT IT'S HUGE IN OUR LIVES

Introduction

Katie was pregnant for the first time and was with her partner when she found out that her son, Bernard, had the fatal condition of Trisomy 13. This diagnosis happened after her 20-week anatomy scan. She gave birth to him when she was in her 23rd week of pregnancy.

Katie's Story

About this time about 4-years ago, we just found out we were pregnant, and it was our first pregnancy, so we were all quite excited about it. Everything was carrying on very normally. All the checks we had were good and we went for our 12-week scan with no problems at all. Then we turned up for our 20-week scan, but they couldn't see a few things, so we were asked to come back. That made me a little bit worried. But we thought 'oh well that can happen' so we went back a couple of days later. Little Bernard's position was slightly different, and they'd struggled to get a good image of his face and heart because his hands were covering those regions. When they finally got a little snippet of his face, they found a cleft. At that point everything changed. The mood in the room just completely changed and they went back to try and look at the heart and they were still struggling because his hand was still in that same position. So, this was now late in the evening, and we were sort of left, not knowing what to do with this information. Suddenly being told that this now signals that there could be a major problem. My midwife was on holiday, so I didn't have her to ring and, we were just left. They said, 'we'll be referring you to the fetal medicine unit'. So, thankfully my backup midwife rang me the following day, but I'd never even met her before. She was wonderful. She just took me under her wing and talked me through it.

When we went up to the fetal medicine unit it was quite clear there was something significantly wrong. They were talking to us and counselling us leading up to the scan. We went and had our scan, and they still couldn't work out what was going on. We had an amnio and they said that they thought that our baby may have some sort of syndrome. They told us that there were many things going on with this baby and he's going to need a lot of intervention with a lot of specialist teams. This was the point where I brought up that if this baby is severely affected by something, can I elect to terminate at this point. I wasn't sure on the law because by this stage we were at 22 weeks. They talked me through that and then we got the result over the phone later that week and unfortunately it was confirmed as T13. Both my husband and I had gone away and we'd both decided that if it was a fatal syndrome that we would elect to end this pregnancy and not put that little baby through it. So, we went back and had our misoprostol and then were booked into the delivery suite 2-days later.

We were given a diagnosis of Trisomy 13 and this is considered a fatal diagnosis. They weren't sure what the heart defect was exactly, but I knew it would be difficult to resolve and for the baby to have a decent quality of life. I was quite clear that just on that alone without the syndrome it would have been a tough decision. We got the result on the Friday, and we were in the clinic on the Tuesday, so it was only 4-days.

We were booked in for mid-morning. So, we headed up there and when we arrived, we let them know who we were, and I was pretty upset. They took me out the waiting room very, very quickly which was good. We had very experienced midwives with us, and I think it was the staff midwife who greeted us. They put us in an exam room as they didn't have a delivery room available just at that time. It was probably 2 or 3 hours before we were moved to delivery suite. So, we had quite a long wait where we were just in limbo. We were moved into the delivery room, and we'd already had cannulas and every blood test. That was where they put the pessaries in and then they left us. As a much younger person I had had an elective termination for very early pregnancy, and it was the same process. It had been a medical induction and so I was quite familiar with all that. What I wasn't prepared for is how different it all is that far through pregnancy. I was just expecting to sit down on the bed for a bit and then gets a few cramps and then everything would start. Instead, people were talking to us about having my overnight stuff saying that we might be here for a while. I just wasn't aware. I had brought some overnight stuff just in case, but I wasn't really, prepped for that. We started realising this wasn't going to be done by the end of the day which is what we expected. Not long after this there were a few cramps coming and I got quite ill and started feeling very nauseous. I was quite sick. I think we must have started pain relief quite early because it was quite a difficult process. They'd sort of left us for the first hour just to let everything settle but within the hour we had them back in the room because I was just so unwell. So, we were on morphine quite early, and I pretty much was bed bound through the sickness and the pain. I was on fentanyl the whole -time and they'd given me paracetamol and everything else as well. It was just very tough because it seemed as if we needed a lot of pain relief through those hours. We started the induction around midday, and he was delivered the next morning. I was very dazed, and I couldn't eat anything. My husband was just constantly worried because I just was so sick and in so much pain. I know that at one point, because there was the scheduled re-dosing of the oral meds and we refused a few of those doses because I was in so much pain. I felt that the less experienced midwife had been given a schedule and was told to follow this process and was scared to jump away from that.

The more senior midwife had looked at the situation more holistically and said that I seemed to be progressing. They warned me if everything stops completely, they'd have to start off again.

The cramping was so frequent. I know at one point as we were getting closer to actual delivery, a younger midwife was put in our care and was insistent that I took the meds. The misoprostol really didn't go well and made me extremely ill. A senior midwife ended up coming in and I think that was close to when we transitioned. At that point, they were trying to get more pain relief for me but there was no anaesthetist available because they were all in theatre. Earlier in that process we'd seen the anaesthetist and they said that they couldn't do much as we had the fentanyl running. I asked them if I could have an epidural. It was a very junior anaesthetist who said that his senior was in theatre and that he'd go and talk to them and that was the last I heard from them. I felt very helpless in a lot of ways, and I was just being given a lot of opioids and feeling so ill and wanting this whole thing to be over. At the same time, I wanted to cherish those last memories. So, it was just very, very difficult. Once the delivery happened, suddenly it was just a relief, and I was flooded with hormones. It was beautiful. The midwives were so caring and so peaceful. They tucked him up, left him with me, and they just left us, they just quietly walked out and just left us with him. After all the struggles, it was just such a beautiful moment. It was worth it in the end.

I think, the initiation of labour was too quick. I feel like I went from being very comfortable to being very uncomfortable and it was a very prolonged period of discomfort. One thing that I felt was that I just hadn't been prepared that it was a labour. I was going in there thinking that this was a few hours, and I was going to cramp a bit. It was a bigger baby, so you know it was going to be a bit of discomfort with the delivery itself. I just wasn't expecting that whole early phase leading up to actual delivery to be so uncomfortable. I think that's what really threw me. The main thing was just feeling so ill, the whole time and I was in a lot of pain and the only relief I could get was to have things that made me ill. I think that was the thing with the whole induction... I just felt sick. I felt awful and rotten. Yet I was appreciative that I was 'with it' and I gave birth. I know if it had been earlier, we would have been offered a Dilatation and Curettage (D&C - a method of evacuating the contents of the uterus using suction Abortion Services in New Zealand, n.d.) and that would have been completely pain free. It was better for me to have gone through the process. The induction process made me very uncomfortable; it caused a lot of pain and sickness and that made the whole process so hard. The whole day was just emotional. I hadn't elected for me to decide. I could still feel my baby moving and I knew this was going to kill my baby.

Every decision I made I knew I was doing it for the right reasons, and I didn't question why I was doing it and I never once thought that I shouldn't do this, but I knew what I was doing, and it felt awful.

When we went for our initial appointment with fetal medicine, they said there were lots of things going on and we would need to see a cardiologist before we knew the extent. The idea of termination came from me, and I felt it was my choice. Having had such a late diagnosis, I didn't feel like I had a lot of time because the viability of the baby. I knew that would be lot more controversial and so the choice was taken away from me, and it was a hurried choice because of that. I didn't have time to sit back and think about it. I also know that I'm someone who does tend to make decisions quickly. But I never felt that I was being pushed. I distinctly remember the fetal medicine team telling me that whatever decision I made they would be supportive of it. I honestly believed that at the time as well.

My midwife was on leave. She contacted me when she got back and that was the day we went in for the first tablets. Her backup midwife had stayed in contact with me the whole time, and she had walked us through it. I'd never actually met her in person as this had all been over the phone. She was the one who was chasing up all the results for me. She was the one who rang me first with the result. She was very involved, and she went on to be our midwife in subsequent pregnancies because of the good relationship we'd formed. My main midwife did visit me and she talked through a lot of stuff. She also was very supportive but it was just unfortunate at the time she wasn't available.

When I first saw Bernard, I got such an oxytocin surge, I just was in love. I didn't feel sad. I was proud of him. I didn't care that he had an abnormal face he was my baby and I just loved him. My partner cut the cord. Initially when Bernard was delivered, he was put on me and we all sat as a family, embracing. Bernard was with us that whole time. I sat for quite a bit with him, and my husband held him and then we put him in the special cot. He slept beside us for the night. We were just all exhausted. When we woke the next day there was no hurry for us to move and my husband spent quite a lot of time with him, holding him. My husband was very involved in the whole thing.

The next day they arranged for handprints to be done. He was taken out of the room, and I didn't appreciate at the time that I could have gone with him. They dressed him, which was lovely but, in hindsight, I didn't feel at the time that it was made clear that I was able to go and do that process with him. That's probably one thing that I wish I had done. Then he was returned to our room, and we had the heartfelt photographers come and my in-laws came to visit as well. Around midday we felt like we were ready to go. They were in no hurry to move us they said we could stay another night with him if we wanted to. I made the decision to leave Bernard at the hospital. My husband wasn't sure, but I thought this was the best way to do this. So, we left. Then, overnight, I didn't feel right about it, so we went back and got him and brought him home. The staff explained to me that he will change. They were right and as he changed, I felt ready to let him go.

So, we brought him home and several friends asked to see photos and to meet him. We opened our home and had an open casket for him. That was just incredible because we had so many friends come, and we put him in his little cot. I completely left it up to everybody so they could visit him or just come into the house. I had a friend who read him a story. That was so beautiful. We were so pleased we did that.

Everyone around us knew we were pregnant but we hadn't made a lot of announcements to people we didn't see regularly. How do you tell people when a lot of them are only just finding out we're pregnant? I contacted my family pretty much straightaway as soon as I knew there were abnormalities, and my partner did the same with his family. They were all aware of what was happening and very supportive of the decision we were making. I had a couple of close friends that I talked to, and my workplace were aware because I was still working. They all knew what was going on. Most of our friends we didn't tell until the delivery. We never felt wrong about our decision, and we never felt judged. It was their problem if they weren't happy with what we decided, they weren't in our shoes. But there was more to it. There was just so much else to think about and so much emotion and everything going on that we needed to just get through the delivery before we could start talking and handling that process. We hadn't lost him at that point, and we needed to just have that time to ourselves and not have lots of people around us. We wanted just that quieter time. I remember the whole thing very, very clearly, it's just etched in there so, so clearly.

We have a photo book and a memory box. We have teddies and things, and I have all the letters that people wrote. Just all the little bits and bobs associated with Bernard's birth, and when we had the open casket, we invited people to bring him gifts. They were with him when he went to the cemetery and to the crematorium. We kept his ashes, so the memory box also has his ashes in it. The funeral director warned us that with such an early birth that there wouldn't be a lot of ash. They said if you do want to have more ashes to do some rituals with then we were best to use extra bedding and toys. At times I think that a lot of these ashes aren't him but the ashes were also the gifts and letters. To me they were the love. That was important that Bernard's ashes aren't just his ashes – they're the love as well.

A friend of mine said that her horse had just been broken in. I was very early pregnant, and she asked if I wanted to sit on her horse one day. I hadn't told her I was pregnant, so I went and sat on this horse and had a little walk around and then afterwards I fessed up to her. She was so excited. Then when we lost Bernard, she told us that she going to bring a lock of the horse's hair because she's the horse that Bernard rode. It was special things that family and friends brought that went in the casket. Things like rosemary. It wasn't even that there was a lot of it, but it was all just personal stuff. That helped us, you know feel that warmth around us. That was like such a good experience for us because we didn't feel isolated. That was a huge thing. We didn't talk to people a lot before it happened but then friends flew from across the country and just so many people just opened their arms to us and were so lovely. Even people getting in contact who'd had their own losses but hadn't talked to anyone about it and just wanted to let us know that they didn't understand our loss but they understood loss. I think the biggest thing was that whatever our experience of loss is, whether we lose a pregnancy or a baby, we find it hard to talk about it but. My experience just taught me that that's not the right thing to do because as soon as you do, you just are so supported. The only thing I would say is I think we found it easier knowing that we had a fatal diagnosis.

That's one thing I've always looked back on because my family over in the UK talked to family and friends and they didn't tell them what the reason was and a lot of them just presumed that it had been Trisomy 21. I think, that would have been harder to talk to people about and it would have been a harder decision. I always felt in some way a bit lucky that it was a fatal diagnosis we received because it made telling everybody easier because we had a very justifiable reason.

So, I go back to the choices and decisions and how we got to that place, and I think working in an environment where euthanasia is a common discussion, and I saw it more as euthanasia than a termination, I just thought if this situation presented to me, I wouldn't want what's ahead of us or what's ahead for our child sugar coated. I realised that not everybody would understand that decision as well because everybody comes into those discussions from a different viewpoint.

A lot of the midwives who cared for us talked in very similar ways during the birth and afterwards that it was the right thing to do, and the experienced midwives coming and telling you that, you know it's such a kind thing to do to not put the baby through all of that. It just felt to me that if we continued and we'd had a live birth and we tried to help Bernard or even just make him comfortable until he drifted off, however we were going to do that, that was going to be uncomfortable for him. You can cuddle and you can love and everything else, but in this situation it was never going to be OK.

We do a lot of diagnostics and we're more likely to find these things out and that means a lot more people go through a lot of distress, but I think we're empowered provided everyone has a choice and understands what they're doing.

Bernard's story is a little story but it's a big story at the same time. It's not a very long story but it's huge in our lives. He was moving right up until I started to transition even though he wasn't much of a mover. When he was born, his hands were in that same position as in the scans. One of his little hands was over his face and one was over his heart. He obviously had just been like that the whole time. We never met him as a moving living baby, but you could just know that he wasn't going to be a wriggly little baby. He had so many things that he couldn't tell us. It wasn't just his heart, it wasn't just his cleft, he was severely ill.

Regret is not the right word, but I don't look back and wish that had never happened. I don't wish we'd never had that pregnancy. I look back and I'm grateful for it, but I wish it had gone a different way. It's funny when you talk about choice because I didn't really have a choice. I had options and I chose the option I was most comfortable with. People talk about choice, and they're not being given a choice, and I think well actually, very rarely does choice mean that you get what you want. People say you choose to let your baby die but I was given the options of having a baby who would likely die anyway. I did it to try to not put him through anything more and to try to save him from suffering. I also looked at it from my own health and my family's health. With a later term delivery, I was more likely to have complications, that I wouldn't have a future family or have some sort of damage. I had to go through this with my husband who must deal with this afterwards as well. I have family overseas and I need to be healthy and come out of this okay for them. So, I did look at it from that angle because why would I risk a full-term birth for potentially a lot more risk? It sounds a little bit selfish, but I felt it was important to not forget what's the safest situation for me as well for a pregnancy and a birth that's not going to bring me a healthy child.

Bernard is still with us. We don't know whether we'll keep him with us forever. Potentially he will be buried with us. His photos are everywhere, his birth poster with all his details is up and we talk about him, so he's very much known to his younger brother. It may well be something we discuss with them as they get older, as the family gets older because he's their brother. I think it's important that they grow up knowing that. He was severely affected; he was obviously a tough little bugger. Bernard shouldn't have been here. He was obviously a strong character even though we never knew his character. I feel good has come from his life – it really was, and it brought us closer with friends and family.

Moments

Katie 1: A Moment Without a Compass

> *When they finally got a little snippet of his face on the scan, they found a cleft. At that point it just changed everything. The mood in the room just completely changed. We were left not knowing what to do with suddenly being told that there could be a major problem here. And then my midwife was on holiday, so I didn't have her to ring. We were just left.*

Although there was no intention of the sonographer or her midwife deserting Katie, the feeling of being abandoned was still very real for her. For Katie, she felt as if there was something bad happening, but she was not included in the secret. This feeling of impending doom was highlighted with Katie's perception of a change of energy in the room, a tension that was unspoken but so obvious. Katie felt ill-at-ease but had no explanation of why, other than being told that there was a problem with their baby.

The sense of 'everything changing' would have turned Katie's world on its head. Nothing was the same, nothing could be assumed or relied on. What she had anticipated was no longer a reality. The unsettling thing was that because everything had changed Katie was now forced to change as well. Her pregnancy had taken an unexpected and unknown path and that would have felt like she was floating in the ocean without a compass.

Katie 2: A Moment of Illusion

> *We went up to the fetal medicine unit and it was quite clear that there was something significant going on.*
>
> *They told us that our baby was going to need a lot of intervention with a lot of other specialist teams. That was the point where I said, if this baby is severely affected by something, can I elect to terminate? We got the result over the phone later that week and unfortunately it was confirmed as T13. We'd both decided that if it was a fatal syndrome that we would elect to end this pregnancy and not put our little baby through it. I always felt in some ways a bit lucky, that it was a fatal diagnosis we received because it, it made telling everybody and everything easier because we had a very justifiable reason. I didn't have a choice, I had options, and I chose. I think, in these circumstances, 'having a choice' does not mean that you get what you want.*

Katie acknowledges the illusion of choice as, in fact, she didn't have a choice; rather, options which, ironically, would lead to the same outcome. To have a choice, Katie believed would entail deciding between two or more possible paths. Knowing that her baby had an un-survivable condition, the possibilities may seem, to the onlooker, to be about choices but there were no meaningful choices for Katie. The term 'between a rock and a hard place' seems relevant in this situation as there was nowhere for Katie to go that would give her a softer place to land. The paradox of Katie's decision making was in effect deciding when to end her son's life rather than if his life would end. Regardless of what Katie decided to do, her son was not going to survive; therefore; her choices seemed futile.

For Katie to decide on the timing of her son's birth and death she may have felt that, in fact, she was limiting other choices she may have. That is, time being pregnant, time to prepare for his death, and even time to *know* her son. These may reflect life changing consequences for Katie and this, no doubt, added tension to her decision making, whether she was cognisant of these factors. To be able to openly talk about why she was ending her pregnancy, Katie felt 'lucky' that her son's diagnosis was a fatal condition, so she was less likely to have to explain her decision and it would lessen the risk of others judging her supposed 'choice'. It was as if having a justifiable reason to end her pregnancy made it seem to others as she was making the 'correct' choice.

Katie 3: A Moment of Helplessness

> *I think, the initiation of labour was too quick. It went from being very comfortable to being very uncomfortable. I just hadn't been prepared for it being a labour. I think that's what really threw me. I was going in there thinking that this was going to be just a few hours and I was going to cramp a bit and it was going to be slightly uncomfortable.*
>
> *I had morphine quite early. I was bedbound because I felt so sick and because of the pain. It was very tough because I needed a lot of pain relief. I was very dazed. My husband was just constantly worried because I was so sick and in so much pain.*
>
> *I asked about getting an epidural. I spoke to a junior doctor, and he went off to talk to a senior doctor, but I never heard back from him. I felt so helpless, and I was just given a lot of opioids. They made me feel so sick and I wanted this whole thing to be over but at the same time I wanted to cherish those last memories.*

Katie hadn't really comprehended what was going to happen during her labour. The unknown-ness would have been unsettling and when it happened so quickly, she just was not prepared at all. She felt *thrown* into a labour that she believed would be quick and uncomfortable, at worst. Instead, she found herself in an alien world where she had no control; a long, painful, and bewildering experience that left her feeling unsure what was happening to her. Even the pain relief added to her distress by making her feel so sick and seemingly not reducing the pain she felt. Her feeling of helplessness of having her request for an epidural ignored would have , again, added to her distress; as indicated by her having done what she could to gain help with managing her labour but still she felt unheard. How was she meant to cope with this overwhelming situation if no one was acknowledging what she needed? She was left to face her suffering without anyone truly understanding what she was going through. Perhaps those caring for Katie felt they were giving her everything she needed to help her cope but, from Katie's point of view, none of this met her needs. It would have left Katie feeling as if she had lost control and was a continuation of her powerlessness throughout the whole situation.

The irony for Katie was that while she wanted the pain and sickness to be over, she wanted to have fond memories of the birth of her son. She wanted to treasure and honor his birth and his death but instead she was desperate to get through the misery of the labour.

Katie 4: A Beautiful Moment

> *Once the delivery happened, suddenly it was just a relief, and I was just flooded with hormones. It was beautiful. I remember the first time I saw our baby, Bernard, I just was in love. I didn't feel sad. I was proud of him. I didn't care that he had an abnormal face, he was my baby and I just loved him.*
>
> *My partner cut the cord and then we all sat as a family, embracing.*
>
> *The midwives were so caring and so peaceful. They tucked him up with me and they just left us, they just quietly walked out and just left us with him. After all the struggles it was just such a beautiful moment. Just holding our baby. It was worth it in the end.*

Thankfully, Katie remembers her son's birth as peaceful and beautiful. She was overflowing with a sense of relief that finally she had her son in her arms. Despite her son being born still she was still in a euphoric state of hormonal bliss. Just like any new mother, she was bathing in the beauty of the moment of holding her baby. After all the anguish she had gone through, she could finally put all her doubts and worries to one side and just be in the moment with her boy.

Katie 5: A Hurried Moment

> *I didn't want to make the decision but ultimately it was my choice. Having such a late diagnosis, I didn't feel like I had a lot of time to decide. The viability of our baby was going to be a lot more controversial. That's where the choice was taken away from me. It was a hurried choice because of that. I didn't have time to sit back and think about it,*

> *but I never felt that I was being pushed. I knew I was doing it for the right reasons, and I didn't question why I was doing it and I never once thought I shouldn't do this, but I knew what I was doing, and it felt awful.*

Having to make, what Katie interpreted as, a snap decision must have been one of the most difficult yet straight forward of decisions for her to make. While this may seem contradictory, Katie felt her decision needed to be made with haste to protect her baby from suffering. So, while she felt a decision was needed promptly, she knew in her heart what her decision needed to be. She never doubted her decision because her priority was to protect her baby; however, the reality of what she was agreeing to was not lost on Katie. She would have felt a readiness to move forward with ending this pregnancy for the sake of her baby. During this critical moment for Katie, she did not feel any outside pressure but a sense of urgency from within. This would reflect a concept of decisional certainty which, although offers some resolution to the immediate 'here and now', does not necessarily ease Katie's heartache at losing her baby. The irony for Katie was that she felt such a closeness to her baby by wanting to save him any distress while at the same time feeling a separateness, so she was able to cope with ending the pregnancy.

Katie 6: The Moment My Baby Died

> *I could still feel my baby moving, and with everything we were doing that day, I knew was going to kill my baby.*

This moment is undeniably beyond heart-breaking. The reality of what is about to happen is so profound it is difficult to comprehend. Each minute takes Katie one step closer to *not* feeling her baby move and acknowledging the end of his life. It seems as if time has been stretched out as if to elongate the intensity of what is happening in real time. Each second feeling like an eternity but, ultimately, ending in the moment her baby dies. The fragility of each passing moment, knowing that at any point her baby's heart will stop. Could Katie see this moment as a jubilation that reflects her baby's reprieve from his suffering? The oddness of a somewhat scheduled death cannot be denied but can only be accepted as the inevitable outcome.

Katie 7: A Moment of Knowing Bernard

> *He was moving up until I started to get very close to birth. When he was born one of his little hands was over his face, and the other was over his heart, and he obviously had just been like that the whole time.*

> *We never met him as a moving living baby, but you could just know that he wasn't going to be a wriggly little baby. He had so many things that he couldn't tell us. It wasn't just his heart, it wasn't just his cleft, he was severely ill.*

To Katie, her son Bernard was very real, and she could envisage what he would have been like as a living baby. Despite all the complications, Katie could see past those to what sort of baby he would have been, had he lived. This construction of Bernard's persona may have remained hidden or unknown if Katie had not seen him as her child, her son. This connection between mother and baby grew into their shared story; a story of how Bernard would have been a quiet, calm baby and how he would try to tell his parents about what was happening to his body.

Although Katie had lost Bernard, she would not lose her interpretation of who Bernard would have been as a baby. By devising a mental image of Bernard, she was creating a memory of him that was more than a tiny stillborn baby.

Katie 8 A Moment of Letting Go

> *I made the decision to leave Bernard at the hospital, so we left. Overnight though, I did not feel right about it. So went back to the hospital and got him and brought him home. They explained to me to expect he would have changed, and they were right. But as he changed, I felt ready to let him go.*

The final letting go of Bernard coincided with him changing from 'her newborn baby' to the 'body of her baby'. This transition of perception is what enabled Katie to let Bernard go. As she left hospital, she was leaving her baby and because this did not feel the right thing to do, she went back to the hospital to get him.

Katie 9: A Moment to Meet Friends

> *I had several friends who asked to meet him and so we opened our home and had an open casket for him. We invited people to bring him gifts or write him letters that stayed with him. That was just incredible because we had so many friends come, and we just put him in his little cot. I had a friend who read him a story, and it was absolutely beautiful. We were just so pleased we did that. I knew that a lot of the ashes were not him, but to me they were the love as well.*
>
> *I friend of mine remembered that I had sat on one of her quiet horses when I was only just pregnant. After that I fessed up to her that I was pregnant. When we lost Bernard,*

> *she said that she was going to bring a lock of the horse's hair because she is the horse that Bernard rode. Someone even put a sprig of rosemary into his casket for remembrance. So, it was special things that went in the casket. It was all personal things that meant so much. That helped us feel that warmth around us. We didn't feel so isolated by what had happened.*

For many bereaved parents, feeling alone in their grief is a reality. However, Katie and her partner felt those around them honored and loved Bernard and provided gentle and thoughtful support to them. For their supporters to show this level of acknowledgement of the monumental event in Katie and her partner's life, indicates their compassion towards them and acceptance of Bernard's brief story.

For Katie to gain such solace and meaning in their actions speaks volumes about the impact of those surrounding the bereaved family. These actions would reinforce that Bernard was real and his life and death mattered. They were able to see Bernard as the much-loved child of their friends and provide almost an on-going legacy for his life. By constructing the notion of *knowing* him before he was even born, enabled Katie to begin his life's story from early in her pregnancy. Little did they know that these memories would become so important in the near future.

Katie's sense of warmth around her resonates with the connection she felt with those supporting her. The sensation of warmth indicates genuine emotional support and a soothing presence.

Katie 10: A Moment to Catch Their Breath

> *We never felt wrong about our decision, we never felt judged. It was somebody else's problem if they weren't happy with what we decided, they weren't in our shoes.*
>
> *There was just so much else to think about and so much emotion and everything going on that we needed to just get through the delivery before we could start talking and handling that process. We needed to just have that time to us and not have lots of people around us. We wanted just that quieter time really.*

To walk in someone else's shoes is to experience what they have gone through and to get a glimpse of the holistic impact of the experience; that is, the emotions, context, meaning attributed to the experience as well as the back story of how they got to this position. Katie was content with how they came to their decision to end the pregnancy. Rather than dwelling on how they decided, she was able to rationalise what needed to be done for the sake of their son and his future suffering. She was able to trust her decision without regret or self-doubt. Instead, she was able to be guided by doing the right thing by Bernard, her son. Some would consider this an example of *a mother's love*, reflecting Katie's ability to know when to let her son go. She intentionally sacrificed her own need to have her living son in her life for his peaceful death.

From the time of making up her mind until the birth and death of her son, Katie was totally focused on getting through each moment. To protect herself from being so overwhelmed that she couldn't take the next step, she narrowed her vision to what was important in that moment. She put the emotions and heartache to one side so she could "manage the process". There is a thought that being or becoming a mother puts everything else into perspective and everything else disappears. For Katie, this concept rings true as she acknowledges that she let everything else disappear while she concentrated on Bernard. She needed to quieten the voices from outside so she could sit with what had just happened and begin to make sense of it. To do this herself she wanted to disappear or to retreat into the shadows to be able to catch her breath or to pause for a moment.

Katie 11: A Moment of Shared Understanding.

> *People just opened their arms to us and were so lovely. There were people who got in contact who'd had their own losses that they'd not talked to anyone about but just wanted to let us know that they understood what loss felt like. I think the biggest thing was that however we experience loss, lose a pregnancy or a baby, we find it hard to talk about it. My experience taught me that as soon as you talk about it you just, are so supported. People just want to look after you.*

The silence of their shared grief became apparent when one bereaved parent reached out to another. The loss of a baby, by whatever means, can stir some very intense feelings and memories in those with enough empathy to recognise what the loss meant. Katie did not comment on the sharing of how they lost Bernard; instead, just relished the feeling of support. To trust that others have been through this experience, and they are now opening their hearts to another parent can perhaps highlight their common stories of baby loss. Rather than feeling completely alone, the acknowledgement and honoring by others may offer some comfort, remembering that feeling alone in one's own grief while amongst others is entirely possible.

Katie understood that it is difficult to talk about losing a baby but is this because of the risk of opening their emotional wounds or because no one truly knows what it is like unless they have experienced this themselves? The concept of 'being or feeling looked after' implies that someone 'cares' for the person requiring looking after. It suggests that a person comforts and attends to that person's needs. This may be a pathway towards the beginning of healing as providing care concludes with the person feeling better or ‘healing’, if not fully but able to take some steps towards this. Even if this positive change does not happen immediately, the act of ‘looking after’ allows for a time of holistic ‘relief’.

Katie 12: A Moment of Looking Back

> *It’s been 3 and a half years since Bernard was born and I remember the whole thing very, very clearly. It’s just etched in there so clearly.*
>
> *I don’t look back and wish that it had never happened. I look back and I’m grateful for it. I do, however, wish it had gone a different way. It’s a little story but it’s a big story at the same time. It’s huge in our lives.*

Katie’s memories of Bernard’s birth have not faded; in fact, she remembers what happened very distinctly. As time passes, it could be expected that those memories might dim but, as Katie suggests, her memories are etched into her mind. It seems they have become part of her and part of her story. The feeling of Bernard being in her arms and the wave of love she felt when she saw him will surely offer her a deep connection to her son and a reminder that she is his mother and always will be.

Katie can reflect on the life and death of Bernard with a sense of gratitude. She wishes that it had turned out differently but nonetheless she can see past this to appreciate what happened and how she felt about it. She appreciated Bernard’s brief life story and felt a sense of acceptance of what had happened.

Interpretation of Katie’s Experience

Katie’s rendition of her story highlights her unpreparedness. Although she had been through what she believed would be a similar experience, what unfolded was nothing like she expected. From the time of diagnosis of Bernard’s fatal condition, through to the overwhelming feelings of love and pride for her son, Katie felt caught off guard. Everything was more intense, more potent, and more overwhelming than she had imagined.

To experience such a physically challenging labour and birth seemed to override her own sense of how she would cope with the known-ness of past experiences. She was taken aback with the reality of birthing her baby and was not at all ready for what happened. She used pain relief to help manage the pain, but nothing seemed to work. Instead, the medications just made her feel worse. Katie talks about ‘we’ are having pain relief as if her pain was shared by her partner. This ‘we-ness’ language is considered to indicate a shared responsibility and partnership which, in this context, may have been also a coping mechanism for Katie (Sabu, 2022). This language could also reflect a collective experience that offers Katie a sense that she is not alone.

Although many of her friends and family knew about the circumstances of Bernard's birth and death, Katie still felt cautious about sharing her story with everyone. Not because she was fearful of judgement; rather, she was comfortable with some people assuming what had happened. She believed that those who were not directly told why they had ended the pregnancy would make up their own version of the story which would, in turn, release Katie from having to explain, time and time again, what happened. It could be seen as a chosen silencing of Katie's story. Others' conclusions would develop unaided by Katie or, in fact, reality.

Chapter Summary

This chapter told Katie's story of losing her son, Bernard. It offered an interpretation of her story, along with 12 moments highlighted within her story. Throughout the re-telling of her story, Katie appeared to mainly flow with the chronological passing of time. For Katie, this may have been how she recalled what happened and was able to show the stepping *through* the experience.

CHAPTER SEVEN: PAIGE: HARPER GAVE US THE OPPORTUNITY TO HAVE CHILDREN BECAUSE SHE LET US KNOW ABOUT THE GENES WE CARRY

Introduction

Paige was pregnant with her first child, Harper, when, at her 20-week anatomy scan, it was discovered that her daughter had some major abnormalities. She had a condition called Meckel-Gruber or Joubert syndrome. By the time this diagnosis was confirmed, Paige was 25-weeks pregnant.

Paige's Story

It was an unexpected pregnancy! I found out we were pregnant in April 2017, with Miss Harper. We eventually went in for the 20-week scan and the lady doing the ultrasound realised that there was not any fluid inside the sac. She left the room to get a supervisor who came in to check. It was so traumatic how they went about it. She just said, "I'm really sorry there's no fluid in the sac". I asked what that meant. We were then referred to Auckland to have another ultrasound with a specialist to see why there was no fluid. At the scan up in Auckland they identified no fluid, and both kidneys were full of cysts. She had a bit of fluid in the back of her head and her kidneys had grown so big from cysts they were squashing her lungs, her heart, and her bladder which was causing the lack of fluid. So, we were given three options after that scan. Either continue the pregnancy and try to get to full term and see what happens or continue with the pregnancy and then most likely have a miscarriage, or, finally, terminate at this point in the pregnancy. This was at about 24-weeks into the pregnancy. We had a meeting back at Waikato Hospital the following Monday. They gave me some medication and told me to come back on Wednesday, 2-days later. We asked why we would be coming back on Wednesday. The woman told us that we'll be having our baby on Wednesday. So, then we got induced 7o'clock in the morning. We had her at about 5.30. It was very quick. They said that she had a condition called Meckel-Gruber or Joubert syndrome and there's not really many cases of it. It seems that both my husband and I carry this gene which apparently is about 1 in 800,000 chances of it affecting a child. She ended up going up to Auckland so they could do some tests to find out everything that they could. They told us that if we were to fall pregnant again there was a 1 in 4 chance that it would happen again but now that we've gone through IVF that our chances are a lot higher because Ivy carries the gene that we carry. We had 8 eggs tested and out of those 8, 5 of them carry the same gene as Nick and me.

We got to have her at home with us for a night and then we had her cremated. So, we had her at 26-weeks gestation. She was quite big, and she was very long.

Our understanding of what would happen was very basic. I recall one of the medications was to slow down her heartbeat. I'm not too sure exactly if they were waiting for it to be like a stillbirth... I'm guessing. And then I'm not too sure what the other ones were for.

Apparently, she took a few breaths once she was out, so she was born inside her sac as well, so she took a few breaths and then she kind of just went.

I think at the time I didn't really process that it was really happening because everything happened so quickly. In hindsight that was an absolute blessing because if they had given me more time to think about it, I would have freaked out and said that I couldn't do it. So, it was the appointment in Auckland on the Friday, and they offered us time to think about what choices we would like to make. We just looked at each other and we said we need to do this now. All the symptoms and everything that she had, we felt that it wasn't fair to try and bring her into this world where she's just going to struggle. From what they had told us, the diagnosis was an extremely severe case. They said to us that if we did make it to term, the chances of her being able to breathe on her own was very, very slim and there was a very high chance that she would pass away anyway. Being told that, we could not put ourselves through a full-term pregnancy knowing that we are not going to have a child at the end.

So, on the day, we were put in a special room where these types of births are done. The day was very full on, and it all happened so very fast. It was quite overwhelming as well because the hospital had given us the option to have family there. Now, looking back at it, I would change my choice of having the whole family in the room. So, it was me and my husband, both of his parents, both of my parents, and both sets of his grandparents, both of his siblings, and our sister-in-law. I also had my best friend there as well. There were a lot of people. It was very beautiful because everyone then got to meet her, but then there were a few other people as well. Some of our friends also decided to invite themselves to the hospital. The hospital just let them in without our knowledge and I wondered why there were all these people. I was quite comfortable to have everyone there because the room was so large. I didn't have anyone near where my husband, the nurse, and I were. So, I guess I did feel quite secure in my situation. But also, I knew that I had the support there if I freaked out. It was weird though. When I got to the point that I was ready to push, I didn't even think of who was in the room. I was also on morphine as well, so I didn't really process what was happening. I just focused on the nurse. Then my husband's brother and his wife left the room because they weren't comfortable being in there while I birthed her. Everyone tried to make light of the situation. The nurse said, "the head's coming, does anyone else want to have a look". My best friend came and had a look and she said, "oh it's fine we've all seen it before Paige". I just thought, "let's get this done".

It was all very nice, a good situation and process until the shift change over at the hospital. Earlier in my pregnancy, I was feeling very unwell, so I went up to the hospital. The nurse who cared for me was very rude to me. Unfortunately, on the day we had Harper, once the shift changed, we ended up having her care for us. I had a massive mental break down and I looked at the nurse and I just couldn't have her in the room with me. I couldn't even explain why I felt like that. So, eventually, my mother-in-law, went out into the corridor with her but she was told that I didn't have a choice; she had to be my nurse. After the birth she apologised to me and said that she felt horrible for what she had said to me previously. In the end she was amazing throughout the process but knowing that she was coming in really freaked me out.

By the time I got to the hospital, at 7am, I just wanted this over with. I didn't realise how quickly everything would kind of kick in. By 9am I started getting contractions. It was a very, very quick process. It was so nice and to be able to have some time with her, prior to having to send her off. We got out of the hospital at 11o'clock that night so it ended up being a such long day and we had her at home for the first night but then we had to have her back at the hospital by 7 in the morning for her to be transported up to Auckland. We got her back again that night, which was cool.

I can't remember when I needed the morphine. If it was right from the beginning or not. I just know that I went through a lot of morphine, and it was useful. As soon as I'd had Harper, I think within about half an hour I just felt so gross and needed to get in the shower. While I was in the shower I was just standing there vomiting and had blood clots absolutely pouring out. Which I then decided that I'm never having morphine again because it made me feel horrible. I felt great during it but afterwards I was like this is not okay!

Everyone was very supportive of the choice that we were making because everyone knew what else could happen. Within our family we all had a very similar outlook, especially if a child is not going to have a proper quality of life. It would not have been great for her to be hooked up to machines for her whole life.

It's coming up 5-years since we had Harper and during this pregnancy with Ivy I had some real tough moments. My husband wanted to know why I was finding it so hard. I really struggled to wrap my head around it because we had Harper and they did all the testing on her. Now we had Ivy and if we had never gone through that with Harper we probably would have been dealing with that now. Harper gave us the opportunity to have children.

So, because they did all the research, they said that I carry the gene and my husband carries it. Also, one of each of our parents has got it and so forth throughout the generations. I realised that this condition hasn't just come from us. It's throughout our whole family but we've never heard of anyone in either of our families ever experiencing what we'd experienced. It gave us a fright when we got told what the chances are of it happening again. I was like wow. It is crazy how everything works.

When I was getting ready to birth Ivy, I said to Nick that I remember how I felt when birthing Harper. I remember with Harper I was so ready to have her and to meet her. I wanted her with us. We were told what her physical appearance could be like. We were told that she would possibly have a lemon shaped head which wasn't the case. It wasn't as bad as what they had assumed it would be. Then, her chest cavity was sort of outwards, even round due to the size of her kidneys. She still looked like a normal baby. But there were no real physical differences.

It probably made it harder to process why we had to do it because we knew that inside wasn't good. So, I think it just made the process a little bit harder in the long term. Her size was like a normal baby, for her gestation as well. When I knew she was coming I was scared because I freaked out about her just coming out. The nurse had told me that because of her size I wouldn't need to push much, and she will just come out. We were also very surprised that she came out in her sac. I didn't see her in her sac because they took her out of her sac, and they rubbed her off a bit and then they put her on my chest and wrapped her up. So, it was nice to still have that moment, just like a normal birth. I don't recall having a specific emotion at that point because I think I was still trying to process that it was really happening. Once, I'd say probably about an hour or two after the birth I really clicked on to what we'd just been through. I just felt quite broken. I think it took a while for me to get some time with Harper because they wanted the family to leave, and she got passed around everyone for them to have their time with her. It was after that I started to process what was going on. Seeing her with everyone made it real, I think.

I think everything really kicked in after we'd taken her to the funeral home. That was when it became so real. I know that both my husband and I didn't emotionally process what we'd been through for at least 4-years. I think afterwards, we kind of just decided to block it out. I hadn't been on any contraception and then in 2020 we fell pregnant. I had a miscarriage on my husband's birthday. That was when we decided to do IVF. We hadn't fallen pregnant for 3-years, so we wondered if maybe Harper is telling us that we're not ready. It wasn't until after that that we decided we needed to seriously process what we'd been through.

We were quite open with a lot of people about the decision but now thinking back to it I think I hadn't processed what I'd been through. I knew I'd been through it and what happened and why it happened, but I hadn't emotionally processed it. It was a massive thing.

When we first found out what was ahead of us, we did think, why us? Why are we the ones going through it? When we went into the room where we were going to have Harper, they've got this massive board behind the bed, with images and notes from women who have also birthed their babies there and have lost them. So, you walk into the room, and you realise that we are not the only ones going through something like this. We are not alone in this. It is quite odd but not a lot of people will talk about it. Which then, to a lot of people, makes them feel like they're the only ones going through it or that no one else has ever had to deal with it. I think people are scared to talk about it. I don't want to talk about it if there is surrounding judgement. No one wants to openly talk about it. A lot of people do have their own viewpoints on it.

Something that really bugs me with a lot of women these days who are quite young and they just get pregnant, they just don't process anything else that could happen. For people like me who go through IVF because they can't or shouldn't conceive naturally, it seems that other people don't realise how hard it can be to get pregnant. Sometimes it's the only thing that a woman wants. I guess that's where we got so lucky because we had one collection, one transfer, and got pregnant. I have struggled to see other women doing 5 or 10 cycles, and still haven't got their baby. I just couldn't imagine how we would have felt, if we didn't get that phone call saying that we are pregnant.

I think I mourned for a little while. I struggled with everything that we had to go through. I did not want to go through what we went through with Harper. Going through IVF I always knew that I was going to mentally struggle because one of my biggest fears is needles. We're going to go through this whole process and what if it doesn't work? I'm producing this child through hormones and it's a lot of work to get to that. It was not only hard for Nick and me, but it took me awhile to realise how much it had affected our extended family. My husband's brother, they've been trying to conceive for 10 years and, then this whole fear came around the family and our siblings because they could carry this gene too.

I'm so grateful that we still have these memories with Harper, and we've still got her with us. Nick and I have both decided that Ivy will know about Harper. Harper is still our daughter.

Paige 1: A Moment of Truth

> *We went in for the 20-week scan and the lady doing the ultrasound realised that there was not any fluid inside the amniotic sac. She left the room to get a supervisor. It was traumatic how they went about it. She just said, "I'm really sorry there's no fluid in the sac". I was not sure what that meant. It turned out that both of her kidneys were full of cysts, and she had a bit of fluid in the back of her head. Because her kidneys had grown so big from cysts, they were squashing her lungs, her heart, and her bladder which was causing the lack of fluid.*

When Paige found out that there was something wrong with her baby, she felt distraught. Not only with the bad news but also the way the news was conveyed. Although the sonographer told her the truth, without any malice, the words still distressed and confused Paige. She heard them but could not make sense of their meaning. Her disbelief of what was happening affected her ability to grasp what she was being told. Perhaps, in any other circumstance, Paige might have been able to interpret what was being said; but, in this instance, she was not prepared for the news, and she felt blind-sided. Urban myth suggests that when the sonographer leaves the room to get someone more experienced, the news is often bad. This is what Paige experienced.

Paige 2: The Moment of Supposed Options

> *We were given three options after that scan. Either continue the pregnancy trying to make it to full term and see what happens or continue with the pregnancy and most likely have a stillbirth or terminate at once. I was 24-weeks pregnant by this point.*
>
> *They told us that we can have time to think about it and make up our mind on what we would like to do. My husband and I just looked at each other and we said we need to do this now. It's not fair to bring her into this world where she's just going to struggle. From what they had told us, she had an extremely severe case.*
>
> *If a child is not going to have a proper quality of life, then I do not believe it would have been great for her being hooked up to machines for her whole life.*

How does it feel to even be in the situation to have a conversation about the option of either continuing a pregnancy or ending it? To get to 24-weeks into a pregnancy and then discover that your baby is doomed, this is surely such an unexpected situation to be in. Paige had clear thoughts about their baby's future quality of life which made the decision more straightforward, and it could be made in good faith. This is not to say that the situation was straightforward, but the decision making was.

Paige was able to use her heart to make the initial decision and then justify it with logic. She desperately wanted to avoid their baby suffering and she knew, from her diagnosis, that she was likely to have an extremely poor quality of life, if she survived at all. In this instance she could listen to both her heart and mind. By having this heart-mind synchronicity, she was able to gain a sense of certainty and clarity.

Paige 3: A Moment of Unknown-ness

> *They gave me some medication and they told me to come back on Wednesday. We did not even know why we would need to come back. I asked, "What is going to happen on Wednesday?" She told us that we will have our baby on Wednesday. I think one of the tablets was to slow down her heartbeat, I am not entirely sure. They were waiting for her to pass away before she was born, like a stillbirth. That is what I was guessing. I am not too sure what the other tablets were for.*

Paige describes the embodiment of *unknownness,* unsure of what was physically happening or about to happen to her. How could she be given medication to end her pregnancy and this lack of critical information be unacknowledged? Paige unwittingly finds herself in a place-in-between-places; that is, where others assume her position while she is unaware of her position. This *in-between space* appears murky, where her knowledge is mismatched to what others believe she knows. Is this because she has not grasped what is about to happen or have others informed her in such a way that she did not comprehend?

Paige was willing to trust that those providing her care were trustworthy. To Paige, this was plausible as they were the experts and knew what they were doing. Whereas she felt her trust was justified as she had never been through this before and had no idea what was going on, except that she was ending her pregnancy. If she could not trust the 'experts' then who could she trust? Perhaps she could see that both her and those caring for her had the same intentions, so she had no reason to mistrust them, and she followed their lead. Without trusting those around her she would not be able to stop her unborn daughter from suffering. Some may peer into this situation and see a naivety in this level of trust but what choice did Paige have? Her vulnerability forced her to trust others.

Paige 4: A Moment of Making an Invisible Bond

> *Why are we the ones going through it? We went into the birth room, and they have a massive board behind the bed with images and notes from women who have also birthed their babies there and have lost them. You walk into the room, and you realise that you*

> *are not the only ones. Not a lot of people will talk about it. Which then makes them feel like they're the only ones going through it or that no one else has ever had to deal with it. I think people are scared to talk about it. No one wants to openly talk about it.*

To believe that you have been singled out to go through something so traumatic as losing a baby must be the epitome of private suffering, especially when you think that you are alone. As if your pain is penance for a bad deed that you do not remember committing. For Paige, to see the faces of others who have also suffered the loss of a baby, must have given her a sense of solace, of knowing that others have gone through what she is going through, that she is not alone. Even though the other parents were not physically with her, she could perhaps feel a sense of connection and togetherness. The notion of support from strangers was unexpected but highly valued by Paige. She no longer needed to feel so alone and knew that others had gone through this shared experience. For a moment she could focus on feeling propped up rather than of being dragged down into an unknown and scary place.

Paige 5: The Fearful Moment of Birth and of Tranquil Death

> *She was born inside her sac then she took a few breaths and then she kind of just went. Everything happened so quickly which, in hindsight, was an absolute blessing because if they had given me more time to think about it, I would have freaked out and said that I cannot do it. I was scared. The midwife said that I would not need to push much because of her size. She said that she will just come out and it would not be hard. That freaked me out. Knowing that she would just come out. So, it was like a normal birth. They took her out of her sac and then they put her on my chest and wrapped her up. It was nice to still have that moment. I was trying to process that it had really happened. About an hour or two after the birth I really clicked on to what we had just been through. I just felt quite broken.*

Paige had been *waiting* for this moment, even though she was unsure how it would unfold. As it turned out, Harper's birth and then her tranquil death was understated. Paige remembers the birth happening so quickly she did not have time to overthink her decision. To her, the quickness seemed like the universe was doing her a favour as she felt she might not be able to continue if it had been drawn out.

Paige expressed her fear from the innocent remarks of the midwife. While trying to reassure her that the birth would be rather effortless, she, in fact, frightened Paige with an image of the baby suddenly appearing. Again, Paige was unaware of what she was about to go through so imagining that her baby would abruptly materialise gave her a sense of unpreparedness which scared her.

Ultimately, Paige's memory of the moment Harper was born was one of peace and even normality. What happened after the birth enabled her to spend some time with her baby, just like any other mother. However, she still found herself in a fog of reality, trying desperately to make sense of what had just happened. It must have been overwhelming to realise that she was now a mother, her baby had been born and had died, all in a matter of moments, or so it seemed. As she was thrown into the acute awareness of what had happened, she broke.

Paige 6: An Unplanned Public Moment

> *It was quite overwhelming because the hospital had given us the option to have family there. Looking back at it, I would change my choice of having literally the whole family in the room. So, it was my husband and me, both of his parents, both of my parents, and both sets of his grandparents, both of his siblings, and our sister-in-law. I also had my best friend there as well. Then there were a few other people from our friend group who decided to invite themselves to the hospital as well. The hospital just let them in without our knowledge and I wondered why there were all these people?!*
>
> *They wanted the family to leave so she got passed around the room for everyone to have their time with her. It was incredibly beautiful because everyone then got to meet her. But I ended up having such a short time with her, after she was born. I think it was then that I started to realise what had just happened. It was when I started to process what was going on. I was seeing her with everyone, and it hit me.*

Again, Paige was unaware of what was about to happen and, because of this, took the option of having supporters at her birth, literally. This innocence ended up with Paige feeling overwhelmed and somewhat inundated with spectators, albeit caring spectators. She was thankfully able to see the specialness of the moments family and friends got to spend with Harper.

The collective memories of Harper's birth became a tangible shared experience for all those in the room. Paige is no longer the sole owner of the story as everyone present will be able to recall the birth and death of Harper from their own vantage point. This could either dilute or intensify the event, depending on whose narrative is being heard. For those standing beside Paige at the birth, the account may be highly emotive with memories coming directly from that space. The sights, the sounds, the physicality of Paige birthing her daughter are bound to be explicit and powerful.

Paige had a sense of stalled parenthood with Harper as others got to meet her before she did. While she was delighted seeing her family and friends hold her, she felt her time with Harper had been taken away. The concept of ownership of Harper could be considered in this instance or perhaps it was believed that she 'belonged' to everyone.

It was in these moments of connection between the family and Harper, Paige became acutely aware of what she had lost. She had been robbed of her baby as well as, in that moment, robbed of time spent with her. Her sense of loss must have been acute and so intense.

Paige 7: A Moment Alone with Harper

> *We had her at home with us for just one night. It was so nice to be able to have some time with her prior to having to send her off. We had to have her back at the hospital by 7 in the morning for her to be transported up to Auckland. Then but we then got her back again that night, which was cool.*

Spending time with their baby daughter gave them a sense of peace and was rich with meaning. To create memories of this time would be a once in a lifetime possibility and they were grateful. For such a fleeting moment, they were together and whole; this time would become part of their family's story. By having Harper at home with them they were able to acknowledge her existence and see her as *real*. The shared experience of placing her in her bed, wrapping her in her blanket and *protecting* her, allowed Paige and her partner, even for a short time, to be Harper's parents.

Paige 8: A Moment Paige Remembered

> *Earlier in my pregnancy I was feeling unwell, and I went up to the hospital. The midwife looking after me bluntly said "oh well you're probably not going to have this child". I remember thinking what she said was so rude. Then the day that we were having Harper in the shift change over it was her and I had this massive mental break down. I said that I cannot have her in here. I could not even explain why that happened so my mother-in-law went and spoke to her. She was told that I did not have a choice. I had to have her as my midwife. After the birth she apologised to me and said that like she felt horrible for what she had said to me previously. In the end she was amazing throughout the process.*

What is said in a moment often stays around longer than intended. The experience Paige had of an off-hand comment from a midwife stayed with her until she met her again when she was about to give birth to Harper. Paige describes having a massive mental break down when she saw the midwife that had upset her earlier in her pregnancy. In Paige's mind, the midwife about to care for her had treated her poorly and with little empathy. She had suggested that her unborn baby was unlikely to make it. It could be assumed that a person caring for another who is vulnerable, afraid, and unwell would show kindness, compassion, and have a caring attitude. This was not Paige's experience of this person, so understandably she was reluctant to accept their care again. To be told that she had no choice but to be cared for by the same midwife that had upset her, must have surely felt as if the mistreatment would be repeated.

The layers of vulnerability Paige experienced would have felt like a holistic nakedness. Her physical needs would be evident but her emotional and spiritual susceptibility would have been visible only to those who could see past the physical symptoms. The assumption of what care should feel like was altered for Paige. To encounter the same person when she was even more vulnerable is hard to comprehend. The risk of further harm was real, yet she was not given a choice.

Paige 9: A Moment to Process

> *I know that both my husband and I didn't emotionally process what we'd been through for at least 4-years. I think afterwards, we kind of just decided to block it out. We hadn't fallen pregnant for 3-years. So, we thought maybe Harper's telling us that we're not ready. It wasn't until after that that we decided that we needed to seriously process what we'd been through.*

Blocking out what they had gone through when they lost their daughter, Harper, may have been their way of coping with their grief. It seems that they were stuck in a place of numbness, of wanting to steer away from the pain and heartache. By pushing their feelings of loss down deep, they were able to carry on as normal. This self-protective measure could only stay in place for a period before something or someone made it bubble up again to the surface. For Paige and her husband, not getting pregnant for over 3-years was their sign that there were feelings that needed to be addressed before they felt ready to receive another child. For them, Harper triggered a sense of necessity to release their pain and confront what had happened to them. It could have been indicative of a sense of compounding grief for Paige and her husband as not only had they lost Harper but they had not been able to conceive. Both circumstances perhaps combining to represent an undeniable emptiness that required their attention.

Feeling that their daughter, Harper was ‘speaking’ to them reinforces her continuing presence in their lives. The meaning and comfort that Paige and her husband gained from accepting that Harper still was very much part of their family would have been a way of keeping her memory alive. Harper was also able to remind her mum and dad that it is never too late to acknowledge their loss and to give themselves permission to grieve.

Paige 10: A Moment of Enduring Connection

> *I am so grateful that we, you know, we got to experience that, and you know we still have these memories of Harper, and we have still got her with us.*

Memories of their baby Harper are all they have left, and these memories help Paige and her partner feel as if Harper is still alive. To feel a sense of gratitude even after the loss of their baby girl, Harper, is a gigantic feat in resilience. Paige feels Harper is still part of their lives, and she feels her presence around her.

Interpretation of Paige’s Story

Paige’s unknown-ness stands out right from the beginning of her story. She seemed unaware of what was happening; yet, she followed along, trusting those leading her. There is a sense of innocence in Paige’s story. She went along with what was offered and admits that her knowledge of what was to come was “basic”. Rather than be given information about what was happening, Paige was forced to guess. Whether she did not feel able to ask questions or chose not to is unclear but instead Paige made up her own story. Obviously, the story she was being told by those involved in her care seemed credulous and Paige went along with their plans. Perhaps Paige used this assumed knowledge as a way of protecting herself from the scary truth. Just like a person with a broken ankle knows that they have hurt themselves, but they do not want to look at their injury for fear of acknowledging what they have done, how much it hurts, and how scared they are. By ‘looking’ or knowing what is happening, Paige is potentially opening herself to more pain than she is already feeling. As Budda believed, “the root of all suffering is attachment” (https://wisdomquotes.com/pain-quotes/). With Paige’s separation from the finer details of the termination, she can detach herself from what is ahead of her, as if to shut off or shut out the painful reality.

Paige also appeared to take the advice offered, literally, regarding inviting family and friends to attend the birth. She ended up with many people in the room and although she, at times, felt the situation to be rather surreal, she was surrounded by those who cared for her and her baby. At times, she felt overwhelmed by the number of people who were at Harper's birth. They all wanted to meet and then say good-bye to her, which meant that, ultimately, she was separated from her baby, Harper. Her memory of this time is tinged with regret because she felt that while family and friends spent time with Harper, she did not.

As with many of the other women, Paige made the decision to end her pregnancy with the desire to lessen her unborn baby's suffering. They knew the likelihood of their baby dying during the pregnancy, during the labour, or soon after birth and equated this as prolonging the baby's agony. As Harper's mother, she was committed to doing everything in her power to protect her unborn daughter.

Paige felt that she walked through the termination without stopping to think too much about what was happening. She felt that the reality only caught up with her when they left Harper at the funeral home, awaiting cremation. Even 4-years after she lost Harper, she and her partner are still dealing with their grief. She believes that they delayed processing the loss of Harper because of they just did not know how to begin to grieve. After experiencing a miscarriage, sometime after losing Harper, they decided they should go down the IVF pathway. Paige found meaning in their experience by believing that their miscarriage and difficulty in conceiving again as a message from their lost daughter. Paige believed that Harper's birth and death highlighted the need for careful assistance in having a healthy baby.

Chapter Summary

This chapter told Paige's story of losing her daughter Harper. It offered an interpretation of her story, along with 10 moments highlighted within her story. Paige's story shows the ebb and flow of Paige's memories of the birth and death of her daughter, Harper. One memory triggered another memory which led to another. This is how Paige remembered what happened and reflects the interrelatedness of each moment of recall.

CHAPTER EIGHT: TUI: I SAT DOWN AT THE SEWING MACHINE AND MADE HER A LITTLE GOWN. I HAD SEWN A PINK RIBBON ON IT FOR HER.

Introduction

This was Tui's fifth pregnancy, after having two miscarriages and two live babies. Tui and her husband had decided to give themselves a deadline to get pregnant again, so the news of a pregnancy was seen as amazing. Tui's baby, Hazel, was diagnosed with Trisomy 18 and she was born at just over 18-weeks gestation.

Tui's Story

We were very excited to find out we were pregnant again. We do have two living children and then, after the second living child, we experienced two early on miscarriages and we were absolutely devastated by those. We did get to the point where we were debating whether to try again or not. It was a dream of mine to have four children. That obviously didn't eventuate, but I guess in a way made a deadline. If it doesn't happen, by the end of the year, we'll call it quits. I still remember the day that I found out we were pregnant. My husband and I were at home together and I kind of had that feeling and my period was late. I thought maybe but of course I didn't want to get my hopes up. It was nearing that end of the year deadline! So, we stopped at the pharmacy and bought a pregnancy test, brought it home and 'yay', we were pregnant. 'Oh, my goodness we actually are'. We were stupidly excited. We said to each other that we shouldn't get too excited because of what happened last time. We didn't really want to tell anybody because again we didn't want to get our hopes up. I remember the previous time we'd done research on bigger cars and things we would need for 3 children. As soon as I found out I contacted the midwife that I had for the two losses. She was very excited for us, especially knowing what we'd been through before.

We hadn't told the children because we were waiting until the 12-week scan. Our oldest child who's now 6 and a half said to us a few times that he would love to have another baby in the family. So, things were fine, and we went to the 12-week scan. I still remember going to the scan for the child we lost with the miscarriage and being told by the sonographer that there was nothing there and of course those words devastated us. We knew deep down that was happening with that child because I'd had so much bleeding that I just knew. So, the first thing I said, to the sonographer was "can you see anything?" because of course we were worried about what had happened last time. We could see the heart and hear the heartbeat and then she was taking measurements. She could see that the nuchal measurements were quite large. All I was worried about was that there was something there.

We told our two children that “mummy has a baby in her tummy”. The older child was so excited he gave me a big hug and said that he always wanted to have another baby in the house. Then my midwife texted me asking if she could come around to our place to talk with us. I just knew that deep down it was going to be bad news. She talked about the scan and how the nuchal measurements were quite large. I was hoping this is all a big bad dream because it felt like a recurring nightmare. It reminded me of our miscarriages. My husband walked in the house, and I could see that his eyes were quite glossy looking. Then he walked up the hallway straight to our room and he just burst into tears and said, “we’re going through this again” and I could tell how devastated he was. He also knew that it was going to be bad news.

She explained to us that we will get referred to fetal medicine and they may want to do a chorionic villi sampling (CVS) or an amniocentesis, depending on what stage we are at. I was quite thankful that it was picked up at the 12-week scan because I know a lot of parents their journey starts at the 20-week scan. That’s a whole lot further on and they think they’re going to find out the gender of their baby and instead they find out that something is wrong. We did know that because of the measurements of the nuchal fold we knew that it was most likely going to be one of the three trisomy’s. I had known of a few people who had gone through a similar situation, so I messaged them just to find out the process and to reassure myself.

We went to fetal medicine and saw doctor and had a scan there as well. They suggested that they do a CVS. They tried so hard to get a sample, but they couldn't. So, I had to go back a whole week later and do it all over again. It was the most emotionally painful thing. I’m not worried about needles but emotionally it was difficult because I knew the reason was to find out what was wrong with my baby. It was even more devastating when they couldn’t get enough samples. I felt like I’d been poked and prodded with needles for nothing because they couldn’t get enough samples. It was exactly a week later that we went back. Another specialist helped the original specialist just to make sure because they knew what they’d put me through the week before. The week before I was crying bucket loads of tears the whole time just because of the whole emotional side of it and the second CVS I was doing the same thing.

I got the phone call from the specialist, and I knew as soon as I answered the phone, that deep down it wasn’t going to be good news. Sure enough, the specialist went straight to the point and said it’s not good. She asked if we wanted to know the gender. I was torn because, we went right through both our pregnancies and never found out the gender. We just never wanted to; we wanted a surprise. Anyway, I asked her to tell me because, for me I think that helped, the process of knowing what the gender was inside me. She told me that it was a little girl with Trisomy 18 or Edwards syndrome. She said that there were multiple things wrong with the baby. Then she told me that, obviously, we had some decisions to make. I phoned my midwife, when I found that out because I just wanted to talk to her. She'd been there for me for my previous losses. It was a such a horrible thing to go through because it was a choice, but it wasn't a choice. We had to do what we had to do because we didn't want our little girl to suffer. She was what was going to make and complete our family. She made our deadline for us to get pregnant, so she was meant to be. We were getting older. We didn't even have our first child until we were 36 and of course like over 35 you're considered geriatric when it comes to having children. I guess probably we were a little naïve as to how pregnancies can go wrong sometimes. Through no one's fault. We hardly ever drink alcohol, and we never touch drugs. Why should something bad happen to us? And you do, even though you know that this is pure bad luck, just absolute fluke, you start to blame yourself. I had to keep telling myself it was not my fault. I found it very hard. Our midwife came around and saw us again. She sat us down and explained about what the next process would be. She told us that fetal medicine would be in contact with us again to arrange a date if we chose to go ahead... to say goodbye. We knew that deep down it was the right decision for us because we couldn't have our baby suffer. I remember the first time the midwife came and visited us after I'd given birth. She was really surprised that our baby made it that far. So, I guess that did give me some sort of relief and comfort.

It kind of made me realise how many parents go through this and it is something that's not really talked about. I feel like there's still a lot of judgement around things like that. There are people in my life that will never find out that we had a choice because I feel like they will judge us. During the whole process the medical staff were very kind to us and when we got emotional, they could see that we just need a little time, they would just pass us the box of tissues if we needed them.

When we got the date, a couple of days before I was due to go to give birth, I came down with the worst head cold! I guess it was my body's way of, I don't know, my body knew it was stressed out, my body knew I was going through a lot, and it was just trying to tell me to slow down. I think the COVID alert levels had changed slightly around that time as well. I figured I didn't need to be in the hospital with people staring at me going oh my goodness has she got COVID? So, I got a date for a week later, and I was really worried about when they were going to give me a date for because I knew that my oldest child's birthday was coming up around that time as well. I was just hoping that they wouldn't give me a date on his birthday.

In the end we had to go to the hospital the day before his birthday and sign the consent forms and have the first lot of medicine. Then we went back the day after my oldest child's birthday. I look back on his birthday and we have a photo of the four of us with him blowing the cake and in that photo, you could see that I was pregnant; there was no hiding it. I did choose to tell a few people and just told them that we were pregnant but it's not good. It was a way of saying that we really want this baby but she's not going to make it. I thought it was better to let them know, I guess. So, the day before my oldest child's birthday and going to the hospital and knowing I was signing these consent forms to birth my much-wanted baby; and then, having the first dose of misoprostol. As I swallowed that, I just knew, why I was taking it. To me, that was the most horrible thought of why I was taking that pill.

I'd said to our boys that the baby's heart was not very good, that she has got something wrong with her heart. We just tried to simplify everything for them, and we were grieving as well so we didn't need to inflict that on them.

On the day of her birth, it was a beautiful day. We parked near the hospital and then we chose to walk because we knew it was time to reflect and talk to each other. So, we walked to the hospital, and you could see the sunlight beautiful colours in the sky from the sunrise. I was just sort of taking all that in just thinking I know where I'm walking to right now. And why. We got there and we got checked in at reception. Then we were taken to a room. I just kind of looked at my husband and we just didn't even know what to say to each other. Then I asked my husband to take a photo of me. This was the last time I was going to be pregnant—like this is it.

The nurse came in and she was so lovely. We filled in all the paperwork, and it was the first question she even asked me, and I bawled my eyes out, just burst into tears. She just wanted to check my temperature and take bloods. She showed me where the bathroom was and explained to me that in the toilet there was a silver pan there in case I accidentally birthed in the toilet, so that way the baby wouldn't disappear down the toilet.

As I said before it was a bloody hard decision because it wasn't really a choice because we both really wanted a baby. Maybe an hour or so after the first lot of misoprostol I felt some real intense pain. The nurse could see from my face that I was in pain. During the labours for my two living children, I never had any pain killers at all for either of them. The nurse told me that it was okay to take pain killers. She said that she could tell by my face that I was in immense pain. It was kind of weird for me because I had had my other two children without taking anything. I don't know why but it was just different. But I did have some Panadol and some codeine, but it was kind of weird because I don't normally take anything. I felt was letting Hazel down, but it was just different. Even though it was painful because the contractions hurt just as much as a full-term baby it was the emotional pain. I was really taking the pain relief for that. I'm sure that knowing that I was giving birth to this baby that was so wanted but all we'd get would be cuddles and that's it. So, emotion, emotional pain was just way up there.

I felt nothing was happening, so I walked up and down the corridor and I felt so bad because I'm sure people were thinking here is this woman just walking up and down the corridor. I was so hungry as it had been a long time since we'd eaten. I feel like they'd forgotten to hand out the lunches or something! The nurse did say to me that once the waters break, I couldn't eat anything after that. Just in case I needed to go to theatre. Suddenly, I got back to my room, and I felt my waters break. I was just outside the toilet, and I thought "not now, not now"! I started yelling out "no, no, not yet". I felt like I was peeing my pants. My husband said, "you're alright", and he rang the bell for the nurse. My pants were soaked by then and suddenly something started to happen. I still remember getting on the bed and I was up on all fours to birth our baby Hazel. I'll never forget it. I can see her coming out and just yelled out, "my baby". Just seeing how small she was. I remember the sound of both me and my husband, just wailing, as soon as I crowned my baby. I'm sure we were very loud! The nurse was right there because they could see the baby was coming. That's not how I imagined our third child would be. We knew we'd birthed a baby that we couldn't take home. It was horrible. When you give birth to a living child you know that it is going to cry, you know that you get to take it home and, you breastfeed it. I imagined our third child going to term and there be nothing wrong with it. It was a bit of a nightmare.

I'm extremely grateful that the nurses were so kind and caring and never once did they try to hurry us out of the hospital. Just like my other births it took a while for the placenta to come. I was having lots of cuddles with Hazel, and I was just bawling my eyes out because I just loved her so, so much. I was so grateful for that cuddle time. As part of my grief process before I birthed her, I sat down at the sewing machine and made her little gown that I could wrap over her. I had sewn a pink ribbon on it for Hazel. My husband took her with the nurse down the hallway to go and get her weighed, and she said that she would find something to dress her in. I said it's okay we've got something; I've made her something and we pulled the wee gown out of our bag. I think the nurse was quite touched that I'd made it myself. My husband dressed her and then brought her back to me and I was still sitting on the hospital bed waiting to birth the placenta.

My husband sat down in the chair with Hazel and had cuddles with her as well. The tears were rolling down his face. It was so hard seeing my husband just bawling his eyes out, cuddling this baby, this tiny baby. We just wanted to sit there and cuddle. I counted all her fingers and toes, just like you would for any other birth. I'm just so, so grateful that we had that time to cuddle our baby. I was talking to her and just telling her how loved she is, how we wanted her so, so much. The nurses brought us a little memory box and a little purple box that we were to place Hazel in. They asked if we wanted to keep her placenta or if we wanted to put her placenta with her. As she was so small, we decided to keep her and her placenta together, and so that went in the little purple box with her. When I knew that it was probably time that we started heading for home, the hardest thing, was to put her in that box and put on the lid. That was so, so hard. I had to lift the lid again. I couldn't do it. I lifted the lid just to say, "I love you again", bent down and gave her a kiss. The nurse walked out with the purple box with Hazel inside. We were just bawling our eyes out and she turned around and just gave us a sweet smile and she said to us, "we'll take real good care of her for you". That was all we wanted to know. We chose to get her cremated. We left the hospital, and we walked across the park, to our car park again, there was people in the park playing cricket and the sun was starting to set. We had walked across that same park in the morning when the sun was rising and then we were walking across when the sun was setting, and we saw the same beautiful colours with sunset. We walked past these cricket games, and we had our backpacks on and here I was carrying the Sands memory box. It was bloody hard walking across that park. Carrying this box. Without a baby. The baby we so desperately wanted.

We got to our car, and I just said, wow, I just can't believe what we've done today. We made a few phone calls saying that Hazel had been born at around 1o'clock at 18 and a half weeks and she was born sleeping. I also said that she was much loved, and she knew how much we loved her. Then that night after tea we got the children ready for bed and we sat them down for the most horrible bedtime story ever. The social worker had given us a book which is a beautiful book and it's called *What Had Happened to Baby*. This was the hardest story I'd ever read in my life. We sat down the children on the couch and told them that the baby was quite sick. We told them that we'd had the baby and that she'd died. So, we read this book with them, and the book has got beautiful pictures. What I loved about the story was that there was a ginger cat in the book, and we've got a ginger cat at home as well so it kind of suited our family.

Compared to the pain of birthing my other two children full term (and she was so tiny!), the pain was far, far worse because it was all the hidden emotional pain of knowing that I'd made this choice. We had footprints of Hazel, but we didn't get any handprints because her hands were clenched. We were told that was a sign of the syndrome that she had. We also had a photo of me sewing at my sewing machine making her little wrap. We had the book we were given from the social worker, the child's book "What Happened to Baby". I didn't put a physical photo of Hazel into the memory box because I didn't want to put a physical photo of her there. Then I wrote a long post on social media. Never once in that post did I mention that we had to make a choice. Again, I was so scared of the judgement that people could have made. I wanted people to know she was a much-wanted child, and she is our third child.

The boys still talk about Hazel, and we'll make sure that they always will. I thought also it would save a bit of awkwardness as well. Living in a small-town people would have seen me and noticed that I was obviously pregnant and then a couple of months later they would have wondered. That would have been very awkward for them, probably more awkward for them then it would have been for me if I turned around and said that I had her and she was dead. I make sure that I drop her into conversation. I want others to know that we have had another baby, and we are acknowledging her. My midwife was amazing. She did as many postnatal visits for me as she would have done for any other mother that had given birth. I remember saying to her on about the third visit and she was making an appointment for the next one, I remember saying to her you really don't have to because you probably have got quite a few clients to go and see that have got real life babies that need support. And she turned around and said to me 'you've given birth to a baby as well, don't forget that'. And sometimes when she'd come and see me, we'd just sit on the couch in silence and that was fine. I knew she was there in case I needed to say anything. She was amazing like that. Even a couple of months later I got a text message from her asking how I was. She wanted to drop by and see me give me a big hug. I had such a good experience with my midwife. I know of other people that have been through something similar and they've never heard from their midwife again. I guess some midwives are scared of the grief side of things.

So much can go wrong in a pregnancy and a lot of people are naïve to what can happen. As a midwife, you've got to be prepared for every situation there can be. On the Sands site, I have met other bereaved parents. They've all got different situations and different backgrounds to their bereavement but we're all there with each other, we all know what it's like to lose a baby. I would love to have Hazel right here now, but that pregnancy wasn't going to be like that.

I just thought I don't want anyone else to go through what we're going through. I knew it was going to happen and I couldn't avoid it. I'll always be broken because of Hazel. Always. Because I never expected to have to go through that. It was a horrible thing to have to go through. Changed in the inside how I am as a person. It broke me. I will take that to my own grave.

It's such a lonely road because no one really knows, no one talks about it. In terms of society, when I go to the supermarket, or a school pick up. I am pretty good at acting. In a way, us bereaved mothers do make it lonely for ourselves because we don't talk about it. I think that's because we fear how the people will judge us. Until you've walked in those shoes, you have no idea what you would do yourself.

Tui 1: A Moment of Cautious Celebration

> *We were very excited to find out we were pregnant again. We had experienced two miscarriages and we had been absolutely devastated. I kind of had a feeling so I didn't want to get my hopes up, but we were stupidly excited. We said to each other "well let's not get too excited because you know what happened last time". We didn't want to tell anybody, just yet. We thought we would wait until after the 12-week scan. It was the 20th of November last year that I found out that I was pregnant, and I still remember that date clear as anything.*

Tui describes the balancing act of wanting to get excited about their pregnancy but wanting to downplay their news for fear of losing their pregnancy, again. To declare their joyful news was tempting fate and exposing themselves to the disappointment of another miscarriage. This feeling of foreboding joy implied that they were terrified of being blindsided by pain. They felt frightened because if they allowed themselves to feel joy, they were inviting disaster. Silenced by the potential for heartbreak, Tui and her husband guarded themselves and kept their news quiet. This purposeful detachment settles the inbuilt fear of losing another baby, like a protective shield. They have had to emotionally detach from or let go of the babies they have lost, so this response is seen as protective for any future loses.

Tui 2: Reliving a Moment

> *At the 12-week scan, we were so nervous remembering our last scan, when they had told us we had miscarried. But this time we could see the heart and we could hear the heartbeat. They did tell us, however, that the nuchal fold measurement was very large.*
>
> *Straight after the appointment my midwife texted me asking if she could have a chat about the scan results. I just knew that deep down it was going to be bad news.*
>
> *When my husband got home from work, he walked in the house, he walked up the hallway and straight into our room. He burst into tears and said, "we're going through this again". I could see how devastated he was. He knew it was going to be bad news, too. She confirmed that the measurements on the scan were large and there was a high possibility that the baby would have one of the three trisomy's. I was just hoping this was all a big bad dream. Really, it felt like a nightmare.*

Reliving their nightmare, their bad dream of losing a baby sent them back into that 'deep-down' place of loss and pain. Knowing without even being told of the bad news that was coming and the devastating pain they would, again, feel. It was like bracing for the storm that they knew was bearing down on them. This ‘thrownness’ into remembered pain was seen as a matter of fact. Thrown back into the world, the world of pain. What they had feared the most was about to become reality, even though they had seen the evidence of there being a baby.

Tui 3: The Moment of Finding Out

> *We went for our appointment at fetal medicine to have a CVS. The obstetrician tried so hard to get enough of a sample, but she couldn't. I had to go back a week later and do it all over again. It was the most painful experience, emotionally. I knew that the reason I was going through this was to find out what was wrong with my baby. It was even more devastating when they couldn’t get the samples. I felt like I’d been poked and prodded with needles for nothing. The week before the first CVS I was crying bucket loads of tears because of the whole emotional side of it and the second CVS, I was doing the same.*
>
> *I got the phone call from the specialist, and I knew deep down it wasn’t going to be good news. They said that the results weren't good and there were multiple problems. They asked if we wanted to know the gender and I said, ‘yes’. For me, I think that helped with the process, knowing if I was having a boy or a girl. They told me it was a little girl with Trisomy 18 or Edwards syndrome. They told me that, obviously, we had some decisions to make.*

For Tui, having the first attempt at a CVS fail and having to go back again may have seemed like double torture. She uses the vivid imagery of being poked and prodded with needles and found the experience to be very painful. She clarifies, however, that she recognised the pain as emotional rather than physical. Interestingly, Tui still talks of pain regardless of the source or how the pain is felt.

She recalls that she was crying frequently leading up to both the procedures and was devastated that the first attempt failed to get adequate samples for testing. Tui reports that she “knew deep down” that the results would be bad even though she had not yet received any results. This must surely have added to her feelings of anxiety about both the procedures and the results. Considering this possibility, Tui sensed that there was not going to be any “good news”. She was dreading confirmation of her intuitive feelings and preparing for the worst.

Tui 4: A Moment to Choose

> *It was a really horrible thing to go through because although it was a choice it wasn’t really a choice. We didn’t want our little girl to suffer so we had to do it. We knew that*

> *deep down it was the right decision for us. It was still a bloody hard decision because we both really wanted a baby. We had to choose to say goodbye to our baby.*

Tui had to go deep down within herself to find the ability to make the decision to end her daughter's life. However, it may have been that she had nowhere else to go. She saw this as the most horrible dilemma that she could face with neither choice having a positive outcome. She needed to decide what she could live with.

Finally, her choice was based on what mattered most to her and that was the desperate desire to keep her baby from suffering. The irony was not lost on Tui as she was aware that there was only an illusion of choice. Regardless of what she decided to do, she was going to see the death of her baby.

Tui 5: The Moment of No Return

> *Going to the hospital and knowing I was signing the consent forms to birth my much-wanted baby. As I swallowed that first tablet, I just knew why I was taking it. To me, that was the most horrible thought of why I was taking that pill.*

Knowingly doing something that will ultimately end in the death of her baby, Tui was acutely aware of what she was doing. It was her alone who was swallowing this medication, her alone who embodied the experience of this moment. While others may have looked on with empathetic eyes, it was something only she could feel. For Tui, "taking that pill" symbolised the horrible truth that she was ending her much-wanted baby's life. The picture in her mind of her baby being alive, her taking the tablet, and then her baby dying may have been a construct of her thoughts. From her perspective, she was consciously doing something that no parent would happily consent to. Tui's future and that of her baby are now inescapable; her entanglement in the moment is undeniable. The burden of the decision was now in front of her, and it was Tui who was figuratively and literally internalising that decision. Her conscious realisation that the journey towards the birth and consequent death of her baby had begun and there was no turning back, could be described as the moment when desperation and courage collide.

She did not take the medication to be cruel or wicked; instead, to show merciful love for her baby.

Tui 6: A Moment to Ask Why

> *We hardly ever drink alcohol. We never touch drugs. Why should something bad happen to us? Even though you know that this is pure bad luck, just an absolute fluke, you start to blame yourself. I had to keep telling myself it was not my fault. I found that so hard.*

Tui is asking why bad things happen to good people. Why do some people suffer such tragedies while others dodge misery? Some may say that nature is blind and does not distinguish between good and bad or reward and punishment. It could be suggested that we live-in-the- world that is not perfect and does not keep tabs on who deserves or does not deserve pain and suffering. Tui tallies up her life and is confronted with what she sees as unfair. The conventional concept of fairness offers no explanation to their pain and suffering. In this situation there are no rules or principles that guide what is fair and what is not.

Tui is trying to talk herself out of blaming herself, like covering a burn with a salve in the hope it will calm the pain. Logically she understands that her baby's devastating condition was not her fault. Nor was it her fault that she made the choice to end the pregnancy when she felt there really was not a choice. Her feelings of guilt imply, to her, that she has done something wrong. To some she may have made the wrong decision but, to Tui, her decision was not based on finding an easy solution. In fact, quite the opposite, she made the decision when neither decision was considered easy.

Tui 7: Poignant Moments

> *It was a beautiful morning. We parked near the hospital and then we chose to walk to the hospital. We knew it was a time to reflect and talk to each other. We could see the beautiful colors in the sky from the sunrise. I was taking it all in. I was thinking, "I know where I'm walking to right now". When we got to our room at the hospital, I just looked at my husband and we didn't even know what to say to each other. I asked my husband to take a photo of me. I said, "this is the last time I'm going to be pregnant; this is it". And so, he took the photo just before I had the baby.*

These poignant moments talk of making memories knowing full well what was ahead of them. It seemed hard for Tui and her husband to put words to what was about to happen as if they were unable to think of what to say. The moment was so big it seemed beyond words. Perhaps there were no words to express their thoughts and feelings. Instead, the silence told the story.

It seems that the world that they inhabit with ease and familiarity is thrown out of joint and collapses. In that moment they realise that everything around them is suddenly pitched into chaos. It is hard to make sense of what is happening, it does not seem real.

Tui and her husband were trying to be in the moment and be mindful of the “right-here, right-now”. It reflects a sense of inevitability that although they want this to be over; ironically, they do not even want it to start. They cannot even contemplate what today will hold; all they can do is wait for something to happen.

Tui 8: A Moment of Relief

> *An hour or so after the first dose of medicine I felt some real intense pain. The midwife could see from my face that I was in pain. I didn’t have any pain killers at all for either of my first two births. The midwife told me that it was okay to take pain killers. She said, “I know by your face that you are in immense pain right now”. It was kind of weird. I don’t know why but it was just different.*
>
> *The contractions were so painful and hurt just as much as a full-term baby, but my body still needed to contract to let this baby out. I think it was the emotional pain. I was really taking the pain relief for that. I’m sure that knowing that I was giving birth to this baby that we really, really wanted but all we’d get would be cuddles and that’s it.*
>
> *Compared to the pain of birthing my other two children and even though she was so tiny, the pain was far, far worse. It was because of all the hidden emotional pain of knowing, that I’d made this choice.*

Tui was able to distinguish her physical pain from her emotional pain. She could conceptualise why she was feeling such intense pain but associated the pain with the emotional ache she was feeling rather than the known pain of labour. The midwife caring for Tui could see the acute pain registered on her face and offered Tui medication to manage the physical pain. Is this a case of ‘any pain relief is good pain relief, regardless of the source of the pain’?

To distinguish between physical and emotional pain can be a blurred line but Tui had the insight to understand that while she experienced labour pain, she related it to being an emotional ache.

For Tui to feel as if she was letting her baby, Hazel, down because she accepted pain relief would be considered the epitome of motherly guilt. The concept of taking pain relief versus keeping Hazel ‘safe’ would be nonsensical to most; but to Tui, these feelings confirmed her motherly concern and love for her baby.

Tui 9: The Moment Hazel Arrived

> *Suddenly, I felt my waters break and I screamed "not now, not now! No, no, not yet". My husband rang the bell for the midwife. Something started to happen. I remember getting up on the bed; up on all fours to birth our baby Hazel. I remember the sound of both me and my husband just wailing as soon as I crowned my baby. I would hate to think how loud our wailing was. I remember yelling out, "my baby". That is not how I imagined the birth of our third child would be like. It was a bit of a nightmare.*
>
> *We knew we'd birthed a baby that we couldn't take home. It was horrible. Giving birth to a living child you know that the baby is going to cry, that I'll get to breastfeed it and that you get to take it home. Just seeing how small she was. I counted all her fingers and toes just like you would for any other baby. It was a horrible thing to have to go through.*

Tui was not ready, but Hazel was on her way, ready or not. In Tui's mind she needed more time to get ready or prepare for Hazel's birth. Tui does not initially seem to see her baby; rather, she talks of "hearing the sounds of birth". The sounds of her crying out that she was not yet ready to give birth; the wailing in response to recognising that she had, in fact, given birth; and her calling out to her baby. It could be believed that Tui had her eyes shut and all she could sense was what she was hearing. Finally, after the intensity of Hazel's sudden birth, Tui and her partner were able to lay eyes on their daughter. Like any other birthing couple, they were then able to gaze at their baby. Being able to see that she had all her fingers and toes but somehow not focusing on her stillness.

Tui experienced a 'thrown-openness' or an acute awareness of Hazel's existence. Hazel became 'what she already was' at the time of her birth. In other words, she became "my baby".

Tui 10: A Moment for Cuddles

> *I was having lots of cuddles of Hazel, and I was just bawling my eyes out because I just loved her so, so much. I was so grateful for that cuddle time.*
>
> *Before I birthed her, I sat down at the sewing machine and made her a little gown that I could wrap her in. I had sewn a pink ribbon on it for Hazel.*
>
> *We went to dress her, and I pulled the wee gown out of our bag. The nurse was quite touched that I had made it myself.*

> *My husband sat down in the chair with her, having cuddles, and tears were rolling down his face. It was so hard seeing my husband just bawling his eyes out, cuddling this baby, this tiny little dead baby.*
>
> *I was talking to her and just telling her how loved she is, how we wanted her so, so Much. We just wanted to sit there and cuddle. I am so grateful that we had that time to cuddle our baby.*

Cuddling their baby, showing how much, they love her. For Tui and her husband, spending time together with Hazel just cuddling her was all they could do. Every moment desperately etched into their minds to be remembered when Hazel was no longer with them. They saw Hazel as real now, as their much-wanted baby. Every minute that went by lessened their time with her. This time would not be retrievable, so Tui and her husband immersed themselves in their sadness and their love for Hazel. Emotions ran free while they cuddled her and eventually, they dressed her in a gown that Tui had made for her.

Tui 11: A Moment of Reflection – Leaving the Hospital

> *We left the hospital and walked back across the park, to our car. There were people playing cricket. We had walked across that same park in the morning when the sun was rising and then we were walking across when the sun was setting. They were the same beautiful colors. We had our backpacks on, and I was carrying the Sands memory box. It was bloody hard walking across that park, carrying this box, without a baby. The baby we so desperately wanted. We got to our car, and we could not believe what we had just done.*

It must have been surreal to see people going about their day, not knowing what Tui and her partner had just been through. They had met their baby for the first time and then said good-bye to her. Only they knew what had happened that day. To the outside world, life continued. Tui and her partner looked like a couple out walking but their world had been turned upside down and would never be the same again. The intimacy of the shared experience reflected the oneness or 'known-ness' of the experience. It was a connection that defies description, and they are confronted by the realisation of what they had both gone through. Tui and her partner each saw the grief on each other's face – in that moment they knew what each other felt. This self-disclosure represents a sense of communion or the sharing of intimate thoughts and feelings. An experience that fosters 'a togetherness'.

Tui 11: The Purple Box

> *They brought in a little purple box that we were to place Hazel in.*
>
> *She was so small, so we decided to keep her and her placenta together, so that went in the little purple box with her. When I knew that it was probably time to leave, the hardest thing was to put her in that box and put the lid on. That was so, so hard. I lifted the lid again because I couldn't do it. I needed to tell her that I loved her again, so I bent down and gave her a kiss. Then the midwife walked out with the purple box with Hazel inside. We were just bawling our eyes out and she turned, and she said to us, "we'll take good care of her for you". And that was all we wanted to know.*

Through this whole ordeal, Tui just wanted to be reassured that Hazel was alright, that she was taken care of. This was a way of protecting her baby, as any parent would do. To say a final goodbye to her baby and close the lid of "the little purple box" must have been bittersweet. Knowing that she would no longer suffer but, at the same time, not being ready to let her go. To tell Hazel, one last time, that she is loved, marks an end point to her life. Putting the lid on Hazel's coffin was a definitive moment for Tui. There would be only memories and photos of Hazel left to remind them of her existence. The moment the lid is placed onto the box Tui's baby is relegated to the past, to no longer exist in real form. The only thing left is the memory of Hazel, and this is at risk of fading. This is the last moment she will see her baby, the last moment she will kiss her baby, the last moment she will 'know' her baby.

Tui 13: Acknowledging the Moment

> *My midwife was amazing. She did as many postnatal visits for me as she would have done for any other mother that had given birth. I remember saying to her that she did not have to visit me because she needed to see women who have real life babies that need support. She said to me "you've given birth to a baby as well, don't forget that". Sometimes we would just sit on the couch in silence and that was fine. I knew she was there in case I needed to say anything. A couple of months later I got a text message from her asking how I was. She dropped by and gave me a big hug. I had such a wonderful experience with my midwife. I know of other people that have been through something similar and they have never heard from their midwife again. I guess because their midwives fear the grief side of things.*

To be supported by her midwife, unconditionally, must have been such a validating experience for Tui. The midwife reminded her that she was still a mother, even though her baby had died.

To be able to sit and say nothing indicates such a mindful presence for Tui. When she was ready, she was able to talk about Hazel with someone who had met her and knew her. A shared memory of the moment Hazel was born, how she looked, and how it felt to finally meet her. Together, Tui and her midwife maintained a unique connection because of Hazel's life and death. Acknowledging that Hazel was a real baby instead of denying that she was ever born, guards her existence and justifies what Tui is going through. Her midwife was able to offer a trusted "listening ear" rather than trying to make it better for Tui.

Tui 14: A Moment of Pretense

> *It's so easy to make small talk with people sometimes. So easy yet so hard but you do the small talk thing because you don't want to let it all go and let people know what is going on.*
>
> *Like walking around the supermarket, thinking no one knows I have just had a baby two days ago. You act your role. You just pretend. I got pretty good at acting.*

Tui was aware that she was acting as if appearing to be fine. She describes what may have felt like a parallel universe, a surreal place where what you see is not always the truth. She was able to make small talk with those who did not know what had just happened while holding all her emotions in check. By pretending to be all right perhaps she could believe that she was perfectly OK, for now. Hiding what she had just been through could have been a protective shield. She could not express what she was truly feeling so she restrained herself. Instead of breaking down, making others feel awkward, or revealing her heartache, she chose to pretend as if nothing untoward had happened. This, for Tui, was her preferable reality, as if switching into a grief survival mode. By behaving normally, she was fitting in with the norms of society. By avoiding the grief spotlight being shone on her, she played a role that implied she was no different to anyone else. To hide the rawness of her scars was like covering them over with a veil of denial. What others saw was a sanitised version of Tui, the socially acceptable Tui. She was almost an imposter in her own life by successfully giving the allusion of normalcy. By concealing her own perceived stigma of ending her pregnancy, she hid herself to others. She was hiding in plain sight.

Tui 15: Broken Into Pieces

> *The experience changed how I am as a person on the inside. It broke me. I'll always be broken because of Hazel... always. I never expected to have to go through that.*

Tui states that because of losing Hazel she felt "broken". When considering the definition of being broken, images of something that is fallen apart, not working, or separated are brought to mind. To this end, Tui's concept of being broken may not only represent her being 'in pieces' but also missing some pieces of herself. A sense of incompleteness – the opposite of feeling whole. When something is broken it usually stops working. For Tui 'the world stops working' as she knows it. Nothing is the same, everything is different, unfamiliar, changed. Brokenness is the place we are forced to stop in our tracks, to recognise that nothing will ever be the same again. For Tui, it seems that what she once was, she is no longer. Ironically, she reflects that she is changed *on the inside* which could imply that she looks the same but feels completely unrecognisable, to herself.

For Tui, the unexpectedness of losing Hazel, could be seen as the collapse of what should have been. She was thrown into an experience that ended her hopes and dreams. The expectedness of getting pregnant, having a baby, and building a family all came crushing down around her, destroying the meaning she had placed on this experience.

Tui 17: Moments of Aloneness and Judgement

> *It is a very, very lonely road because no one really knows, no one talks about it. In a way us bereaved mothers make it lonely for ourselves because we fear how people will judge us. Until you have walked in those shoes, you have no idea what you would do yourself. There are people in my life that will never find out that we had a choice because I feel like they will judge us. Not once did I mention to anyone that we had to make a choice.*
>
> *Again, I feared the judgement. All I wanted people to know was that she was a much-wanted child, and she was our third child.*

Tui describes being on a journey of aloneness and threatened judgement. A journey with no end, on a road that is rather desolate and deserted. Only those who have experienced choosing to end their pregnancy in this way can walk in these shoes. This description of being alone congers up a vision of a road that is hidden from view and, consequently, offers protection from other's judgement, including self-judgement. The implied silence of not talking about it may be seen as a paradox considering no one really knows and may have a contrary relationship with the unspokenness of the termination of a pregnancy. The only people found on this road are "us bereaved mothers", as if access to this path is restricted to those who have supposedly forsaken their babies.

Only a chance encounter with another traveler allows them the possibility of sharing their story, a revelation of mutual understanding. The experience is hidden in plain sight as if to camouflage the reality of choosing to end a pregnancy. To share their story is to lay bare what is often not spoken of and to, again, expose themselves to judgement and, even more importantly, re-expose themselves to self-judgement.

However, covering does not equate to disappearing but enables something else to appear. For Tui, it enabled her to let others know that her baby was a much-wanted baby, and she was very much part of their family. By hiding the reality of having made a choice to end her pregnancy, Tui is able to place both her experience and her baby in a space of invisible scaredness. This protects her from unwanted misinterpretation of her story and supports her own rememberings of the birth and death of Hazel.

Interpretation of Tui's Story

Family and having another baby were such priorities for Tui and her husband. The memories of losing two of their earlier pregnancies were still like an open wound, so when they found out that Tui was expecting a baby, they were cautiously over-the-moon.

Pure devastation is reflected in Tui's story of the birth and death of her daughter, Hazel. When her husband predicted that they would lose this baby, when they couldn't get any sample for the CVS, when she knew the results would be bad news, when she learnt her baby was a girl, all began her journey of heartbreak.

To be conscious of taking medication to end her pregnancy, Tui was beyond grief-stricken, but she knew what she had to do. Tui's care providers were kind, unhurried, and supportive of what she was going through, which meant so much to her. It enabled her to stay in the reflective mood she had had all day. From the time she walked to the hospital until she was walking away from the hospital, without her daughter.

Tui's memory of the pain she felt as she was birthing Hazel did not correspond to what she had experienced when she had birthed her other children. She showed deep insight into the pain and saw it more as emotional pain rather than physical pain. The type of pain that she had not expected to have to deal with and she felt that she had let Hazel down by taking mild pain relief. Tui felt a strong link between how she "birthed her babies" and her image of herself as their protective mother. She was seeing Hazel as her third baby rather than the baby that was not going to survive and wanted to do the best for her baby.

Tui also felt a sense of unpreparedness when her daughter suddenly appeared. She didn’t feel ready for her baby to be born. When she realised that she was coming anyway, Tui called out. In that moment, although unprepared, Tui birthed her baby.

Chapter Summary

This chapter told Tui’s story of losing her daughter, Hazel. It offered an interpretation of her story, along with 17 moments highlighted within her story. Tui's rememberings of what she went through were stirred by what she recalled and shared with me. One thought led to another, and this is how she told her story. For Tui, her memories are closely linked to what was happening to her children at the time and the emotions around them seemed to trigger further memories.

CHAPTER NINE: URSULA: WHAT AM I DOING TO MY BABY?

Introduction

Ursula lost her second daughter, Hazel, 2-years ago. Her baby was diagnosed with Truncus Arteriosus, a rare heart defect. Ursula gave birth to her at 25-weeks gestation after going through a feticide.

Ursula's Story

You can only talk so much; you can't just go on and on and on. My husband's great but probably has found it much harder than me and I don't want to bring him down when I do feel the need to unload something.

So, it's just over 2-years on now and I think that I've done the grieving with my husband. In the last year I think I've done quite well to suppress it, because we had been trying for another baby so there's no point in trying to do that when you're feeling down and out; so you kind of file those feelings somewhere else while you're trying to remain upbeat and healthy and positive and have a great outlook on life. But in the reality, it's still there.

I'm assuming it's the same with any sort of death or grief, you know it's still there but there's only moments that I feel I can share it. I feel in that first year or so I felt very validated in doing that, and beyond that I felt less so. I don't want to burden anyone, and I don't want it to overtake my life. But for me it's still there. It's an everyday experience. I've found it quite fascinating seeing the difference between myself and my husband. Sometimes he says to me, do you still think about Hazel? And I think, really? Yeah, probably about 50 times a day. You see your body every day and you know how your body looks different because of what you've been through. There are reminders in every part of my day but I'm not sad every day and I'm not in tears every day. But it's sure as hell not at the back of my mind. There are very real reminders for me every day whether it's seeing a baby who would have been the same age, as my one. I can't look at that kid without thinking that's what Hazel would have looked like or that's what Hazel would have been doing. I think guys are just wired differently and I'm not saying it's a lesser pain that he's going through but it's different and I can't begin to understand it because it's so different from me.

Goldie was IVF and so was Hazel. Goldie was my first try, which was amazing. I didn't realise how amazing that was, when it happened because why wouldn't it? Ignorance is bliss. Goldie was a very easy pregnancy; she was a healthy baby and all went well. One year after that, I had my only other embryo implanted and that worked as well. That was Hazel. So again, I had no idea how lucky I was. At our 20-week scan there were signs of a heart abnormality. I'm a 'glass half full person' and I won't panic or worry until I've got the facts. So, I genuinely believed they were wrong and that us going back for a second opinion was going to verify that. That wasn't to be, and the first diagnosis was Transposition of the Great Arteries. There was nothing certain about that diagnosis either, so I was thinking you've got it wrong too, but we'll come back the next day. That scan verified that there was certainly something wrong but that it was a different diagnosis called Tetralogy of Fallot. That hit hard because I thought "hold on a minute this is not happening. This is not what happens to me". I've never experienced grief. I've not had anyone close to me die so feeling this trauma, the mental trauma, was very new to me. The news was devastating. Unfortunately, there was quite a delay between that first scan and getting the final diagnosis which was probably 4-weeks later.

The actual diagnosis was Truncus Arteriosus. That was quite a blow because the first two diagnoses from our research were very common, and the outcomes were okay. They say not to go on Google, well what else are we going to do? Of course, you're going to Google, that's what everybody does. They can tell you not to till they're blue in the face but that's where people source information these days. We realised that, ultimately, we might have a huge decision on our hands. The doctors said they saw, maybe 3 or 4 a year. So, not only were we dealt with this blow, but the information was minimal. What did it mean for our baby? What did a kid look like at 5 years old with this? How long do they live? They couldn't tell us. It was a rock and a hard place situation because I didn't have a baby that was incompatible with life. It was just a very rare situation where nobody could really say. We wanted to make our decision based on some good facts. Both Ben and I enjoy an active life you know we're sporty, we're not slobs, we get out there and we enjoy life.

I felt incredibly selfish asking how will this impact our life? What a selfish thing to say when I say it out loud, but it was more, we've got another child, Goldie. She came into the decision making more than I expected. They'd said surgeries were an absolute. Probably three before the age of 2. For the more common conditions, it seemed that the surgeries were like a correction that was made in the first year or two of life and then those kids mostly go on to lead normal lives. This condition was different because there was absolutely no assurance of that. So, it meant that one of us would have to be in hospital, with the baby, alone, because you've got a toddler at home. That's where it all fell apart for me. I was trying to work out what was the fairest outcome here and, I, we, ultimately decided that it wasn't fair to Goldie. To create that scenario which would have hugely impacted her life, in a negative way, but I don't really know. We were also concerned about the stress on our relationship which was a very selfish viewpoint, but it was something I felt. Also, huge concern for Hazel's actual life and how comfortable she would be, how able she would be, how happy she would be. So, basically, I wanted black and white answers and I'd say to the cardiologist look, what would you do? I wanted doctors to tell me what to do because what a position to be in. The scary thing was that there was nothing else wrong with her; I didn't feel comfortable about that. You know her brain was fine, her lungs were fine, everything else was fine. Just her heart. I feel very differently about this decision now than I did then. For those three things, the impact on Goldie, the impact on us and our relationship, and is it fair for the baby's sake to let the pregnancy continue ? And we decided, no. I would have been about 42 when I had her. They said, it's quite possible there could be learning problems, slow learning development. They kept throwing all these extra things on top, which was also scary.

It was so far from a black and white situation it's not funny. I struggled with that the most because I am a black and white person. Give me the facts, I'll make an assessment and I'll decide. I have never felt so conflicted with what to do, in my life. So, while Ben and I agreed, that this is what we were going to do, I wasn't 100% on that decision but we had to decide.

So, 2-days prior to the labour, I had the injection to end her life. That was obviously tough. Sorry. I'm just going to get a tissue because I feel a tear coming.

Ben and I often talk about what day is her anniversary because there were obviously two steps you know having that horrible day where you have the injection to end her life and then of course delivering her 2-days later. To me there's two massive steps in that process.

I think I was feeling a huge amount of fear. One thing that tripped me up was that I had an elective caesarean with Goldie. I just assumed that I'd have a caesarean with Hazel. I was very scared when they told me that I would have to deliver her. I had placenta previa as well so they told me to be aware that this could be an issue. All the risk factors were thrown at me, and they were all daunting. We talked with a social worker, but I can't remember her name. She was lovely. I think of her often but at first, I was a bit defensive because I thought, I don't know who you are and we're talking about some full-on things here. We had to talk about what happens after the birth, what we want to do with Hazel, and it was just like 'wow, okay this is real'. I'm going to be dealing with a body and going to have to do something with her. And she was the one that had to... that was the first time someone... I'm sorry I'm crying.

I hadn't thought about that. I think in my head abortions or terminations are taken away, but I didn't think of it as being my problem and it was incredibly confronting. I was thinking oh my God I haven't even done this yet and it was all very overwhelming. I just didn't realise that was part of it. Then I went in to have the injection. I left Ben in the room because I didn't think he needed to be there, and it had to be done. They gave me some pretty amazing drugs and for the first time in about a month my mind wasn't on, on this horrific event. So, whatever they gave me was amazing. Then you have to sit around for 2-days and wait for this thing to happen and it's just so surreal. Baby is not alive. It's no longer kicking. You have to look at your tummy in the shower and know that it's... and you did that. The guilt of it. I can't describe the guilt. Then going into deliver. I thought it would be in and out. I've never been in labour, and I've never been induced so I didn't know. I just thought couple of hours and we'll be done. The tablets worked quite quickly but they said that I might be there until midnight, or it might not happen until tomorrow. I thought, 'what the heck, what do you mean? I haven't brought an overnight bag', you know it was all a shock. But it worked very quickly. I was bleeding a lot and God, the nurses, they were just so amazing. I know this happens to people all the time, so I didn't feel there was anything special about me. These nurses and doctors must see this happen all the time. But they made me feel so important to them that day. Takes someone special to do that. They were just so kind we had jokes, we laughed. I was in a funny place because obviously the grief of going in to get the injection is one part of it but then going in to deliver has very different emotions. I was scared because of the labour. Ben was really scared. But the doctors and the nurses were so unbelievably professional. It was always all under control.

I had a room to myself, and it was a lovely big room and that was hugely important to me. That I had the privacy of the space. Sometimes people were in there, sometimes it was just Ben and I, you know, which was amazing. I thought it would just be hustle, bustle, rushing me from one room to another and sharing, I just didn't know. I felt like I was getting the royal treatment. I was bleeding a lot, and they made that decision to take me to theatre. Ben was obviously panicking like anything, and I was being sick. I had that those shaky shakes you know. Ben was sitting there completely helpless, and it was very scary for him. So off I went to theatre and my doctor Eva was there. That was the thing that scared me the most; that I would be alone. I wanted familiar, I just wanted the feeling of someone that knows me, knows my situation to be there, it was just somehow so important to me. They kept saying yeah, but I almost didn't believe them because I thought well there's live births that are happening, but they showed up and I had two of them. I just felt that I couldn't have had two more amazing support people than those two. I felt like I was in the best hands. It was really scary. When I got back to the room, I saw Ben and he was holding Hazel. They had a bit of trouble getting her out. I was beaten up and bruised down there. I just wasn't dilating apparently, so there was a lot of force needed and that did damage Hazel. So, she was put in a little Moses basket, and she had a little hat on. The care they took of her was amazing. Like she was a live baby. I didn't know what to expect but I didn't expect that, and the respect shown to her was just absolutely, out of this world. Seeing Ben hold her I just felt so proud of him because God what a thing to have to go through, what a thing to have to watch. Even though Hazel wasn't alive he was holding her and so proud of her.

Talk about a mixture of emotions. The whole time the midwives and the doctors who were around me in my daze, were just so sympathetic. I had two blood transfusions, and I don't know what that means. They all made me feel just so comfortable being upset with my scenario. Most of the time I don't really do that. I don't want to show huge amounts of emotion, especially with people I don't know. I got to know them so well and just the respect they were showing me for what I have been through, and that I was not just another person coming through the door. I'll never ever forget that. They gladly gave me that extra night in hospital which I very much appreciated because I didn't feel ready to walk out of there.

The first time I saw Hazel was scary because she didn't look like a normal baby. We had her at 25-weeks, so she had developed. She had a nose and eyes. She was just a miniature version. Something about Ben holding her there, and his reassurance that it was OK and that he was looking at this baby before I had, just from afar so I couldn't see her, that he was looking down at her, something about that picture, made it OK. That I'd be OK looking at her. When I did see her, I wasn't afraid which was hugely reassuring. We were given the choice whether we wanted to see her or not and at the time we weren't sure. You know beforehand we didn't know. I think we might have done some reading and read that it can help the healing process to have seen her. So, we had some time with her. We've got some roses at home and one of them is a yellow rose. We didn't know that these babies were known as rose babies when they pass. Ben's quite a sentimental guy and he brought in a rose in a little test tube with water in it. We just sat that in her Moses basket and there's something symbolic for me. We've still got the rose and it makes me feel sad looking at it now because of what we associate it with. It was quite significant for us that, something from our home, it looked beautiful, it was perfect, and it stayed perfect the whole time that we were able to see her.

They gave me heaps of pain relief. Eva, the doctor made it clear to everyone, give her as much as she wants, she doesn't need to feel anything. To be honest I was more concerned about the blood coming out of me than how I was feeling because I was quite scared about that. I was nervous about the pain. In fact, I was very scared about the pain. If there was any chance of me having any pain, I didn't want it. I didn't want to remember this moment for something painful. There's enough going on. I don't need to endure that. I stopped feeling the blood that was coming out of me. Watching their faces, I knew I was losing a lot of blood. Ben was right by my side. I just never for a minute doubted what decisions the doctors made. We weren't interested in deliberating with them. You tell me what needs to happen, and we'll do it.

I thought that maybe I wasn't worthy of their attention not from a self-esteem perspective just hey, there's got to be people a lot worse off than me you know in severe pain or baby deaths. God, I know it gets so much worse than what I went through, so how come all this attention? I probably don’t appreciate how serious my situation was with the blood loss and then the decision to go into theatre. So, it might have had something to do with that. All I know is that I was so well cared for.

We got Hazel cremated. We had both a Catholic and Anglican priest or minister come in and bless Hazel. My mother-in-law kindly organised a tiny little coffin for her, so she was put in there and I carried her down. I didn’t want to have her at home. My feeling was that the sooner that we did this the sooner we could heal. I didn’t want anyone else present; I didn’t want a service; I didn’t want anything like. Then we collected her ashes a couple of days later or a week later.

I feel like I’m quite a different person from the experience, in a few ways. I’ve never experienced real grief before this. So, my empathy for others has just gone through the roof. I’m ashamed to say that I’ve discounted so many events that have happened to people and friends. I’ve thought, well it’s happened but you’ll get over it. I feel like winding back the clock and acknowledging all these miscarriages that have happened to so many people. I just didn’t understand. It’s all about understanding, isn’t it? The reality is until you’ve been through something... then you get it. That’s a positive thing that’s come out of it. What I’m grappling with now is that we wanted another child. We wanted as many as we could but I’m 44 now. After I had Hazel, I got my period within 3 or 4 weeks and we got straight back on the IVF train. I did back-to-back cycles and I’ve not had a pregnancy since. It just didn’t work. I was losing my mind from the ups and downs of IVF but to be honest there were no ups, you know the ups stopped with Hazel when I got pregnant with her that was the last ‘up’, the rest have all just been downs. If only I could fix what I’d done. If I got pregnant you know my mindset was that I could fix this. Goldie would have a sibling, we’d have another child, that would have been some sort of reprieve from the grief. I must find another way to reach acceptance with Hazel. To make it happen I needed a positive attitude and a healthy mind. IVF is easy, no side effects, no nothing. I didn’t understand what all the fuss was about, but I get it now. Ben would have kept on trying, trying, trying, ever the optimist but I couldn’t do it anymore. Knowing that every month it didn’t work my chances were getting less and less. I thought for the sake of my sanity, to be a good mum to Goldie because I don’t think I was being a very good mum. I wasn’t very happy. I was trying to battle, trying to stay normal when your body’s full of drugs that aren’t normal is a battle. Now I’m trying to deal with a huge amount of regret. I’m having more thoughts of how Hazel would have been if she was here. We were very negative on the diagnosis, and it may not have been as bad as that and we might have got through the first couple of years. She might have been fine. While regret is a useless emotion to have, God, I feel it.

Continuing with IVF didn’t have the maternal pull for me. I went through it for Goldie. I’m one of 9 kids. I never ever imagined that I’d only have one child.

Again, it's hopeless going backwards but my mind is doing it a lot lately, I wish that I had had Hazel earlier as in I was able to have a termination earlier, so I didn't have to deliver her. Having to go through that and deliver her and hold her. I wish that bit didn't happen. I wouldn't have known her or seen her as a real baby; whereas I was kind of forced to because I was too far on. I still remember the trauma from it. I got some counselling and one of the first things that I had to get off my chest was that I did remember the doctor struggled a bit with the injection. She had to be quite forceful with what she was doing. I hadn't told anyone about because I didn't want to scare them, especially Ben. While it was only in the very back of my mind because I was quite drugged, that was something that gave me nightmares because I asked myself "what am I doing to my baby". I thought it would be very simple and peaceful. I wouldn't even know about it, but I did know about it. Ben would have been upset to hear that and, anyone that hasn't been through something similar they just wouldn't understand, and I don't think they need to. There'd be no point, so I kept it in. And the very first session I was crying so hard that the counsellor couldn't understand me. For the first time in 6 months, the grief was just pouring out of me. I just felt so much better after that because I had not shared that with anyone, and it did scare me. When my mind would go there.... It will never leave me but I'm not so traumatised by that little fact. It's just like this little thing.

One of the biggest things is how little people talk about this and how it can be hard to share. But I wished there was someone who had done this too, that I could have talked to. Someone who had similar emotions to me—to know I wasn't alone. I felt like I was the only one, making the decision to terminate. The selfish one out there choosing to terminate a baby that would live but would have complications. I was told that there are a lot of people out there like me. It's just that no one wants to talk about it and knowing that offered me some comfort. I hope they were telling me the truth, not just paying me lip service.

The one thing I've tried to do is be very open about it. I know that can be upsetting at times because it rears its head. I can be at a party, at a happy occasion, and someone will ask something, and I'll tell them. Then the conversation can go downhill from there and you think God why I don't just give a different answer? I haven't done this because I'm a bad person which is something that we struggled with. Does this make us bad people? I'm not a bad person and so telling mum and dad was hard. They're staunch Catholic and don't believe in this but they're also reasonable. When I was able to explain to them why we're doing it, what it could mean if we didn't, whatever their hearts were doing inside, they supported me. I thought how amazing for 80-year-olds, with religious beliefs, to put that aside. I don't think they've shared this with family as I think it would just be met with shock and judgement. So, I think the older members of the family think I just lost the baby and that's all they need to know.

There must be a reason to have gone through all of this. There has got to be a bigger reason. There's got to be something to come out of this because I refuse to believe that I'm being dealt this blow for no reason and I'm not a bad person so it's not because of that. I really believe that, and I don't know what the future holds for me but if I could help somebody else that's struggling. Perhaps, though, I'm not in any position to do that because it's still so raw for me. I refuse to believe that there's not a reason why I had to go through something so significant. Hopefully that's to help someone else. That's ultimately what would be amazing.

Ursula 1: A Silenced Moment

> *It's a topic that I don't talk a whole lot about. You can only talk so much; you can't just go on and on and on.*
>
> *I've thought about writing it down myself. Not for anyone else to see but just perhaps it's inside and needs to be outside.*
>
> *It's a bit like when you have a good old cry when it's out of you, you just feel so much lighter. But in the last year I'd say I've done quite well to suppress it but in the reality it's still there.*
>
> *There are only certain moments that I feel I can share it. I don't want to burden anyone, and I don't want to have it overtake my life.*
>
> *Someone will ask something, and I'll tell them. Then the conversation can go downhill from there and I think "God, why don't I just give a different answer". I'm not going to, it's not fair, why should I? I'm not a bad person, which is something that I have struggled with.*
>
> *I haven't told my brothers and sisters because I think it would just be met with shock and judgement. The family think I just lost the baby, and they don't ask questions, that's all they need to know".*

The experience of deciding to end her pregnancy left Ursula feeling like she had been through something that she could not and, more poignantly, should not talk about. Whether it would entail judgement, social discomfort, or the need to justify her actions, Ursula was left to put the experience into a box, place the lid on it, and keep it shut.

To talk about her experience would make her vulnerable and at risk of being abandoned for the decisions she had made. By hiding what had happened she could control any additional distress, leaving her to internalise and manage her own experience. Although Ursula felt uncomfortable talking about Hazel's death, she was able to show *herself* compassion and understanding, where others may not be able to afford her that level of support.

By considering that she could write down her own story, she would be able to release what she had hidden inside. Her innermost thoughts and feelings would then have their own place externally and perhaps give Ursula a sense of breaking free of her own history.

Ursula 2: Moments of Remembering

> *I think of Hazel probably about 50 times a day.*
>
> *You see your body every day and you know how your body looks different because of what you've been through. There are just reminders in every part of my day but I'm not sad every day. I'm not in tears every day but it is not at the back of my mind either. There are very real reminders for me every day.*

Ursula's body shows the conspicuous signs of having birthed Hazel; yet, she does not have Hazel with her, except in her thoughts and memories. To be reminded every day of what she has been through and thinking of Hazel throughout the day indicates that these memories are never erased. It is not that thoughts of Hazel are intrusive, or the memories are unwanted; in fact, quite the opposite. Ursula's rememberings are intimately private to her as she looks at her reflection in the mirror. The familiarity of her body and how it has changed is visible every day and perhaps keeps Hazel close to her. It is with her own body that she knew Hazel, felt Hazel, created Hazel, carried Hazel, birthed Hazel, and, ultimately, lost Hazel.

Ursula 3: A Moment of Disbelief

> *At our 20-week scan there were signs of a heart abnormality. I usually will not really panic or worry too much until I've got the absolute facts. I genuinely believed they were probably wrong and that us going back for a second opinion was going to verify that. Then it was confirmed that our baby, Hazel, had a serious heart defect. That hit hard, and I thought, "hold on a minute this is not happening". This is not what happens to me. I've never experienced real grief; I've not had anyone close to me die. This was all new to me, this feeling of mental trauma. That was devastating news.*

Ursula did not want to acknowledge the truth of her baby's terrible diagnosis; and although she heard that her baby had something wrong with her heart, she was compelled to believe they were wrong. She was not prepared for any bad news about her baby as it was not something she *knew* how to cope with. Her own life belief was that this sort of thing did not happen to her, and she was almost willing them to admit they were wrong.

The uncertainty of the diagnosis may have implied that before long she would be told that there was, in fact, nothing wrong with her baby. By denying that there was anything wrong her baby, Ursula was leaving room for her to be given the good news she was expecting. It could be suggested that she was inadvertently giving herself time to come up with an 'internalised' plan for any response she may have to bad news. She could not fall back onto known responses from past experiences; she needed to create, in her own mind, what all of this may mean.

Ursula 4: A Moment of Uncertainty

> *Hearing the final diagnosis was so tough because, it was very rare, about 1 in 33,000. So not only were we dealt with this blow but the information was minimal. What did it mean for our baby? They couldn't tell us. This felt like a rock and a hard place situation. We were having to decide based on very few real-life stories and very little information. I wanted black and white answers, and I wanted doctors to tell me what to do.*
>
> *I didn't feel comfortable that there was nothing else wrong with her. Her brain was fine, her lungs were fine, everything else was fine. Just her heart was not fine. Is it fair for the baby's sake to let the pregnancy continue? And we decided, no.*
>
> *I have never felt so conflicted with what to do, in my life. So, while Ben and I agreed that this is what we were going to do, I wasn't 100% on that decision but we had to decide. That's where it all fell apart for me.*
>
> *I feel very differently about this decision now than I did then.*

Not knowing which way to turn, what decision to make, or even how to make the decision must have seemed like a 'no-win' situation. Regardless of what decision they made, the consequences of that decision would change the course of their lives. For Ursula, she felt ill-prepared to make such a monumental decision. She wanted to put her usual "black and white" logic to their decision-making but she was not given the facts to be able to do this. Without this information, Ursula then wanted someone else to make the decision for them. The stakes were so high that she felt unable to decide. She perhaps had lost her reference point that she used to guide her.

To remain undecided was not an option so, together, she and her husband made the most difficult choice to end the pregnancy. It was a decision that did not sit well with Ursula, but she did not feel she had a choice. The pain of what they had decided was to stay with Ursula like a thorn in her side.

Perhaps, for Ursula, making this decision was the only way she could influence the course of her family's life. She was committed to protecting what her family already had over what they may or may not have in the future. She was desperate to make the right decision but she was not able to make the decision right.

Ursula 5: The Moment Hazel Died

> *I had the injection to end her life. That was so tough.*
>
> *I didn't think Ben needed to be there and that was fine. They gave me some amazing drugs and for the first time, in about a month my mind wasn't on this horrific event. Then you sit around for 2-days and wait for this thing to happen and you're just... it's surreal. Baby is not alive. She's no longer kicking. You look at your tummy in the shower and know that you did that. Far out. The guilt of it. I can't describe the guilt".*

That moment of witnessing her baby's death was, for Ursula, something she felt she could do alone. Trying to protect her husband from what was about to happen seems to be about Ursula taking responsibility for everyone and everything. She was able to disappear from the moment with the acceptance of medication that separated her from what was happening in that moment and from what had been sitting on her mind for some time.

Just like a shadow casting its gloom, Ursula waited for this dark ordeal to be over. She was just trying to keep herself together while being in what could be described as a dreamlike state, knowing her baby was dead inside her and blaming herself for making this so.

For Ursula to feel this intense guilt for supposedly causing her baby's death was indescribable and all consuming. She knew, so intimately, that her baby was not moving inside her and there was no going back. Hazel was no longer alive, and she knew exactly when and how her she had died.

Ursula 6: The Moment of Reality

> *I had a huge amount of fear when they said that I would have to deliver her. I was so scared of that. They obviously explained to me that it's not an option to have a caesarean when I was not that far on. There were complications talked about because I had placenta previa as well, so I had to be aware of that. All the risk factors were thrown at me, and they were all daunting.*

For Ursula, giving birth to her baby, Hazel, frightened her as she had not experienced this with her first daughter. She was experiencing fear of the loss of the familiar; that is, birthing via a caesarean section. It seems ironic that she had an operative birth for her healthy child but was expected to go through a labour with her deceased child. It seemed merciless to put her through a labour and birth to end up without a live baby. Everything about this scenario was foreign to Ursula and the fear of the unknown was overwhelming. The uncertainty of what may or may not happen, whether she would be able to cope with the labour and birth, as well as who would be there for her, all played on her mind. The complications would have added to her fear and the whole event would have seemed monumental, looming in front of her. In fact, Ursula may have not feared birth itself but feared what the birth represented. The birth of her daughter that she had witnessed the death of.

Ursula 7: The Confronting Moment

> *She was so kind and lovely, and I can't remember her name, but I think of her often. At first, I was a bit defensive because I didn't know who she was, and we were talking about some full-on things. We had to talk about what happens after the birth, what we want to do with Hazel, and it became so real. Wow, I'm going to be dealing with a body and I must do something with her. That was the first time someone had talked about that. I hadn't thought about it. In my head they are taken away, so I did not think of it as being my problem and it was incredibly confronting. I haven't even had her yet and I'm having to think about this. It was all very overwhelming. I just didn't realise that was part of it.*

Of course, Ursula's defensive response to someone she had never met, and who was wanting to talk about Hazel's body, would have been a normal response of self-protection. Intertwined in Ursula's response may have been a sense of being threatened or judged. To be asked about Hazel may have opened the wound Ursula felt about her decision to end the pregnancy. She was already feeling fragile about her decision and felt secretly distraught remembering the moment Hazel died. Now there was a woman bringing up confronting questions that may have led to a comment about this decision. There was the possibility that Ursula would hear comments that would shatter her own story about how she sees herself in the world. She felt her guard was up, and Ursula wondered if she came across as being belligerent. To be asked to discuss such a confronting subject would have also been shocking to Ursula as she had not even considered anything past the labour and birth. This, again, was uncharted territory for her, and it would have seemed if everything was unfamiliar with no internal guidelines for her to follow. She had already experienced more confronting situations than ever before and this one only added to her collection.

Ursula 8: A Moment of Faith

> *I had my tablets at 8 or 9 o'clock. I thought I would be in and out. I've never been in labour or been induced so I didn't know what to expect. I just thought couple of hours, and we'll be done. They told me that it may not happen until tomorrow and I thought "what do you mean"? I hadn't brought an overnight bag, so it was quite a shock. But the tablets worked quickly. I was scared because of the labour.*
>
> *I had that those shaky shakes and I was vomiting. Ben was sitting there completely helpless, and it was very scary for him. I needed to go to theatre because I was bleeding so much. One thing that scared me was not having anyone with me that knew me and my situation. It was just somehow very important to me.*
>
> *So, while it was scary and we were panicking, we had our entire faith in the staff looking after me, and we never, for a minute, doubted them. Whatever decisions they made we just went with it. "You tell me what needs to happen, and we'll do it".*

A blind faith in those caring for Ursula showed how desperate they were to trust someone. When they were overwhelmed with what was happening, they felt that they could and should put all their faith in them. The term *blind faith* is not used in a disparaging way; rather, as a reflection of how Ursula and her husband felt confident and reassured by the abilities and intentions of those around them. The urgency of the developing situation would have added to Ursula's feeling of needing to trust those caring for her. It could be suggested that the more vulnerable Ursula felt the more support she needed and, therefore, the increased need to trust. It is a double-edged sword with her being at even greater risk of 'harm' if the trust was not justified. When they felt unsure or hesitant with what was happening, it seemed like the right thing to do. On some level, passing the responsibility to others may have been a way of lessening the extreme burden of Hazel's birth and death. Ursula had already felt the weight of their decisions and it seems that, at every turn, more unfamiliar and confronting decisions had to be made.

For Ursula to be unaware of the unpredictable timeframe of her labour may indicate a true *unknowingness* that left her feeling vulnerable. It did not even occur to her that it would take some time and how would she have known if no one had discussed it with her beforehand? Feeling in the dark would have added to her fear of what was about to happen.

Ursula 9: A Moment of Safe Space

> *I had a room to myself, and it was a lovely big room. That was hugely important to me because I had the privacy of the space. Sometimes people would be in the room with us and sometimes it was just Ben and me. It was amazing. I didn't think that would happen. I thought it would be hustle, bustle rushing me from one room to another and sharing, I just didn't know.*

For Ursula, having a private space that she felt was her own turned out to be so important to her. The expectation of a busy hospital that would be too busy to appreciate what they were going through was not founded. Ursula had assumed that she would tumble along within the busyness and be consumed by what else was happening. She may have expected that what she was going through had a sense of *every-day-ness* to those caring for her but in fact, every woman experiencing the loss of their baby was seen as exceptional by those caring for them. This over-arching care philosophy would have positively impacted on Ursula's sense of a 'safe space'.

Ursula 10: A Moment to be Numb

> *I remember the doctor making it clear to everyone, to give me as much pain relief as I wanted. She said, "she doesn't need to feel anything", so they gave me heaps of pain relief.*
>
> *I was very scared about the pain, but the midwife said that because the baby was so small that I wouldn't have any trouble delivering. But I wasn't comfortable with that. I just didn't believe it. If there was any chance of me having any pain, I didn't want it, I didn't want to remember this moment as something painful. I didn't want to have to experience any discomfort if there is something they could give me them give it to me. There's enough going on and I don't need to endure that.*

The meaning Ursula placed on feeling pain during the birth of Hazel was perhaps one of unnecessary affliction and something that she did not want to endure. Pain, to Ursula, was something she desperately wanted to avoid as it was entangled in such negative and heart-breaking emotions.

Ursula could not attribute the pain of giving birth as positive or purposeful; rather it was something that could only represent Hazel's life and death, a death that her parents consciously, if unwillingly, agreed to.

The way Ursula describes, feels, or interprets pain is entirely up to her to determine. When she associates pain as a negative consequence of birthing Hazel, it only stands to reason that this relates to the grief and emotional pain of losing Hazel. The context of this pain is not related to the celebration of the birth of their daughter, to the empowered birthing experience, or the addition to their family, perhaps quite the opposite.

Ursula 11: A Moment of Pride

> *I went off to sleep and next thing I knew I was being wheeled back to my room.*
>
> *Ben was holding Hazel. Seeing him holding her made me feel so proud of him because what a thing to have to go through, what a thing to have to watch. Even though Hazel wasn't alive he was holding her, and he looked so proud of her. Talk about a mixture of emotions. Something about Ben holding her there, and his reassurance that it was OK and that he was looking at this baby so although I couldn't see her, something about that picture, made it OK and it meant I didn't need to be afraid to see her. It was a bit scary because I didn't know how she would look.*
>
> *We weren't sure if we wanted to see her or not. Beforehand we just didn't know. Which was hugely relieving because I didn't know how I would feel.*

The fear of the unknown when Ursula was about to see Hazel for the first time was lessened after seeing her husband holding her. For him to have done something that they were both feeling unsure about gave Ursula the confidence to see her daughter. She felt a sense of pride that after the trauma of what they had been through in the last month, he was able to put all his fears and trepidation aside and be Hazel's dad. For once, Ursula may have felt shielded from the constant anguish she felt. For Ben to take the lead in navigating their way through this ordeal may have helped her feel as if someone else was carrying the burden, even for a moment.

Perhaps her feelings of pride in her husband also reflected feeling proud of herself, that she had coped and come through this ordeal. She had managed to get through it even though she was overwhelmed with all the unknown-ness that confronted her. Ursula had made it, even though she had experienced complications and ended up having to go to theatre to birth Hazel. Her relief at this being over would have given her a sense of solace and now she could at least breathe.

Ursula 12: A Moment of Real Grief

> *I feel like I'm quite a different person from the experience. I've never experienced real grief before this. So, my empathy for others has just gone through the roof.*
>
> *I've not had a pregnancy since as the IVF just didn't work. There are "ups and downs" with IVF but to be honest the 'ups' stopped with Hazel. When I got pregnant with her that was the last 'up', the rest have all just been downs. I have a feeling of needing to fix something. If only I could fix what I'd done. If I got pregnant my mindset was, I could fix this. My daughter would have a sibling, we'd have another child, that would have been some sort of reprieve from the grief. It hasn't happened so that for me has been my latest challenge in accepting, that not only has that not happened, but I need to find another way to reach acceptance.*

Ursula sees herself as being different after going through the loss of her daughter Hazel. The experience has heightened her empathy for others who have been through the loss of a baby. It has come about from Ursula gaining a deeper understanding of 'real grief'.

Accepting the deep sense of loss has been difficult with Ursula's on-going issues with her IVF journey. As each cycle comes and goes and she does not conceive, the wound of loss must become raw again. She felt the need to 'fix' something, as if losing Hazel caused something to be broken. She sees her family as being in pieces because she cannot have another baby. By giving her first daughter a sibling, her family would be whole. Ursula also sees that by her having another baby her grief will be spared. It implies some sense of guilt that needs to be pardoned.

Ursula 13: A Moment of Seeing the Real Ursula

> *There must be a reason to have gone through all of this because we were so upset, we were so sad. There has got to be something to come out of this because I refuse to believe that I have been dealt this blow for no reason, why I had to go through something so significant. I'm not a bad person.*

The interpretation of good and bad seems to be balanced on a knife edge for Ursula. On some level she judged herself as having done something bad or unacceptable, but her self-image was not one of being a "bad person". How could she be bad when she felt so upset and sad at the loss of Hazel? She felt like she had been dealt a blow, as if she had been attacked or even ambushed by what had happened.

The ‘real’ Ursula saw herself as a good person who had been forced to endure something so traumatic that she could not believe the randomness of it. Something like this could not happen indiscriminately, there must be a more logical reason rather than bad luck or fate.

It sounds as if Ursula is saying ‘see me as a bereaved mother rather than seeing what I have done; see the real me’.

Ursula 14: A Hidden Moment

> *We got her cremated. We were in hospital for 2-days and in that time, we wanted her to be blessed. I’m Catholic, Ben’s Anglican. We had both a Catholic and Anglican priest come in and bless Hazel. My mother-in-law organised a tiny little coffin for her, so she was put in there and I carried her down to the car. It was incredibly upsetting carrying Hazel. I remember it being a very silent walk and, I just wanted to get in the car. I wanted to go from my bed to the car and I wanted to skip that bit in the middle. We took her straight to get cremated. I didn’t want to have her at home. I felt that the sooner that we did this the sooner we could heal. I didn’t want anyone else there, I didn’t want a service, I didn’t want anything like that. Taking her to the crematorium was a bit brutal so the walk back to the car after that was horrible. Then we collected her ashes a couple of days later. We haven't decided what we will do with her ashes. It’s still quite a confronting discussion to have with Ben, it’s not a comfortable discussion.*

Nothing to do with Hazel's final journey was made into a shared experience. It was as if keeping this time invisible made it less painful for Ursula, or at least on the outside. It seemed as if she was holding her breath from the moment, she left hospital to the moment Hazel was delivered to the crematorium. Ursula chose not to publicly acknowledge that Hazel had been born and had died. To do so may have called attention to what had happened. It was easier for it to remain unseen, to package the whole ordeal securely to give some distance between the trauma and the healing. Unfortunately, denying what had happened did not appease Ursula's own memories and emotions.

Ursula 15: A Moment of Reassurance

> *One of the biggest things is how little people talk about this and how it can be hard to share. I wished there was someone that I could have talked to about it who had similar emotions to me. On Facebook there were women going through what I’d been through, and to read that the feelings I was having were normal, was reassuring. Some of my thoughts and feelings were so awful. It showed me that I wasn’t alone. It’s so weird*

> *because the doctors would keep telling me that this kind of thing happens every day. I felt as if I was the only selfish one out there choosing to terminate a baby that would live but would have complications. It's just no one wants to talk about it and that to me, offered me some comfort in knowing that. I hope they were telling me the truth not just paying me lip service.*

Ursula felt an allegiance with others who had been through a TOP, just like her. Her steps towards healing or at least coming to terms with what had happened involved seeking out others who had gone through a similar thing. She could empathise with their pain and suffering because she was still experiencing the raw emotions of losing Hazel.

The doctors reminded her that many others go through this as well. Her faith in her decision was restored, for a time, and reassuringly she did not feel alone.

Disturbingly, Ursula still felt that she had been selfish in choosing to end her pregnancy even though her decision was based on her love and concern for Hazel.

Ursula 16: The Moment of Knowing Hazel

> *I just wish that I had had Hazel earlier, so I didn't have to deliver her and hold her and go through that. I wish that bit didn't happen, and I could have not known her. I would have preferred to not see her as a real baby whereas I was kind of forced to because I was too far on in my pregnancy. I remember the trauma from it.*

To remove herself from the bitter reality, Ursula wished that she had not given birth to Hazel. Perhaps she would have preferred the distance given with a more surgical approach. When she gave birth to her, saw her, and held her, the realness of her daughter's existence was insufferable. Even with Hazel being so tiny, Ursula felt like she had 'known' her. For most people, the concept of 'knowing someone' comes from having a relationship with that person, a history with them that lets them into their world, rather than a mere acquaintance. For Ursula to state that she 'knew' Hazel may represent the knowingness of a mother. Perhaps with the birth and death of Hazel, Ursula experienced the birth and death of herself as a mother. The irony of taking Hazel's life while giving birth to her may reflect a tearing apart of Ursula, as a mother. This may have been why Ursula remembers the trauma of 'knowing' Hazel.

Ursula 17: The Hidden Moment of Hazel's Death

> *One thing I hadn't told anyone, especially Ben, was that I did remember when I had the injection to stop Hazel's heart and the woman struggled a bit towards the end. She needed to be quite forceful with what she was doing. That was something that gave me*

> *nightmares because of what I was doing to my baby. I thought it would be just a simple, peaceful thing and I wouldn't even know about it, but I did know about it. That was something that I didn't want to share with Ben because I didn't want to scare him.*
>
> *He would have been pretty upset to hear that and anyone that hasn't been through something similar they just wouldn't understand, and I don't think they need to. There'd be no point, so I kept it in. I had a counselling session, and I was trying to explain it, but I was crying so hard that the therapist couldn't understand me. For the first time the grief was just pouring out of me. I had not shared that with anyone, and it kept my mind in a bad place.*

For Ursula to carry this secret must have been like carrying the weight of Hazel's death on her own shoulders. Although Ursula and Ben both made the decision to terminate this pregnancy, it seems that Ursula somehow wanted to shield Ben from the brutal reality. Perhaps the decision was so hard to make, Ursula hid the nightmarish details from Ben to soften the blow of the decision, if not for Ben but for her. By sharing what happened during Hazel's death, it may have combined with Ursula's unspoken doubts and made the intensity of the situation unbearable. Focusing on the outcome was what Ursula chose to do rather than focusing on the process to get to the outcome.

If the hidden reality of the torture of Hazel's death came to light, Ursula's own containment of the story may be at risk. The impact of others knowing the truth may have been too much for Ursula to manage. By holding onto it she was able to shield others from the truth; but, in doing so, put herself in harm's way.

Interpretation of Ursula's Story

The main theme that comes from Ursula's story is one of absolute anguish. Although 2-years have passed since Hazel's birth and death, Ursula still lives with the nightmares of the experience. It suggests that time does not necessarily cure the torment she is feeling.

For Ursula, finding out that her unborn daughter Hazel had a potentially life-altering heart condition forever altered her assumed pathway of having a large family. She had envisaged that she would have several children but found herself the mother of an only child. Time ticking by, her age, difficulty conceiving, and this experience put paid to her dream.

Once she and her husband decided to end this pregnancy, Ursula went through a feticide alone. She didn't feel that her husband needed to witness the death of their daughter, so she carried this story on her own shoulders. She was unprepared for the reality of the procedure and will forever remember the heart-breaking experience of witnessing her daughter's demise. She spoke to no one about what she had gone through for fear of putting words to a surreal and tortuous experience.

The labour and birth of her daughter, Hazel, was complicated, painful, and terrifying. All she wanted was familiar faces during an experience she had no prior knowledge of. To have to go through a labour for her dead baby was not something she had expected having had an operative birth with her first daughter. It felt like prolonged agony for Ursula, and she dreaded feeling the physical pain on top of the overwhelming emotional pain she was experiencing. To her, any pain was to be avoided at all costs, regardless of the source of the pain.

Sometime after the birth and death of her daughter, Hazel, Ursula still remembers her own unspoken doubts about ending the pregnancy. She has a deep sense of regret that she made the wrong decision, especially now that her childbearing years are behind her. She does not share these memories easily as they are still painful, but she wonders how it would have been if a different path had been taken.

Chapter Summary

This chapter told Ursula’s story of losing her daughter, Hazel. It offered an interpretation of her story, along with 17 moments highlighted within her story. For Ursula, right from the beginning of the re-telling of her story, she recalled the intense emotions of her experience. She soon describes what happened but poignantly she starts with memories surrounding the TOP.

CHAPTER 10: EXPLORATION OF FINDINGS

Introduction

This chapter offers the interpretations of the main concepts that emerged from the narratives. Four overall notions have developed and influenced how the concepts, thoughts, and meanings are connected while immersed in the women's stories. Sitting in the narratives, the commonalities appeared and seemed to come together. These are not considered themes but a community of shared understandings. The women's stories offered a sense of congruity and coherence that brought ideas together that made sense.

For each concept, the participants' narratives are considered and the evolution of understanding surrounding these narratives are offered. The four concepts are:

- Aloneness vs. loneliness vs. connection
- Silenced grief
- Unpreparedness
- Vulnerability

Aloneness vs. Loneliness vs. Connection

Aloneness

"Aloneness is a state of being whereas loneliness is a state of feeling" (Townes Van Zandt, n.d.).

The state of being alone can reflect an emptiness, a disconnect or a state of separation from those around you; if not physically, then emotionally or spiritually. If the world, or those in it, cannot provide comfort, the state of being alone is noticed. It could be described as being by oneself even when others are around. As Husserl (1973), the German philosopher, suggested, when we are alone, we are in a *"sphere of ownness"* (p. 93) which considers the sense of self as an experience that exists separately from the world of others. The vision of this phrase implies an enclosed circle of self-inclusion, and an invisible partition that sets apart the 'self' from others. Additionally, aloneness could be described as 'being with oneself', perhaps in a contemplative way that reflects a deeper connection to 'the self'. From a positive viewpoint, being alone is a state of peaceful 'at one-ness' that allows for being by yourself without feeling that something or someone is missing. Whether aloneness is constructed as a positive or negative concept, it still refers to 'being alone' or 'without others'.

Katie remembers; "*We were just you know sort of left... they said, we'll be referring you to the fetal medicine unit and go from there. We were just sort of in limbo*".

Katie describes a feeling of 'being in limbo' which implies a sense of being forgotten or ignored. Not knowing what to do next, not knowing what would happen next, or even when something would happen, left them feeling insecure, alone, and without clear direction. They were waiting for some sort of indication of what to expect but were left in a place of uncertainty. This would have felt as if they were in 'no place in particular' or an emotionally bleak place.

Tui felt a sense of being alone when she went out in public;

> *It's so easy to make small talk with people sometimes. So easy yet so hard but you do the small talk thing because you don't want to let it all go and let people know what is going on. Like walking around the supermarket, thinking no one knows I have just had a baby 2-days ago. You act your role. You just have to pretend. I got pretty good at acting.*

Tui reflects on how she played a role that would be seen as acceptable in public. All the while feeling alone in her experience, an experience that was concealed to others. For Tui, the possibility of 'letting it all go' in public was not something she wanted to risk; instead, she buried her loss for the time being and pretended. To be this alone with her grief and to not allow herself to let others know what had happened must have given her a sense of 'otherness' or being separated from those around her. All of it was to protect her, in that very public place, the world. In this instance, being alone in her grief was preferred rather than exposing her broken heart to those she met. Vagle (2021) talked about 'becoming' through or because of an experience and Tui reflects on 'becoming' the role of someone who does not have a care in the world; that all is as it should be even though her baby has just died.

Ursula recalls being alone while the feticide happened and being alone with the memory;

> *One thing I hadn't told anyone, especially Ben, was that I did remember when I had the injection to stop Hazel's heart and the woman struggled a bit towards the end. She needed to be quite forceful with what she was doing. That was something that gave me nightmares because of what I was doing to my baby. I thought it would be just a simple, peaceful thing and I wouldn't even know about it, but I did know about it.*
>
> *Anyone that hasn't been through something similar they just wouldn't understand, and I don't think they need to. There'd be no point, so I kept it in. I had a counselling session, and I was trying to explain it, but I was crying so hard that the therapist couldn't understand me. For the first time the grief was just pouring out of me. I had not shared that with anyone, and it kept my mind in a bad place.*

To protect her partner, and perhaps, even more poignantly, herself, Ursula chose not to have anyone with her when Hazel's heart was stopped. To endure such a devastating experience, alone must have been almost impossible for Ursula to bear. By being alone, Ursula ended up with no one who knew what she had gone through. She was unable to share the experience with anyone so to recall what had happened only occurred in her nightmares. Vagle (2021) proposed the concept of a phenomena (in this case Ursula's experience of feticide), moving, shifting; they provoke and produce *things.* This concept relates to Ursula going through the feticide, keeping the experience to herself. Only many months later, she is able to untangle the experience. She can unpack it and see it in a different context. This example highlights how an experience can 'become' something through the movement of time.

The sense of aloneness Ursula felt may have appeared to contain or control the desperate reality of their decision. While she and her husband had made the decision to end the pregnancy together, Ursula recalls not feeling totally sure of the 'rightness' of the decision,

I have never felt so conflicted with what to do, in my whole life. I wasn't 100% on that decision but we had to decide.

By being 'alone' as Hazel died, Ursula was shielding herself from her own doubts as there was no one to hear or debate her uncertainty. Ursula was able to be 'alone' in her misgivings. This would stop any last-minute impassioned plea to not go ahead with the feticide or termination by removing anyone who would listen to her doubts. By being 'alone', any ambiguity in the decision made would be silenced. After the feticide, Ursula would have also recognised the possibility that anyone who knew of Hazel's tortuous death may have blamed her for making her baby suffer. To keep her secret to herself would have protected her from the risk of condemnation. Ursula's story shows that she alone knew what happened and she alone carried the trauma of Hazel's death.

Paige recalled a moment of feeling alone, in a crowd;

> *They wanted the family to leave so she got passed around the room for everyone to have their time with her. It was incredibly beautiful because everyone then got to meet her. But I ended up having such a short time with her, after she was born. I think it was then that I started to realise what had just happened. It was when I started to process what was going on. I was seeing her with everyone, and it hit me.*

Although Paige remembers this time as beautiful, she saw the image of her family and friends meeting her daughter and felt an 'outsider', as if looking into the room rather than being present in the room. This subtle 'aloneness' was indicative of Paige being the 'other' that consequently meant that she was not able to immerse herself in meeting her daughter and 'becoming' Harper's mother. Her 'being-on-the-outside' forced her to grasp what had just happened. As

Vagle (2021) suggested, Paige's experience provoked a sense of otherness or being separate from others. It was as if the pictures of her story were being played out in front of her and she was somehow distanced from it. This was until 'it hit her' which implies that reality touched her suddenly and with some force. She, alone, gave birth to Harper and she, alone, is the bereaved mother of Harper. There is no one else who can say that of the situation.

Ursula recalls reading social media comments by women who had also made the decision to end their pregnancies because of abnormalities.

These women were going through just what I'd been through, and I thought thank God to read that these feelings that I'm having which, some of them were awful, are normal and I wasn't alone.

Feeling different may produce a sense of aloneness, especially when your 'difference' feels like an invisible barrier to connecting with others. That is, it is 'unseen' by others but known to the woman. For Ursula, although she had not felt able to openly share the loss of Hazel with others, she felt connected when she could read about these women's stories of loss. She was able to acknowledge that the 'awful feelings' she had were considered 'normal' by other bereaved mothers. Reading their stories helped her feel she was not alone, that others had experienced a similar loss and that she was 'just like them'.

Loneliness

Contrastingly, loneliness is a consistent emotion of needing or desperately wanting to connect with someone when there is no one to connect with. Loneliness is "a lack, a feeling that something is missing, a pain, a depression, a need, an incompleteness, an absence" (Dove, 2017). The person who feels lonely has not chosen to feel this way; rather, through circumstance, the feelings of loneliness prevail. "Loneliness is a phenomenon that belongs to life, to existence" (Dahlberg, 2007, p. 195). This is a feeling that Heidegger (1995) explained as representing our relationship with the world; loneliness can make the world more remote and leave us without connection, completely abandoned. As Arendt (1962) stated, "loneliness happens when all by myself I am deserted by my own self" (p. 476). It implies that a person can feel lonely even when surrounded by others, or others are 'with them'. Heidegger stated that a human being enters into a nearness to what is essential in all things, a nearness to the world. This represents a realisation that we all regard connection or a nearness to something or someone as essential to being human.

Ursula relates her fear of feeling loneliness;

I wanted familiar, I just wanted the feeling of someone that actually knows me, knows my situation, it was just somehow really important to me.

Ursula was entering an unknown or unfamiliar place, physically and emotionally, and it unsettled her. She was aware of how important it was for her to have someone stay with her. To her, loneliness at such a vulnerable time filled her with angst. Through this feeling Ursula was able to identify what was important to her and, consequently, enabled her to name what she needed to cope. Vagle (2021) proposed the concept of *centering* or how someone engages or interacts in their world. Ursula's desire to be in the familiar represents this concept. The sense of being abandoned was real for Ursula and to have a familiar face would offer her the comfort she needed. To have someone with her, who knew her story, would provide a sense of reassuring *known-ness* or a space that did not require explanation or justification. The important details were openly known and not obscured to those sharing the experience. This sense of familiarity provided an attachment to each other, as is the antithesis of loneliness.

Tui's memory of the aftermath of losing her daughter Hazel reflects how lonely she felt;

> *It is very, very lonely road because no one really knows, no one talks about it. In a way us bereaved mothers make it lonely for ourselves because we fear how people will judge us. Until you have walked in those shoes, you have no idea what you would do yourself.*

There is a paradox within Tui's feelings of loneliness. She explains how lonely the journey of the bereaved mother is and acknowledges that no one wants to share their experiences because of the fear of being judged. The interrelatedness of the loneliness felt and the need to be protected from the opinions of others is obvious. She, along with other bereaved mothers, has rejected the possibility of understanding and support from those around her because of her fear of having her decisions or choices be seen as wrong. To separate herself from the world is to imply that she is 'not of the world'. This separation sits with the notion that others do not understand as they have not had to make the decision to end a pregnancy. The loneliness Tui feels would be potentially minimised through a sense of belonging or connection with those who have either been through a TOP or have the adequate empathy to acknowledge her grief. Tui's social identity or how she sees herself, how she wants to be seen by others, and the groups she identifies with, is one of 'bereaved mother'. However, because of the self-imposed yet understandable unspokenness of her loss, she remains distanced from others who have lost a baby through the termination of their pregnancy.

Connection

The notion of connection comes from a feeling of being seen, heard, and acknowledged by others. Heidegger (1995a) suggested that 'being' is always about 'being in the world', and the world is always something that we share with others. This sense of connection is considered the relatedness between self, others, and the living world; however, that is interpreted. It is characterised by a yearning to have a conscious and meaningful relationship with someone or something; to have an embodied or tangible experience of the lived world as if being tethered to it. The sense of connectedness comes from an awareness of others from a mainly emotional or cognitive standpoint rather than simply being physically close or near to someone. Sometimes the connections are entangled and complex, sometimes they are fleeting and seemingly inconsequential. Regardless of the duration or intricacy of the coming together, a connection is, by definition, a joining with someone or something.

Tui felt that the midwife truly acknowledged her experience when saying goodbye to their daughter, Hazel:

The midwife walked out with the purple box with Hazel inside. We were just bawling our eyes out and she turned around and she said to us, 'we'll take real good care of her for you'… and that was all we wanted to know.

Tui felt a sense of meaningful connection when she could see that the midwife appreciated the significance of the moment Hazel was taken. Without words, the midwife acknowledged the emotions Tui was feeling and promised to look after her daughter. That level of empathy and caring enabled Tui to feel 'visible' and from that she felt as if the midwife 'got it' and had embraced what Tui was going through. She dared to see Tui's suffering and did not disconnect from her. The connection was unspoken, and the trust Tui felt from the midwife's thoughtfulness would have helped Tui feel validated. When one person values, acknowledges, and 'sees' another, it reflects human connection.

Tui also remembers feeling such a comforting and peaceful connection with her midwife, after the birth.

> *She said to me "you've given birth to a baby as well, don't forget that". Sometimes we would just sit on the couch in silence and that was fine. I knew she was there in case I needed to say anything.*

The humanness of this silence conveys a true connection between Tui and her midwife. To be able to sit in silence and be comfortable doing so indicates a mindfulness and 'being-in-the-present' for both Tui and her midwife. Tui was able to be herself with the midwife and gained a sense of being nourished by their relationship. The connection with her midwife was one of nurturing and healing. The intimacy of this connection is complex, and it cannot be assumed that Tui and her midwife would automatically have this level of togetherness. This interrelatedness can be seen as a two-way path between Tui and her midwife, with both feeding off the positive intentions of the other. Connection does not happen in isolation as it is reliant on each person paying mindful attention to the other. Tui's experience with her midwife represents what Vagle (2022) considered to be 'being-with-connectedness', a togetherness that speaks to both the human nature of relationships and the togetherness of two people.

Silenced Grief

To be silent in the depths of grief seems like a contradiction to the response many would expect. The silence may be seen as either the deeply buried emotions of loss or the enforced hush of an inappropriate release of feelings or even the sense of being 'at a loss for words'. However, for some, the silence may be a moment of respite, a time to acclimatise to what has happened or a moment of searching for meaning. The stillness may be a result of the exhaustion felt after a previous release of emotions and reflects a sense of peace that comes from letting go. It is the being-in-silence that allows those who are grieving to wander and wonder in an unknown space while seeking a pause to literally catch their breath. For many, grief is confusing, confronting, and immensely overwhelming, so the need to escape into a suspended reality seems to be a logical choice.

Ursula recalls trying to bury her memories of losing Hazel;

> *In the last year I'd say I've done quite well to suppress it ...but in the reality, it's still there*.

Ursula remembers never being completely comfortable with their decision to end the pregnancy, so supressing the thoughts of losing her daughter may have seemed like the most self-protective thing to do. She did, however, concede that her memories were still in her mind, unable to completely forget what had happened. She believed the silencing of her grief would enable her to move forward from the experience; but, as she recalls, the reality of her loss had stayed with her. Ursula attempted to self-silence her memories; instead, she temporarily hid them, only for her to realise that they had not gone anywhere. In fact, Ursula believed that if she was ever going to conceive another child, she would have to bury her grief 'to be happy and healthy enough' to have another child. Over the next year, despite many attempts, she was unable to conceive. To Ursula, these attempts implied that she was not 'happy or healthy' enough to get pregnant and she related this to her unresolved grief and the regret of the decision they made. This narrative illustrates Ursula's interpretation of the power of her experience of losing Hazel and the consequences of her decisions. As she stated, *I got back onto the IVF train but to be honest there were no ups (good times), you know the ups stopped with Hazel when I got pregnant with her that was the last up.*

Ursula reflects that her life has been 'joyless' since losing Hazel. From then onwards, her life has been a series of further losses with not being able to conceive again. Her happiness was based on her having another baby and without achieving this, her life threatens to remain a continuing struggle of 'what might have been'. Her sense of unfulfillment is almost palpable and feels like she has lost hope of finding the joy she once felt.

Tui talks of feeling the full force of her emotions while talking to another woman who had just had a baby,

> *I was holding back the tears, but she had no idea that I was holding back the tears*.

Instead of breaking down, Tui silenced her memories of losing her baby to avoid an awkward social situation. To share her own tragic loss of her baby would have been seen as inappropriate and rather morbid, so Tui remained silent. Her secret left out of sight. However, the recognition of her own motherhood was highlighted by hearing of the new-born's birth. What Tui was hearing reminded her of the bittersweetness of birthing baby Hazel, even though she had died. She still saw herself as a mother but to others she was 'a bereaved parent' which, to some is not the same as being a mother. Her identity of a mother was put in her own private spotlight—a spotlight only Tui could see. Motherhood may have seemed like an illusion as she had no child to care for; yet, she had given birth to a baby. How could she see herself as a mother if she did not have a child to care for? She felt she could not share the news of the arrival of her baby, could not share the joy of meeting her baby for the first time, or imply a commonality with other new mothers. Her motherhood was concealed to others as an inconvenient truth that Tui, alone recognised.

Tui's own hesitance to share her own story of loss is highlighted;

> *It is something that's not really talked about – there's still a lot of judgement around things like that*.

The fear of being judged hindered Tui's ability to talk of her experience. Tui self-imposed her own silence to protect herself from the opinions of others. The threat of others condemning her decision would have felt like a distant humming of rejection like a freight train that never passes by. This perception of being judged is never challenged because Tui chooses to keep Hazel's birth and death private, only sharing the experience with those she can trust will not blame her.

The concept of 'daring to share' is entangled with the dilemma of whether to keep hiding it to keep safe or to share it and live with the consequences.

Ursula remembered the thoughts inside her head that told her that she would be judged for ending her pregnancy, that nobody would want to hear such a terrible story or that no one else could have possibly done what she had done.

I felt like I was the only one making the decision to terminate. The selfish one out there choosing to terminate a baby that would live but would have complications.

How could Ursula hold onto these thoughts and move forward? Her silenced grief had nowhere to go, not even to be shared with her partner. She talks of 'out there' as if she is distancing herself from others because of her extreme decision. She believed that everyone else in her situation would have made a different choice, one that was not so 'self-indulgent'. The concept of being 'out there' reflects the world or 'others' being aware of her decision and condemning her for it, when in fact she has kept her thoughts and feelings to herself.

Katie stated that she needed time to "get through the delivery" before she could start to process what had just happened. She was not silenced through fear or trepidation of what others might think; rather, she had not had time to formulate the story in her own mind. She needed time to evaluate and make sense of it all before she could begin to 'talk about it'.

> *There was just so much else to think about and so much emotion and everything going on that we needed to just get through the delivery before we could talk, start talking and handling that process.*

It seemed that Katie felt overwhelmed and needed time to put the experience into context. By reflecting on what had happened she would be able to bring forward past experiences and behaviours that may inform how she could react or cope with this situation. This need to 'take a breath' implies that the events were happening so quickly that Katie was unable to keep pace with them and needed to pause.

Paige believed that many people do not talk about terminating a pregnancy, especially so far into a pregnancy.

Not a lot of people will talk about it. Not talking about it makes them feel like they're the only ones going through it or, that no one else has ever had to deal with it. I think people are scared, scared to talk about it and they are fearful of the surrounding judgement.

As Paige suggests, perhaps people do not want to share their experiences with others; and, even more poignantly, share their thoughts and feelings *with themselves*. That is to suggest that by putting words to the experience cements the reality of what happened and why it happened. By not talking about it, the woman is able to keep her story secret, even to herself. Paige talks of the potential for others to judge but, in fact, the judgement may come, again, from *themselves*. By bearing your experience to others there is the possibility of someone answering by saying "me too". This, however, is the eternal risk that some women choose to take.

Paige believes that people are often scared of talking about terminating a pregnancy, whether they have been through it or not. 'Choosing' to end a pregnancy past the very early stages of pregnancy is seen by many as harsh or cruel at best, and immoral at worst. The adage of 'we don't talk about what we haven't seen' or, more pertinently, 'what we don't want to see' may be seen as relevant.

In contrast, Katie experienced support when she was not silent and chose to share Bernard's story of life and death.

> *Whenever a pregnancy or baby is lost, we find it sometimes hard to talk about it. My experience taught me that's not the right thing to do because as soon as you people are so supportive. They're understanding and they just want to look after you.*

Katie refers to the need to share her story with others as if to 'get something off her chest'; in response, she found kindness, compassion, and empathy for what she had been through. She uses the word 'we' when describing who it is that finds it hard to talk about terminating a pregnancy. This sense of community, albeit a hushed community, supports the sharing of each other's tales but too often these stories of loss are concealed. Interestingly, Katie reflects that keeping silent *is not the right thing to do* which could imply that this statement holds its own judgement about right and wrong. From her experience, the confiding in others led to her feeling supported so it is assumed that she was able to share her baby's life and death with people she trusted and felt would offer her non-judgemental support. This may indicate Katie's bravery or her faith that others would acknowledge and hold her up, regardless of their own opinions. But what about those women who did not feel able to reveal their stories? If they had known how the recipient would react would they have been able to share their experiences, or would the risk of judgement be too high?

Ursula speaks about going to a counsellor and how she felt she could 'get things off her chest', implying that she was holding her memories close to her heart and finally could release them.

> *I got some counselling and one of the first things that I had to get off my chest was that I did remember the doctor struggled a bit with the injection. She had to be quite forceful, with what she was doing. I hadn't told anyone about because I didn't want to scare them,*

> *especially Ben. While it was only in the very back of my mind because I was quite drugged, that was something that gave me nightmares because I asked myself, "what am I doing to my baby"? I thought it would be a very simple and peaceful. I wouldn't even know about it, but I did know about it. Ben would have been upset to hear that and, anyone that hasn't been through something similar they just wouldn't understand. And I don't think they need to, there'd be no point, so I kept it in. And the very first session I was crying so hard that the counsellor couldn't understand me. For the first time in 6 months, the grief was just pouring out of me. I just felt so much better after that because I had not shared that with anyone, and it did scare me. When my mind would go there… It will never leave me, but I'm not so traumatised by that little fact. It's just like this little thing.*

Ursula even described her traumatising memories of her baby dying as a 'little fact', 'like this little thing'. In her mind she had minimised the event although it had caused her great distress. Doing so enabled her to silence her thoughts somewhat and hid the horrible reality deeper and deeper until she let the memories 'pour out of her' in front of the counsellor.

Unpreparedness

Feeling unprepared for an unexpected event would be a reasonable response for anyone in this situation. The nerves are heightened, the uncertainty mounts, and the heart quickens. For women who are told that their unborn baby has a serious health condition, these feelings are understandable. What was considered a normally progressing pregnancy suddenly turns into a nightmare that, ultimately, will end their baby's life. To find peace in these circumstances would be considered the exception to the rule. The holistic impact of such news would likely overwhelm and confuse most who find themselves in this space.

"But no one can prepare for the worst. The worst doesn't only dash hopes; it tears through everything in ways that are almost meant to hurt, to punish, to shame" (Aciman, 2017).

This situation is unwanted, unprepared for, and is shocking and anxiety provoking for the woman. There is nothing in a social construct that would prepare her for the loss of her baby in this way and requires a total adjustment of her expectations. There is no rule book for how to cope with or manage this scenario, so even the woman's reactions are ill-prepared. The 'not-known-ness' is enough to unsettle anyone and even compromises a person's ability to comprehend what is happening.

Katie remembers how everything changed when they found a problem with their son Bernard.

"When they finally got a little snippet of his face, they found a cleft. At that point everything changed. The mood in the room just completely changed.

This was Katie's first pregnancy. Her first scan showed no concerns so she expected the same would happen with her next scan. She was happily ignorant to any concerns that others had and assumed that sometimes repeat scans were needed. During the repeat scan, however, what she was certain about was how the mood in the room changed. Something seemingly familiar had changed and she felt it with trepidation. Even without knowing the details, she sensed that the path of her pregnancy had just altered in a way that she was yet to discover. There is no way to prepare for such feelings or even to anticipate their possibility. Suddenly, Katie's pregnancy journey was about to deviate to an experience that she had not anticipated and was not prepared for, and this was announced with a 'change of mood in the room'. Katie's sense of change represents feelings of being emotionally unprepared for a different outcome that she had not considered.

Paige was given the unexpected news that her baby, Harper, had serious health issues. She was given several options regarding continuing or ending her pregnancy. She chose to end the pregnancy and went into the hospital to discuss this outcome.

> *They gave me some medication and they told me to come back on Wednesday, 2-days later. We asked why we would be coming back on Wednesday. The woman told us that we'll be having our baby on Wednesday*.

Paige was unaware of the need for her to return to the hospital 2-days after the initial medication. It implies that she was unprepared for the realities of the TOP process and knowing that she would need to come back 'to have her baby' must have come as a shock to her. The thought of birthing her baby meant that there was a real baby to birth rather than a release of something that represented her baby. There seemed to be a discrepancy between what Paige understood would happen and what was going to happen. It was not that she had been misled; rather, the assumption had been made that she knew how the TOP process worked. The person she was talking to understood and appreciated the situation, but Paige did not. Paige must have felt blind-sided by these instructions and at a loss to what was happening. These feelings would have generated so many more questions for Paige. It could be asked 'how did it get to this point without her knowing what to expect?' Paige's trust in those providing her care implies that she followed their led without questioning what was happening, until now.

Tui remembers being unprepared for her baby, Hazel, to be born.

> *I felt my waters break. I thought "not now, not now"! I started yelling out "no, no, not yet". Then suddenly something started to happen. I still remember getting on the bed and I was up on all fours to birth our baby Hazel. I'll never forget it. I can see her coming out and just yelled out, "my baby". Just seeing how small she was. I remember the sound of both me and my husband, just wailing, as soon as I crowned my baby. That's not how I imagined our third child would be. We knew we'd birthed a baby that we couldn't take home. It was horrible. I imagined our third child going to term and there be nothing wrong with it. It was a bit of a nightmare.*

Tui had experienced birthing a baby before but because Hazel came so quickly, she felt unprepared. The shock of such a sudden birth made Tui plead for more time, time to prepare, time to get ready, time to anticipate what was ahead of her. Tui wanted to saviour the known-ness of birthing her baby, to be fully present, to be able to welcome her baby; instead, her baby just appeared. Tui anticipated a 'moment' of birthing Hazel, a conscious and mindful time that she could pin her memories to. Instead, she experienced an unprepared for sense of panic that made the comforting familiarity of birthing into something unfamiliar, and it shocked her. Rather than experiencing the birth of her baby, 'something' happened to her. It did not happen how she had envisioned, and her memories speak of her baby 'coming out' rather than Tui birthing her. It left Tui feeling that she was in the middle of a nightmare that happened suddenly and something she will never forget.

Ursula found herself in an unreal space, a space that she was not prepared to be in. She did not accept that she might lose her baby because these things did not happen to her. The reality confronted her and left her feeling traumatised.

> *That hit hard because I thought, "hold on a minute this is not happening. This is not what happens to me". I've never experienced grief. I've not had anyone close to me die so feeling this trauma, the mental trauma was very new to me. It gave me a huge amount of fear.*

The relationship Ursula had with grief was new to her and she did not like the prospect of falling into its grip. Like a stranger forcing themselves into your life, whether you have invited them in or not, Ursula was unprepared for this intrusion and insisted that this "was not happening". She was almost indignant that it was happening, as if terrible grief happens to other people, not her. This denial may have worked for Ursula for a time but, finally, the devastating reality sat with her and became very real. She talks of the news 'hitting her hard', as if the actuality of what was happening had physically impacted her. It reflects the shock and trauma being felt in a palpable, bodily way. Ursula also felt unprepared for *how* she would give birth to her daughter. Her first baby had been a planned caesarean section, so she had no idea what would be involved with an induced labour.

> *I thought I would be in and out. I've never been in labour, and I've never been induced so I didn't know. I just thought perhaps just a couple of hours, and we'll be done. The tablets worked quite quickly but they said that I might be there until midnight, or it might not happen until tomorrow. I thought, what the heck, what do you mean? I didn't bring an overnight bag you know it was all a shock.*

Ursula was dumbfounded when she realised what lay ahead of her. She was under the impression that her baby would be born quickly and then she would be able to go home. She was confused when she learnt that the labour and birth may take some time. Either she had not been informed about what to expect or she was unable to comprehend what would happen. Her unpreparedness was seen as simply not bringing her overnight bag which, on the surface, is seemingly inconsequential. However, for Ursula, it reflected her unawareness of what was about to happen and signified her 'readiness' or lack thereof. She was so unprepared she did not bring anything with her, and this unknown-ness led her to feel shocked. Again, like the other women interviewed, she felt at a loss, taken aback at the reality of what was happening. Her confusion and feelings of uncertainty knocked her off guard and seemed to come like a bolt out of the blue. What she was going through had no resemblance to anything she had ever experienced before. Her previous experience of giving birth was seemingly unrelated to what was about to happen and what lay ahead of her was like going to a foreign country, unfamiliar and alien.

Ursula recalls having a conversation with the social worker about what she wanted to do with her baby's body. It had not entered her head that she would have to deal with this matter, let alone make decisions about what she wanted to do. When reality hit her, she felt even more unprepared.

> *We had to talk about what happens after the birth, what we want to do with Hazel, and it was, wow okay this is real. I'm going to be dealing with a body and going to have to do something with her. That was the first time someone... I just hadn't thought about that. I think in my head abortions or terminations are taken away, but I didn't think of it as being my problem and it was incredibly confronting. I was thinking oh my God I haven't even done this yet and it was all very overwhelming. I just didn't realise that was part of it.*

Ursula uses the phrase ‘had to’ as if she was forced into this conversation and the responsibility was hers, whether she was ready to accept it or not. For Ursula the sense of unpreparedness was both overwhelming and confronting. It implies that Ursula was just managing to cope in real time and had not even considered what would happen after the birth. She emotionally distanced herself from the presence of a baby by using the phrase ‘terminations and abortions are taken away’. It protects herself from the reality of these procedures involving a ‘real’ baby as if the relationship between a procedure and the death of a baby is not as visible. This self-protective disconnection is used when trying to prevent being overwhelmed and alleviate the emotion pain.

Vulnerability

Vulnerability implies a susceptibility to being hurt, to being misunderstood, or misrepresented. Quepons (2020) suggested that “vulnerability appears as an emotional awareness of risk involving not only bodily fragility but a dimension of the concrete existence of individual persons, namely, the intimate affectation of being harmed, injured or deprived” (p. 1). As such, it is a “susceptibility” to be wounded rather than an actual failure or frailty. As Quepons stated, “nothing is essentially fragile in itself; nonetheless, almost anything could be considered fragile or vulnerable depending on the circumstances” (p. 2). In other words, vulnerability has the possibility to show itself *because* of the circumstance rather than because of the person’s own delicacies. Their predisposition to feelings of likely, holistic ‘harm’ is revealed in the circumstance and is dependent on them. The person feeling vulnerable sees the “horizon of possibilities” (Quepons, 2020, p. 2) for harm along with the situation they find themselves in.

From an even more intimate standpoint, Brene Brown (2010) suggested that “vulnerability is the core, the heart, the center of meaningful human experiences”; so, to be vulnerable in front of others (whether strangers or not) is surely one of the most challenging things we can do. Despite these definitions of ‘vulnerability’, Briscoe et al. (2016) stated that there are often unclear and vague definitions in literature which often lead HCPs to either form their own interpretation of vulnerability or remain unsure and confused about its actual meaning and place in care provision. There is plenty of rhetoric around how HCPs ‘manage’ a woman’s vulnerability, with suggestions of providing more support, acknowledging inequity in maternity care provision, and offering more resources; but these could be seen as adding a ‘band-aid’ to the proverbial wound as these measures are difficult to evaluate or even provide.

Literature is often focused on external sources of vulnerability such as poverty, domestic violence, or mental health concerns. While these are certainly valid, what of the internal, embodied experience of vulnerability in women who have decided to terminate their pregnancy? Women going through this procedure may experience vulnerability connected with external factors; but what of the more holistic nature of 'being at risk' that includes not only physical but also emotional, spiritual, psychological, cultural, and social vulnerability? It could be suggested that vulnerability be viewed as a complex phenomenon rather than a singular concept especially when considering the multitude of trigger points of vulnerability (Briscoe et al., 2016). Crowther and Hall (2015) talked of the 'tapestry' of a woman's existence and any experiences a woman encounters are experienced in this sense of wholeness. The vulnerability that accompanies her existence is made apparent *because* of this holistic way of being-in-the-world.

In the context of terminating a pregnancy, a woman's vulnerability may involve being exposed to how others perceive her decision to end a pregnancy. It may also involve a level of self-exposure with the potential for judgment, whether conscious or not, from both those providing care and the woman, herself. In addition to these sources of vulnerability, there are physical vulnerabilities that are inherently connected to the very nature of labouring and birthing a baby. Management of pain felt, invasion of personal and intimate space by those around her, and the obstetric interventions that may be required, can all contribute to her feeling at risk of harm.

I had a massive mental breakdown and I looked at the nurse and I just couldn't have her in the room with me. I couldn't even explain why I felt like that.

For Paige, her instant reaction to the nurse was unexplainable but she still felt that she could not have her care for her. Her previous experience of care reminded her of her own defenselessness and exposed her need for self-preservation. This highlights that vulnerability is often unspeakable until the risk shows itself again.

For some women, there was the progressive feeling of lack of control over the circumstances that came with the emotional awareness of risk constitutive of the feelings of vulnerability (Quepons, 2020). Katie reflects this notion when she requested adequate pain relief but was unheard or at least not responded to;

> *I asked them if I could have an epidural. It was a very junior anaesthetist who said that his senior was in theatre and that he'd go and talk to them and that was the last I heard from them. I felt very helpless in a lot of ways.*

Katie also recalled the interweaving of both the physical and emotional 'pain' she felt. Not only was she vulnerable physically to the pain of labouring and the emotional pain of ending her pregnancy, but all the while she was reminded that she was losing her baby, even though he was still moving inside her.

> *The induction process made me very uncomfortable; it caused a lot of pain and sickness and that made the whole process so hard. The whole day was just emotional. I could still feel my baby moving and I knew this was going to kill my baby.*

For Tui, her feelings of vulnerability started well before the birth of her daughter. She recalls strong emotional pain related to the physical act of gaining diagnostic samples. These left her feeling devastated as if she was having salt rubbed into an open wound. She was reminded of why they were doing these tests and what the impact of the results would be.

> *They tried so hard to get a sample, but they couldn't. So, I had to go back a week later and do it all over again. It was the most emotionally painful thing. I'm not worried about needles but emotionally it was difficult because I knew the reason was to find out what was wrong with my baby. It was even more devastating when they couldn't get enough samples. I felt like I'd been poked and prodded with needles for nothing because they couldn't get enough samples. The week before I was crying bucket loads of tears the whole time just because of the whole emotional side of it and the second CVS I was doing the same thing.*

The concept of cultural vulnerability is also apparent in the women's narratives. This concept could be described as feeling at risk of being culturally harmed by circumstances, people, or experiences. Gunaratnam (2011b) described this concept two ways; firstly, as the "complex and promiscuous interrelations between bodies, environments and technologies" (p. 106). Secondly, Gunaratnam (2011a) proposed that cultural vulnerability is that which is;

> "...mobile and that has topological features: the capacity to change and to be changed; to be inconsistent and contradictory; to move with or against the relationships and circumstances that it finds itself in. In this conceptual schema, cultural identity and experience have no inherent, fixed qualities; instead, their qualities and meanings are understood as emergent and relational" (p. 339).

This last definition reflects an ever-changing feeling of vulnerability that is dependent on the person and the circumstance they find themselves in. Katie reflects this sense of cultural vulnerability when considering the act of decision-making and how this is impacted by a cultural compass.

> *Every decision I made I knew I was doing it for the right reasons, and I didn't question why I was doing it and I never once thought that I shouldn't do this, but I knew what I was doing, and it felt awful.*

Katie felt her decision to end her pregnancy as a culturally appropriate one. As culture is seen as a 'way of being in the world', Katie felt at ease with her interpretation of her baby Bernard's condition and made what she believed to be the 'right', albeit a hard, decision. In turn, she guarded her own cultural vulnerability by first, making a decision that was consistent with her own beliefs; and second, 'living' with her decision.

For many women, having family or other support people with them during a TOP may be seen as protecting their cultural vulnerability (Jones et al., 2017). It could be seen as putting family as a buffer between 'others' and the woman, allowing her space for the experience. Paige, however, felt inundated with so many of her family members present. While culturally, having family with her may seem as a 'normal' thing to do, Paige took the hospital's suggestion literally and ended up having too many people with her. Subsequently she felt even more vulnerable than she expected to feel.

It *was quite overwhelming as well because the hospital had given us the option to have family there. Now, looking back at it, I would change my choice of having the whole family in the room.*

Tui stated that she felt concerned that others would judge her for her difficult decision and as culture is, in part, how we view the world and how others view us, Tui found this possibility distressing.

There are people in my life that will never find out that we had a choice because I feel like they will judge us.

Ursula came from a Catholic family where it was common for families to be large. Not being likely to follow her family's culture of having many children, left her feeling culturally adrift.

I'm one of 9 kids. I never ever imagined that I'd only have one child.

She wondered how she would 'fit in' with other family members having had only one child. She felt like an outsider or 'different' to those she knew so well. For Ursula, the cultural context of family meant many children and a large extended family. She, however, did not fit this expected scenario.

A woman's self-image and feelings of self-esteem are deeply connected to her experience, especially if she sees herself as a mother and of her ability to mother her baby (Hutchinson & Cassidy, 2022). Her vulnerability is seen when her own perceptions of who she is and her place in the world are challenged by the loss of her own child through the decisions she has made.

> *Both my husband and I had gone away and we'd both decided that if it was a fatal syndrome that we would elect to end this pregnancy and not put that little baby through it.*

Tui's self-image was firmly based on being a "good" person and she queried why this situation had happened to her. She was tempted to consider that she had somehow caused this bad outcome and found it difficult to convince herself otherwise. All of these thoughts would be hidden from view in case someone implied that she was as bad as she thought and, in fact, she deserved this bad situation.

> *I guess probably we were a little naïve as to how pregnancies can go wrong sometimes. Through no one's fault. We hardly ever drink alcohol, and we never touch drugs. Why should something bad happen to us? And you do, even though you know that this is pure bad luck, just absolute fluke, you start to blame yourself. I had to keep telling myself it was not my fault. I found it very hard.*

Human vulnerability is not mere physical fragility but a spiritual dimension which is certainly explicit in embodiment and seems to reveal, at the same time, the individuality of what is under threat (Quepons, 2020). It suggests that each woman experiencing a TOP sense their own vulnerability, and the holistic nature of this experience as an individual, unlike or moreover not compared to anyone else's experience. Crowther and Hall (2015) speak of the spiritual well-being of women in their childbearing year, stating that "spirituality is becoming acknowledged as core to our humanness; an aspect of our being that provides access to self-fulfillment, peace and ability to meet the challenges in healthcare" (p. 173). Therefore, a woman's spiritual well-being could be seen as pivotal to how she finds meaning in her experience. If her interpretation of her experience reflects the life-altering decisions she has made about her baby's life, this unspoken burden must surely impact on her spiritual welfare.

It's still so raw for me. I refuse to believe that there's not a reason why I had to go through something so significant.

If, in her state of vulnerability, she has feelings of guilt and shame about decisions made or even the possible relief felt, she may condemn herself as being punished for what she has done. As Ursula commented,

I felt like I was the only one making the decision to terminate. The selfish one out there choosing to terminate a baby that would live but would have complications.

For a woman going through a TOP, the deeply personal embodied experience demands an intimacy with others that is not anticipated or prepared for. Brown (2012) suggested; "there is no intimacy without vulnerability" but is the opposite true? Does vulnerability depend on intimacy? In other words, can or does the relationship between woman and caregiver reflect a vulnerability because of the intimate nature of the relationship that comes with labouring and giving birth? If the woman remained 'un-attuned' to what was going on, could she 'protect' her vulnerability? Almost as if remaining situationally numb to what she was going through.

Boublil (2018) suggested, "vulnerability is a multifaceted concept depicting our relational and embodied nature (ontological vulnerability) and our necessarily situated and unpredictable existence (situational vulnerabilities)" (pp. 183-184). The question that might be asked is; could this experience of vulnerability ever have the potential for self-transformation rather than feelings of victimisation and/or trauma? Is there the potential for vulnerability, in this context, to be seen as a positive experience and be a possible path to being open to the world and to others? Ursula certainly mentioned it as;

> *feeling like I'm quite a different person from the experience. I've never experienced real grief before this. So, my empathy for others has just gone through the roof. I'm ashamed to say that I've discounted so many events that have happened to people and friends. I've thought, well it's happened but you'll get over it. I just didn't understand. It's all about understanding, isn't it? The reality is until you've been through something… then you get it. That's a positive thing that's come out of it.*

Ursula shows that she has navigated her way through a level of spiritual vulnerability by finding meaning in her experience of loss. For 'something good to have come out of it' is her way of seeing her own personal growth of empathy for others who have experienced the loss of a baby too. She found the opportunity to experience self-enlightenment of her spiritual self.

Tui also felt vulnerable to share the "real truth" with everyone about how she lost her daughter, Hazel. However, she, too, came to understand that she was not alone in her experience of terminating her pregnancy. Although she felt that it was not often talked about, she had become aware that other parents had gone through the same thing; losing a child.

> *It kind of made me realise how many parents go through this and it is something that's not really talked about. I feel like there's still a lot of judgement around things like that. There are people in my life that will never find out that we had a choice because I feel like they will judge us.*

Alongside feelings of vulnerability sits the concepts of trust and mistrust. Quepons (2020) suggested, "perhaps the most radical possibility of vulnerability is to be found in the experience of trust" (p. 7). Feltman (2008) offered a definition of trust as "choosing to risk making something you value vulnerable to another person's actions" (p. 9). Feltman also offered a definition of mistrust as being "what is important to me is not safe with this person in this situation" (p. 10). Another perspective of trust is related to 'bonding oneself to another' in an act of commitment that includes shared beliefs, priorities, and implied outcomes. This definition reflects the sharing of trust between the woman and her carers. Quepon goes on to state that in the act of trust, circumstances depend upon the actions of an agent able to take over the situation, and particularly someone able to understand the meaning of this social act. This is pertinent to the trusted relationship with the HCP. Poignantly, Steinbock (2014) stated;

> When I trust, I do more than merely live in a straightforward belief attitude; I invest myself "personally" in the other person, and therefore in what the other person says or in how the other person acts; I give myself over to him or over to her "word". Trust binds me to another. (cited in Quepons, 2020, p. 7)

If, as Brown (2021) suggested, trust is "more of a cognitive assessment than an emotion" (p. 191), it would presume that this sense of safety is assessed deep in the psyche. There are, of course, emotions that spring from the feelings of trust (or mistrust) and all four women in this research expressed these emotions in their stories. Emotions that range from fear, numbness, defensiveness, and silence, through to openly grieving the loss of their baby and feeling cared for and acknowledged by those around them.

Katie remembers the feeling of being taken under the midwife's 'wing' which gave her a sense of trusting her information and being able to build a relationship with her, even though they had never met.

So, thankfully my backup midwife rang me the following day, but I'd never even met her before. She was wonderful. She just took me under her wing and talked me through it.

Paige was led along the termination pathway with what she recalled was 'very basic information'. Yet, she had enough trust in her HCP that she complied with taking medication and attending the maternity ward, as instructed. Her assessment of whether she could trust them (or not) was based on her knowing no different. She had decided to end the pregnancy, so this was what she had to do to achieve that end.

> *Our understanding of what would happen was very basic. I recall one of the medications was to slow down her heartbeat. I'm not too sure exactly if they were waiting for it to be like a stillbirth.... I'm guessing. And then I'm not too sure what the other ones were for.*

This must surely be an example of extreme trust in the process as Paige was willing to take medication, but she was not fully cognizant of what they were for. Was her response reflective of fear, numbness, or 'don't tell me, I don't want/need to know'?

Ursula's response to an unclear but still worrying diagnosis of her baby's condition showed a sense of 'untruthfulness' rather than so much of an assessment of mistrust. But still, she wanted to believe that they had made a mistake, and all would be revealed at the next scan. She shows an emotional numbness that may well protect her from the horrible possibility that her baby is seriously unwell.

There was nothing certain about that diagnosis either, so I was thinking you've got it wrong too, but we'll come back the next day.

Ursula showed a deeply held sense of trust with her known HCP and she was desperate for them to always be with her. Her fear was based on 'not being known' or being treated like a stranger. Ursula felt that there was a 'givenness' in her already mature relationship with her doctor. This did not negate the trust (or mistrust) with others caring for her but illustrated the sense of safety Ursula felt with those who knew her and her story. The assessment of trust, in this situation, where misinformation or lack of understanding of her story could have felt to Ursula as if she might not be able to trust others as much as she could trust her own doctor, was a significant and pivotal point for a woman to feel trusting of those caring for her.

> *So off I went to the theatre and my doctor Eva was there. That was the thing that scared me the most; that I would be alone. I wanted familiar, I just wanted the feeling of someone that knows me, knows my situation to be there, it was just somehow so important to me. They kept saying yeah, but I almost didn't believe them because I thought well there's live births that are happening, but they showed up and I had two of them. I just felt that I couldn't have had two more amazing support people than those two. I felt like I was in the best hands. It was really scary.*

Ursula also remembers feeling defensive when the social worker came to talk to them about what would happen to Hazel's body after birth. This woman was an 'unknown quantity' and as for many people feeling vulnerable, the first response is to defend oneself from strangers, especially those who want to talk about confronting subjects.

> *We talked with a social worker, but I can't remember her name. She was lovely. At first, I was a bit defensive because I thought I don't know who you are and we're talking about some full-on things here. We had to talk about what happens after the birth, what we want to do with Hazel, and it was just like wow okay this is real.*

Ursula's interpretation of the social worker was that she was a 'lovely woman', but this did not stop her feeling an instant sense of mistrust because of her unknownness. These feelings resolved once they got to know each other but still the instant protective assessment from Ursula was one of mistrust.

Tui remembers saying the final goodbyes to her baby, Hazel, then putting her in 'the little purple box'.

> *The nurse walked out with the purple box with Hazel inside. We were just bawling our eyes out and she turned around and just gave us a sweet smile and she said to us, "we'll take real good care of her for you". That was all we wanted to know.*

The nurse reassured Tui that she would 'take good care of her' and this statement supported the deep sense of trust Tui had in handing Hazel over to the nurse. It was a simple statement but, for Tui, it meant everything. For Tui, handing over her baby was the greatest sign of trust in another that she could have shown. To give up her child to a stranger knowing that she could no longer protect her baby and had to trust the nurse to do so, would be seen as the ultimate belief in another.

Self-trust is the hidden and highly personal version of trust. The definition of self-trust, according to Bloom and Bloom (2019) is the firm reliance on the integrity of yourself. Brown (2021) stated that "we stop trusting ourselves when we hurt others, get hurt, feel shame, or question our worth" (p. 193). For women experiencing a TOP, self-trust must surely be threatened, especially when they are required to make a choice when there is no real choice available. To be self-trusting, one requires clarity and confidence in one's choices (Bloom & Bloom, 2019). This is often not the case with regards to terminating a pregnancy for fetal abnormalities. To be able to self-trust that decisions made will protect what they hold dear, was shown to be all important to the women in this research. For some of these women, the word mistrust of self could also read as self-betrayal, especially when considering their own images of being a mother. It appears that these feelings of self-mistrust are disguised as feeling silenced, publicly, about the experience. To declare openly what they have done is potentially highlighting their own motherly worth (or self-perceived lack of) and, therefore, better kept undisclosed.

As Ursula recalls, she is caught between being open and honest about what happened and at the same time wishes she could just not talk about it.

> *The one thing I've tried to do is be very open about it. I know that can be upsetting at times because it rears its head. I can be at a party, at a happy occasion and someone will*

> *ask something, and I'll tell them. Then the conversation can go downhill from there and you think, God why I don't just, give a different answer?*

As a way of self-protection, they keep quiet about what they have been through. It may be because of the fear of judgement from others, but it is highly possible that it protects them from judging themselves in a more overt and public way.

For some women, they live with feelings of regret because of their decisions; and although to regret is to be human, the overwhelming depth of their regret was boundless, for some. Ursula regretted 'knowing' her baby, Hazel, which seems incongruent with many but, indeed, her regret was reflective of her heartache knowing that she had given birth to her baby, and this meant she was real, and her loss was real.

> *Again, it's hopeless going backwards in my mind but I wish that I had had Hazel earlier as in I was able to have a termination earlier, so I didn't have to deliver her. Having to go through that and deliver her and hold her. I wish that bit didn't happen. I wouldn't have known her or seen her as a real baby whereas I was kind of forced to because I was too far on.*

Ursula also talked about her deeply and personally felt regret about the decision she made to terminate her pregnancy.

> *Now I'm trying to deal with a huge amount of regret. I'm having more thoughts of how Hazel would have been if she was here. We were very negative on the diagnosis, and it may not have been as bad as that and we might have got through the first couple of years. She might have been fine. While regret is a useless emotion to have, God, I feel it.*

Her feelings are heartbreaking to read as she clearly recalls how things may not have been as bad as they first believed that Hazel might have eventually been fine. For Ursula, uncertainty around her baby's quality of life and the impact of her condition on the family were driving forces in her decision making.

Katie felt at peace with her decision, and after her baby Bernard was born, she felt an overwhelming sense of relief:

> *Once the delivery happened, suddenly it was just a relief, and I was flooded with hormones. It was beautiful. The midwives were so caring and so peaceful. They tucked him up, left him with me and they just left us, they just quietly walked out and just left us with him. After all the struggles, it was just such a beautiful moment. It was worth it in the end.*

Paige felt at peace with her decision to end her pregnancy. As she states, her family shared the same values regarding a baby's quality of life and supported her in her decision. She was relieved to be able to protect her baby from a life of tests and procedures.

> *Within our family we all had a very similar outlook especially if a child is not going to have a proper quality of life. It would not have been great for her to be hooked up to machines for her whole life.*

For Tui, regret was not an option. As she says, "we had to do what we had to do" to avoid their baby daughter suffering. For her, the meaning she gained from 'making the choice' would have reflected her spiritual vulnerability. She could hear that her inner wisdom was telling her to protect her baby and for her, the choice was clear.

It was such a horrible thing to go through because it was a choice, but it wasn't a choice. We had to do what we had to do because we didn't want our little girl to suffer.

All the women testified that any regret is fruitless, as they regarded their place of decision making as being between a 'rock and a hard place'. Bagnoli (2000) suggested, "the fact that they did not commit any mistake in deliberation: they could not act otherwise, no less regrettable alternative was available to them" (p. 171). The range of intensity of feelings of regret signifies the negative outcomes of an event and the feelings of responsibility for the outcome (Zeelenberg et al., 2008). Some women deeply regretted going through a TOP, while others found solace in their decisions that were made 'for the sake of the baby'.

Chapter Summary

This chapter introduced the findings of this research. The narratives of the four women interviewed were deeply considered and four main understandings were highlighted:

- Aloneness vs. loneliness vs. connection;

- Silenced grief;

- Unpreparedness; and

- Vulnerability.

The following chapter investigates these understandings to an even deeper level and provides further discussion on these findings.

CHAPTER 11: DISCUSSION OF FINDINGS

Introduction

This chapter follows on from the previous chapter by offering discussion on the findings or understandings gained from the participants' narratives. Each of the four concepts are discussed followed by my reflections as the researcher. These are intended to provide insight into the process of gaining understanding of the women's narratives and how it was to immerse myself in their narratives. The four concepts are;

- Aloneness vs. loneliness vs. connection
- Silenced grief
- Unpreparedness
- Vulnerability

Aloneness, Loneliness, and Connection

The notion of aloneness and loneliness is described by Brene Brown (2021), an American researcher, as "the places we go when we search for connection" (p. 152). The experience of being alone or lonely propels a person towards finding human connection as a means of enduring the lived experiences that caused these sensations in the first place. For some, this search is a natural everyday response to 'being-in-the-world'; while others push forward with more resolve only when life forces them to feel even more connected.

Existentialist philosophy regards loneliness as an essential trait of being a human. Every person is separate from everyone else which implies that we are inherently alone. As Ruggiero (n.d.) suggested, loneliness, as well as the sense of being alone, sits in the innermost being of the self, becoming more apparent as a person experiences the ultimate life stories; upheaval, tragedy, joy, time passing, and death.

> "(Wo)Man is ultimately and forever lonely whether his (her) loneliness is the exquisite pain of the individual living in isolation or illness, the sense of absence caused by a loved one's death, or the piercing joy experienced in triumphant creation. I believe it is necessary for every person to recognize his(her) loneliness, to become intensely aware that, ultimately, in every fiber of his (her) being, (wo)man is alone — terribly, utterly alone. (Moustakas, 2016, p. 3)

The women in this research who experienced the loss of their baby all felt this sense of being separate to those around them and all longed to feel a connection with others. Vagle (2022) alluded to the concept of 'being stuck' in a place and these feelings of being alone while others are around implied that these women were 'stuck' in their aloneness. They had a sense that something vital was missing that could not be remedied by simply having someone sit beside them. It was not that they felt that this experience was unique; but unique to them, personally, intimately, spiritually. They even felt strangely separated from themselves as if they did not even recognise their own embodied experiences. They described a sense of unexpectedly being in an emotional bubble that they could not find how to escape from. At times, the women did not recognise *being alone* or *feeling lonely.* However, they all described being without something; '*at a loss, a very, very lonely road, in limbo, fallen apart, needed someone familiar*'. Consequently, women felt solitary and isolated in their experiences. They did, however, recognise those around them, supporting them. They just felt deeply and existentially alone.

The commonality of these descriptions was the need for connection with or to someone or something. Brown (2021) stated that "connection is the energy that exists between people when they feel seen, heard and valued; when they give and receive without judgement; and when they derive sustenance and strength from the relationship" (p. 170). Wong's (2008) Theory of Meaning-Centered Counselling for Bereavement shows that expressing and sharing feelings of grief with others gives rise to feelings of connection with others. Sharing can affirm or instill a sense of meaning regarding the death of their baby and encourages connections that facilitate social and cultural support.

Conversely, experiences of *disconnection* are described as emotionally painful and often lead to social isolation, loneliness, and feelings of powerlessness (Brown, 2021). The women interviewed expressed these emotions and it could be assumed, therefore, that they felt a sense of disconnect with what they were experiencing. This disconnect would be considered holistically impactful with a separation of mind, body, and spirit. These women, like all human beings, craved connection and searched for meaning in their lived experiences. When these women felt this sense of disconnect, they were at risk of feeling out of sync with their feelings and intimate inner experience. This reportedly hurts on a deep level and the impact is long felt.

> "...the belief that loneliness, far from being a rare and curious phenomenon, peculiar to myself and to a few other solitary (wo)men, is the central and inevitable fact of human existence. When we examine the moments, acts, and statements of all kinds of people -- not only the grief and ecstasy of the greatest poets, but also the huge unhappiness of the average soul… we find, I think, that they are all suffering from the same thing. The final cause of their complaint is loneliness". (Wolfe, as cited in Ruggiero, n.d.)

Wong (2008) suggested in The Meaning-Centered Model of Grief Work that, commonly, those who are bereaved experience a yearning for reconnection with those they have lost. This is reflected in the women's narratives regarding feeling alone and isolated from their baby which, in turn, leaves them feeling a sense of disconnect from the world, especially when they are dealing with the pain of their loss.

Heidegger (1962) stated that existentially death is the ultimate source of loneliness; but does not state whose death is likely to create this emotion (self or others). The women interviewed all expressed a sense of loneliness and/or aloneness and it could be suggested that these emotions stem not just from the spiritual, physical, or emotional separation from others during the loss of their baby but, more importantly, the separation from their baby. The 'other' they are 'missing or have lost' may be their baby rather than a more internalised sense of isolation or distancing. If loneliness or feeling alone reflects a sense of wanting or needing someone or something to be with them, do these women crave their babies rather than family, friends, or their midwife?

I know you're somewhere out there, somewhere far away
I want you back, I want you back
You're all I had, you're all I had
At night when the stars light up my room
I sit by myself talking to the moon
Still trying to get to you
(Mars, 2010, Talking to the moon)

From a conceptual viewpoint, the woman and her baby may be seen as being connected by an attached string. When a baby is lost, the woman is still holding onto the string but the other end of this string floats free, attached to nothing but memories. Without the expected connection to her baby at the other end of the string she feels afloat, untethered, alone.

"The joy of connection; the agony of disconnection" (Graham, 2021).

For the HCP, consideration of the sense of being alone or feeling lonely should be seen as more than the need of a physical presence. The nuances and complexity of these sensations are often hidden, even to those who are feeling them. Instead, what is felt is a sense of missing something or someone. To this end, the role of the HCP is to 'be with' the woman and 'listen' to what is happening. The connection between the woman and the HCP can sit in a sacred place that reflects the humanness of both. By attuning themselves, their relationship is able to take on an intuitive unspokenness. The HCP pays attention to the woman even if not in an obviously conscious manner but in a transcendent way. This act of 'paying attention to' the woman implies that the HCP notices and catches sight of what the woman is saying, even when she is silent. The subtleties of her actions, her breathing, who she is looking at, how she is holding herself —all of these ‘speak to’ how she is in the situation. It is often the seemingly inconsequential things that often convey the strongest messages.

Perhaps one of the most pivotal points in the relationship between a woman experiencing a TOP and her HCP is at the beginning of the relationship when she is the most fearful. The tone of that first encounter impacts how the woman sees the experience unfolding and conveys to the woman how she will be cared for. The acknowledgement of what she is going through, and the feeling of welcome, must surely be key to building a trusting and respectful partnership. This day is potentially going to be one of the most memorable days in her life, as well as one of the worst days of her life; the birth and death of her baby. For the HCP, being mentally and physically prepared and knowing what has happened in the woman’s pregnancy to get her to this point should all be understood. This concept of partnership is seen as the cornerstone of midwifery care in Aotearoa New Zealand, where this study originates (NZCOM, 2018). The woman/family-centered care philosophy reflects the possibility of the nurturing of this trusting and respectful partnership.

The data gathered from the four women revealed that they yearned for something more than just someone who was neutral or formulaic, bound by policy (Crowther & Hall, 2015). The possibility of having a mutual understanding with another is reflective of the idea of the sameness of self and other and suggests that women crave ‘sameness’ (Gurevitch, 1988). While the HCP may be inclined to remain slightly separated from those receiving their care, to remain objective and impartial, these scenarios of TOP require the HCP to journey into a more vulnerable space. This is not to suggest that the HCP instead offers subjective care or care that reflects their own feelings and emotions; rather, reflects unconditional positive regard for what the woman is experiencing (Ackerman, 2018). The concept of unconditional positive regards is defined as;

> To be with another in this [empathic] way means that for the time being, you lay aside your own views and values to enter another’s world without prejudice. In some sense it means that you lay aside yourself; this can only be done by persons who are secure enough in themselves that they know they will not get lost in what may turn out to be the strange or bizarre world of the other, and that they can comfortably return to their own world when they wish. Perhaps this description makes clear that being empathic is a complex, demanding, and strong—yet subtle and gentle—way of being. (Rogers, 1995, p. 119).

This relationality between the HCP and the woman enables both to be more human, more vulnerable, more real. If a woman is afraid that the HCP will judge her or think negatively of her, she is less likely to surrender to the experience and be able to accept the 'situation sensitive' care the HCP is offering.

> When the other person is hurting, confused, troubled, anxious, alienated, terrified; or when he or she is doubtful of self-worth, uncertain as to identity, then understanding is called for. The gentle and sensitive companionship of an empathic stance… provides illumination and healing. In such situations deep understanding is, I believe, the most precious gift one can give to another. (Rogers, 1980, p. 160-161)

As a way of connecting with bereaved women, an authentic and curious approach may be considered. While being respectful of the woman's personal boundaries, enquiring about how she is travelling through this experience addresses the birthing woman first and foremost as a woman and focuses on her lived experience more than just her clinical picture. However, when asking questions, a sign of genuine interest requires waiting and truly listening for an answer. When an answer is received, a moment of reflection and contemplation shows a true regard for the woman's response. This approach may lead to asking additional clarifying questions or general discussion which, in turn, leads to a connection, though shared conversation. When a woman's story is heard, acknowledged, and respected, the outcome is likely to be a sense of trust borne through sharing and a level of connection that reflects a human relatedness.

Researcher's Reflections

After so much thought and pondering on the women's experience of being alone or feeling loneliness, I intuitively followed the concept of connection or, conversely, disconnection. This all made sense and seemed to explain the cause and effect of their 'aloneness'. It was not until I stopped thinking in such a process orientated manner that I 'saw' what I had not noticed before. It was 'hidden in plain sight' and I did not notice the notion that these feelings of aloneness and/or loneliness were from missing their baby more than anything else. I was so focused on the external factors that impacted on their experiences that I ignored what the core relationship was about. Indeed, family, friends, supporters, and midwives all played a part in the 'seen' or obvious care, but I feel I was missing the trees for the forest, as such.

The quote from Moustakas (2016), as seen above, struck a chord with me and made me pause and see what I had been blind to: "ultimately, in every fiber of his (her) being, (wo)man is alone — terribly, utterly alone". The ending of this quote pushed me to consider how or why we are terribly, utterly alone. I came to recognise that a woman may have caring, kind, and empathetic people around her but in birth she is alone. The family, supporters, and the midwife cannot share her innermost experience. Deeply, intimately, and existentially, the woman who is pregnant gives birth, as an embodied experience, alone. The baby comes from within her, by her own effort and ability to surrender.

Research has confirmed the birth of a child is found to be "a unique, mysterious, powerful, transforming, accentuated, unifying, meaningful and transcendent experience beyond the physical world" (Hansen et al., 2021, p. 336). This is reiterated as being relevant even in the circumstance of ending a pregnancy due to fetal abnormality. HCPs understand and appreciate all these descriptive words but the phrase "beyond the physical world" portrays the unknownness of each woman's unique and highly personal relationality of her experience.

Silenced Grief

For women to be able to talk openly about terminating their pregnancy they require the ability and the desire to talk about what they experienced. 'Talking about it' is reliant on them having the words to describe the experience and the ability to express themselves. They carry the responsibility and have the choice of communicating (or not) as they are the people with the embodied memory of what happened. But what about society's need or responsibility to hear such talk or whether society is willing to listen?

The woman who can share openly is seen as brave, resilient, and confident in her experience; whereas the woman who is silent about what she has been through is unfortunately seen as either being in denial, unaffected by it, or withdrawn from others. For others who are silenced, they may be unable to find the words that adequately express what happened or have not yet developed their own story and the meaning surrounding it. Instinctively, they block out painful memories that are likely to come to the surface when telling their stories. Wong (2008), when considering meaning-centered grief work, suggested that part of finding personal meaning sits with self-validation, which consists of self-acceptance, self-affirmation, and self-integration. However, validation may be a difficult concept to navigate because of the woman's inability to consider 'herself', in the first place. In other words, the ability (or inability) to situate herself in the experience, to acknowledge her lived experience and to put words to what she has been through. To "feel the feelings" is not something the faint of heart would do willingly. That is not to suggest that women who do talk of the loss of their baby do not feel aching memories. Instead, they have found a path through their grief and are able to give others the directions to their stories. They may have been able to 'make sense' of what happened and find a place for their thoughts and feelings that sit in a more accepting space. This sensemaking reframes the experience and brings these thoughts into the woman's reality. By accomplishing this reframing, the woman can take control of her own narrative and, ultimately, her own self appraisal of what she went through.

If a woman is seen as continuing to grieve, past what society deems as a normal length of time, she is more likely to be seen as vulnerable, self-blaming, or unable to 'move on' (Kersting et al., 2012). It is assumed that her grief has become complicated, and she will have a delayed recovery from her loss. Kersting et al. (2012) stated that complicated or prolonged grief responses are seen much more frequently in women who have had a TOP for fetal abnormality. This may well reflect the silencing of women's stories by both society and the woman, herself. When a trauma cannot be talked of, it stays and festers, leaving the bereaved person stuck in middle of the trauma. TOPs have been highly stigmatised because of the assumed 'choice' women make to end their pregnancies (Jones et al., 2017). Therefore, the shame and guilt felt by the women adds to the feelings of potential rejection and isolation, especially if others know about their story (Carr, 2012). To reduce this risk, women often choose to remain silent about what they have been through. As Brene Brown (2012, https://www.ted.com/talks/brene_brown_listening_to_shame?language=en) explained regarding shame, "If you put shame in a Petri dish, it needs three things to grow exponentially: secrecy, silence and judgment".

Wong (2008) placed the expression and sharing of feelings in the space of mourning which helps the bereaved work through any inner conflict. Instead of remaining silent, when women give their story a platform and a voice, they are more likely to make sense of it and acknowledge what the experience meant to them. The potential for their story telling to be cathartic and liberating is apparent. As related to the concept of existential psychology, this represents a humanistic approach that enables the woman to have a deeper understanding of her experiences as well as the choices she has made (Stanford Encyclopedia of Philosophy, 2021). Wong talked of the reconstruction of life as part of a meaning-centered process. This is related to the development of a new reality but is reliant on the woman re-authoring her story, whether she shares it or not. A story that represents the 'truth' as the woman sees it.

When a woman feels silenced either before, during, or after an extremely impactful experience in her life, she can consciously or unconsciously hide her responses to appear unaffected. In fact, for many, their silence is a direct response to their feelings of trauma. Langutaine (n.d.) suggested that trauma changes the brain, with the speech center impacted, explaining the experience of having no words to describe the pain and the hurt. Silence reduces the possibility of exposing a person's vulnerability by not adding fuel to a potential bonfire of judgement, rejection, and the gaze of others. It seems that our brains are wired for connection but trauma re-wires them for protection.

Thus, the silenced woman is in protection mode while the HCP is trying to facilitate connection. A silent woman may be seen as a compliant woman but, potentially, she has a lot to say if only someone would listen. As the woman is ensuring her own protection, the HCP can add to her sense of being safe by staying with the woman to reflect an uncompromising regard for her. That is not just the physical nature of being in the room with the woman but 'being there with her', even when she appears to be 'absent'. Being receptive to her needs, being a predictable presence, and showing a commitment to her well-being offers her a sense of surety and allows her the possibility of 'returning', safely. Neumann (2023) used the phrase "being tied to the experience or event" (p. 21), showing how the HCP can be receptive to the woman experiencing the event. This phrase also reflects a familiarity between the event, the woman, and the HCP, and relates to a knownness between them. It would be considered a mistake to assume that just because a woman is silent, she has nothing to say.

Sitting with the woman and facing her as she is asked, "how are you going?" offers the woman a chance to tell the HCP how she is and to put words to her thoughts and feelings. The HCP can respond by truly listening to what is being shared rather than trying to fix something or justify why something has or has not happened. This question has the potential to deepen the connection between the woman and the HCP as it transcends the clinical requirements and, instead, focuses on hearing the woman's voice.

It is easy for the HCP to interpret the woman's silence as either compliance, satisfaction, or even a defensive mechanism. Any of these assumed reasons for silence may be deemed as not needing any further investigation or thought. For the woman, however, this silence is, at that time, her mode of communication. By not speaking she is in fact screaming out loud. However, when a potentially traumatic experience like having a TOP is unspoken of, the pain has only one place to dwell, and that is deep inside the woman.

Researcher's Reflection

I am often aware of the power of silence. Although sharing and expressing feelings of sadness, regret, or any other feelings around the death of a baby is known to be therapeutic, I have great respect for that space with no words. Whether the silence comes from shame or regret or being overwhelmed or even numbness, silence allows us to breathe, to pause for a second to get our thoughts together. How does a woman even make sense of what is about to or what has just happened? Is it even humanly possible to make sense of deciding to end the life of your child?

For me, sometimes the silence is deafening. It is in the silence that the answers to all the questions can be found. For many HCPs, silence is awkward and there is an inbuilt need to fill those silent moments. Perhaps silence implies that we are overwhelmed, disengaged, or unsure of what to do. Instead, the power of silence should never be underestimated. The silence that is mistimed and leaves everyone feeling fidgety is not the silence I am meaning. Instead, I refer to the mindful and 'being present' silence that comes when those present are consciously in the space, engaged and have 'shown up'. Silence should not be feared or avoided but embraced and 'sunk into'. To be able to sit without noise, chatter, and activity is a powerful and humanly rich space to be. When there is active silence, the ability to 'hear' becomes acute. Intuition comes to the surface and the interactions of others come into focus. Our energy calms, our thoughts gain clarity, and our intentions become obvious. We are all able to catch our breath and reconnect with ourselves and those around us.

In the context of a TOP, and society's perception of what happens in this situation, silence is often seen as an enforced response. Others do not want to hear about what the woman went through. It feels raw, ugly, and unspeakable. The struggle the women experience is too confronting and best left alone. But what would it be like if *we* went through a TOP? How would *we* cope? Would we shut down and never speak of it again or would we start a crusade for moral justice and women's choice? I am not sure how I would navigate my way through a TOP. I can not begin to imagine how I would feel or how I would cope. What I do know is that I would feel so incredibly vulnerable and scared. The vulnerability of what others might do to me would put me in a space of frozen terror. I would be scared about the intensity of the experience, the emotions, and the physicality. I would be terrified of what I might see, feel, and do during the TOP. Who would protect me, who would watch over me, who would make sure I survived?

Unpreparedness

All the interviewed women felt a sense of unpreparedness, regardless of their previous birthing experiences. The reality took them by surprise and left them shocked and overwhelmed. They all found themselves waiting for the unknown and then surprised when something did happen. For example, going for a scan to check for abnormalities and being shocked when something is discovered. This phenomenon is to be expected as we often do not know that something is going to happen until it happens. Often there is no pre-run or predictability that something will happen so, therefore, a sense of unpreparedness prevails. Dastur (2000) talked of expecting a surprise and the sudden happening of an event. In other words, the reality that comes from the surprise as it becomes real. As Dastur states,

> The definition of an event that surprises us is that which takes possession of us in an unforeseen manner, without warning, and which brings us towards an unanticipated future. The event appears as something that dislocates time and gives a new form to it, something that puts the flow of time out of joint and changes its direction. (p. 182)

The relationship between time passing and events happening relates to the unpreparedness the women felt; as if time passed, an event happened, and they struggled to catch up with reality. This experience could be described as lagging behind the event. The women are not conscious of what they do not know until the unknown-ness appears in front of them and shows itself as unpreparedness.

Heidegger's (1996) concept of thrownness is relevant here as it describes someone being 'thrown into the world', whether they planned it or not. The word 'thrown' means to be put roughly and abruptly in a place, or to be sent suddenly into a particular state or condition (Philo-notes, 2023). It reflects the women's unpreparedness when they found themselves in 'this place'. To be thrown into a situation which they did not choose, they are faced with the responsibility of deciding their own path during this involuntary sending. For these women, 'landing' in the unwanted place of ending their babies' lives, they could not comprehend in a logical way what was happening and how they should cope with it. Words like confused, overwhelmed, and uncertain reflect the lack of clarity they felt when they found themselves face-to-face with the shocking truth that their babies were going to die.

Kubler-Ross (1981) talked of the possible first reaction to the death of someone close as being denial. It helps the feelings of grief pause for a moment as if to slow down the full impact of what has been lost. It is as if the denial acts as a sedative to the emotional shock they are feeling. Unpreparedness may be associated with this accepted phase of grieving. Part of pausing could include a hesitation to move forward into the future, staying in the moment to numb the truth, even for just a short while. The further they move into the future the more real it becomes. As they gather more information and experience more sensations, the closer they get to the reality that their baby will inevitably die. Part of this response could be that 'nothing makes sense', so potentially, even if the woman has been informed of what is happening or about to happen, she is not able to fully comprehend the information.

The women's feelings of not being ready or prepared for what was happening related to their perceived lack of information. As above, the information may have been given but the retention was impacted by what they were going through. Littlemore and Turner (2019) suggested the information women receive regarding their baby's birth and death may feel fragmented and disjointed and it is left up to them to make sense of it. However, the women were often unable to do so because of their confused and overwhelmed state. Coming to terms with such a shocking and unexpected end to their baby's life certainly impacted their thought processes and left them floundering for clarity. They had to be both protective mother as well as the decision maker about their baby's death. These supposedly opposing roles are, in fact, one and the same; but for the woman, the internal conflict is evident.

The women interviewed reported that they had assumed or taken for granted what having a TOP would entail. They had individual thoughts about how it might unfold, but these were not necessarily based on the information given to them. Instead, their assumptions were often based on 'non-thinking' or a disconnection from what they had been told. It does not reflect negatively on the relationships they had with the HCPs; rather, implies a sense of 'otherness' or a sense of 'it's not happening to me'. As Gunderson (2021) suggested, this illustrates a marginal consciousness of what is happening, and is often seen in times of crisis. This lack of attention is not a conscious decision but a coping mechanism for when a person is experiencing a time of embodied overload (Eisma et al., 2020).

To be able to work their way through all the information given to them they needed time to consider it and figure out what they wanted to do; all the while being in the depths of the reality that they were going to lose their baby. The response to the information overload was to not take it all in, to give over control, or to just simply stop thinking. Not only do the women have difficulty processing all the information, their perception of what is going on around them is altered. Eisma et al. (2020) discussed the concept of behavioral avoidance when intense grief responses are felt. They reflected on how "thinking hurts" and to reduce the amount of 'pain' felt, some tasks are avoided or delayed which resonates with what the four women interviewed reported.

Wong (2008) considered this sense of unpreparedness or 'feeling distanced from' using the Meaning-Centered perspective and suggested that those who have experienced the loss of a loved one to be in conflict with the myriad of emotions being felt. To navigate these inner conflicts, a person can sit outside the experience, as if looking in on the events and feel disjointed or, as described by these women, unprepared for the reality.

The women experienced a type of alteration of consciousness as they dealt with the surge of devastating grief at the prospect of their baby dying. Through the shock and confusion, they were likely to feel a certain disconnect from what was happening around them. This separation from their 'everyday-ness' lead them to feel unprepared and unaware of what to expect throughout the experience. The HCP needs to accept this unpreparedness, even if supposedly ample explanation is given to the woman. It is likely that only small snippets of information are understood and retained, even when comprehension seems evident. The need for repeated conversations and an apparent lack of information retention is anticipated. Time to digest the information aids understanding, as does a variety of mediums for that information. For example, written, pictorial, or videos of various topics may be useful. Facilitating time for the woman to go over the information and ask questions is imperative to improve comprehension. Using language that is honest and clear is appropriate while avoiding euphemisms that are likely to add to their confusion. For example, "Your baby is sleeping... your baby has gone to a better place".

Effective communication is known to be an important component of high-quality maternity care (Wakelin et al., 2023); thus, a critical component in any HCP's repertoire of skills. Reflective and active listening, an empathetic approach, and the careful use of curiosity or questions are all tools that maternity HCPs may use to support women. Often women will already have had an internal monologue of what she is experiencing but sharing or talking with another person often helps put her thoughts in order and words to her experience. For any HCP, the ability to effectively communicate with another requires clarity regarding their own judgements and presumptions of a situation or person. Without this, the HCP is inclined to assume the needs of the woman and offer care that is informed by these beliefs rather than what is truly required. It is important to take the time to reflect on what the woman shares and how, together, the woman and the HCP can work towards care that is truly personalised to her. Those who are experiencing a bereavement often remember the words and phrases that are used in conversations, so the acknowledgement of their grief is important to validate their loss. Simply saying "I am so sorry for your loss" or "If there is anything I can do, please let me know. I'm willing to help in any way" or "I'm just really sorry you've had to go through this" is often most appropriate when there is uncertainty about what to say.

Finding a quiet and private space to talk allows for the uninterrupted flow of conversation to take place. Asking for clarification or exploring an issue further are appropriate communication tools to aid the HCP and the woman to connect on a truly human level. By incorporating an emotional component into conversations, both the emotional and physicality of the TOP can be combined; therefore, seemingly becoming more relevant to both the woman and the HCP. This speaks of the dual pathways the woman is on during the TOP. That is, the embodied or physical experience and the complex and intertwining emotions she is concurrently experiencing. Deciding together when certain conversations should take place adds to the woman's 'preparedness' for such conversations and allows her time to focus on and consider what will be discussed rather than abruptly bringing up sensitive subjects.

Quinn (2016) talked of the relational safe space that surrounds the woman and the HCP, a space where the woman can emotionally connect with the HCP when she most needs it. This space allows for a pathway of communication that is based on kindness, openness, trust, dignity, sensitive and honest communication, consistent and accurate information, guidance, and support. These points are reflective of the attention given to the woman during her care experience from a holistic viewpoint rather than just a clinical or physical stance. In the context of midwifery care offered to the women in New Zealand, the concept of 'whanau/family-centered' care reflects the woman being central to the care but her whanau/family are intimately involved. To care for the woman implies, culturally and relationally, that the whole whanau receives and is impacted by this care (NZCOM, 2018).

The use of silence or, more precisely, compassionate silence is a useful concept when communicating with bereaved women. Back et al. (2009) described it as "recognizing a spontaneous moment (or longer) of silence that has emerged in the conversation, often when the clinician (HCP) and patient (woman) share a feeling" (p. 1114). Further, it could be suggested that together, the woman and the HCP experience a moment of recognising in each other a shared understanding or shared thought that allows conversation to pause for a moment. It reflects a human connection and an unspokenness between them. It is a contemplative place that enables an awareness of the actuality of what is happening. Back et al. stated that;

> in compassionate silences, clinicians (HCPs) can find that the silence has a moment-by-moment character that patients (women) can experience as a profound kind of being with, standing with, and contact in a difficult moment. This kind of silence can nurture a mutual sense of understanding and caring. (p. 114)

Rather than filling the silence or forcing the conversation to move forward, taking a pause to respect and acknowledge connection is invaluable to the relational energy between the woman and the HCP. These silent moments catch the attention of both parties and quietens the mind. By hushing the words, the moment washed over the two of them. Pauses can also invite the woman to share her thoughts, ask questions, and share her feelings. By giving her time to catch up with herself, she can literally gather her thoughts. It offers her a chance to breathe, silence worrying thoughts, calm her racing heart, and remind herself that she is OK, and she will get through this experience.

Without a doubt, putting all these notions into practice is challenging for the HCP. To 'be with' a woman could be seen as simple; yet all the layers make it complicated. It requires a connection that is often indescribable and subtle in character. For a HCP, it is the deep sense of seeing the woman as she is, where she is. To see her as a human being who needs and deserves the utmost attention and consideration. The aim is to shed assumptions, preconceived ideas, and conjecture about how the woman came to be in this space. The care should be finely tuned to meet her needs with no excuses or bias. To accomplish this connection requires mindfully spending time with her. That is, sitting with her as she makes sense of what is happening or about to happen, to be curious about what she is thinking and feeling, and affirming what she is sharing. Being present and engaged with a woman takes energy but is the most precious thing HCPs can offer her. When HCPs are consumed about what task they are required to perform, what time frame we need to work within, what else must get done, they are not able to be present in the moment which impacts the connectedness with those who are receiving the care. It is impossible to be mentally present with someone when we are full of our own thoughts, concerns, and presumptions. Trying to think of the right thing to say or do, often shades being present and 'in the moment'. Re-orientating to see the situation from the woman's point of view is critical for mindful caring and allows HCPs to put their own way of seeing the world to one side, even temporarily. The notion of 'listen more than you speak' may be useful in these circumstances and encourages a conversation that is sensitive, relevant, and situation-specific for that woman, at that time. This concept is more likely to allow for 'listening for understanding' and offers a way of connecting with the woman in a meaningful way.

Researcher's Reflections

The consistent unknown-ness that the women talked of repeatedly surprised me. It was like they were describing being in a bubble of innocence. But then this should not have taken me by surprise because why would they not be in a bubble, a self-protecting sphere that kept them immune to the hard reality of what was happening? The amount of trust they placed in those around them was both reassuring and concerning. Did they want to hand over control to others and, if so, was this because they were so overwhelmed with how they were feeling? Did they feel that they had a voice or were able to be involved in what was going on? Why did they not seek clarification or ask to make a plan regarding their care? I can only assume that they were either swept along in the process and defaulted to what their HCPs suggested, or they were essentially unable to decipher what was happening and therefore silenced their queries.

It was incredible to think that several of the women believed that the TOP would take just a few hours and then they would head home. That it would be slightly uncomfortable, that the baby would be 'taken away', and it would be all over. How would they have known any different if they had never been through a TOP before? Do we assume that all women understand what will happen and how they will be impacted? I acknowledge the overload of information, but I also wonder if these conversations are difficult or awkward so they are not as comprehensive as they could be. I appreciate that the subject matter is sensitive and HCPs are cautious about upsetting the women by talking about these issues. These two issues may well compound the transference of meaningful information.

Vulnerability

Feelings of vulnerability can initially be hidden and may only be uncovered in times of desperation. These feelings are highly personal and sit deep in a person's journal of emotions, to the point of not even being acknowledged by the person feeling them. Often, it can be difficult to pinpoint vulnerability as conflicting feelings such as self-doubt, perceived misinterpretation of the situation, or other overwhelming sensations may override their existence. For the women in this study, the feelings of vulnerability or 'being at risk of harm', coincided with the context of their experience of terminating a pregnancy. MacLellan (2020) suggested that the experience of vulnerability during birth is a significant contributor to the birthing woman's interpretation of the birth and her place within it.

Brene Brown (2012) suggested that trust is a product of vulnerability, but it could be argued that this relationship is tenuous. For those who feel vulnerable or 'at risk of harm', if those around them abuse this fragility then the product must surely be mistrust. Anderson (2022) stated that "we're never so vulnerable as when we trust someone but paradoxically, if we cannot trust, neither can we find love or joy".

From a phenomenological perspective, we can only acknowledge our vulnerability in the act of bringing truth into being. That is to become conscious of feeling vulnerable rather than just having an 'ill-at-ease-ness' about a situation (Fraleigh, 1991). To arrive at the acknowledgement of vulnerability, meaning is attributed to feelings of something being 'out of kilter' or of feeling insecure. These feelings are related to the past and the future, as phenomenology supposes that both are part of the present and influence 'in-the-moment' feelings. As Heidegger (1962) described, this as the "horizon of being" (p. 164), as present time takes meaning from the past and impacts the future. Fraleigh (1991) stated, existence is the truth behind vulnerability where instinct, reality, and the present moment converge and become something. Heidegger described these times when the past and the future are recognized in the present as "the moment of vision" (p. 239). Being-in-the-world puts a woman on a trajectory of vulnerability both because of what she is experiencing and the thoughts she may have of what she might be about to experience. This concept of 'being-in-the-world' relies on others' connection and relatedness to the person feeling vulnerable as the 'other' adds to or diminishes the feelings of being at risk.

Not only can women be vulnerable from a physical and cultural standpoint but also social, spiritual, and psychological perspectives (Feijen-de Jong et al., 2022). It is considered, therefore, that vulnerability involves situations that become entangled and complex for both the woman, and in the context of midwifery care, those providing her care. However, making assumptions of a woman's vulnerability is ill-advised as generalisations can potentially lead to patronising and stigmatised care (Clark & Preto, 2018). Instead, the acknowledgement that a woman may feel vulnerable in certain circumstances allows the HCP to be consciously aware of the human trait of vulnerability. This means that we do not 'cure or solve' vulnerability; rather, appreciate that it may exist. An HCP's care should not exacerbate these feelings but offer a woman the sense of empowerment and a realisation that she is central to the care provided.

Cultural vulnerability can be associated with any maternity experience, even more so when the woman finds herself in an often-stigmatised experience of TOP (Jones et al., 2017a). Since caring is culturally expressed and understood differently in different cultures (Leininger, 2006), the need to be cared for by friendly, sensitive, and respectful staff can potentially ease a woman's cultural vulnerability. Wikberg (2021) found that when the cultural aspect of care was ignored, women were likely to feel neglected or insulted. Women would often become quiet, frustrated, and feel isolated. If women felt misunderstood or humiliated, they would sometimes interrupt or consider interrupting their relationship with the midwife. The four women interviewed saw their care as being mainly culturally sensitive and appropriate. It seemed that their cultural 'risk' was internalised, with the women reflecting on their own views of right and wrong and how their own behaviours may have impacted their cultural beliefs. There was certainly evidence of the sense of vulnerability that led women to back away from the care offered until 'the risk' was managed or navigated.

As part of building trust between the HCP and the woman, culturally safe care should be provided; not based on assumptions but through clear and respectful conversation about what is important to the woman. In other words, her own self-identity, what values are important to her, and how her culture plays a part in her life. The conversation should address how she sees herself placed in the world. This intimate and often not discussed concept of self may be represented in how she sees herself as a pregnant woman, a mother, and a bereaved parent. A sense of loss of identity may be felt and give the woman a sense of uncertainty of where she fits in society. Wong (2008), in The Meaning-Centered Grief Work, suggested that this may represent an 'identity crisis', of sorts and involves questioning our own self-identity and life purpose. In these circumstances, culturally safe care is not solely based on ethnicity but a more holistic view of culture. The development of a shared understanding of what is important to the woman is pivotal to her care provision and will allow her own individual interpretation of culturally appropriate care (New Zealand College of Midwives [NZCOM], 2018). The woman receiving this level of care is seen as the main stakeholder so should be considered the driving force behind any care offered. Doing so allows the HCP to provide culturally appropriate care as they can identify and acknowledge the woman's preferences, including understanding that any power imbalances must be addressed, negotiated, and changed to provide equitable, effective, efficient, and acceptable care that is determined to be such by the woman, herself (Fleming et al., 2019). To provide culturally safe care, the HCP is encouraged to reflect on and be aware of their own values and beliefs, and unconscious or conscious bias (Fleming et al., 2019). The development of a shared understanding of what is important to the woman is pivotal to her care provision and will enable her own individual interpretation of culturally safe care (NZCOM, 2018).

A woman receiving culturally specific care is more likely to engage comfortably in her own care and a power-balanced relationship can emerge and help guide her experience (Jones et al., 2017a). The woman is enabled to develop a sense of security with her care and care providers which, in turn, supports her having choices, making decisions, and feeling a sense of control over her care. Ultimately, this is likely to reduce her feelings of vulnerability, mistrust, and self-doubt, while nurturing feelings of trust in her care providers.

To gain clarity around the concept of culturally safe care, another perspective that should be explored is that of the community. For example, in the Aotearoa New Zealand context, partnership with local iwi and elders, including Te Tāhū Hauora (Health Quality and Safety Commission), especially Ngā Pae Hiranga (Consumer Hub), would be advisable to gain insight into the best care that can be offered (https://www.hqsc.govt.nz/consumer-hub/). Mindfully honoring Te Tiriti O Waitangi in Aotearoa New Zealand health care settings is vital to ensure health care for Māori wahine and their whānau is ‘fit-for-purpose’. This care needs to be designed to meet Māori needs and reflect all that is important in their care provision. Ultimately, the aim of this partnership is to facilitate an improvement in hauora Māori outcomes and reduce the inequity in health care for Māori (NCNZ, 2023). Partnership would be best facilitated by those involved in policy development in maternity care. Elders and advisors of other community groups should also be consulted. This information is considered as complementary to each woman accessing bereavement care rather than overriding the woman’s individual needs and desires.

Remembering that culturally safe care also acknowledges the spiritual aspect of care, HCPs can provide women with the possibility of finding meaning in their TOP experience. Acknowledging the woman’s own inner wisdom of birthing allows her to have a focused awareness of what she is feeling and what she needs to do to give birth to her baby. This state of mindfulness may alleviate some of the anguish the woman is feeling and is likely to reduce her spiritual vulnerability (Crowther et al., 2015). When the HCP acknowledges the sacredness of what the woman is experiencing, the woman can be in the other-worldly space of the event.

Culture and spirituality are deeply connected as a woman’s cultural identity impacts her spiritual life just as her spirituality impacts her cultural practices (Crowther et al., 2015). Crowther and Hall (2015) speak of the spiritual well-being of women in their childbearing year, stating that “spirituality is becoming acknowledged as core to our humanness; an aspect of our being that provides access to self-fulfillment, peace and ability to meet the challenges in healthcare" (p. 173). Therefore, a woman's spiritual well-being could be seen as pivotal to how she finds meaning in her experience. Wong (2008) suggested that discovering new meanings for loss and suffering is part of the complex web of 'being in' the experience. If a woman's interpretation of her experience reflects the life-altering decisions she has made about her baby's life, this unspoken burden must surely impact her spiritual welfare. Accompanying women on their journey of birthing their baby enables the woman to transcend the minute-by-minute reality of what they are going through. She has someone to walk beside her, to trust and to take care of her needs, leaving her to focus on the internal and intense work of birthing. All four women interviewed commented on their decision making and how they were conflicted about ending their wanted pregnancy but desperately not wanting their baby to suffer. Bartel (2004) reflected on the connection between spirituality and suffering, and suggested that human spiritual needs include love, hope, faith, virtue, and beauty. These notions are potentially entangled when a woman is required to decide to end her baby's life. Ironically, it is *because* of her love for her baby that she ends her baby's life to prevent her baby suffering.

Trusting another, especially an HCP, is not a forgone conclusion for any woman; and is even more precarious when a woman is experiencing a TOP (Jones et al., 2017b). It was apparent in the narratives of the women in this research. All four women wanted to trust those providing their care to reduce feelings of both vulnerability and fearfulness.

Research done in The Netherlands that considered midwives' experiences of caring for vulnerable women (holistically vulnerable) showed that some midwives felt tense and uncertain while at the same time worried and compassionate for the woman (Vlassak et al., 2022). Brygger Veno et al. (2022) suggested that in the assessment of vulnerability in women having a TOP, HCPs use their clinical knowledge of the indicators of vulnerability; for example, (but not exclusively), dissociation or withdrawal from connection or communication with others, past medical or obstetric history that may have traumatised them, or extreme caution or fearfulness regarding care provision. When considering the myriad of possible points of vulnerability a woman may have in the context of a TOP, it is appropriate that these are given genuine attention by the HCP and the relevant resources and support be offered. When HCPs show empathy and sincerity in their care, the woman's sense of self-esteem may be enhanced, and she may feel able to build her own self-reliance. Further, it is helpful for the HCP to have contemporary procedural knowledge of TOPs to understand the trigger points that may escalate any feelings of vulnerability; for example, intravenous cannulation, pain management, or physiological progression of labour in the context of a TOP. Finally, it is essential that the HCP has the appropriate interpersonal skills to assess vulnerability and pay attention to focus on vulnerability.

Boublil (2018) suggested that “vulnerability is a multifaceted concept depicting our relational and embodied nature and our necessarily situated and unpredictable existence” (pp. 183-184). This statement could be seen as meaning that vulnerability is forever influenced by what is happening around us and how we interpret the meaning of those events. Our feelings change depending on our interactions and connections with those around us and those sharing our journey.

As part of the woman’s care, and a tool to acknowledge and address any vulnerabilities felt by the woman, the concept of birth planning is as critical in the situation of fetal loss as with any other labour and birthing experience. A birth plan is a document written by the woman in consultation with the health care team that considers what is important to her and what her preferences are (NZCOM, n.d.). The presumption of a birth plan, in this context, is that it would enable women to express their expectations and needs about the process of TOP. The sense of physical vulnerability is, therefore, addressed when discussion regarding the bodily experience of having a TOP is considered. For example, what to expect when taking misprostol, how a TOP labour and birth may progress, what pain relief options may be appropriate, or how the baby may look at the time of birth.

The birth plan should be more than a checklist and reflect the woman’s preferences and emotions as well her own concept of birth and her need for safety and support (Lothian, 2006). Ahmadpour et al. (2020) found in their study of women’s positive and negative recollections of their birth experiences, their responses were related more to feelings and exertion of choice and control than to specific details of the birth experience. As suggested, vulnerability is based on the fear of harm by others so encouraging a woman to discuss, consider, and document what is important to her is likely to address, at least in part, any fearfulness. Utilising a care plan also enables culturally appropriate care which, in turn, impacts the woman’s feelings of vulnerability from a holistic standpoint.

The issues of trust/mistrust/self-doubt, considered possible consequences of feelings of vulnerability, are also addressed in the use of birth plans through hearing and paying attention to what the woman says about her expectations and assumptions about what is to follow. Cook et al. (2012) suggested the use of a birth plan can highlight and enhance the connectedness between the woman and her HCP. When a woman feels heard and acknowledged, a sense of trust can be built. After the appropriate discussion between the woman and her HCP, the women’s own birthing philosophy can be identified enabling her to confirm her ‘knowingness’ about her own birthing experience.

As Lothian (2006) suggested, the focus of birth plans should be to answer three woman-focused questions: What will I do to stay confident and feel safe? What will I do to find comfort in response to my contractions? Who will support me through labor, and what will I need from them? These questions can address most of the issues, but the current study recommends that another question be considered in a birth plan: What is important to you during your labour and birth? Together, all four questions have the potential to illustrate the main concerns a woman may have and provide answers or ‘plans’ to manage these issues. There is the opportunity to add other questions specifically relevant to the woman as appropriate.

It is important to add to the birth plan any unexpected outcomes that may occur without painting a disastrous picture for the woman. Rather than itemising every possible outcome it may be pertinent to discuss what and who might be involved if the unexpected happened (e.g., other midwives, obstetrician, anesthetist, pediatrician). This discussion may invite further questions from the woman, and she may gain a sense of trust when she knows that other experts/specialists are available if required. The reality of labour and birth is that plans often change during the process and unfold in a way that is not expected. Addressing this possibility with the woman offers further insight into her expectations and readiness. It is important to gain an understanding of what is important to the woman if something unexpected happened; for example, the labour took longer than expected or the placenta was retained, and surgical assistance was required.

Lothian (2006) talked of the possible tension that some HCPs may feel with the use of birth plans, stating that “the goals of the hospital system are often at odds with goals of an individualized birth plan. Tensions arise from conflicting beliefs about birth, choice and control, and power balance between women and their caregivers” (p. 297). This tension can be overcome by seeing a birth plan as a discussion tool rather than a ‘set in concrete contract’ between the woman and the HCP. In the context of a TOP, labour and birth often involve unexpected or unprepared for events (both good and bad), and preparedness and information sharing is more important than steadfast rules. Open and honest communication between the woman and the HCP, negotiation, and a shared understanding are some of the cornerstones of partnership (McAra-Couper et al., 2014). The concept of partnership between woman and her caregiver can potentially impact the woman's feelings of vulnerability, trust (or mistrust), and self-doubt.

Lothian (2006) concluded;

> nurses (HCP) need to have a deep respect for women who set out to do the work of birth. They deserve respect as they navigate the maze of modern obstetrics and work to have a deeply satisfying birth. Women need to be able to shape their environment so that they feel safe, supported, and comforted. (p. 300)

This statement is true for all birthing experiences, so is relevant for women experiencing a TOP. For a woman to have a 'deeply satisfying birth' while going through a TOP is highly possible, even though she will ultimately lose her baby. Feeling fulfilled depends on how involved she felt in her own care, how her care reflects her own way of birthing (and grieving), and how her birthing experience was acknowledged by those around her.

Researcher's Reflection

The clinical implications and recommendations seem straight forward and 'do-able' but are some of the most challenging issues for both the woman and her HCP to navigate through. Vulnerability often shows itself as disengagement, lack of connection, and pure unadulterated fear. None of these responses bode well when the clinical situation cries out for the exact opposite—engagement, connection, and a feeling of holistic safety.

Brown (2021) suggested "there is no intimacy without vulnerability" but is the opposite true? Does vulnerability depend on intimacy? In other words, can or does the relationship between the woman and caregiver reflect a vulnerability because of the intimate nature of the relationship that comes with labouring and giving birth? If the woman remained 'un-attuned' to what was going on, could she 'protect' her vulnerability? Almost as if remaining situationally numb to what she is going through.

On reflection, perhaps the issue is more that both the woman and the HCP have the same feelings of vulnerability. The woman's feelings may stem from a fear of the unknown and the huge emotional burden she is carrying, and not knowing how to cope. While the HCP's vulnerability may be more about not wanting to 'make things worse' through lack of experience or lack of supposed predictability of the situation. It could be suggested that the commonality between the woman and the HCP's vulnerability is 'fear of the unknown'. How the woman will react and, more precisely, what will she need from the HCP; and will the HCP 'know' how to meet these needs. Both people in this situation may feel unprepared, disconnected, and overwhelmed. For many HCPs, these feelings are not relevant because of their experience in caring for women who have had a fetal loss and level of resilience in the workplace setting of fetal loss, as well as the ability to sustain their practice. However, resilience to and sustainability in clinical situations are variable experiences for many HCPs. Factors such as practice autonomy; the ability to self-care; cultivation of relationships, both professionally and with women/families; and a passion, joy, and love for midwifery all support a HCP's resilience and sustainability in the profession (Crowther et al., 2016). How then does this relationship work? Two people feeling similarly vulnerable and having no 'map' for making it through the journey, together.

Care Concepts in Relation to the Four Concepts

The concept of Trauma Informed Care (TIC) should be considered when providing women with TOP care before, during, and after the event (Center for Health Care Strategies, 2021) to acknowledge the potential for trauma and allow the HCP to create a safe physical, social, and emotional space for care. The 'safety' of this space is determined by the woman and reflects what she needs to feel 'safe'. It requires communication, honest discussion, and choices being offered. An example of TIC might involve recognising triggers that may add to the woman's trauma; for example, the language used or the body language a woman displays when she feels trauma. Silence is potentially an example of a triggered trauma-based response. Another example of TIC involves the manner in which holistic clinical information is shared among HCPs. When a woman is required to repeat herself to a multitude of caregivers, the potential for repeated trauma is evident. Unfamiliarity with the woman's situation and clinical pathway may lead to assumptions, miscommunication, and misunderstandings in her care. The re-telling of her story to every caregiver may re-traumatise the woman and lead her to feeling 'unsafe' in her care.

The five principles of this care provision are safety, choice, collaboration, trustworthiness, and empowerment (Buffalo Center for Social Research [BCSR], 2023). By utilising the five principles in the development of clinical guidelines and practice recommendations, women experiencing a TOP can play an integral part in their own care. However, not every woman may feel capable of accepting these concepts because of the overwhelming feelings she is experiencing. The BCSR (2023) argued that when trauma is present, it affects an individual's sense of self, their sense of others, and their beliefs about the world. Again, the HCP must be mindful of the possible impact of trauma on a woman, and instead of expecting a woman to actively be engaged the HCP may need to instead advocate on behalf of the woman. This is especially relevant for women who go on to have another pregnancy after their experience of loss through TOP. The TIC principles of care would be ideally utilized for care planning for any subsequent pregnancies. Any past trauma related to the TOP (or from other experiences) could be addressed and support offered.

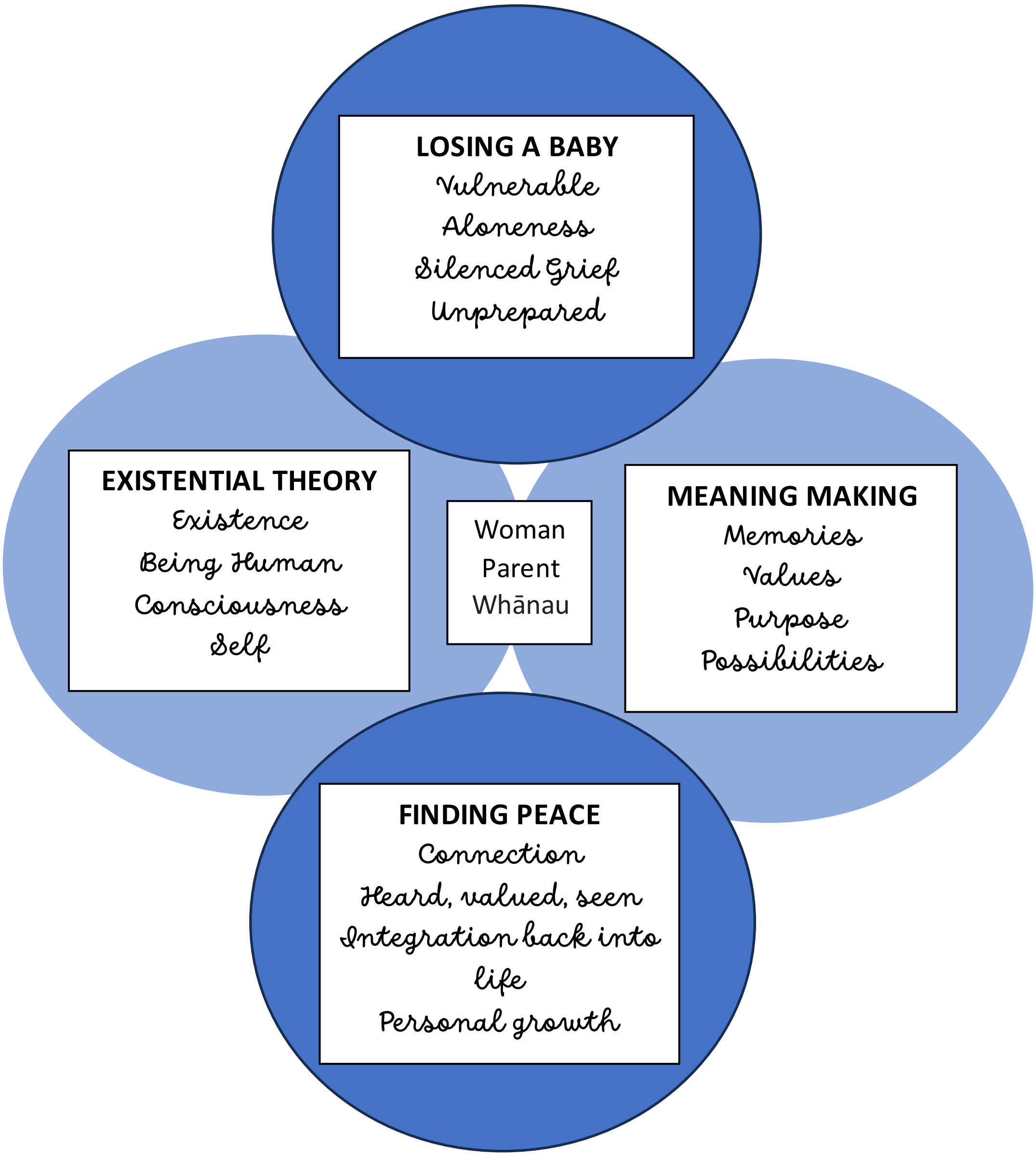
Birth plans have been discussed earlier in this chapter and their utilisation in practice should be examined. These foster a sense of partnership and trusted communication between the woman and the HCP. For the woman, being able to talk through her expectations, concerns, and wishes may, in part, alleviate some of her possible feelings of being alone, not having a voice, feeling unprepared, and feeling like she is at risk of harm. Asking mindfully motivated questions, when appropriate, may offer the woman a sense of being of utmost importance to the HCP and a feeling of being heard and seen in a holistic way.

The Jones' Finding Peace Model

The understanding gained from the current research has culminated in the development of a graphic illustration of the main findings, theories that support these findings, and, finally, what is desired by the women. It is suggested that the model summarises how a woman travels through the experience of terminating a pregnancy towards 'finding peace'. The model has been created to offer a representation of the key factors that are involved in the woman's holistic experience and offers prompts for the HCP to work with when caring for women in this situation.

Figure 3

The Jones Finding Peace Model



Summary of Chapter

This chapter further developed the understandings gained from immersion into the participants' narratives. Following on from the previous chapter, the current chapter offered discussion on the four concepts developed from the narratives. With each concept and with the support of the methodology of PIP, researcher reflections were offered to acknowledge my experiences of sitting in the data. To complement the discussion, the concept of TIC was introduced as a framework for caring for women in relation to the four main findings of the current study.

The next chapter provides discussion on the meaning, importance, and relevance of the research. It brings together the recommendations developed through the findings and shows how the previous chapters come together to illustrate, overall, the impact of the research.

CHAPTER 12: DISCUSSION

Introduction

This chapter delves into the meaning, importance, and relevance of the research. It focuses on explaining and further evaluating the findings and how they relate to literature to answer the research question, leading to the overall conclusion of the study. Recommendations for practice, education, future research, social change, and care provision are presented, along with the strengths and limitations of the research.

The Research Problem Answered

For this thesis, the post-intentional research question was “What is the experience of women having a TOP for fetal abnormality?” For women who experience TOP for fetal abnormality, the phenomenon is embedded in the context of their lived experiences and is impacted by how they find themselves placed in the world. It is widely accepted that having a TOP for fetal abnormality is unquestionably devastating to the woman going through it. It is known to be impactful from physical, emotional, cultural, and social perspectives; and is likely to be a life-changing experience. While previous research can confirm these notions, current research is not able to reflect the deeply personal and intimate embodied experiences of having a TOP that are often hidden in plain sight.

While the findings of the current research illustrate the deeply embodied experience that symbolises the devastating nature of a TOP, there are also camouflaged components of the women’s experiences. For women going through a TOP, their experiences are often covered over, felt internally, and not obvious to those around them. On the outside, the women look as many would expect, mourning the death of their baby. The current research and the methodology used are primed to answer the research question with a depth of introspection that has not yet been obtained. The use of Vagle’s (2018) PIP enables probing underneath the entanglement seen in the women’s narratives. PIP provokes and produces answers to the question and finds the gaps in current knowledge by exploring the phenomenon as it is unravelled. Therefore, this significant research provides an enriched and existentially based understanding of the experience of having a TOP for fetal abnormality. PIP supports the use of a wider lens that considers both how an experience can impact those living it and the context of that experience. Vagle also supported the notion that narratives of the experience ebb and flow, twist and turn, depending on the current ‘position’ of the storyteller. It acknowledges that with any story, there may be many versions of that same story depending on where the storyteller sits within their story.

The findings appear to desperately reflect the realities of what the women went through and illustrate how their memories are influenced by time. Sometimes the passing of time has buffered their recall but at other moments, their memories have grown as their understandings have developed.

These findings lend themselves to impacting guidelines and policies that are actioned when a woman goes through a TOP for fetal abnormality. They also support the HCP's understanding of how care provision can influence the woman’s experience of having a TOP. These notions, however, could be considered as just the tip of the iceberg. The deepest impact of these findings could be seen as the fuel to fire the change in how 'others' interpret what women endure when having a TOP. There are natural consequences to these findings. For those who choose to sit in a place of judgement or value-laden opinions, to be able to find a way to express human emotions of empathy and compassion is the ultimate consequence.
Some might suggest that "I don't need you to walk a mile in my shoes to understand me…just acknowledge that I have already walked that mile and it broke me"

Discussion of Findings in Relation to Literature

Previous research regarding the experience of having a TOP tended to focus on some time before and much later after the termination, whereas the current research focuses more on the experience immediately before, during, and after the termination. Jones et al. (2017b), in their meta-synthesis of research on women’s lived experiences of having a TOP, highlighted the devastating impact of such an event, as supported by the findings of the current study. Both studies agree with the immensely impactful experience women have when going through a TOP. However, the findings of my research are seen to be even more current than Jones et al.’s (2017b) work as the literature they used only included studies published before 2017. The relevance of my study reflects the knowledge and understanding gained regarding the experience of having a TOP in more recent years. That is, the feelings of unpreparedness that women experience as well as the increasingly social stigmatisation of having a TOP for fetal abnormality.

International abortion laws have, in recent years, become more liberalised, so the current research is seen as having greater relevance for those accessing TOPs as well as those providing TOP care (Center for Reproductive Rights, 1992-2023). More liberalised laws mean potentially more women accessing TOP services; therefore, their experience of having a TOP will be highlighted and needs to be understood by those providing TOP services. The findings of the current research, therefore, may be seen as potentially being more reflective of any woman's experience of having a TOP, regardless of where they are residing. The lived experience shown in these findings is not based on ethnicity or the country they live in but the embodiment of the experience. For example, Sunil (2022), studied Indian women's experiences of having a TOP in India, a country that has legitimised the accessing of abortion services in recent years. This implies that more women have the legal ability to access TOP services. The social, cultural, and medical accessibility of a TOP is another matter as the legalisation of TOPs does not equate to the accessibility of a TOP (Raman, 2022). These current research findings could now be seen as relevant to women in countries that have made, in theory, TOPs legitimate and legally available.

Study Strengths

For a study that considers such an intimate and sensitive phenomenon, the use of PIP was the study's main strength. While the methodology appears from the outside to be complex, demanding, and formidable, it is in fact quite the opposite. It allows the researcher to flow into the data, immerse themselves in it, then come back out to ponder their journey. The concept of data having a multitude of truths offers a wealth of possibilities for meaning-finding that is not held rigidly withing certain boundaries. This does not imply that the researcher can manipulate the data to find meaning; rather, can be open to insights that grow with sitting in the data. Instead of looking for the 'right' interpretation, the researcher is offered the ability to suspend disbelief and be open to new meanings. This methodology encourages the researcher to adopt a deeply reflexive stance and to embrace the entangled, sometimes messy nature of PIP. It is in this intensity that the richness of meaning is situated, and it is in the 'becoming with' the data that a deep appreciation of the phenomenon can be found.

A secondary strength of this research comes from my own practice experience of caring for women having a TOP. It may be assumed that these experiences reflect a bias in the experiencing of a TOP but, instead, it has offered me many opportunities to reflect on how these experiences are unique, sacred, and holistically impactful. These experiences have opened a depth of appreciation for what women go through that has provided the motivation to delve deeply into the lived experience from the woman's perspective. It is with the development of understanding that clinical, social, and cultural changes can be initiated and actioned to have an impact on these experiences.

Study Limitations

The initial research plan was to recruit a wide range of participants who reflected a variety of cultural, social, and ethnic backgrounds. There was an assumption that this plan would be straight forward and there was an anticipation that participants would be eager to tell their stories. What I had not anticipated was my euro-centric view of the sharing of personal stories did not necessarily reflect the views of others. Sharing such intimate and profoundly personal stories did not have the generic acceptability that I had assumed and resulted in fewer than expected participants consenting to being part of the study. The participants ended up being representative of the ethnic majority of Aotearoa New Zealand and, therefore, the research data did not reflect people from minority groups.

On further reflection, and unpacking of my own assumptions, I have gained insight into the complex and potentially high-risk activity of sharing such stories. Historically, people of ethnic or cultural minorities have been at risk of experiencing racism and discrimination, and by sharing such private experiences these risks are elevated (The King's Fund, 2020). In the past, their experiences may have been dismissed and devalued and deemed not relevant to others. This study would have been greatly enhanced by a wider range of cultures and it is suggested that this be the aim for future research.

The study sample size may be considered a limitation but, in retrospect, the data gained from the four women interviewed were rich in meaning and insight. The depth and extent of the data enabled equally deep immersion into the narratives, offering immense understandings to be unpacked through analysis. Boddy (2016) stated that sample size is contextual which implies that it is not necessarily the numbers that are pivotal to the study but the methodology of the data analysis and how meaning is interpreted.

What Can be Concluded From This Study

The study findings show that the experience of having a TOP for fetal abnormality is a highly significant, devastating, and life-changing event. Having a TOP is emotionally and physically complex, holistically impactful, and overwhelming to those experiencing it. The findings reveal that the care provision surrounding this experience adds to the impact of the TOP process. The study also confirmed that women who are going through a TOP can feel highly vulnerable because of feelings of being alone, publicly silenced, and unprepared for the reality of the process. For many, the feelings of shame and guilt can stay with them long into the future.

Researcher's Reflections

The development of recommendations that evolved from this research has been a challenging and uncomfortable journey for me. I see HCPs as autonomous practitioners and the words 'should or must' contravenes this personal philosophy. Out of respect for my fellow practitioners, I struggle to be so directive and be seen as potentially patronising. I have had many discussions with my supervisors as well as myself about what I want and need to say. After immersing myself in these stories and reflecting on my own experiences of caring for women having a TOP I have such deep regard for what women go through, I can't justify keeping my thoughts to myself. To this end, I feel that I need to honor women's experiences and provide recommendations that may be confronting to some. This notion is perhaps purposeful in clearing any misguided opinions regarding who should provide TOP care to women and the context surrounding this care.

Recommendations for Practice

When considering clinical practice related to caring for women who are experiencing a TOP, specifically addressing the concepts of aloneness, silenced grief, unpreparedness, and vulnerability is required. Not all women having a TOP will experience these, but for the HCP to have an awareness of the possibility of the woman having these emotions is an important, reflexive notion. Exceptional communication skills are essential when caring for the woman and are likely to enhance her feelings of feeling heard, seen, and acknowledged.

There must be acknowledgement that the experience of having a TOP for fetal abnormality can be traumatic for many women and can be exacerbated by previous, even unrelated, trauma. The care provided should be informed by the five concepts of TIC principles (Te Pou, 2023):

safety, choice, collaboration, trustworthiness, and empowerment.

It should be recognised that the experience of a TOP may highlight or trigger past trauma for women. If this occurs, the implications for the woman's health are potentially immense. Thus, mindful attention to the women's stories, their responses to care, and woman centric care are essential.

Up to date clinical knowledge is essential when providing TOP care, as is knowledge of bereavement care. As part of the care, birth planning should be included in discussions with the woman and the following questions are suggested as part of this process:

- What are your main concerns or fears at the moment?
- What can I do to help you feel supported right now?
- What is the most important issue for you today?
- Do you have specific things that you would like to have happen today?

These questions offer the woman an opportunity to have a sense of being pivotal to the care she is offered. They also allow a sense of partnership and connection with those providing her care.

For those HCP who declare they conscientiously object to providing care to women who are terminating their pregnancies, it is strongly recommended that these HCPs are supported to opt out of this care. However, The International Federation of Gynecology and Obstetrics (Oct. 2021), state that the right of HCP to *not* provide this care is considered a barrier to women seeking a TOP. The notion of HCPs who oppose providing this care being obliged to do so because of staff shortages or the lack of HCPs with this level of clinical experience is both inappropriate for the HCP but even more importantly, the woman. It is up to each obstetric care facility to find solutions to this situation as Aotearoa New Zealand law safeguards HCPs from doing clinical work that is contradictory to their belief system (MoH, 2023b). Ramsayer and Fleming (2020) state that this legal issue is complex and situational but the woman receiving care should not be forgotten when staff chose not to provide care. Women requiring care during a TOP have the right to be cared for by an HCP that is accepting of a woman's right to determine her own health outcomes without the added context of the HCPs own beliefs impacting on her care provision. Many HCPs would declare that their own beliefs never impact on the care they provide but that in itself defies logic. If this were the case, there would be no need for conscientious objection laws as all HCPs would provide the same level of care to any woman, regardless of the choices she makes. As stated earlier, this level of care encompasses *all* the HCP has to offer the woman, not just the agreeable or comfortable parts. As this research shows, women going through a TOP are especially vulnerable and highly sensitive to the care offered to them so having an HCP that disapproves of what they have 'chosen' to do can be *felt* by them, whether consciously or unconsciously. It is ironic, however, that many women cared for in an obstetric setting have made lifestyle choices that contradict the HCPs moral, ethical or personal values but still the HCP steps up to provide care that focuses on the woman/family's needs and not their own opinions or beliefs.

Practice Recommendations in Summary

- HCPs who conscientiously object to providing TOP care are to be supported in declining this care provision, regardless of staffing pressures.
- A woman’s vulnerability should not be assumed. All women, whether assessed as being vulnerable or not, are able to be autonomous and self-determining in their care.
- Intuitive, authentic, and open communication is required to acknowledge and respect the woman's individual needs.

- Birth plans are an essential part of bereavement care and should be routinely offered and utilised in this care provision.
- Appropriate and woman/family centric care equates to culturally safe care and should reflect the specific requirements of the woman/family.
- The five principles of TIC practices should be incorporated into service provision planning and clinical guidelines.

Recommendations for Education

A recent publication "*Perinatal Bereavement Support Environmental Scan Report*" from Te Whatu Ora [Health New Zealand] (2023), stated that formal health education for HCPs does not prepare them with the necessary skills to provide bereavement care. The report recommends specialist perinatal bereavement support training so those providing bereavement care can increase their confidence and skill base for caring for those who have experienced the death of their baby.

Both the under-graduate and postgraduate education space requires contemporary and specific education input regarding the TOP process (Doherty et al., 2018) from the woman's point of view as well as a holistic clinical perspective. Introduction or expansion on the theory of meaning-making care and the lived experiences of women having a TOP is required to support students to gain a deeper understanding of this level of care (Dezelic et al., 2014), and would nurture empathy, compassion, and woman-centered care.

Women accessing TOP services are impacted by the law of the country in which they live; therefore, clear and pragmatic discussions with students related to how TOPs fit into the country's legal boundaries are vital. Equally important is the discussion on where TOPs sit in the provision of health care from a political and feminist standpoint (Taylor, 2017). Equity in the accessibility of TOP services is a vital component of inclusive and equitable health care and should be part of the overall discussion with students. Importantly, access to timely TOP care that reflects the needs of all, but especially Māori, Pacific, rainbow, and disabled communities, should be included in TOP educational curriculum to enable the provision of a rounded and holistic viewpoint of care (MoH, 2023a). Internationally, it is commonly recognised that Indigenous women and those in the LGBTQIA+ community (amongst others) often experience inequity in health care, including reproductive services (Monchalin, 2022). The notion of equity in reproductive health care for all people should be instilled in all midwifery students to facilitate fair and accessible care.

While the current study considers a woman's preparedness to go through a TOP, attention should be paid to the student's own feelings of preparedness. Clinical theory, as well as coping strategies, should be covered in an honest and safe manner. By introducing the complex and situation-sensitive care required in the context of a TOP, students can develop their reflective practice to explore how they are able to meet the woman's needs. Standards of practice related to midwifery Code of Ethics, Code of Conduct, and evidence-based midwifery practice should be addressed to guide practice (International Confederation of Midwives [ICM], 2014), and should include clarity around the concept of conscientious objection to providing termination care as the provision of this level of care and HCPs' commitment to it should not be assumed. A protective and nurturing educational space is required to support students while they consider the topic of TOP. A student-focused and holistic approach to learning about TOP is required in all institutes that provide midwifery education (ICM, 2021).

For postgraduate and registered HCPs, on-going and contemporary educational opportunities are important to provide current best evidence practice guidance. These also allow for HCPs to share their thoughts and feelings about providing this level of care and gain support from their colleagues. Providing the opportunity for HCPs to further develop communication and clinical skills will enable optimal care experiences for women going through a TOP and would ensure that women are offered correct and reliable information from their HCP which, in turn, will enable them to make informed decisions about their care.

Education Recommendations in Summary

- Undergraduate educational curricula to include the clinical theory and practical skills of caring for a woman experiencing perinatal loss, grief and loss, and coping skills for the HCP providing bereavement care.
- Undergraduate study to include law and ethics related to women accessing TOP care, as well as the law and scope of practice for HCPs providing such care.
- Those who have experienced a TOP should be included in any curriculum development in this area.
- Postgraduate study includes training workshops on bereavement care that extend the HCP's skills.

Recommendations for Future Research

There is the need for further research on women's experience of having a TOP from a cultural standpoint. Consideration of how a woman's ethnicity, cultural norms, and cultural expectations impact her experience of TOP would be considered valuable. The inclusion of those who are not cis women would offer a contemporary understanding of the lived experience of a wider group of people. Future studies also need to address how a woman's preparedness is perceived and managed in the context of having a TOP by those providing her care. This includes information sharing and how a woman gains adequate information regarding the process. The issue of pain management needs to be researched to understand how a woman experiences a TOP in relation to pain and how the pain relief does or does not meet her needs.

Regarding international laws around TOP, any law reforms that influence women's accessibility to a TOP should be studied to ascertain how they impact women and those HCPs caring for women accessing this service. Since 2000, 38 countries have changed their abortion laws which must surely have had an influence of the accessibility and acceptability of abortion services for women worldwide (Council on Foreign Relations, 2023). From an Aotearoa New Zealand point of view, with the 2020 Amendments to The Abortion Law (NZ Govt., 2020), research is needed to investigate the quantitative aspect of TOPs in New Zealand; that is, the numbers of women accessing a TOP, the number of TOPs performed, and the outcomes of the TOPs.

The age of the participants of this research were between mid 20s – mid 30s. This leads to the question of whether women of different ages, specifically younger/teenage women, experience a TOP differently to women of different ages. It would certainly be a topic for future research as statistics indicate that women under the age of 20 have higher incidences of fetal abnormalities (Chen et al., 2007; Chen et al., 2022; Sirakov, 2012).

Future Research Recommendations in Summary

- Research that represents the lived experiences of pregnant people having a TOP from different cultural backgrounds, social minorities and a wider age range, is required.
- Studies that investigate women's preparedness for having a TOP and how it may be improved are considered important.
- Investigation into pain relief and pain management effectiveness and acceptability for those having a TOP is required.
- Research that reviews accessibility to services and impact of any changes to laws that are related to reproductive rights is needed.

Recommendations for Social Change

As part of the study methodology, PIP, the concept of research for the purpose of social change is an important aspect of this work. The stigmatisation of TOPs is well documented (Jones et al., 2017b) and society often struggles to see the ending of a pregnancy because of fetal abnormality as a health issue rather than a moral issue (Steinbock, 2023). Instead, moral and value laden judgement is often apportioned to women who make this decision. It is recommended that laws that support a woman's right to access safe and legal reproductive health care be prioritised. Ideally, any law that applies to a woman's reproductive rights should be based on ethical considerations and adopt the notion of a community of compassion and empathy that reflects the reality of women's lived experiences (Steinbock, 2023). These experiences are real, highly impactful, and life-altering; and those experiencing a TOP are forever changed. The impact of the experience of terminating a pregnancy has been clearly illustrated through the current study and the conclusion that this experience is devastating and traumatising needs to be acknowledged and respected. If the purpose of health reforms and law is to protect, promote, and improve the health of the citizens of a country, then these need to be fit for purpose (Taylor, 2017). A health system that reflects equity and accessibility for all, is coordinated and people-centred, is, or should be, the gold standard for every country that values its citizens.

Countries that regard ending a pregnancy because of fetal abnormality as a criminal or immoral act are encouraged to see the lived experience from the woman's perspective and show a humanistic attitude. Termination of a pregnancy should be seen as a reproductive health service and part of a woman's human rights (New Zealand Family Planning Association [NZFPA], 2023). The right to choose, the right to make informed decisions, and the right to be respected in the health care setting make up the foundation of basic human rights. A woman's ability to make a decision regarding her pregnancy should be trusted and respected, regardless of what policy makers may think or assume. The accessibility of termination services for women is seen as part of a wider political and social construct and often reflects the negative impact on women who, historically, are disadvantaged regarding health care (NZFPA, 2023). Whether through cultural acceptability, physical access, or the restriction to the full range of health care services because of financial and other barriers, women are routinely denied open and judgment free care options (NZFPA, 2023).

The social construct of the language used around the TOP is primed to dehumanise, demean, and, again, stigmatise women who seek this care (American College of Obstetricians and Gyneacologists [ACOG], 2023; Danner, 2022). For example, some descriptors of women who seek a TOP are said to have an 'unwanted' pregnancy. There is no justification for this social assumption that the pregnancy is unwanted or even mistimed. It cannot be assumed that women seeking a TOP for fetal abnormality are pregnant with an unwanted child. This notion adds to the stigmatisation of why a woman would 'choose' to end a pregnancy. It is seen as discrediting women who experience a TOP and adds to both the internal and external burden the women and society place on their decisions. The terms that represent opposite viewpoints, ‘pro-choice and pro-life’ suggest that the moral stand is always black or white and is often far from the truth as terminating a pregnancy because of fetal abnormality often sits in the grey zone of ‘a rock and a hard place’ that no woman chooses to be in. Society seems to want to adopt the notion of ‘good reasons vs. bad reasons’ for having a TOP, which highlights the judgement placed on women’s decision about their own reproductive health. Even the concept of ‘choice’ is contentious as women find themselves having to decide when their baby will die rather than whether they should continue with their pregnancy. Describing such a decision as a ‘choice’ seems to be an inappropriate description of women’s reality.

For societal change, TOPs need to be seen as a health issue rather than a moral issue, and the act of women making informed decisions about their own health should be normalised, acknowledged, and supported within public discourse (NZFPA, 2023). Women’s health autonomy should be seen as a human right and respected as such (Fos Feminista, n.d.). Media and social forums are required to cease the dramatisation of TOPs as this adds to the ‘otherness’ of women who have experienced a TOP. There is a need to continue to work with policy makers so that health care does not further marginalise and stigmatise those who access these services.

If the stigmatisation of women having a TOP because of the societal aversion to ending a pregnancy continues, then the incidence of unsafe TOPs will be even more of a reality for women and maternal mortality will continue to rise (WHO, 2021b). The marginalisation of women worldwide who access TOP services leads to negative health outcomes that have long lasting consequences on the woman and her family.

Social Change Recommendations in Summary

- Laws that support a woman’s right to access safe and legal reproductive health care should be prioritised.
- Termination of a pregnancy should be seen as a reproductive health service and part of a woman’s human rights. Laws and service guidelines need to reflect this stance.
- Media and social forums should be required to cease the dramatisation and sensationalism of TOPs.
- Implementation of laws related to reproductive rights should be standardised by ensuring the public, HCPs, and policy makers are well informed regarding the law.

Recommendations for Health Care Provision

This study revealed that women’s experiences of having a TOP for fetal abnormality are highly impactful and the memories of their experiences are long lasting. Health services are required to have an appreciation for this experience, and on-going and specific health care needs of the women need to be addressed. National clinical pathways for bereavement care are required that support the women, their families, as well as the HCPs who provide care during this time (NBCP, n.d.). A coordinated pathway that allows women to access care and support before, during, and after the TOP should be prioritised to provide holistic and situation-sensitive care. Each hospital that provides TOP services, in this context, should have a dedicated bereavement HCP team that coordinates this level of care. Part of the bereavement team's role should be advocacy for women who access the service as well as for the staff who provide the service. This recommendation would be reliant on both the HCPs and the institution having a clear and comprehensive understanding of the law that guides the health provision system. A dedicated bereavement HCP team would facilitate an increase in the overall knowledge of women's reproductive rights and services, as well as improve the quality and accessibility of this care provision.

Health Provision Recommendations in Summary

- A health system that reflects equity and accessibility for all, is coordinated and people-centered should be the gold standard for every country that values its citizens.
- Equity in accessibility to TOP services should be highlighted at all levels of service provision including practice meetings, audits, and clinical reflections.
- All service providers of TOPs should have policies that spotlight health equity and cultural safety.
- Staffing allocations should provide those who conscientiously object to providing TOP care an 'opt-out' ability. Management should be aware and respect those HCPs who decline to provide this care as part of the HCPs own cultural safety.
- The provision of care should not vary in quality because of ethnicity, decisions made by the woman, social determinants, or personal philosophy.
- All health care facilities that provide TOP services (and all perinatal loss care) to have a dedicated bereavement team that offers information and support for those going through a TOP at all stages of the experience, including subsequent pregnancies.
- The development of national bereavement clinical pathways is a priority to provide consistent and acceptable care provision.
- Any health provision plans, developments, and implementation should be in collaboration with those who have experienced a TOP.

Contribution to Body of Knowledge

This study offers a reflective narrative for women who have experienced a TOP for fetal abnormality. The findings highlight the often unseen and, therefore, unnoticed embodiment of this experience. The knowledge gained explicitly defines the devastation felt with the loss of a baby in the context of a TOP and the highly impactful consequences on women from the embodied and holistic experience of having a TOP. The women in this study give these experiences a voice to what was previously concealed. The understandings gained from the women's narratives and the interpretation of these understandings allows others to gain insight into their lived experiences. With this awareness, HCPs can appreciate what it is to have a TOP and how their care can impact the experience. The research adds to what has been written about this phenomenon by providing even deeper, intimate evidence of the gravity of the experience.

This research supports the utilisation of the mindful use of birth planning tools to aid communication regarding the woman's expectations, hopes, and wishes for the birth of her baby. The introduction of a TIC initiative is supported by the research findings. This initiative offers a comprehensive and situation-sensitive practice that supports a safe environment for women to feel empowered by their care rather than traumatised or overwhelmed. While TIC has been used in many different environments of care, the combination of this care initiative and TOP care has not been seen. The research offers this new alliance of care provision to be utilised in caring for women having a TOP.

PIP has not previously been used to consider the lived experience of TOP. This methodology adds to the body of knowledge regarding experiencing a TOP by considering the multitude of possibilities in the women's reality of the experience. PIP does not confine the experience to 'one truth' but sees the phenomenon as being authentic to each woman's own interpretation of her experience. The approach is unique as it enables a suspension of disbelief or, conversely, the acknowledgement of each woman's realism in recalling her experience.

Literature suggests that knowledge and practice wisdom in TOP care is lacking for many health care providers (Armour et al., 2023; Te Whatu Ora, 2023). The current research offers key care provision proposals to address these concerns. Worldwide, TOPs for fetal abnormality are becoming more legally accessible for women, therefore, this provision of care will become more common place for many HCPs (Fos Feminista, n.d.). The understandings offered in this research will contribute to collective practice knowledge. The study findings also put a focus on care provision policy that includes holistic and reflexive care ideals that acknowledge the intense and devastating experience of having a TOP.

Finally, this research offers an acknowledgement of the disenfranchised experience of women 'choosing' to end their pregnancy, when ending their pregnancy is the last thing they want to do. It spotlights the harrowing journey that is embarked on and how the reality of their decisions leaves them feeling stigmatised, alone, vulnerable, and uncertain. The findings allow others to see inside their experiences and begin to understand the nightmare they face. The study brings this often hidden and unspoken event into the light and gives it room to be seen for what it is. By opening the dialogue on having a TOP for fetal abnormality, women who go through this experience may be offered some amount of understanding, compassion, and empathy.

Concluding Thoughts

The experience of having a TOP for fetal abnormality is so unexpected, unwanted, and unprepared for, the reality of it is often too overwhelming to comprehend. The woman is led into a nightmare that she cannot leave and must manage her path the best way she can. Those caring for her can offer her empathetic and compassionate care in supporting her and acknowledging what she is going through. The experience, however, is felt on such an intimate and personal level that the woman is often in a place of solitude that others cannot easily access.

One of the goals of any health care experience is to acknowledge the uniqueness and individuality of the person experiencing the care. For women having a TOP, this notion offers them the opportunity to be seen, heard, and affirmed. The philosophical concept of 'being with' the woman is even more relevant in this situation and encourages the expansion of a collaborative partnership between the woman and her HCP.

From a wider lens, the holistic backdrop to this experience must encompass all the cornerstones of woman/family centric care. That is, on-going care that is determined by the woman, an environment that nurtures rather than alienates, care providers who are well informed and supported, and a society that can respect what the woman is going through.

With the development in recent years of the equipment and knowledge that enables the diagnosis of fetal abnormalities, and the liberalisation of abortion/termination laws internationally, more women are finding themselves in a place of decision-making about ending their pregnancies. The lived experience of terminating a pregnancy is often shrouded in secrecy and the untold stories are never heard. Women's experiences are left to only be observed and not truly understood. This research opens the door to a deeper appreciation of what women go through when having a TOP and enables others to offer support, compassion, understanding, and positive regard.

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Appendices

Appendix A: Definition of Terms

Antenatal diagnosis: Diagnostic procedures carried out on pregnant women to detect the presence of genetic or other abnormalities in the developing fetus (Oxford Reference, 2021).

Fetal anomaly: Also known as birth defects, congenital disorders, or congenital malformations. Fetal anomalies can be defined as structural or functional anomalies that occur during intrauterine life. Also known as fetal abnormality (WHO, 2021a).

Miscarriage: A baby dying in utero under 20 weeks gestation (NZ Govt, n.d.).

Neonatal death: The death of a baby after birth. An early neonatal death is defined as a baby that dies from birth to 7 days; a late neonatal death is defined as a baby that dies from 8 to 28 days (NZ Govt, n.d.).

Stillbirth: Fetal death occurring after 20 weeks gestation but prior to birth. If the gestation is not known, then if the fetus weighed more than 400 grams or more when born (NZ Govt, n.d.).

Appendix B: Participant Information Sheet

14/06/2021

Project Title

Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy: a post-intentional phenomenological study.

An Invitation

My name is Kay Jones, and I am a bereavement midwife of 23 years' experience.

As part of my PhD studies, I am wishing to hear the stories of women who have experienced a medical termination of their pregnancy between 14 and 28 weeks pregnant, because their baby has a condition that may be life-limiting. For any woman who has experienced this and feels that she would like to share her story with me then I warmly invite her to contact me to discuss her involvement. If any woman would like to consider being part of this research but ultimately decides she would prefer not to then there will be neither advantage nor disadvantage to the woman.

What is the purpose of this research?

A diagnosis of fatal abnormalities in an unborn baby profoundly alters the childbearing journey that most women and their families were expecting. Although there is a growing body of literature exploring concepts such as grief, decision making and mothering in the aftermath of such an event there is very little evidence about how a woman, who decides to terminate her pregnancy, makes meaning of her labour and birth experience. This research aims to hear women's lived experiences of labour and birth in the context of a medical termination of pregnancy for fetal abnormality in the second trimester of pregnancy.

Who is involved involve?

I plan to recruit 10 women from networking and referrals from midwives or obstetricians. Data collection will be from individual, private and in-depth interviews. Data analysis will seek to enable the meaning of the experience to be understood while maintaining the uniqueness of your own story. To hear about your journey as *you lived* it, your awareness of what it felt like to be *you* during this time and what meaning *you* attached to this life event. It offers the chance to enter another's world; by 'lighting' the experience for others to see more clearly. This will be achieved by drawing heavily on your spoken words and sitting in and with your experience.

Women who chose to participate will be asked to share their experiences, both positive and negative, to offer health care professionals who care for women in this situation, insight, understanding and practice wisdom.

How was I identified and why am I being invited to participate in this research?

You have been approached to participate in this research because you have experienced the loss of your baby through a medical termination of pregnancy. The midwife that cared for you during your labour and birth or your own Lead Maternity Carer (midwife or obstetrician) or a member of a support group has identified you as a potential participant because of this experience.

You can be included in this research if you:

- have experienced a medical termination of pregnancy between 14 and 28 weeks of pregnancy because your unborn baby had a fetal abnormality
- speak, read and comprehend English
- consent to being part of this research
- are not personally or professionally known to the researcher.

- are aged 20 years of age or over.
- live in New Zealand.
- experienced the termination in New Zealand within the last five years.

meet the ethnicity selection criteria (women's ethnicity will reflect the occurrence of this situation amongst certain ethnic groups)

This research project has exclusion criteria or reasons why a woman may not be eligible to participate.

A woman who:

- has experienced on-going and debilitating grief responses to the loss of her baby.
- is culturally or spiritually at risk from re-telling her story (self- determined)
- is unable to access follow-up support (if required) as offered via the participant information document.
- is unable or unwilling to recall her experience (grief, mental health concerns, time since experience)
- becomes overly distressed or ill-at-ease before or during the interview (if during the interview and the interview is discontinued then the participants have the option to reschedule the interview if appropriate).
- declines to give continuing consent to participating in the research.

How do I agree to participate in this research?

To participate in the study, you can email Kay on kay.jones@aut.ac.nz to say that you want to participate and ask further questions.

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You can withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

Being part of this research involves you being invited to attend an interview with me, the researcher (Kay Jones). The location and timing of this interview is decided primarily by you. It can be at your home or at an appropriate venue that offers privacy and is comfortable. If you would prefer, I can organise a venue for the interview. The interview will last 60-90 minutes and, with your permission, will be audio recorded. You are encouraged to discuss any rituals/ceremonies that you would like to incorporate into the research, for example, karakia. Also, you are more than welcome to bring a support person with you to the interview.

Before the interview, I will talk through this participant information sheet to ensure you are provided answers to any questions you may have. You will be asked to bring your signed consent form (provided in your research pack) along to the interview and your on-going consent will be obtained. Part of the consent process includes you being aware that the data that is collected will only be used for the purposes for which it has been collected.

If you wish to take part in the study, we would ask you to do the following:

Read this participant information sheet

Contact me at kay.jones@aut.ac.nz. Please include your cell phone number if you are happy for me to ring you to talk further about participating in this research. I will also go over this sheet with you to answer any questions you may have.

What are the discomforts and risks?

Remembering and talking about your experience of giving birth to your baby may cause you to have some sad feelings. This is a normal response for many women. The interview will be a safe place to think of those feelings and there is ample time for you to “take a breath”, if needed. I am an experienced bereavement midwife and will support you throughout you telling your story, in your own way and in your own time. Remember that follow-on support will be available to you, if required. Anything that you share during the interview will remain confidential and to protect your identity the audio tape of your interview will be assigned a pseudonym or made up name. You will be encouraged to decide what “name” you would like used.

How will these discomforts and risks be alleviated?

AUT Health Counselling and Wellbeing can offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly because of participation in the research and are not for other general counselling needs. To access these services, you will need to:

> drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
>
> let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on

http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

For participants who live outside of the Auckland region please contact any of the following agencies:

- Sands NZ https://www.sands.org.nz/supportgroups.html
- Phone or text 1737 to talk to a trained counsellor.
- PADA Family/Whanau support – Pada.nz

What are the benefits?

The outcome of this research will enable your story to be validated and acknowledged. The findings will fill a gap in knowledge thus providing maternity health care professionals with greater insight into the physical, emotional and spiritual needs of childbearing women as they meet the challenge of labouring and giving birth to a baby they know will not survive. Findings will also support the development of woman centred education materials, policies and practices that will help clinicians work with women in a way that honours the meaning women ascribed to their own individual experiences. At the conclusion of my research, you may wish to gain access to the crafted story I have created from your interview and experience. If you would like to receive this, please let me know.

How will my privacy be protected?

The interviews will take place in a private and comfortable location. The only people who will have access to your interview will be the typist who transcribes the interview, me (the researcher) and the research supervisors. The typist will be required to sign a confidentiality agreement that means that they must not discuss any information from the interviews. Again, your transcript from the interview will be allocated a made-up name to provide you with further confidentiality. The data from the study will be stored on a password protected site and only be accessible to the researchers.

What are the costs of participating in this research?

The main cost will be your time spent at the interview (60-90 minutes). You will be offered a koha for your time and travel expenses.

Researcher Funder: The New Zealand College of Midwives and Auckland University of Technology are funding this research.

What opportunity do I have to consider this invitation?

One month.

Will I receive feedback on the results of this research?

Yes, if you would like to know the final conclusions of this research, a summary of the findings can be sent to you at the end of the research project. Please remember to provide your email address so this can be sent to you.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Associate Professor Andrea Gilkison, andrea.gilkison@aut.ac.nz Ph: 09 921 9999 ext 7720

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, ethics@aut.ac.nz , (09) 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Kay Jones kay.jones@aut.ac.nz

Project Supervisor Contact Details:

Associate Professor Andrea Gilkison andrea.gilkison@aut.ac.nz (09) 921 9999 ext 7720

Approved by the Auckland University of Technology Ethics Committee on 14th June *2021*, AUTEC Reference number *21/102*

Appendix C: Participant Consent Form

Project title: ***Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy: a post-intentional phenomenological study***

Project Supervisor: *Associate Professor Andrea Gilkison*

Researcher: *Kay Jones*

I have read and understood the information provided about this research project in the Information Sheet dated

I have had an opportunity to ask questions and to have them answered.

I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

I agree to take part in this research.

I wish to receive a summary of the research findings (please tick one): Yes ○ No ○

I wish to receive a copy of my own crafted story (please tick one): Yes ○ No ○

If you identify as Māori, please state your Iwi/Hapu……

Participants signature: ……………………………………………………………………………………………

Participants Name: ……………………………………………………………………………………………

Participants Contact Details (if appropriate) :

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……………………………………………………………………………………….

……………………………………………………………………………………….

Date:

Approved by the Auckland University of Technology Ethics Committee on 14 June 2021 AUTEC Reference number 21/102

Note: The Participant should retain a copy of this form

Appendix D: Inclusion and Exclusion Criteria for Potential Participants

Inclusion criteria:

Women who

- have experienced a medical TOP between 14 and 28 weeks gestation for fetal abnormality
- speak, read, and comprehend English
- consent to being part of the research
- are not personally or professionally known to the researcher
- are aged 20 years or over
- live in Aotearoa New Zealand
- experienced the medical TOP in Aotearoa New Zealand within the last 5-years.

Exclusion criteria:

Women who

- have experienced complicated grief responses to the loss of their baby
- are culturally or spiritually at risk from re-telling their story (self-determined)
- are unable to access follow-up support (if required) as offered via the participant information sheet
- are impaired in recalling their experience (grief, mental health concerns, time since experience)
- Become overly distressed or ill-at-ease before or during the interview (if during the interview and the interview is discontinued then the participant has the option to reschedule the interview if appropriate)
- decline to give continuing consent to participating in the research

Appendix E: Confidentiality Agreement

Project title: ***Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy: a post-intentional phenomenological study***

Project Supervisor: *Ass Professor Andrea Gilkison*

Researcher: *Kay Jones*

I understand that all the material I will be asked to transcribe is confidential.

I understand that the contents of the tapes or recordings can only be discussed with the researchers.

I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: ……………………………………………………………………………………………………

Transcriber's name: ..Shoba Nayar……………………………………………………………………………………

Transcriber's Contact Details (if appropriate):

…snayar19@gmail.com…………………………………………..

………………………………………………………………………………………….

………………………………………………………………………………………….

………………………………………………………………………………………….

Date: 9 February 2022

Project Supervisor's Contact Details:

Dr Andrea Gilkison

andrea.gilkison@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 14th June 2021 AUTEC Reference number 21/102

Note: The Transcriber should retain a copy of this form.

APPENDIX F: Confirmation letter for Ethics Approval

14 June 2021

Andrea Gilkison
Faculty of Health and Environmental Sciences

Dear Andrea

Re Ethics Application: 21/102 Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 11 June 2024.

Non-Standard Conditions of Approval

Please ensure that post-analysis your data will be stored either on an AUT network drive with restricted folder permissions or on a removable storage device in a secure location on AUT premises, preferably with your primary supervisor.

Include in your Researcher Safety Protocol of a timeframe for contacting emergency services should you not be contactable after an interview.

Removal of the template instructions preceding the Consent Form.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: kay.jones@aut.ac.nz; jmcaraco@aut.ac.nz; Tania Fleming

APPENDIX G: Data Management Plan Auckland University of Technology Ethics Committee (AUTEC)

DEFINITION & PURPOSE:

A data management plan describes how researchers are collecting, storing, and managing the use of data collected as part of their research. It describes how data is being stored now and in the future. It describes who has access to the data and for what purposes. It records the conditions under which the data was collected. It describes who has control over access to the data.

Data collected as part of research undertaken by Auckland University of Technology (AUT) students or staff will normally be stored on AUT premises in a specified location. It is to be returned to the participants or destroyed once it has been kept for a minimum of six years. Health data is to be kept for a minimum of ten years.

AUT Staff and Students are recommended to read the Library's advice about Research Data Management and Te Mana Raraunga - Principles of Maori Data Sovereignty

The following questions are provided as prompts for writing the plan. You need to use them taking into account the context of your project.

Project title and brief description:

Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy: a post-intentional phenomenological study

This research aims to hear 10 women's lived experiences of labour and birth in the context of a termination of pregnancy for fetal abnormality in the second trimester of pregnancy. Data will be collected through in-depth interviews followed by thematic analysis of this data using post-intentional phenomenology.

Kay Jones

Supervisors or other researchers

Professor Judith McAra-Couper, Dr Tania Fleming.

Who will have the primary responsibility for the data at the different stages of its life cycle?

Kay Jones

What is the nature of the data being collected and produced?

What type of data will be produced? Verbatim stories from each women who have experienced this phenomenon

How will data be collected and in what formats? Through in-depth interview with each woman. The interviews will be audio-taped. Interviews will either be face-to-face or via virtual platform (Zoom).

How will the data collection be documented so that others can work out what is involved? The primary researcher will be the only person collecting the data. The research supervisors will have access to the transcribed interviews that will have their own unique pseudonym attached to them.

Will the data be reproducible? No.

How much data will it be, and at what rate will it grow? How often will it change? The data will comprise of 10 interviews with each interview being 60-90 minutes in duration. The data will not change.

Are there tools or software needed to create or process or visualize the data? No

What costs, training, or resources are needed to implement this? N/A

Will pre-existing data be used and if so, from where will it be sourced? No.

Where are you collecting data?

Where are you collecting data? From the in-depth interview recordings

What jurisdiction requirements apply to the collection of data? N/A

If you are collecting personal data from non-NZ residents are you compliant with relevant local data protection legislation? N/A

Note: If you are collecting the personal data of European Union residents you will need to comply with the General Data Protection Regulations.

What are the data storage plans?

What are the data storage and backup strategies? What would happen if it got lost or became unusable later?

Information will be handled in a manner that ensures its safekeeping and protects the confidentiality of participants.

The transcribed interviews and signed consent forms will be stored separately on safe storage cloud files (Office 365 or OneDrive). These will also be kept, separately, on single-purpose USB devices and will have password accessibility only. This is considered backup storage of data. This USB will be held securely by the researcher. The hard copies of the consent forms will be securely stored in the Midwifery Department, AUT Manukau Campus, Auckland.

Will any data be stored on portable devices (e.g. audio files on a mobile phone)?

No.

How will the security of any temporary storage be assured?

The only temporary storage device will be the audio-recorder used for recording the interviews. This will be stored securely in a locked cabinet at the primary researcher's residence.

Will the data be securely stored or transferred to a secure data repository?

The transcribed interviews and signed consent forms will be stored on a safe storage cloud in separate files (Office 365 or OneDrive). These will also be kept on separate single-purpose USB devices and will have password accessibility only. This is considered backup storage of data. These USBs will be held securely by the researcher.

What data will you keep and what data will be destroyed?

The audio recordings of the interviews will be destroyed once the interviews have been transcribed and checked for accuracy. The transcribed interviews will be kept securely, as above.

When and how will data be destroyed?

The audio recordings of the interviews will be destroyed once the interviews have been transcribed and checked for accuracy. The transcribed interviews will be deleted from the storage devices after ten years.

What are the ethical requirements for your data?

How sensitive is your data (Has a data safety management protoco9l been created)?

Yes, a data safety management protocol has been completed.

The data will involve each participant discussing her experience of labour and birth during a medical termination of pregnancy. This experience could be considered highly sensitive and personal in nature.

How identifiable is your data and will this alter? When?

The data will be unidentifiable as any participant will be allocated a pseudonym. This will be the only identifying marker of the interviews. The pseudonym will be allocated prior to the interview.

What will happen to the identifiable information?

The audio recordings will be the only possible identifying data collected. Once this has been transcribed and checked for accuracy, the audio recordings will be deleted.

Should some data be destroyed or returned? When and how? By whom?

As above, the audio recordings will be deleted as soon as the data has been transcribed and checked for accuracy.

How will the undertakings about consent, confidentiality, deidentification, and other ethical considerations given to participants be assured?

Via the participant's information sheet and also when discussing participation in the research. Consent, confidentiality, the use of a pseudonym (deindentification) and other ethical considerations will be clarified just prior to the interview. Any data collected from wahine Maori will be considered as a taonga and before destruction, those wahine Maori will be consulted regarding the destruction process.

How is your data being organised and what documentation and metadata is being used?

What is the plan for organising, documenting, and using descriptive metadata to assure quality control and reproducibility of these data?

There will be only one source of data (transcribed interviews) so any verbatim quotes used will be able to be verified by the transcriptions. As each woman's stories will be unique, the reproducibility of these data is not applicable.

What standards will be used for documentation and metadata and what version controls are in place?

Any documentation will be coded by date (Eg: 01022021) so chronological data analysis can occur.

Also the initials of the participant (pseudonym) will be used on the document to enable clear recognition of any analysis completed for that particular participant. (Eg: AA)

Title casing will be used. (Eg: InitialAnalysis)

Version number will be used (Eg: V1)

So a document may appear (Eg; 01022021AAInitialAnalysisV1)

How is the use of good project and data documentation formats or tools being assured and evaluated?

My research mentor (Dr Tania Fleming) will assist with this by assuring and evaluating this documentation process.

What folder and file naming convention will be used?

See above.

What project and data identifiers will be assigned?

MTOP Project

What community standards for metadata sharing or integration might be involved?

N/A

What are the plans for data sharing and access?

Have you discussed data sharing with your research collaborators or supervisor?

Yes. The research supervisors will only access deidentified data. If feedback on a particular section is required, the researcher will stipulate what sections. Any feedback will be done through tracked changes. One supervisor will be sent any data requiring their input and then, once completed the data will be then sent to the next supervisor (if appropriate). This will enable the second supervisor to see any feedback offered by the first supervisor.

What steps will be taken to protect privacy, security, confidentiality, intellectual property or other rights?

We have an authorship agreement (between supervisors and primary researcher).

The supervisors will not be able to identify the participant as they will only see the transcribed interviews that have been deidentified.

Is a data sharing agreement needed?

No.

What are the access concerns associated with your data?

Nil.

What process does someone undertake to access your data?

They will require access to the virtual storage cloud. However, data will be shared electronically with the supervisors, as appropriate.

Who controls access to the data (e.g., primary researcher, student, lab, University, funder)?

The primary researcher.

What special privacy or security requirements are needed (e.g., for personal data, for high-security data)?

All data will be stored in a virtual storage space (Office 365/OneDrive). Data will also be stored on a password protected data storage device (backup).

Can your data be released immediately, or should you embargo (delay access to) the data?

No embargo required.

What embargo periods need to be upheld?

N/A

Have human participants been advised about the plans for sharing data in their Information Sheet?

Yes, they will be aware that only myself and my supervisors will have access to their transcribed and deidentified interviews. They will also be aware that they will be assigned a pseudonym to protect their identity.

When your research involves people, have you obtained appropriate consent for data sharing?

Data sharing will only be between the primary researcher and the research supervisors. The typist that will transcribe the interviews will not have the participant's name other than their allocated pseudonym and they will be required to sign a confidentiality agreement.

How will people's rights to access, correct, and remove information about themselves be managed?

If any participants wish to review the transcribed interviews then their transcription will be made available to them to review. Any participant has the right to withdraw from being a participant in the research up until the data is being analysed.

Does your research funder have specific data management and sharing requirements?

No.

For how long should data be available?

Until analysis has been completed.

If you allow others to reuse your data, how will the data be discovered and shared?

The data will not be reused by anyone other than the researcher and supervisors.

What are the likely audiences for reused data? Who will use it now? Who will use it later?

N/A

When will you publish and where?

Results, findings, discussion and conclusions will be published once the research is completed. These will be published in midwifery, obstetric and gynaecological and midwifery education journals.

What tools or software are needed to work with the data?

No specific tools or software will be required.

What are the plans for data preservation and archiving

How will the data be archived for preservation and long-term access?

Data will be archived on storage device at AUT, with the primary researcher and Dr Tania Fleming (supervisor).

How long should it be retained (e.g., 6 years, 10 years, permanently) and how is this being assured?

Data will be retained for ten years and then deleted from data storage devices. The primary researcher will ensure that this data is retained and then destroyed at the appropriate time interval.

What file formats are involved for electronic data? How will future accessibility be assured?

The data will be in words format. Future accessibility will be from accessing the password-protected data storage devices, only.

Are there existing data archives that are appropriate for your data, whether subject based, institutional, public?

AUT has appropriate storage of this data.

Who will maintain the data for the long-term?

The primary researcher will be responsible for maintaining the data up until the point of deletion.

What are your main data challenges? Who can help?

What training or support do you need and what is available?

Nil required

What University policies are relevant to your project? Have you read and understood them?

- Researcher Safety Protocol.
- Sensitive Data Protocol.
- Te Ara Tika: Guidelines for Maori Research Ethics.
- Research Ethics- guidelines and procedures.
- AUT Code of Conduct
- AUT Public Health Guidelines
- Copyright for Researchers Guidelines.
- Guidelines for Researchers on Health Research Involving Maori (2010) V2

I have read and understood these.

Don’t forget to update your data *management* plan regularly:

May 2021

APPENDIX H: Conference Contributions Resultant from this Thesis

Jones, K. (2023, November) Women's experiences of having a termination of pregnancy for fetal abnormality. Verbal Presentation at New Zealand College of Midwives. NZCOM 16th Biennial Conference, Christchurch, New Zealand.

Jones, K. (2023, November) Vulnerable families/whānau, bereavement care and the health professional. Verbal Presentation at New Zealand College of Midwives. NZCOM 16th Biennial Conference, Christchurch, New Zealand.