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# Women's Long-Term Life Experience After Pregnancy Termination for Fetal Abnormality: Interpretive Phenomenological Study

Heba A. Hassan

*The University of Western Ontario*

Supervisor

Dr. Marilyn K. Evans

*The University of Western Ontario*

Graduate Program in Nursing

A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy

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WOMEN'S LONG-TERM LIFE EXPERIENCE AFTER PREGNANCY TERMINATION FOR  
FETAL ABNORMALITY: INTERPRETIVE PHENOMENOLOGICAL STUDY

(Thesis format: Monograph)

By

Heba Hassan

Graduate Program in Nursing

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies  
The University of Western Ontario  
London, Ontario, Canada

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## ABSTRACT AND KEYWORDS

Advances in prenatal screening and its availability for every woman have resulted in increasing the number of identified fetal abnormalities. The discovery of fetal abnormalities in the second trimester of pregnancy can force pregnant women into the dilemma of deciding the fate of their wanted pregnancies. A woman's decision to terminate her pregnancy for a fetal abnormality in the second trimester is a very difficult and complicated decision.

An interpretive phenomenological approach was used to gain an in-depth understanding of the long-term experiences of women who terminated their pregnancy for fetal abnormalities and reveal the meanings embedded in their experiences. Conversational in-depth interviews were conducted with ten women who had terminated their pregnancy more than five years previously. Thematic analysis guided by van Manen's approach was used to uncover the meaning of the women's experiences. Six themes were identified as characteristics of the women's experiences over time: encountering the unexpected, making sense of the unexpected, facing the inevitable decision, living with the decision, feeling supported, and changing perspectives.

The findings inform health care professionals about the complexities of these women's experiences, perinatal grief and bereavement. It is hoped that health care professionals will evaluate their prenatal screening and counseling practices, and review their present models of care in light of these findings. Implications for practice and recommendations for future research are discussed.

Key words: pregnancy termination, pregnancy loss, fetal abnormality, perinatal grief, prenatal screening.

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## CHAPTER ONE

### Introduction

The pregnancy experience presents as a positive transition in the lives of many women. According to Mercer (2004), pregnancy is a time for transformation because the women's self-image changes to incorporate new responsibilities, commitments, and roles. This transition begins with the women's acceptance of and adjustment to the pregnancy, imagining future child, preparing for parenthood, and assessing important relationships and how they will change. This process facilitates realistic expectations, relatedness to the fetus, and family preparation for the expected child (Leifer, 1998). Rapidly developing technological advances in the reproductive arena have led to an increase in prenatal screening and diagnosis of fetal abnormalities (Phadke, Agarwal, & Aggrawal, 2011). Prenatal screening and diagnosis is most often performed through blood tests, ultrasound, or chromosomal analysis, and is used to identify genetic and congenital abnormalities in a developing fetus (Evans, et. al., 1996). The Society of Obstetricians and Gynaecologists of Canada (SOGC) published a new guideline on prenatal genetic testing (July, 2011) which recommends every Canadian woman, regardless of her age, be offered the choice to undergo non-invasive genetic screening during her pregnancy for the detection of fetal abnormalities. Similar recommendations have been made by the American College of Obstetricians and Gynecologists (ACOG, 2007).

With this advancement of diagnostic testing during pregnancy, identification of fetal anomalies and the legalization of abortion, women are faced with making life and death decisions for their fetus. Childbearing in the 1990s brought a wide range of reproductive genetic testing options (Rapp, 1999; Roberts, 1997; Trent, 1995). Along with these options have come

new challenges. One of the most difficult issues is that, although prenatal testing can disclose a multitude of disorders, treatment is available for only a few (Boyle, 1996).

Previous studies have consistently indicated that a prenatal diagnosis of fetal abnormality is an emotionally devastating and profoundly stressful event for women. It involves women making a difficult reproductive decision such as continuation of pregnancy with no intervention, elective termination, or, in selected cases, experimental fetal therapy (Evans & Britt, 2004; Higgins, 2001; Leuthner & Jones, 2007; Rempel, Gender, Lynam, Sandor, & Farquharson, 2004; Singer, 2004).

In the majority of such cases, especially when the fetal anomaly is perceived as severe, parents choose to terminate the pregnancy electively (Evans et al., 1996). Termination of pregnancy (TOP) is defined as ending the pregnancy by any means before the fetus is viable. Viability is reached between 23 weeks and 0 days and 24 weeks and 6 days of gestation (Aiken, & Brockelsby, 2013; Julian, 2001; Rennie, 1996; Statham, Solomou, & Green, 2006). Doyle (2004) indicated that the gestational age at which at least half of the infants survive is 23 to 24 weeks gestation. Raju and colleagues (2014) indicated that the period from 20 0/7 through 25 6/7 weeks of gestation is called the periviable period that reflects the gestational age range in which survival rates range from 0% at 20 weeks to more than 50% at 25 weeks of gestation (Raju, Mercer, Burchfield, & Joseph, 2014).

Second trimester or mid-trimester is a period ranging from 13 to 28 weeks of gestation, which is subdivided into an early period between 13 and 20 weeks and a late period between 20 and 28 weeks (Lalitikumar, Bygdeman, & Gemzell-Danielsson, 2007). The decision to perform a second trimester termination of pregnancy (TOP) is complex. Contributing to its complexity is an array of psychological, societal, and ethical/moral factors. One of the most debatable factors

that contribute to difficulty in making this decision is the definition of fetal viability. The ethical dilemma of defining when a fetus is viable is impacted by uncertainty, increasing the difficulty of making the termination decision (Chervenak, McClough, Skupski, & Chasen, 2003).

The emotional impact of termination of pregnancy due to fetal abnormalities is thought by professionals to be particularly significant for women who have wanted pregnancies (Muellor, 1991). In addition, women have developed a relationship with their anticipated child by the time they discover fetal abnormalities (Brewster, 1984; Hall, 1990). Fetal movements have been felt and their pregnancies are at a stage when it is apparent to others (Beeson, Douglas, & Lunsford, 1983).

Robinson, Baker, and Nackerud, (1999) indicated that advancements in reproductive technology have encouraged antenatal fetal attachment. Because of such advancements, many women tend to not consider the possibility of finding something wrong with their fetus and therefore, begin bonding with their fetus early in pregnancy. For example, the use of ultrasound as a routine procedure in prenatal care has given parents the opportunity to see their fetus, providing a means for them to visually bond with their anticipated baby. Although, an ultrasound scan is conducted to screen for various anomalies and/or birth defects, many parents see the ultrasound appointment as an opportunity to meet their child, and some are turning to commercial non-medical ultrasounds to obtain a video or still image of the fetus to take home as a keepsake (Simonsen, Branch, & Rose, 2008). According to Detraux and colleagues (1998), the process of attachment is fostered through the use of ultrasound examination because parents are given the chance to visualize their future child (Detraux, Gillot-DeVries, Vanden Eynde, Courtois, & Desmet, 1998). Therefore, these factors might contribute to parental grief reactions

after having made a decision to terminate the pregnancy due to the discovery of fetal abnormality.

Termination of pregnancy for fetal abnormality (TOPFA) is a decision with the implications that the pregnancy was desired which raises questions regarding women's experiences of grief following the termination (Zeanah, Dailey, Rosenblatt & Saller, 1993). The decision-making process regarding pregnancy termination carries with it a unique sense of responsibility by the woman for the loss. Kolker (1985) commented:

After the abortion women usually find themselves alone in their grief. Whereas a baby is real to anyone who sees it, a fetus is real only to the woman who carries it. The loss experienced by the mother is not socially recognized or shared. Medical authorities, societies at large, family members and even husbands tend to trivialize this loss....selective abortion of a wanted pregnancy at any gestational age is experienced as the loss of a child that one will never have and to whom one was already attached. (1985, p. 607).

Korenromp, Iedema-Kuiper, Spijker, Christianes and Bergesma (1992) reported that pregnancy terminations due to fetal abnormalities have many psychological and social consequences on women's health including grief, guilt, feeling genetically inferior, low self-esteem, doubt about rightness of the decision and feeling moral and social pressure from others due to fear of others' judgement.

Rillstone (1999 ) indicated that advances in reproductive technology may be occurring at a much more rapid pace than expectant parents in our society are prepared for psychologically. Advances in prenatal testing have not only expanded reproductive choices, but have also created often difficult challenges for women, couples, and their families (Roberts, 1997).

Much has been written about grief responses among women (Hunfeld, et al., 1993; Keefe-Cooperman, 2005; Kersting et al., 2005; White-van Mourik, Conner & Ferguson-Smith, 1992) after TOPFA. However, little is known about the life experience of women many years after ending a pregnancy for a fetal abnormality. Furthermore, little is known about what it is like for women living with having made this decision. Most previous research on women's experience of termination of pregnancy for fetal abnormalities focused on women up to two years post termination (Hunfeld et. al., 1993; Hunfeld, Wladimiroff & Paschier, 1994; Iles & Gath, 1993; Keefe-Cooperman, 2005; White Van Mourik, et al., 1992; Zeanah, et al., 1993). Findings of these short-term studies indicate that the majority of women have severe psychological symptoms two years after termination of pregnancy. Little is known about the long-term challenges and needs of women who experienced making and living with the decision to terminate a previously wanted pregnancy due to a fetal abnormality.

### **Background and Significance**

As the number of pregnancy termination for fetal abnormalities continues to increase, due to continued use of prenatal screening and diagnostic testing, there is a corresponding need to increase our understanding of women's challenges and reactions to this experience. Statistics have shown that even in the 1990s the worldwide rate of TOPFA had reached is 26 million annually (Wulf, 1999). In addition, 50 % of major fetal anomalies are detected by 18-19 weeks gestation. In the United States, the Alan Guttmacher Institute (1998) estimated that 3% of abortions per year are performed for fetal abnormality and recently in 2011, 1.06 million pregnancies were terminated by abortion in the USA, 2 % of this number constituted for late pregnancy termination for fetal abnormality (Guttmacher Institute, 2014). Statistics Canada (2008) reported that termination of pregnancy due to fetal anomaly constituted 11.6 % of all the

perinatal mortality in 1985 and increased to 40.4% in 2003. The prevalence at birth of congenital anomalies in 2004 including live born and stillborn babies with at least one congenital anomaly was 4.8% (Congenital Anomalies Surveillance in Canada, 2010).

Recently the Public Health Agency in Canada (2013) reported that approximately 1 in 25 babies born in Canada is diagnosed with one or more congenital anomalies every year. The overall national congenital anomaly birth prevalence rate between 1998 and 2009 has decreased from 451 to 385 per 10,000 births. The report indicated that this is mostly due to increased prenatal diagnosis and subsequent pregnancy termination in addition to other factors including implemented measures such as mandatory folic acid fortification in food and changes in health behaviours and practices to reduce the risk for some congenital anomalies such as tobacco smoking cessation and multivitamin use. In a recent report by the Agency of Canada and Statistics Canada (2012) the stillbirth rates increased in Canada from 6.0 per 1000 total birth in 2000 to 7.1 per 1000 total birth in 2009. Joseph et al., (2013) referred this increase to the incidence of pregnancy termination which were responsible for the increases observed in stillbirth rates and were associated with the declines in the prevalence of congenital anomalies among live-born infants.

At least 3 % of pregnancies are affected by a structural or genetic fetal abnormality, and greater than 80 % of pregnant women diagnosed with a fetal anomaly choose pregnancy termination (Boyd, et al., 2008; Crane, et al., 1994; Gawron, et. al., 2013; Hassold, et al., 1996; Shaffer, Caughey, & Norton, 2006). In the USA , approximately 150 000 women per year are faced with the diagnosis of a fetal abnormality, and most women will terminate for that reason (Anderson, Boswell, & Duff, 1995; Boyd, et. al., 2008; Kerns, et. al., 2012; Pryde, Drugan, Johnson, Isada, & Evans, 1993; Shaffer, et. al., 2006). Prenatal screening programs such as



serum alpha-fetoproteins assay (SAFP) and routine diagnostic ultrasound are well-established, and with the offer of amniocentesis to detect chromosome abnormalities, many pregnancies are terminated for fetal abnormalities (Elder & Laurance, 1991). A review of 20 studies found overall termination rates of 92% for Down Syndrome, 64% for Spina Bifida, 84% for Anencephaly, 72% for Turner Syndrome and 58% for Klinefelter Syndrome (Mansfield, Hopfer, & Mareau, 1999). In addition, over the last three decades an estimated 70% to 80% of women and couples diagnosed with fetal abnormality have chosen termination of pregnancy (Barry, 2011; Boyd et al., 2008; Van Allen, et al., 2006).

### **Purpose and Specific Aims**

The overall purpose of this study was to understand the long-term life experience of women after elective second trimester pregnancy terminations for fetal abnormalities through the words of the women themselves. In asking the research question, I was aiming at increasing the understanding of the meaning that women assign to their long-term experience of termination of pregnancy for fetal abnormalities and how they integrated the event and its meaning into their lives; discovering what aspects of the experience of termination of pregnancy for fetal abnormalities made an impact on a woman's life and those elements that may impact health outcomes years later; and learning from the women how health care professionals impacted their lives, before, during, and since the event occurred.

### **Research Questions**

The research question that guided this study was: What is the lived experience of women who have terminated a pregnancy through an elective second trimester termination for fetal abnormalities more than five years ago? Specifically, to uncover how women who have gone

through an elective second trimester termination of pregnancy for fetal abnormalities more than five years ago described their experience, interpreted it and integrated it into their life.

### **Significance of the Study**

Nurses play a crucial role in the promotion of women's health, and thus need to understand the healing experience of post pregnancy termination if it is determined that many women are living with long-term wounds left by termination of pregnancy. For this reason nurses need to deepen their understanding of women's long-term life experience of termination of pregnancy for fetal abnormality in order to provide adequate support.

Understanding the long-term emotions, perceptions and thoughts of women after having experienced a TOPFA, will contribute to expanding nursing science. Understanding this experience might facilitate the development of nursing care processes and interventions that are crucial and influential for ensuring quality care. This acquired knowledge may allow the nurses to imagine, create, and implement nursing care responses that will lead to greater understanding of women's long-term experience of TOPFA.

Through applying the hermeneutic/interpretive phenomenological approach, this research study facilitates the understanding of the holistic context of women's experiences of having undergone termination of pregnancy for fetal abnormality many years previously. The results will improve counseling and support services and inform health promotion programs that are needed for these women.

### **Declaration of Self**

The researcher's beliefs are an important element throughout the research process (Walters, 1995). The researcher in hermeneutic phenomenology and interpretive research serves as an instrument through which the data are collected and analyzed (Gillis & Jackson, 2002:

Rew, Bechtel, & Sapp, 1993) using in-depth interviewing techniques and interpreting participants' stories using the hermeneutic process. Appleton (1995) stated that a “characteristic of phenomenological research is that the phenomenon begins with oneself” (p.1). The researcher writes the final analysis of the texts that illuminates the genuine meanings of the phenomena investigated. It is critical that the researcher be aware of her background assumptions and the ways in which they influence the data collection and data analysis processes. Rather than bracket or exclude these assumptions during the research process, in Heideggerian phenomenology the researcher makes explicit the beliefs, biases, assumptions, and background that she has and “hold them at bay” (van Manen, 1997, p. 47). In keeping with the spirit of declaring the self, I will switch to using first person for this section of the thesis.

I am a doctoral student with an extensive clinical background in maternity and women’s health nursing. Research skills have been developed through studying as a doctoral candidate in the University of Western Ontario as well as working as a research assistant, in addition to the conduct of thesis research for a Master of Nursing Degree completed in 2003.

According to the worldview of positivism, reality is objective. The world is knowable through reasoning and empirical evidence. A postmodern worldview sees reality as subjective, relative, experiential, and personally constructed (Shelley & Miller, 1999). My personal concept of reality is a combination of both objective and subjective view. The investigator in the phenomenological research is the primary instrument therefore, the first question a phenomenologist asks when planning a study is not how to proceed but why the researcher is involved with the phenomenon and why the researcher chooses the phenomenological method (Colaizzi, 1978). Accordingly, it is necessary to reflect on my life experiences. Regarding my clinical experience, I have worked as a clinical instructor in the Maternity-Newborn Health

Nursing Department, Cairo University, Egypt. The women for whom I provided care usually were pregnant and postpartum women. As a Master student, I conducted research concerning the different types of maternal anaemia and impact on fetal and neonatal outcomes, in particular, the development of certain types of fetal abnormalities. I have previously given care to women who experienced a pregnancy with the diagnosis of severe fetal abnormality. In addition, I had a friend who had a child with a severe disability. This friend had discovered her fetus abnormality during her second trimester of pregnancy. Her life had changed drastically since she learned about the presence of a fetal abnormality. There was no medical intervention available to treat her fetus' condition and the option to terminate the pregnancy was not obtainable or even acceptable because of the illegality of pregnancy termination.

Listening to pregnant women who had experienced the diagnosis of fetal abnormality talk about their suffering and the difficulties they had in managing their daily life encouraged me to learn more about this experience. Moreover, I have had a similar personal experience when I was confronted with the experience of making a pregnancy termination decision after detecting fetal abnormality which happened after this current study began.

My personal experience of pregnancy termination decision making has changed my way of looking at this situation for women. Having been in a similar situation as the participants of this present study was completely different than being a nurse researcher or a nurse clinician who looked at the experience from an external point of view. The first time I was asked by my health care provider to undergo prenatal screening tests, I never thought about any possibility of receiving abnormal test results. I had experienced two normal pregnancies, had two healthy daughters, had no family history of congenital abnormalities and neither did my husband's family. I agreed to take the screening tests in order to obtain reassurance that my fetus was

healthy. I did not consider the possibility of having abnormal results for a moment and that is because I had two healthy daughters, I had no family history of congenital abnormalities and neither did my husband's family. Hearing about the presence of a possible fetal abnormality was totally shocking to me. Participating in further testing and waiting for the results was a very stressful experience. Deciding whether or not to terminate my pregnancy in case of a fetal abnormality was the worst experience in my life. I asked myself many questions such as, what kind of life do I want for my child, what kind of life do I want for myself, is ending my pregnancy ethical, is it legal? I was in the middle of a huge dilemma which ended when I received reassuring negative result about the condition of my fetus. Although in the end I did not have to make that difficult decision about my pregnancy I kept asking myself, what if I had to make the pregnancy termination decision. My background as a Muslim woman, born and raised in Egypt where the majority of people are Muslims had influenced my way of thinking regarding pregnancy termination and might cause some challenges during my effort to understand my personal experience as well as my participants' experiences. Terminating a pregnancy is illegal in Egypt and barred by religious authorities. The illegality arises from the religious doctrine and Egyptian civil law. Al-Azhar Mosque, Egypt's foremost religious authority previously issued a 'fatwa' (a ruling on a point of Islamic law given by a recognized authority) that says it is impermissible for the mother to induce abortion if it is proven that the fetus is deformed or suffers mental retardation, it is not a justifiable excuse. One exception is added, abortion is allowed in case the mother's life is in imminent danger. The question of whether or not abortion is morally wrong persists in my heart and mind as well many women when thinking about terminating a pregnancy. Religious arguments concerning abortion widely vary. Some religious beliefs consider the fetus an innocent human being that should not be deliberately killed, arguing

that those who perform abortions prevent the right of life of a potential baby. Others believe that it is permissible to terminate the pregnancy as long as the procedure is carried out before the fetus's heart begins to beat. Others believe that abortion is permitted within the first 120 days and/or 40 days of pregnancy, before the ensoulment. This research study will help me to understand my personal experience of the pregnancy termination decision making process and gain a deeper understanding, as a woman, a mother and a nurse, of the experience of women who do decide to terminate a pregnancy for a fetal abnormality.

My clinical, as well as personal experiences regarding termination of pregnancy for fetal abnormality might be seen as advantageous. My beliefs underlying this research study were formed by my experiences as a woman and a mother of three girls. My beliefs were also shaped by my experiences as a nurse working in Maternal-Newborn nursing, and as a researcher who has studied topics related to motherhood, pregnancy, abortion, pregnancy loss, and fetal abnormalities. Moreover, I have recently experienced a similar occurrence as my future participants in that during my third pregnancy I underwent all the stages of prenatal testing, discovery of fetal abnormality and the decision making process. This background enabled me to deeply understand the women's experience of pregnancy termination for fetal abnormality. In the following paragraph, I will explicitly state my beliefs going into this study:

- 1) Abortion is not socially accepted.
- 2) An individual's experience of loss influences his/her way of living and being.
- 3) Termination of pregnancy for fetal abnormality is a complex experience that is influenced by societal stigma, connectedness to fetus, culture, spirituality, and emotional and physical conditions.
- 4) The fetus is considered a living human being 40 days after conception.

I claim my assumptions about nursing which are significant for this study as the following:

- 1) Caring is the foundation of nursing practice.
- 2) Caring is an interactional process between the nurse and the patient directed at providing comfort and promoting health.
- 3) Caring incorporates respect, honesty and dignity for oneself and for the patient.
- 4) Caring for the patient involves understanding the meanings of his/her life experience.

These beliefs and assumptions were part of my being and my concern that I brought into this research study. It was not possible to set aside my assumptions so they will not influence the interpretation of the data. Stating my assumptions increased my awareness of ways I could be influenced in interpreting the data during the course of the study.

### **Organization of the Dissertation**

This dissertation has been prepared in monograph format and contains seven chapters, including the first chapter which provides the introduction and contextual background information for the present research study. Chapter two provides a review of the related literature. Chapter three describes some of the major arguments related to views on abortion and the ongoing abortion debate. Chapter four presents the methodology of the study in which hermeneutic phenomenology is explained. The in-depth interviewing approach, sample description, data collection, and analysis techniques are described. Chapter five presents the data analysis and findings. Chapter six presents a discussion of the findings followed by chapter seven which outlines the implications, strengths and limitations of the study and directions for future research.

## CHAPTER TWO

### Literature Review

The experience of pregnancy termination for fetal abnormality is not an uncommon occurrence. It is a multidimensional experience that has considerable physical, emotional, and relational impact on the lives of women who terminate their pregnancy. With the advances in reproductive technology, especially prenatal screening and diagnosis, more fetal abnormalities are detected and consequently more women are faced with the choice to continue or to terminate their pregnancy. Eisenberg, Murkoff, and Hathaway, (1991) in their discussion of the social norms for pregnancy imply that good mothers will have these screenings as part of taking good care of their pregnancies as well as their children. Santalahti and colleagues (1998) quotes a woman saying "having a disabled child is seen as a personal fault as earlier having a girl was seen as such" (p.1072). Another woman says "nowadays one does not have the right to reproduce a disabled child, because today it is possible to find out beforehand" (Santalahti, Hemminki, Latikka, & Ryyananen, 1998, p.1072). Though, the norms and women's perception regarding pregnancy are superficially about accepting the best routine medical care, the reality is they often imply intent to intervene, usually by pregnancy termination in case a fetal anomaly is detected (Shiloh, 1996).

### Search Strategy

Databases such as CINAHL, Medline, PsychINFO, Scopus, Embase, and Proquest were searched for nursing, social, and medical research conducted between the years 1980 and 2014. Key search terms used were, late pregnancy termination, termination of pregnancy for fetal anomaly, pregnancy loss, second trimester termination, third trimester termination, fetal abnormality, perinatal grief, bereavement and prenatal screening. In this chapter, the literature



review is presented and discussed in the following categories, prenatal screening and diagnosis, termination of pregnancy for fetal abnormality (TOPFA), grief and bereavement related to TOPFA, perinatal loss and the empirical research concerning pregnancy termination for fetal abnormality.

### **Prenatal Screening and Diagnosis**

Prenatal genetic testing has been performed in Canada for over 20 years (Hutton, et al., 1998). In 1994, the Canadian College of Medical Geneticists and the Society of Obstetricians and Gynecologists of Canada recommended that all pregnant women be offered maternal serum alpha-fetoprotein screening and high resolution ultrasonography examination (Canadian Task Force on the Periodic Health Examination, 1994). The rate of prenatal testing increased dramatically through the use of non-invasive screening procedures (Hutton, et al., 1998).

The current standard for prenatal screening tests has now developed well beyond maternal serum alpha-fetoprotein and ultrasound examination to include many biochemical markers that can be measured in the first or second trimester of pregnancy (Chodirker, et al., 2001). Invasive prenatal diagnostic techniques, including chorionic villus sampling and amniocentesis, are available and offered to women considered at increased risk for having a baby with anomalies (Chodirker, et. al., 2001; Wilson, 2005). When these invasive prenatal diagnostic tests are offered, the procedure occurs late in the first trimester or early in the second trimester of pregnancy and test results take approximately 1 to 3 weeks (Wilson, 2005). Once a fetal abnormality is identified, women can be offered the option of abortion (Seavillenklein, 2009).

Prenatal screening consists of maternal serum screening and nuchal translucency screening which are designed to identify pregnant women likely to have fetuses with

chromosomal anomalies and open neural tube defects. Once identified, these women can be offered further diagnostic testing. While prenatal screening has traditionally been limited to pregnant women considered to be high-risk, the Society of Obstetricians and Gynecologists of Canada (SOGC) has recently recommended that testing be offered to all pregnant women regardless of age, disease history or risk status (SOGC, 2011). Similar recommendations have been made by the American College of Obstetricians and Gynecologists (ACOG, 2007).

In addition to broadening the target population for prenatal screening, the number of fetal conditions being screened for is likely to increase. For decades, prenatal screening has been used to screen for Down syndrome, open neural tube defects, and Trisomy 18. Current studies however, show that prenatal screening might also be used to detect conditions such as Smith-Lemli-Optiz syndrome, Trisomy 13, Turner's syndrome, and Cystic fibrosis (Seavillekein, 2009).

### **Current Practice**

'Prenatal testing' includes prenatal screening tests and prenatal diagnostic tests. Prenatal screening tests are designed to be offered quickly at the general population level to determine who is at risk of certain conditions. Once those at high risk have been identified then diagnostic tests are offered individually to give more definitive results and consider possible interventions (Seavillekein, 2008).

**Prenatal screens.** Prenatal screens are offered earlier in gestation. Maternal serum screens are blood tests that can be offered to pregnant women in their first trimester, second trimester or both. Maternal serum screening have been developed and increasingly made available to pregnant women over the last two decades. These tests analyze the levels of various biochemical markers in the women's blood or serum. The findings of intact fetal cells and cell-

free fetal DNA in maternal blood has allowed the development of non-invasive prenatal tests to detect Down syndrome, Trisomy 13 and 18 (SOGC, 2013). Unusual amounts of these substances are correlated with an increased risk of certain abnormalities, include Down syndrome or Trisomy 21, open neural tube defects (which encompass Spina Bifida and anencephaly), and Trisomy 18 (sometimes referred to as Edward's syndrome). These conditions primarily occur randomly in the general population, although the incidence of chromosomal abnormalities increases with maternal age.

The first maternal serum screen is alpha-fetoprotein (AFP). Higher levels of AFP are correlated with a greater risk of open neural tube defects while lower levels of AFP are correlated with Down syndrome and Trisomy 18 (Summers et al., 2007). The maternal serum double screen adds a second serum marker to AFP, called human chorionic gonadotropin which increases the ability to detect Down syndrome and Trisomy 18. The maternal serum triple screen has a third marker called unconjugated estriol, and this screen also detects the likely incidence of Down syndrome, open neural tube defects and Trisomy 18. A quadruple screen developed a fourth serum marker, called inhibin-A, its addition to serum markers increases the detection rates of Down's syndrome and Trisomy 18 (Health Canada, 2002; Permaul-Woods, et al., 1999). The results of the maternal serum screen can be made more accurate if they are used in conjunction with ultrasound. The ultrasound scan that is used is called the nuchal translucency test (NT), or nuchal fold. Introduced in 1995, to assess the risk of fetal chromosomal abnormalities such as Down syndrome, the NT test measures the fluid accumulation (or nuchal translucency) in the neck of the developing fetus. This scan must be carried out between 10-14 weeks gestation (Nolan, 1998). A conclusive diagnosis for fetal anomaly can be made early in pregnancy (7-12 weeks gestation) by using chorionic villus sampling test (CVS) or later in pregnancy (15-20

weeks gestation) by using amniocentesis. CVS is the only accepted method for first trimester diagnosis (Brambati & Tului, 2005) and is shown to be as safe and reliable as amniocentesis (Borrell et al, 1999). CVS can be performed two ways; a needle can be inserted into the placenta through the maternal abdomen (known as transabdominal CVS) or a catheter or biopsy forceps can be inserted through the cervical canal (known as transcervical CVS) (Brambati & Tului, 2005). CVS can be done at 7-12 weeks gestation, whereas amniocentesis must be performed at 15 weeks gestation or greater. CVS can detect most conditions that amniocentesis can detect.

Amniocentesis involves the extraction of amniotic fluid (which surrounds the fetus) with a needle. Current techniques allow the use of ultrasound imaging to accurately guide the needle, thus reducing negative effects of the procedure (Seeds, 2004). Amniocentesis enables a sample of fetal cells contained in the amniotic fluid to be acquired and cultured in order to perform genetic analysis (including chromosome karyotyping) (Borrell et al., 1999). A positive diagnosis of a fetal abnormality is followed by introducing the option of pregnancy termination (Hutton, et al., 1998; Society of Obstetricians and Gynecologists of Canada, 2011).

Being diagnosed with a fetal abnormality or multiple anomalies, women are faced with an agonizing dilemma. The pregnant woman has to choose between signing the death sentence of her fetus or accepting the responsibility for bearing and rearing a child with an expected mild to severe disability . This decision carries serious consequences for the mental and physical health of the woman, for the future child and for all their associated family members. If a decision is made to continue the pregnancy, the woman is faced with the burden of being the primary care giver for the child. Whether or not she will be able to do this and what life changes she should expect are also central considerations. Furthermore, this life or death decision must

be made early in pregnancy and quite quickly for the sake of the mother's physical safety (Chandler & Smith, 1998; Hawkins, Stenzol, Taylor, Chock, & Hudgins, 2012).

As prenatal screening tests become an accepted components of reproductive practice, an increased number of women and their health care professionals are confronted with what may be one of the major ethical decisions. One of the most difficult situations for women who use prenatal diagnosis such as amniocentesis is the late diagnosis of an abnormality. Amniocentesis is performed at 15-20 weeks gestation and receiving the results can take up to a further 3-4 weeks. By this time the fetus is at 20-22 weeks gestation and the mother can feel fetal movements (Chandler & Smith, 1998). Termination of pregnancy at this stage is physically dangerous for the woman and cannot be delayed for long. This places considerable pressure on the woman to decide quickly whether to proceed with the pregnancy or to terminate it. The choice to undergo prenatal screening is a double-edged sword, and poses a huge dilemma for the women. It requires the pregnant woman to choose between carrying a baby to term that is untested and therefore potentially has an abnormality or undergoing a test that could result in her having to abort a baby she wanted and dreamt of.

### **Normalization and Routinization of Prenatal Screening Tests**

Prenatal diagnostic technologies are regarded as important tools for pregnancy surveillance and ensuring fetal health and welfare. In addition, they are used to detect fetal defects or abnormalities. Once some defect is found or suspected in the fetus, an abortion is chosen in many cases to terminate the pregnancy (Lafleur, Bohme, & Shimazono, 2007). The World Health Organization (WHO) states that the application of prenatal screening and subsequent abortion cannot be called 'new eugenics' because there is no coercion to have tests and the 'woman's right to choose' whether to keep the pregnancy or not is guaranteed (Wertz,

Fletcher & Berg, 1993). Prenatal screening and diagnosis is not about the ultimate cleansing of the gene pool in which the breeders who were thought to carry the undesirable genes were to be eliminated altogether (Epstein, 2003). The goal of prenatal screening and diagnosis is to help people with a genetic disadvantage and their families to live and reproduce as normally as possible, to improve their quality of life, and to make informed choices in reproductive and health matter (WHO, 1998). However, the opinion of women's health activists is different. They are afraid that the individual woman's choice is now used voluntarily to control the quality of human being born (Yonezu, 2002, as cited in Lafleur, et al.,2007).

Gedge and Waluchow (2012) argued that, the existence of technology and the way it is introduced creates the perception that it is a necessary rather than optional part of prenatal care. Once screening becomes more normalized, it may not even be reassuring to be in a low risk bracket or to have one's risk reduced. As prenatal screening and diagnosis became normalized, they were harder to question or decline and they were considered part of routine prenatal care that is desired by women and expected of women during pregnancy. Lippman (1991) as cited in Gedge and Waluchow (2012) added that routinization of these tests may become enhanced due to increased public acceptance and societal expectations that every woman should undergo these tests.

Ultrasonography is a classic example of a technology that was adapted for pregnancy management and has increasingly been offered to pregnant women to assess gestational age, detect fetal abnormality, and monitor fetal development. This technology is now well established in prenatal care and has come to play an important social and emotional role in pregnancy because of its ability to visualize the fetus. Gedge and Waluchow (2012) argue that this role has been fulfilled despite a continued lack of evidence as to its clinical efficacy.

Regardless of its clinical role, ultrasound is so central to the pregnancy experience and so widely valued that most women offered it have difficulty refusing it at the risk of being judged to be irrational or irresponsible (Gedge & Waluchow , 2012). Moreover, commercial interests have been actively promoting ultrasound for pregnant women through different ways of public advertisement. This commercial application of ultrasound scanning during pregnancy is widespread, offering 'baby look' and 'fun ultrasound' in order to 'meet your baby' with a photograph, 3 D image and home video (Wagner, 1994; Yonezu, 2002, as cited in Lafleur, et al., 2007).

In a recent joint policy statement, the Society of Obstetricians and Gynecologists of Canada (SOGC, 2014) and the Canadian Association of Radiologists (CAR, 2014) stated that it could be considered unethical for private, commercial clinics to offer entertainment ultrasounds purely for the purpose of creating "keepsake" videos for expectant parents. The development of the policy statement was in response to the availability of ultrasound machines to purchase for non-clinical purposes and the proliferation of entertainment ultrasound units throughout Canada. SOGS and CAR (2014) stated that while no definitive proof exists that the high frequency, low energy sound waves emitted by ultrasounds can cause fetal abnormalities, recent studies in animals have reported subtle effects on the development of the fetal brain (Ang, 2006; Schneider-Kolsky, 2009; Suresh, 2008; Yang, 2012). They concluded that commercial use of prenatal ultrasound is a concern because the machine may be used for as long as an hour to get a high quality video of the fetus. The fetus may be exposed to unnecessary high energy levels for prolonged periods, and those operating the machines may be poorly trained to recognize abnormalities that could lead to false reassurance to the woman that everything is normal.

Moreover, both Health Canada (2003) and the Food and Drug Administration (FDA) (2005) in the United States have recommended against the use of commercial and entertainment ultrasound. The CAR and SOGC support the Health Canada recommendations that ultrasound should be used "prudently" and only by qualified health professionals and that energy exposure should be limited to the minimum that is medically necessary.

Hence, women's desires and temptations to view their baby have been exploited for the financial gain of private companies without informing them of the possible consequences. In prenatal interventions that are normalized such as ultrasound, to decline their use poses an enormous burden of proof on those who might want to challenge the norm (Gedge & Waluchow, 2012)

Ultrasonography also represents an example of how familiarity with a technology and its normalization in prenatal care can reduce the impact of choice and even perceived need to ask for authorization. Informed consent in relation to ultrasonography as a screening test is significantly below any reasonable threshold and consequently women prior to screening are no longer offered even a standard of practice (Gedge & Waluchow, 2012). Hence, the widespread desire for and use of ultrasound screening is not accompanied by any significant level of understanding about the meaning or implications of the screen, at least relative to the purpose for which the technology has been medically justified.

Ferguson, Gartner, and Lipsky (2000) indicated that a societal commitment to support children with disabilities is another choice that is often not given as much attention as prenatal screening, diagnosis and abortion options. For instance, it is hard to make an informed choice about pursuing prenatal screening options when there are not adequately socially supported alternatives, such as community and social supports that would make the decision to raise a child



with a disability easier and/or when availability of these services is not known to women during pregnancy. Social and economic pressure, in addition to pervasive discrimination may make a woman feel that she is not able to care for a child with a disability and turn to prenatal screening options as a result. Hence, improved social supports regarding disabilities and the communication of these supports to pregnant women may have an impact on some women's reproductive decisions. While many pregnant women may still choose to pursue screening, diagnosis, and abortion even when social supports are very good and known to them during pregnancy, knowing that there are adequate services available may enhance the ability of some women to make the choice to continue a pregnancy if the choice to do so might otherwise have been restrained by a concern about resources.

Seavilleklein (2009) stated that similar to ultrasonography, the alpha-fetoprotein (AFP) screening test is introduced to women as an uncomplicated and routine part of prenatal care along with their other blood tests. The information regarding AFP screen is introduced in a way that is not comprehensive or informative, this presentation enables all concerned in offering and accepting the testing to remain silent about issues on which there is no societal consensus such as the appropriateness of aborting a fetus for an anomaly and the eugenic implications of the practice. Prenatal screening practice requires consideration of women's rights and informed choice.

### **Autonomy and Informed Consent**

Autonomy means self-rule or self-governance which is well established in contemporary society (Seavilleklein, 2009). Self-governance is a result of the broad socio-political change in the second half of the 20th century by second wave feminism, the civil rights movement in the US, and the development of the Charter of Rights and Freedom in the new Canadian Constitution

(Seavilleklein, 2009). Autonomy is one of the principal values offered in support of prenatal screening. The value of autonomy is discussed in terms of women's choice, and is widely recognized by the medical health care system. Even individuals, such as disability rights activists who object to some or many aspects of prenatal screening, stress autonomy when the decisions about the kind of children one will raise should be made and argue if such decisions must be made it is better left to individual women than to society or the medical profession (Seavilleklein, 2009).

McLeod (2002) claimed that in bioethics and medicine, health care providers are told that they have a duty to respect the autonomy of patients, although this is often reduced to the duty to obtain informed consent. Although autonomy is crucial in society and especially in genetics, there is strong evidence that women are not making free informed choices about undergoing prenatal screening (Seavilleklein, 2009). Several studies that have been conducted about prenatal screening indicated that adequate standards of informed consent are not being met (Gekas, Goudry, Mazur, Cesbron, & Thepot, 1999; Goel, Glazier, Holzapfel, Pugh, & Summers, 1996; Green, Hewison, Bekker, Bryant, & Cuckle, 2004; Jaques, Sheffield, & Halliday, 2005). Obtaining patients' informed consent is an ethical and legal obligation in healthcare practice. Whilst the law provides prescriptive rules and guidelines, ethical theories of autonomy provide moral foundations. Models of practice of consent, have been developed in the bioethical literature to assist in understanding and integrating the ethical theory of autonomy and legal obligations into the clinical process of obtaining a patient's informed consent to treatment (Delany, 2008).

In a specific decision-making context, informed consent is considered reached if adequate standards of disclosure and understanding about the intervention are attained, and if consent

authorization is given voluntarily. Results of a systematic review conducted in North America and in the Western world indicated that informed consent is not being met in the vast majority of cases in prenatal screening (Green, et al., 2004). Green and colleagues (2004) identified and analyzed 78 studies that have been conducted internationally about the psychosocial implications of prenatal screening. Most of the studies were conducted in the US and UK, although several were from Canada and European countries. The findings indicated that there is an inadequacy of current procedures for achieving informed consent. One study conducted in Canada in 2002 reported that of 113 pregnant women surveyed before undergoing their 18 week gestation ultrasound, 55% had not received any information about ultrasound screening from their health care providers, 46% did not understand the ultrasound to be a screen for anomalies, and 26% were unclear about its diagnostic capabilities (Koht, Dewey, & Love, 2002). Favre and colleagues (2008) assessed the level of information and informed consent given to pregnant women for the screening of Down syndrome before their first trimester ultrasound scan. The nature of medical information given and the women's understanding of information were evaluated. Findings revealed that the majority of women underwent the test, unaware of the benefits and harms associated with the screening and uninformed about its non- compulsory nature. In addition, the information provided concerning the consequences of an abnormal test result was insufficient (Favre, et al., 2008). However the women who received written information about screening tests had a higher quality of consent.

Providing adequate information to women about prenatal screening is important to enhance women's ability to understand the test and make an informed choice. The SOGC (2011) recommends that the following information be provided to pregnant women prior to a screening test: details about the conditions being screened for, the likelihood of detection, the method of

screening, the meaning of a positive screen result and a negative screen result, the various choices available following a positive diagnosis, and details on how further information can be obtained.

While full counseling is not recommended, this still encompasses a great deal of information to disclose in a short clinical encounter. Describing the details of the conditions being screened for can take several minutes (Green, Hewison, Bekker, Bryant, & Cuckle, 2004). As Chodirker and Evans (1993) reported physicians spent less than five minutes on average discussing maternal serum screening. In addition, Press and Browner (1994) reported approximately two minutes was used for discussing the screening. In practice, relevant details about prenatal screening are often disclosed incorrectly to pregnant women (Chodirker & Evans, 1997), not disclosed at all, or a discussion does not even take place (Benute, et al., 2012; Goel, Glazier, Holzapel, Pugh, & Summers, 1996; Piro, Mykitiuk, & Nisker, 2008).

Studies evaluating women's knowledge and understanding of prenatal screening showed that women do not understand the testing, including basic facts such as why the test is being done, what conditions are being looked for, what the results mean and what will or may follow after testing (Goel et al., 1996; Green et al., 2004). These findings are the same both for women who choose to have testing and for those who declined.

Informed choice is considered a main purpose and benefit in the practice of prenatal screening as reflected in the SOGC clinical practice guidelines (2011). One of the implications for practice noted by the Health Technology Assessment Review (Bricker et al., 2000) is that "Rapid changes in care may leave maternity staff and women behind. Better information is needed for both" (p. 48). As the number of conditions and features that can potentially be screened for during pregnancy rises, dilemmas about how to achieve informed choice can only

increase (Favre, et al., 2008; Williams, Alderson & Farsides, 1994;). In conclusion, prenatal testing has become a routine practice in order to detect fetal abnormalities and , as a result, a huge amount of genetic information has become available. Pregnant women and their partners are often unprepared for the news that they are carrying a fetus with an abnormality.

### **Perinatal Loss**

Perinatal loss is defined as the loss of a baby from conception to the first 28 days of life and includes miscarriage, stillbirth, and neonatal death (DiMarco, Renker, Medas, Bertosa, & Goranitis, 2002). Elective termination of pregnancy for fetal abnormalities has also been considered as a perinatal loss as the associated grief experience has been shown to be similar in intensity and expression to other types of perinatal loss (Keefe-Cooperman, 2005; Lorenzen & Holzgreve, 1995; Zeanah, et al.,1993). Although perinatal loss is a frequent and profound experience, it has often been underestimated in terms of its impact and significance (Malacrida, 1997).

**Why is perinatal loss unique?** Perinatal loss is reported as one of the most stressful events a woman can experience in her life (Flenady & Wilson, 2008). The experience of perinatal loss is different from other types of loss through death because it represents the loss of future hopes, dreams, and parenthood (Bartellas & Van Aerde, 2003). Women begin the bonding process with their anticipated child prenatally (Letherby, 1993). Each trimester of a pregnancy includes psychological tasks that are parts of the bonding process between mother and anticipated infant (Benkendorf, 1990). The first trimester of pregnancy involves confirmation of the pregnancy, resolving initial ambivalence about the pregnancy, accepting the pregnancy, reviewing one's childhood, and changing feelings regarding body image and sexuality. During the second trimester, the mother begins to realize the fetus as a separate individual, and bonding

is facilitated by quickening (feeling fetal movement) and viewing the fetus via ultrasound. The mother begins to picture the ideal child and to think about her and her partner becoming a family unit. Her expectations about parenthood and the anticipated child increase the sense of loss or failure. In addition, the increase in medical technology might persuade women to believe that their babies will be healthy and not die ((Benkendorf, 1990). Therefore, they tend to begin the bonding process earlier, even prenatally (Letherby, 1993). The sudden and unexpected nature of perinatal loss associated with detection of a fetal abnormality is a traumatic event and, often triggers profound grief (Gold, Dalton, & Schwenk, 2007).

Friedman & Gradstein (1982) stated that maternal-fetal attachment is an important factor in determining women's emotional reactions to pregnancy termination. For many women forming an attachment to their expected baby begins well before birth, and in some cases, even before conception. Soon after conception, the psychological and physiological processes of pregnancy are set into motion. The level of reproductive hormones in circulation increases greatly, the uterus develops a thick lining to support the growing fetus and the breasts enlarge in preparation for nursing. The aim of these processes is to prepare both body and psyche for the expected child. When a pregnancy ends unexpectedly this preparation is interrupted, and the woman is left in a state of physical and emotional readiness for a baby that will never be.

Pepper and Knapp (1980) proposed nine events that contribute to maternal-fetal attachment before and shortly after birth: planning the pregnancy; confirming the pregnancy; accepting the pregnancy; feeling fetal movements; accepting the fetus as an individual; giving birth; seeing the baby; touching the baby; and giving care to the baby. They state the following:

What people do not realize is that for the mother, this infant has been a part of her since conception. She has come to know it in a way that no one else has . . . Maternal love,

whatever its source, reaches deeply into the earliest stages of pregnancy and attaches itself firmly to the growing infant. ( Pepper & Knapp, 1980, p. 29).

Maternal-fetal attachment consists of tangible events such as feeling fetal movements, as well as other more hidden aspects including: preparation and adjustment to pregnancy and thoughts of being a mother to the child, and how her life and her family life will be changed by a baby. There are some additional elements that could have some influence on the development of maternal-fetal attachment. For example, viewing the image of the baby through ultrasound has a huge impact on the maternal-fetal attachment (Grigore & Mares, 2013; Robinson, Baker, & Nackerud, 1999).

Regardless of the circumstances in which a pregnancy ends, there is the loss of the object of an antenatal emotional attachment. The immediate reactions to perinatal loss are mainly manifestations of stress, followed by emotional responses ranging from temporary disappointment to intense reactions, underlined by pronounced, persistent and severe psychological concerns (Korenromp, et al., 2005, 2007; Zolese & Blacker, 1992), characterized by symptoms of anxiety and depression (Adeyemi, et al., 2008; Neugebauer, & Ritsher, 2005). Some studies have shown significant clinical distress after 4 years for 34% of women confronted with these issues (Hunfeld, Wladimiroff & Passchier, 1997). Psychiatric morbidity varies from 13 to 34% (Nichol, Tompkins, Campbell & Syme, 1986), and a state of pathological grief has been reported (Fink, 2012; Heikkinen, 1995; Rousseau & Fierene, 1994). Some factors that contribute to the uniqueness of this loss are: mothers never get to know the object of their grief and the sudden loss also symbolises the loss of her maternal identity, an identity that is furthermore not recognized by society when a living child is not present(Gold, 2007).

## **Termination of Pregnancy for Fetal Abnormality**

The experience of a diagnosis of fetal abnormality is emotionally distressing because women are confronted with the choice to either terminate their pregnancy or let their baby be born and suffer disability and potential death. Whatever they choose, intense grief and loss accompany this difficult decision (Hoeldtke & Calhoun, 2001; Kersting et al., 2005; Kersting et al., 2007; Rapp, 1999; Sandelowski & Barroso, 2005; Wool, 2011).

Howard (2006) asserted that most women when faced with a confirmed diagnosis of fetal abnormality will choose to terminate the pregnancy. Evans and colleagues cite that "Over 80% of women with severe prenatal abnormalities have chosen to terminate regardless of 'when' in gestation the diagnosis was made" (Evans, et al., 1996, p. 354).

The grief experience accompanying the choice to terminate has been found to be similar to those experienced by women who have stillbirths or miscarriages (Howard, 2006). According to Keefe-Cooperman (2005), women who elect to terminate their pregnancy often experience a sense of guilt over ending the life of their child. In addition, Kolker and Burke (1993) proposed that the second trimester termination of pregnancy forces the women to take an active role in the life and death of a potentially viable fetus. The active role women play in the pregnancy termination decision is associated with long term psychological consequences (Howard, 2006). Having to make the decision to terminate a pregnancy for fetal anomaly is the single issue that sets the grief process apart from the grief suffered after miscarriage or stillbirth (Suslak, Scherer, & Rodriguez, 1995). Furthermore, Howard (2006) stated that the stigma associated with both abortion and disability impact women's comfort level with sharing their choice with others which can increase the risk of isolation and vulnerability. Studies suggest that women who terminate their pregnancy for fetal abnormality may not obtain adequate support, even though they mourn



the death of their baby, due to society's lack of acknowledgement of this kind of loss (White-Van Mourik, Conner, & Ferguson-Smith, 1992; Keefe-Cooperman, 2005; Sandeloski & Barroso, 2005). Geerink-Vercamman and Kanhai (2003) stated that women who terminated their pregnancy for fetal abnormality reported experiencing empathetic support from family and friends, but that support lasted too short a time. As stated by Sandelowski and Barroso (2005), “A positive or suspicious prenatal diagnosis sets into motion a series of nested and time-sensitive decisions” (p. 310). Whether they choose to terminate the pregnancy upon confirmation of the fetal abnormality, or whether they continue to term, both experiences are marked by tremendous grief. Social support during this crisis is often compromised or limited because the options available to parents are not necessarily socially acceptable and involve a sense of stigmatization as a result of societal views on abortion and on disability (Howard, 2006).

### **Perinatal Bereavement, Perinatal Grief, and Mourning**

Callister defines perinatal bereavement as : “Perinatal bereavement is a unique mourning situation” (Callister, 2006, p. 227). Krone and Harris (1988) define it as: “Perinatal bereavement is a significant situational crisis for the family and its social network.”(p. 1). Perinatal bereavement is usually preceded by a sudden, unexpected loss of an infant through death from miscarriage, stillbirth, or neonatal death (Barr & Cacciato, 2007), or by elective termination for fetal abnormalities (Van Putte, 1988). Additionally, Hammersley and Drinkwater (1997) affirm “bereavement from perinatal death differs from ‘conventional’ bereavement because of the unusual attributes of the lost subject and socio-cultural attitudes surrounding pregnancy and its perceived ‘failure’” (p. 53).

The bereavement response to perinatal loss is unique (Wallerstedt & Higgins, 1996). In perinatal loss there is no prior knowledge, history or reference point of life to reflect upon during

the bereavement. This distinguishes perinatal loss from other types of loss (Bennett et al., 2005). In the case of a perinatal loss, there may be no body to bury, no customary ritual of mourning, and often no opportunity to express emotions freely if the pregnancy had not yet been announced (Brier, 2008). Perinatal loss represents not only the loss of the pregnancy, but also lost hopes and dreams, (Smith, 1999), loss of the perfect baby, and loss of future roles as parents (Reed, 2003). Bartellas and Van Aerde (2003) indicated bereavement follows the death of a close relative or friend and includes the entire process of loss, grief, and mourning. Apparently, the concept of bereavement is closely associated with death, loss, grief, and mourning.

Loss has been defined by Corless (2006) as the absence of an object or person, while the significance of the loss is determined by the strength of the relationship between the owner and the object or person that was lost. Others have also used grief and mourning interchangeably in describing perinatal bereavement (Gordon, 1989; Ryan, Cote-Arsenault, & Sugarman, 1991; Janssen, Cuisinier, Graauw, & Hooduin, 1997). Mourning and grief have been cited as expressions of bereavement. Grief has been defined as a reaction to loss (Brier, 2008), “the emotion or emotions one feels when one suffers a loss”, (Menke & McClead, 1990, p. 262) and “the characteristic response of sadness and sorrow to loss of a valued object” (Gardner & Merenstein, 1986, p. 8). Grief, is considered “a normal, healthy response to the death of a loved one” (Bruhn & Bruhn, 1984, p. 108) and a symptom of bereavement (Flenady & Wilson, 2008).

Mourning has been defined as “the painful process of detaching from a significant person and reinvesting energy in others” (Theut, Zaslow, Rabinovich, Bartko, & Morihisa, 1990, p. 523). Moreover, Brost and Kenney (1992) differentiate grief as an ongoing interpersonal process, and mourning as a public expression of grief that is time limited. Mourning has been

described as dynamic, differing from person to person and changing over time, (LaRoche et al., 1982) and as painful and “necessary for recovery from bereavement” (Bourne & Lewis, 1984, p. 148). Mourning is described as the manifestation of culturally patterned behaviours during bereavement (Kastenbaum, 2007) that incorporate the experience of loss into the outward expression as life is lived (Ferrel & Coyle, 2006).

The main characteristic of perinatal bereavement is an emotional response that is most commonly manifested as grief. The grief that follows perinatal death is different than the grief of bereavement from losing an older significant other (Hunfeld et al., 1997a) and is unique because of the relationship of the deceased to the bereaved (Stierman, 1987). Perinatal grief is complex and is manifested in a wide variety of psychological and psychosomatic expressions such as sadness, irritability, depression, yearning, anger, and crying (Badenhorst & Hughes, 2007).

Fenstermacher (2011, 2013) found based upon what is known about perinatal bereavement from a synthesis and integration of the findings of a concept analysis that perinatal bereavement is the experience of parents that begins immediately following the loss of an infant through death by miscarriage, stillbirth, neonatal loss, or elective termination for fetal anomalies. It is characterized by a complex emotional response, most commonly manifested as grief in both the mother and father, but often expressed differently between males and females, both in intensity and duration. Perinatal bereavement is manifested by both psychological and psychosomatic responses, and is mediated by situational, internal and external factors. Mourning occurs during perinatal bereavement as an expression of the bereavement and is influenced by culture, religion, and tradition. For the purpose of this research study, perinatal bereavement and perinatal grief will be used interchangeably.

## **Grief and Bereavement after TOPFA**

It was important to define bereavement and grief to understand the consequences of terminating a pregnancy for fetal abnormality. There are other forms of grief reactions that could be experienced with TOPFA. For example, complicated grieving is defined as a group of symptoms including longing for the deceased, purposelessness about the future, anger, bitterness, and a lost sense of security (Melhem, Moritz, Walker, Shear, & Brent, 2007). To evaluate grief responses we need to differentiate between normal and complicated grief.

Normal grief has been defined as “a painful, complex emotional state that changes with time and a process of confronting the loss in the service of gradual detachment from the lost person or object” (Beutel et. al., 1995, P. 518). Uncomplicated or normal grief is accompanied by a multitude of symptoms that impact feelings, cognition and physical sensations (Worden, 1991). Feelings may include sadness, anger, guilt, and self reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, relief, and numbness. Cognitions experienced by the individual during this period may involve disbelief, confusion, preoccupation, a sense of the deceased being present in some way, and hallucinations. Behaviors may also be impacted by the death. The bereaved may exhibit sleep disturbances, appetite changes, absent- mindedness, avoiding reminders of the deceased and social withdrawal (Worden, 1991).

A complicated grief disorder is characterized by intrusive images, extreme feelings of emotion, denial of the importance of the loss to the self and a general neglect of necessary adaptive actions both in the workforce and at home (Horowitz, Seigal, Holon, Bonanno, Milbrath & Stinson, 1997). Complicated grief symptomatology has been found to persevere at least six months (Prigerson et al., 1996). Prigerson and colleagues stated that symptomatology of complicated grief includes yearning for the deceased as before illness or death, preoccupation

with thoughts of the deceased, feeling a need to call the departed person's name, exhibiting an inability to accept the death, being drawn to associations with the dead person, having a mental image of the person, hearing things associated with the deceased, feeling the dead person's presence and dreaming of the person. With uncomplicated grief, these feelings decrease in intensity and the person slowly returns to a subdued interest and ultimately a zest for life.

Peppers and Knapp (1980) mentioned other forms of grief associated with pregnancy loss. They stated as pregnancy loss is often a silent loss; it results in isolated sorrow. Such silent, ongoing grief is described as "shadow grief", reflecting their observation that the experience of pregnancy loss tends to remain with women through their lives in the form of a lingering grief that overshadows their life experience at various points (Pepper & Knapp, 1980).

Disenfranchised grief, defined as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (Doka, 1997, p. 276) may leave mourners disconnected by not acknowledging the relationship to the deceased, the deceased themselves and/or the griever (Doka, 1989, 2002). Frequently, a pregnancy loss is not recognized as the death of a child, and may not be accepted for what it represents to the parent(s), namely the loss of a life that had already been celebrated within the family (Lalor, Begley, & Galavan, 2009). Bereaved mothers often feel isolated in their grief with perinatal loss because there was little or no tangible proof of the baby's existence (Geerinck-Vercammen, & Kanhai, 2003) . Abboud and Liamputtong (2003) suggest this awareness of the unborn baby as a person makes "the loss of the baby more profound because hopes and expectations were set on the potential person" (p.56). Furthermore, such losses, particularly in early pregnancy, are managed as a medical procedure, which focuses on the loss of the "products" of conception rather than the loss of a baby.

When applying current bereavement literature to perinatal loss, several factors must be considered. A pregnancy is confirmed much sooner in today's society than in earlier times due to medical advances. This, combined with first trimester ultrasound, leads to an earlier bonding with the fetus in utero and the development of a mental representation of the anticipated child (Grigore, & Mares, 2013).

The experience of TOPFA contains factors such as a sense of biological failure, isolated grieving, guilt, a possible lack of perceived support and no time for anticipatory grieving (Keefe-Cooperman, 2004, 2005). In addition, memories are of key importance in the process of mourning. Persons gather together to discuss and share memories of the deceased, however with a fetus that has never developed to term, there are no shared memories but only dreams of what could have been if the baby had lived (Keefe-Cooperman, 2004, 2005; Thomas, 1995). The parents are isolated in their bereavement due to the lack of shared memories of the child with other people (Britt, Risinger, Mans, & Evans, 2002; Doka & Morgan, 1993; Keefe-Cooperman, 2004-2005; Rillstone & Hutchinson, 2001). Perinatal bereavement is a hidden grief as there are few, if any pictures of the child (Roose, & Blanford, 2011). Women may no longer think of themselves as mothers and men may negate their self-image as fathers. Also affected are the couples' parents who were to be grandparents to the child, and siblings who may have been preparing for the role of older brother or sister (Callister, 2006; Roose, & Blanford, 2011). Jealousy might be felt towards perceived happy families with children (Kersting, 2012; Thomas, 1995) and going to public places filled with babies may become painful. As a result there is scarcely a chance for anticipatory grieving (Doka & Morgan, 1993). The woman has no time to mentally prepare for the impending loss to accept a world in which the child is not present. There is no time to say "good-bye" to the infant before he or she dies (Doka & Morgan, 1993).

Anticipatory grief has been defined as "the phenomenon encompassing the process of mourning, coping, interaction, planning and psychological reorganization that are stimulated and begun in part in response to the impending loss of a loved one" (Rando, 2000, p. 29).

Research suggests many couples exhibit nonparallel grief that may strain their relationship and cause marital discord that adds to the possible negative experience of the female. The father may attempt to insulate his significant other from the outside world by fielding phone calls or otherwise acting as a buffer between the mother and possible supports (Doka & Morgan, 1993; Kersting, 2012). Beutel, Deckardt, vonRad, and Weiner (1995) found that men tend to grieve less intensively and for shorter periods than their partners. While helping to protect her, the male may be inadvertently serving to only further her feelings of isolation (Gilbert & Smart, 1992). The couple's different grieving processes may cause feelings of distance and discord. The male may be primarily worried about his partner's health, which also impacts the woman's grief because she may feel as if she is the only person grieving the lost child. Also, as he may not achieve as a great bond with the child as the female, his grieving process is likely to be different. The female, who believes he may not care about the lost child, may resent this perceived lack of emotions. Mothers have been found to rate feelings of grief higher than fathers (Fenstermacher, 2013; Kersting, 2012). These dissimilarities may have a negative impact upon the grieving couple's relationship (Lang & Gottlieb, 1993; Lok & Neugebauer, 2007; Wing, Burge-Callaway, Rose Clane, & Armistead, 2001). Other factors that could be associated with the grief response, include fears regarding the ability to become pregnant again and carrying subsequent pregnancies to term (Cote-Arsenault, 2001, 2003; O'Leary, 2004).

## **Empirical Research on TOPFA**

Empirical research on TOPFA will include three sections. The first section will review studies on grief and psychological sequelae due to termination of pregnancy for fetal abnormality; the second section will review studies on the decision making process in pregnancy termination for fetal anomalies and finally qualitative studies that describe the experience of pregnancy termination for fetal abnormality will be reviewed in the third section.

### **Grief and Psychological Sequelae due to Termination of Pregnancy for Fetal Abnormality**

**Short-term studies.** Several retrospective and prospective studies investigated the psychological and emotional well-being of women after termination of pregnancy for fetal abnormality. White-van Mourik, and colleagues (1992) examined the psychosocial sequelae in a convenience sample of 84 women and 68 spouses two years after the termination of pregnancy. The questions regarding psychological adjustment and psychosomatic symptoms were answered using the “Leads scales for the self-assessment of anxiety and depression” (Snaith, Bridge & Hamilton, 1976) and “The General Health Questionnaire” (Goldberg, 1972; Goldberg & Hiller, 1979). The results indicated that two years after pregnancy termination approximately 20 % of the women still experienced regular bouts of crying, sadness, and irritability. The researchers reported that 61% of the women showed a “loss of biological self-esteem” (p.199), signifying the women had feelings of shame and physical inadequacy because of what they believed to be their failure to produce a healthy baby. About 59% of the women expressed what the researchers called “loss of moral self-esteem” (p.199). By this term, the researchers meant that the women reported an “overwhelming sense of responsibility” (p. 199) and shame over having chosen to end the life of their baby. Approximately 82% of the women experienced a strong spiritual disturbance and a preoccupation with positive or negative thoughts about God and religion.



Other women have reported a “loss of social self-esteem” (White-van Mourik, Conner, & Ferguson-Smith, 1992, p.200) and felt alienated and isolated because of how they thought others would react to their having had a pregnancy termination.

Similarly, in a study conducted using a case-controlled approach (Zeanah, et al., 1993), 23 women who underwent pregnancy terminations due to fetal abnormalities were assessed psychologically two months after termination of pregnancy with the Perinatal Grief Scale (Toedter, et al., 1988) and Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961, as cited in Zeanah, et al., 1993). Their grief responses were compared to a demographically similar group of women with spontaneous perinatal loss due to a miscarriage. The results of this controlled investigation indicated that women who terminated pregnancies for fetal anomalies grieved more intensely than those who experienced spontaneous miscarriage. Hunfeld, Wladimiroff, and Passchier, (1994) reported similar findings in their descriptive study of women’s perinatal grief after pregnancy termination for a fetal abnormality. Most women in this study experienced severe sadness and/or anger, eating and sleeping disorders, feelings of failure and feelings of fear immediately after pregnancy termination. Although the severity of the above feelings was significantly reduced three months following termination, grief did not diminish during the study period, and psychological instability was less pronounced at three months after delivery. More women reported anger at the termination experience after three months than they did earlier.

Iles and Gath (1993) conducted a mixed method study to obtain quantitative and qualitative information about psychiatric morbidity in women after termination of pregnancy for fetal abnormality. Two groups of women were compared. The first consisted of 71 women who had experienced a termination of pregnancy for fetal abnormality. The second consisted of 26

women who had experienced a missed abortion which is defined as asymptomatic non-viable pregnancy, diagnosed when there is a history of absent fetal movements and fetal heart tones and confirmed by trans-abdominal ultrasound scan (Tanha, Feizi, & Shariat, 2010). Although both groups had lost their pregnancies in the second trimester, the second group of women had no element of choice. Standardized psychiatric and social measures were used to assess both groups on three occasions after the termination. In both groups, psychiatric morbidity was high and social adjustment was impaired four weeks after the termination. Levels of psychiatric morbidity were near normal six months and 12 months after the abortion. Semi-structured interviews were conducted at the three time intervals to obtain information about the women's experience of grief after mid-trimester termination. For many women symptoms of grief persisted throughout the first year post termination. These symptoms included typical features of grief as well as grief symptoms specific to pregnancy loss.

Davies, Gledhill, McFadyen, Whitlow, and Economides (2005) conducted a cohort study of 30 women, 14 of whom had a first trimester termination and 16 women who had a second trimester termination for fetal abnormality. The purpose of the study was to ascertain and compare psychological morbidity in women undergoing first versus second trimester termination of pregnancy. The main outcome measures were questionnaire data: General Health Questionnaire-28 (Goldberg & Hillier, 1979 as cited in Davies et al., 2005), Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961, as cited in Davies, et al., 2005), Perinatal Grief Scale (Toedter, et al., 1988, as cited in Davies, et al., 2005), and Impact of Event Scale (Sundin & Horowitz, 2002, as cited in Davies, et al., 2005) used at six weeks, six months and 12 months after termination. Results revealed high levels of psychological distress in both

groups at each time point. Women undergoing second trimester termination had significantly greater levels of post-traumatic stress symptoms than did their first trimester counterparts.

In contrast to the previous studies a prospective comparative descriptive study by Keefe-Cooperman (2005) hypothesized that women who terminated a wanted pregnancy due to fetal abnormality would experience a greater vulnerability for emotional problems than females who miscarried spontaneously. The researcher compared psychological and emotional consequences in 23 women who experienced a miscarriage and 62 women who had undergone pregnancy termination for fetal abnormality up to two years previously. The Perinatal Grief Scale (PGS) (Toedter, et al., 1988) which measures active grief, difficulty with coping, and despair, and The Perinatal Bereavement Scale (PBS) which measures the thoughts and feelings experienced by women after a loss were used in this study. In addition, the researcher used The Pregnancy Loss Experience and Needs Assessment Questionnaire (Alderman, 1999) to qualitatively address the experience of loss through miscarriage or termination for fetal anomaly. This measure was developed to evaluate the miscarriage experience but its title was modified by the researcher for use with women who have experienced a termination of pregnancy for fetal anomaly. Findings revealed minimal psychosocial consequences after second or third trimester termination for fetal abnormalities. There were no significant differences in grief response between the miscarriage group and termination group. The groups were then combined to analyze within group factors. Six variables were identified as related to vulnerability for grief reaction. These factors included: time since the most recent loss; counseling intervention; employment outside the home; feeling responsible for the perinatal loss; age of the mother as related to guilt; and gestational length of pregnancy.

Investigators of a longitudinal study conducted in the Netherlands with 30 women who experienced pregnancy termination found that women who felt they had no choice but to terminate their pregnancy for fetal abnormality experienced more intense grief than those women who felt in control of the situation (Hunfeld, Wladimiroff, & Passchier, 1997). Four years later some of those who felt they did not have choice in the decision to terminate continued to experience significant levels of psychological distress.

In summary, the findings from the studies on grief and psychological sequelae after TOPFA indicate that women who terminate pregnancy for fetal abnormality experienced intense grief and persistent adverse psychological reactions up to two years after the pregnancy termination. Most studies utilized one or more of the following measures for assessment purposes; (a) semi-structured interviews, (b) standardized psychiatric interviews, (c) psychometric testing, (d) the Perinatal Grief Scale, and (e) questionnaires/surveys. Studies compromised uncontrolled design, low response rate, and small sample size. Moreover, standardized survey instruments may be inadequate to uncover deep and delayed reactions to the pregnancy termination experience (Reardon, 2011).

**Long-term studies.** Korenromp and colleagues (2005) examined women's long-term psychological well-being after TOP for fetal abnormality in order to identify risk factors for psychological morbidity. The researchers conducted a cross-sectional study with 196 women, 2-7 years after TOP for fetal abnormality before 24 weeks of gestation. The Inventory of Traumatic Grief (ITG) (Prigerson & Jacobs, 2001) was utilized to measure grief; symptoms of posttraumatic stress were measured by the Impact of Event Scale (IES) (Horowitz, Wilner, & Alvarez, 1979). Psychological well-being was measured with the use of three subscales of the Symptom Checklist-90 (SCL-90): depression, anxiety, and somatic complaints. A questionnaire

was specifically designed for this study and contained questions on perceived support, seeking professional help, and feelings of doubt. Standardized questionnaires were used to investigate grief, posttraumatic stress disorder (PTSD) and psychological and somatic complaints. Findings showed that 20% of the participants showed pathological scores for posttraumatic stress. Less-educated women and women who had experienced little support from their partners had the most unfavourable psychological outcomes. Coping problems lasting more than 12 months were reported by 40% of the women. Advanced gestational age at the time of TOPFA was associated with higher levels of grief, posttraumatic stress symptoms and long-term psychological morbidity. Women who reported regret or doubt represented 8 % and 10 % respectively of the study participants. The number of women with pathological outcomes of grief and posttraumatic stress symptoms was equally distributed regardless of the time elapsed after the pregnancy termination, which may indicate that there is no decrease in symptomatology between 2-7 years after the termination (Korenromp, et al, 2005).

The above findings correspond with the results of Kersting and colleagues (2005) who conducted a quantitative mixed method study to compare 83 women who had undergone a second trimester TOP for fetal abnormality seven years previously, 60 women 14 days after a second trimester termination for fetal abnormality, and 65 women after a normal delivery of a healthy infant. They hypothesized that women 2-7 years after TOP would show lower degrees of traumatic experience and grief than women 14 days after TOP. In addition, women several years after TOP were expected to display a higher degree of posttraumatic stress response than women after the spontaneous delivery of a full-term healthy infant. The Impact of Event Scale (IES) (Horowitz, 1979) and the Perinatal Grief Scale (PGS) (Toedter, et al., 1988) were used to measure posttraumatic stress response and grief respectively. The findings revealed that,

contrary to the authors' hypothesis, 2-7 years after TOP, women showed a mean score of 16.13 in the IES scale for the posttraumatic stress response compared to 18.62 for women 14 days after TOP. Women 2-7 years after TOP did not differ significantly from those 14 days after TOP with respect to the degree of traumatic experience. With respect to the experience of grief, women 2-7 years after TOP showed a higher mean score compared to women two weeks after TOP. Both groups differed significantly in their posttraumatic stress response and grief from women who had given spontaneous birth to a full-term infant. Findings of this study indicated that the experience of pregnancy termination for fetal abnormality is considered traumatic by many women even years later (Kersting, et al., 2005).

Kersting and colleagues (2007) conducted a subsequent study to evaluate the grieving process of women after traumatic loss. A sample of 62 women with TOP for fetal abnormality in the second or third trimester was selected. A total of 65 women after a spontaneous delivery of a healthy infant were selected as controls. Complicated grief, posttraumatic stress, depression, anxiety and psychiatric diagnosis were assessed 14 days, 6 months and 14 months after the TOP. Psychiatric diagnoses were performed using the "Structural Clinical Interview for DSM-IV (First, Spitzer, Williams, & Gibbon, 1997). The "Complicated Grief Module" was used to assess the degree of complicated grief (Horowitz, 1979). The "Perinatal Grief Scale" was implemented to measure the grief after TOP (Toedtler, et al., 1988). Posttraumatic stress reactions were assessed using a self-report instrument. The "Beck Depression Inventory" was applied to measure the severity of the depressive symptoms. Self-reported anxiety was assessed with the Spielberger State-trait Anxiety (Spielberger, 1983). Findings revealed a higher percentage of women had relevant psychiatric diagnoses compared to controls' diagnoses at 14 days and 14 months after TOP. In addition 14 months after TOP, 13.9% of the women were diagnosed with

complicated grief and 5.6% with additional psychiatric disorders. The researchers concluded that the majority of women adapted well to the TOP, however, many women after TOP developed a complicated grief reaction and/or psychiatric disorder after the traumatic loss of their unborn infant. Women who experienced a TOP showed at all three points, significantly higher posttraumatic, depressive and anxiety symptoms than women after spontaneous delivery on all psychological scales (Kersting, et al., 2007). This study was well designed but had only a 49% response rate. The persistently high level of distress for 2-7 years after pregnancy termination is striking. The ongoing grief shown by the women is consistent with findings of other studies (Dallaire et al., 1995; Korenromp et al., 2005; White-van Mourik, et al., 1992).

In summary, few studies examined women's long-term psychological well-being after TOP for fetal abnormality. The persistently high level of distress for 2-7 years after pregnancy termination is striking. Findings of these studies indicated that the experience of pregnancy termination for fetal abnormality is considered traumatic by many women even many years later however little is known about the meaning of the termination experience from the perspective of the women.

### **Decision Making Process in TOPFA**

Several factors contribute to the difficulties women face during the decision making process pertaining to TOPFA and can lead to several adverse consequences after the pregnancy termination. Some identified factors include maternal-fetal attachment, women's beliefs and values, gestational age, fetal viability, certainty of the diagnosis and presence of support (Iles & Gath, 1993; White-van Mourik, et al., 1992; Zeanah, et al., 1993).

Doubt, shame, self-blame and regret are frequently reported by women after making the decision to end a pregnancy (Hunfeld, et al., 1994; White-van Mourik, et al., 1992). In a

quantitative study conducted by Rucquoi and Mahoney (1992) the results indicated that couples who received a poor fetal prognosis had several areas of concerns. For example, the parents expressed ambivalence regarding their decision to terminate the pregnancy. In addition, couples felt alone and had fear of the termination itself. They were concerned about the perceptions of family members and friends. They expressed worry about their marriage and a fear about their reproductive abilities in the future. Finally, couples were afraid of a misdiagnosis and felt a sense of failure. Moreover, some health care professionals were described as having different values regarding late pregnancy termination and consequently parents felt confused and misdirected.

A quantitative study conducted in Denmark by Norup (1998) was undertaken to provide knowledge related to obstetricians' attitude towards termination of pregnancy for various reasons including the presence of fetal anomalies. A total of 950 physicians were surveyed about their attitudes toward TOP to reveal consensus and controversy. In the case of severe fetal anomalies, the participants were asked whether the women should have the choice of TOP in the 19<sup>th</sup> week of pregnancy. The rate of acceptance for termination of pregnancy was low in cases where the fetus had a minor condition or late-onset disease, and there was a declining rate of acceptance of TOP with increasing fetal age. Controversy regarding termination was revealed in the case of Turner syndrome diagnosed before 21 weeks gestation, polycystic kidney disease at 13 weeks gestation, and Down syndrome at 24 weeks gestation. These findings showed that the majority of respondents expressed doubt about the acceptability of pregnancy termination in these three situations. This doubt comes from the different beliefs of health professionals regarding the age of fetal viability. These findings also revealed that Danish obstetricians had varying beliefs regarding what are acceptable termination situations and at what gestational age termination



should and should not be allowed. The researchers concluded the differing beliefs of practicing obstetricians might affect the ability of women to make the decision about terminating their pregnancy for fetal abnormality.

Pueschel (1991) in his review stated that low-risk parents who receive unexpected news of a fetal abnormality such as Down syndrome initially exhibit impaired decision-making capacity resulting from the shock of the traumatic news. There are significant ramifications because the parents are required to make such decisions in a limited time and therefore might cause a high intensity grief response.

A retrospective study (Hassed, et al., 1993) conducted with 130 pregnant women diagnosed with perinatal lethal conditions examined factors influencing the women's decision toward TOPFA for fetal abnormalities. Perinatal lethal conditions diagnosed before 24 weeks gestation were examined regarding parental race, education, employment status, age, religious preferences, gestational age and nature of fetal defects. The researchers found that the type and severity of defect were the most significant predictive variables for TOPFA. In another study the process of decision making for pregnant women with positive results for fetal abnormalities was explored (Santalahti, Hemminki, Latikka, & Ryyanen, 1998). The women's intentions regarding pregnancy termination varied from making a firm decision to end the pregnancy to not terminating. Many women remained ambivalent in their decision making. Some factors that influenced the decision making ability of women were mentioned but other factors needed more exploration. Women reported factors such as the general pressure from society and societal hostility towards people with disabilities. Women in this study reported that receiving the information about fetal abnormality with additional support, improving how the results are communicated, and giving more time to make the decision might be helpful for them.

In a systematic review of 32 papers, St-Jaques (2008) identified the decisional needs of women, their partners and health professionals regarding prenatal testing for Down syndrome. All publications in the review used the “Decisional Conflict Scale” as a measure of uncertainty. The findings showed that women need help to address their decisional needs and resolve felt uncertainty about the decision to undergo prenatal testing and dealing with its consequences. The most often reported sources of difficulty for decision making reported by the women were pressure from others, emotions, and lack of information; by their partners’ there were emotions; and by health professionals there were lack of information, length of consultation, and personal values. The most important sources of ease reported by the women were personal values, understanding, and confidence in the medical system; for their partners personal values, information from external sources, and income; and for health professionals peer support and scientific meetings were critical. The findings indicated that women experiencing decisional conflict are more likely to regret their decision and to blame themselves as well as their health practitioner for their problems.

Bishop (1996) conducted a grounded theory study with eight women to explore the process of decision making regarding TOP for fetal abnormality. The length of time since the women had terminated their pregnancy ranged from six weeks to four years. “Choosing a double-edged sword” described the process wherein women recognized that as a result of perinatal testing, they had a choice between giving birth to a live child with an abnormality or ending their pregnancy resulting in the death of their fetus. The women said that having the bad news confirmed was a horrendous, shocking, and traumatic experience for them.

Sandelowski and Jones (1996) utilized a qualitative design to examine how couples framed their decision to terminate or continue a pregnancy after the discovery of a fetal

abnormality. Open-ended interviews were conducted with 15 women and 12 of their male partners who obtained positive or unfavourable fetal diagnosis. All participants were interviewed within 11 days to two months of learning of the presence of a fetal abnormality or of pregnancy termination. Using thematic analysis and interpretive methods of analyzing data, only the information on the perception of choice both before and after it was made was extracted for the analysis. Five themes of choice emerged in the analysis. The dominant theme was that the moral agency or responsibility for the choice to terminate or continue the pregnancy was attributed to being either within or outside of themselves. The women described the categorical narratives of choice within the following themes: (1) nature's choice, which referred to constructions of choice in which there was the diagnosis of a lethal fetal abnormality, with an option to terminate the pregnancy; (2) disowned choice, which also referred to the previous category, but the option to continue pregnancy was made; (3) choice found, which referred to the diagnosis of lethal abnormality without the option to terminate (participants in this category employed hope and optimism in finding other choices such as mode of delivery); (4) choice lost, which referred to the diagnosis of lethal abnormality without the option to terminate (participants in this category were beyond the legal limit for pregnancy termination and determined that they could not choose to terminate owing to the timing of the actual diagnosis); (5) close choice, which referred to couples that had the diagnosis of a nonlethal abnormality, in which they had a less clear-cut choice as to what to do, based on their best interests and those of their family members, as well as the perceived best interest of the fetus. This research study provided insight into the inner, emotional world of the experience of an abnormal prenatal diagnosis and subsequent decision making. Findings of this study may provide clues to health care

professionals as to what promotes psychological adjustment of couples who are faced with making this kind of choice based on their choice configuration.

Similarly, Sandelowski and Barroso (2005) conducted a qualitative study that utilized a metasynthesis technique to integrate the findings of qualitative studies of expectant parents receiving positive prenatal diagnosis. Qualitative studies that involved expectant parents of any race, ethnicity, nationality, or class who learned during any time in pregnancy of any fetal impairment by any means of diagnosis were eligible for inclusion. Metasynthesis techniques including constant comparison analysis and the reciprocal translation of concepts were used to interpret the findings. The emphasis of the analysis emphasis was on the dilemma of choice and decision making. The findings revealed that for parents receiving positive prenatal diagnosis, the experience was one of both chosen losses and lost choices.

McCoyd (2007) reported the qualitative results of a mixed methods study designed to explore the decision-making and bereavement processes of women who terminated a previously desired pregnancy after the discovery of fetal anomaly while placing the processes within the context of societal milieu. In-depth interviews about decision-making, grief and support were conducted with 30 women one year after pregnancy termination. In addition, each woman completed the short version of the Perinatal Grief Scale (Potvin, et al, 1989). Findings of this study revealed two major categories. The first category, “mythic expectations” was related to the women's thoughts and expectations when they become pregnant and soon after the termination. Themes within this category were “our baby would be fine”, “I wouldn’t terminate any way”, “the right decision couldn’t possibly hurt this much”, “by the time of the first visit, the healing would be all done by then”, and “I was very afraid of running into someone who would pass judgement”. These themes revealed the women’s beliefs and expectations that derived from

societal messages. The second category, “exquisite dilemmas” was related to the issues that emerged as the women considered their experience within the societal and medical context of their lives. Themes that emerged under this category were “the dilemma of conception and bonding”, “the dilemma of testing”, “the dilemma of choice”, “the dilemma of identity”, “the dilemma of disability” and “partner’s dilemma of support”. These themes revealed that women were dealing with a set of dilemmas that were inherent in the contradictory norms values and rules that society prescribe to reproductive health. These findings illustrated women who had endured a TOPFA experienced severe grief that intensified with their responsibility for decision-making. In addition, women reported that there were many challenges which interfered with their ability to grieve adequately; stigma of abortion, fear of judgement by others, minimal support especially from partners, negative views of disability and fear of telling the whole story.

Each of these studies focused on measuring how specific factors such as maternal age, reproductive history, or the timing of the diagnosis of the abnormality affected the decision to terminate. Very few studies explored the process of decision-making or the lived experience of having to make this difficult decision. Many variables that impact the decision have to do with moral and ethical beliefs that are hard to quantify and equally hard to measure statistically.

### **Qualitative Studies on TOPFA**

Few qualitative studies have been conducted to explore women’s experience of pregnancy termination following fetal abnormality detection. Furlong and Black (1984) studied the experience of termination of pregnancy from a family perspective. The purpose of the study was to explore the experiences and coping strategies of families who had previously terminated a pregnancy following detection of a serious fetal defect. Their sample included four couples, nine mothers, and two fathers, for a total of 15 pregnancy termination experiences. Individual semi-

structured interviews were conducted 10 to 40 months after pregnancy termination. The investigators reported that the experience was very challenging for participants; many participants experienced difficulty in discussing the termination and reported strong feelings of loss. Nine of 13 mothers and two of six fathers expressed great difficulty in deciding to terminate the pregnancy. Seven participants viewed the fetus after birth and all were satisfied with the experience of viewing the fetus and confirming the presence of the abnormality for themselves. Of the eight participants who did not view the fetus, two expressed regret at not having had this experience. Four participants hid the nature of the pregnancy loss from their family, stating that it was spontaneous miscarriage. While the researchers presented some interesting findings, it is difficult to analyze the quality of their research method as description of data analysis procedures or methods ensuring rigor were not reported.

VanPutte (1988) conducted semi-structured interviews with 14 couples and four mothers to explore the experience of pregnancy termination. The length of time between pregnancy termination and data collection was not specified; however, the investigator stated one termination as occurring eight years previously. The purpose of this study was to determine women's feelings and needs regarding their pregnancy termination experiences. The participants' experiences were described in terms of how they were first informed about the detection of fetal abnormality then, coped with fears of the unknown, and engaged in the decision-making process as well as the need for support from the hospital staff, for respectful treatment, and for follow-up counseling and support. The investigator concluded that women who experience TOPFA need clear, concise information, sufficient time to manage their anxiety and grief, and post-event counselling. The investigator did not describe the methods used to ensure rigor in data collection and analysis.

Another qualitative study compared the psychological reactions of two groups of women who had undergone prenatal testing and subsequent pregnancy terminations (Dallaire et al., 1995). One group of women were known to be at risk of carrying a child with abnormality, while the other group had no known risk factors and a fetal abnormality had been discovered by a routine ultrasound. Semi-structured interviews were conducted at least six months after the pregnancy termination. A psychiatrist had been a permanent member of the prenatal diagnosis programme and had acted as a consultant for women admitted for pregnancy termination for fetal abnormality. The women reported that it was useful to see a psychiatrist. A major theme reported in the findings involved women's feelings of guilt or thoughts that they had made the wrong decision; these thoughts were still being expressed up to four years later. A second major theme reported was the abandonment of the fetus. The women indicated that in cases with no family history of congenital abnormality, the prenatal diagnosis was not expected, making the decision to terminate the pregnancy more difficult than it otherwise might have been. The women commented they had already bonded, named the baby and shared news of their pregnancy with family and friends. Minimal health care professional support, limited time to make the decision to terminate, and minimal information given by the health care providers were mentioned by the women. These results also reflected different counselling skills of health care professionals involved in TOPFA.

Results from a small phenomenological study by Bryar (1997) with three women showed that the decision to abort a fetus with an abnormality was an experience that deeply affected the people involved. Data were gathered through unstructured interviews four to six weeks after the procedure of pregnancy termination. Bryar described the loss experience as “one day you are pregnant and one day you are not”. This theme summarized the changes involved in the

transition from being a pregnant woman with hopes for the infant and the future to a woman dealing with the loss of innocence. The investigator described this transition in two intertwined processes entitled “The hardest thing we ever did” and “Say hello and goodbye”. Four to six weeks after the second trimester termination the women expressed guilt, conflict, fear, cover-up, growth and recovery. Long-term sequelae were not investigated in this study.

Kruszewski (1999) conducted a study to develop a theory of psychosocial adaptation to TOPFA. The investigator used Roy Adaptation Model (Roy & Anderson, 1999) as a theoretical framework to guide theory generation. This research study focused on identification of focal and contextual stimuli and processes of parents following TOPFA. An exploratory descriptive design was developed and a purposive sample of 19 parents who had experienced TOPFA in the past 15 months was interviewed using a semi-structured interview guide developed by the researcher. Data were analyzed using content analysis methods described by Berelson (1952) and Holst (1968) as cited in Kruszewski (1999), yielding categories of focal and contextual stimuli and coping processes. Findings revealed that parents experienced focal stimuli such as threats to the baby's well-being, decision dilemma, physical discomfort, threat to the mother's well-being, losing the baby, responsibility, regret, revealing the loss, risk of recurrence, and trying again. Coping processes for dealing with the focal stimuli included decision-making, transforming the relationship to the baby, constructing a cause for the fetal abnormality, reconstructing meaning of the experience and moral code, reducing awareness, displacing blame, and backgrounding thoughts and feelings regarding TOPFA experience. Contextual stimuli that influenced focal stimuli and coping processes included societal controversy about abortion, social attitudes about disability, the meaning of the baby to the parents, the parents' personal beliefs about abortion, and supportive and stressful social interactions. The findings of this



research study suggested that parents who experience TOPFA are at risk for complicated grief and have few sources for ongoing support.

Rillstone (1999) utilized symbolic interactionism as a theoretical framework for a grounded theory study was to discover: a) the basic social psychological problem experienced by parents faced with a pregnancy subsequent to a pregnancy in which they choose to terminate following the diagnosis of a fetal abnormality, and b) the basic social psychological processes these parents used to address this situation. Two health professionals and 22 parents were interviewed during a subsequent pregnancy. Catastrophic psychic pain was the basic psychological problem identified. This pervasive pain began with the diagnosis of a fetal abnormality in the previous pregnancy. Findings revealed that the pain was unexpected, intense, and never ending. Rillstone (1999) indicated that catastrophic psychic pain resulted from the overwhelming loss these parents endured. This pain had consequences for the parents that included loss of innocence, feelings of devastation and isolation, changes in spousal relationships, fear of hope, and stigma. These findings indicated that there is a need to examine the support system surrounding these parents in order to relieve their pain and avoid causing further pain.

Vantine (2000) conducted a phenomenological research study exploring the experience of women who made the decision to terminate their wanted pregnancies because of the discovery of fetal abnormality. Narrative analysis using self-reports of three women who had chosen to terminate pregnancies within the previous five years was used as a method of analysis. Findings summarized the women's experiences from testing to the aftermath of termination, including grieving and coming to terms with the experience. A list of 20 paradoxes was presented revealing the nature of this decision and the suffering women underwent as they struggled with

non-resolvable dilemmas and ambivalent feelings. Some of these paradoxes included: women's dilemma of seeing the termination as an act of love or as an act of killing; women's dilemma of choosing to end the life of a child they wanted or ending a life of suffering and sadness which would be painful to witness; and women's uncertainty about the rightness of their decision. The researcher indicated that the clarification of the paradoxical nature of this experience is an important key to understanding this decision and its aftermath.

A qualitative research study utilizing a feminist narrative approach (Drake, 2008) was conducted to explore mothers' experiences with decision-making and grief after receiving a lethal prenatal diagnosis for their fetus. Participants for this study included five mothers, who experienced the death of their babies after receiving a confirmed lethal diagnosis with the prognosis of early infant death. Three of the mothers chose to terminate the pregnancy and the other two mothers chose to continue the pregnancy, or expectant management, with the intent of carrying the baby to term. Findings revealed that all mothers had hopes, dreams, and plans for their unborn children, which were shattered with the confirmation of a lethal prenatal diagnosis. Mothers who chose expectant management were offered and provided with perinatal hospice services, while mothers who chose termination were not offered or provided with perinatal hospice services or any other formal bereavement support. Findings indicated that the formal support services and resources for these women need to be evaluated.

In conclusion, this review of literature reveals that the majority of research to date is quantitative and has been done as a follow-up of the women who experienced fetal loss. Past work has focused on examining the emotional and psychological sequelae and measuring grief reactions of women after undergoing TOPFA. Therefore, there is a gap in the literature and nursing knowledge regarding women's long-term life experiences following pregnancy

terminations for fetal abnormality detection. Most previous research investigations on the experience of termination of pregnancy for fetal abnormalities studied women up to two years post termination. Findings of many of these short-term studies indicate that the majority of women still have severe psychological symptoms two years after termination of pregnancy. Little is known about the long-term challenges and needs of women who experienced making and living with their decision to terminate a wanted pregnancy due to learned fetal abnormalities.

### **Summary**

This chapter provided the current state of knowledge on prenatal screening and its practice, some related arguments on normalization and routinization of these screening tests, women's autonomy and the practice of informed consent. Perinatal loss, grief and bereavement, and research studies on the experience of pregnancy termination for fetal abnormality were discussed. The findings of this study will add to this knowledge by providing an in depth understanding of women's long term experience of TOPFA, and its meaning in the lives of the women. In addition, women's needs for ongoing support will be identified to enable more effective intervention.

## CHAPTER THREE

### Ethical Issues Regarding Abortion

One aspect of the women's decision to terminate a pregnancy for fetal abnormality is associated with moral beliefs and ethics. Choosing to end a wanted pregnancy in the face of possible fetal abnormalities almost always involves a moral dilemma. Medically, termination of pregnancy for fetal abnormality is defined as an abortion. The ethical regarding abortion is often applied to this experience. This chapter will discuss the abortion debate and its connectedness with TOPFA.

#### Abortion Law and Policy

Abortion is legal upon request in both Canada and the United States, but the right to abortion has very different foundations in the two countries. Laws and circumstances have diverged to the point where the legal right to abortion is strong in Canada but vulnerable in the USA (Abortion Rights Coalition of Canada, 2006).

**Canada's legal situation.** Canada first liberalized its criminal abortion law in 1969, allowing the procedure to be performed in hospitals with the approval of a therapeutic committee. The law resulted in unequal access for women across the country so the Canadian Supreme Court struck down the entire law in 1988. Although the Canadian legislature soon tried to re-criminalize abortion, the bill failed to pass. Governments have said repeatedly over the years that they do not intend to re-legislate against abortion. Canada is considered one of the few countries in the Western world that does not have any legal restriction on abortion. Since 1989, abortion has been unrestricted in Canada, legal through all nine months of pregnancy up until the point of birth. Many anti-abortion individuals believe that a woman in Canada can access abortion services at any point during the nine months of pregnancy (Abortion Rights Coalition of

Canada, 2005). However, this belief is inaccurate as a Canadian woman cannot have an elective abortion past 24 weeks gestation. Despite what some may believe about the availability of late-term abortion services in Canada, Statistics Canada (2003) has reported that less than 1 % of abortions take place past 20 weeks gestation and nearly 90 % of abortions take place before 13 weeks gestation. The Supreme Court of Canada grounded the right to abortion in Canada's constitution, where the primary protection cited was women's rights to 'security of the person'. One of the judges also found that the abortion law violated women's rights to 'freedom of conscience and liberty' (Day, Shelagh, & Stan Persky, 1988). Unlike in the USA, women's equality rights are enshrined in Canada's constitution, so courts have been very reluctant to confer any rights on fetuses; to do so would interfere with women's established rights.

### **The Abortion Debate**

Abortion is a very sensitive and controversial issue and one in which people hold a wide diversity of views. Two broad kinds of arguments have dominated over the moral permissibility of deliberate abortion or termination of pregnancy [TOP] (Lotz, 2012). One important argument is about the moral status of the fetus, and this viewpoint plays a central role in debates concerning the stage at which a pregnancy may be terminated. Arguments of the second kind treat the autonomy and rights of women as the central consideration. Much of the debate has focused on the first position, the moral status of the fetus.

**The moral status of the fetus.** Coady (2002) argued whether it is morally permissible to terminate a pregnancy, and if so at what gestational age termination may occur. These decisions depend entirely upon the moral status of the fetus itself. It is claimed that the moral status of the fetus must be determined before we can resolve the claimed conflict within the abortion debate: a

woman seeking the abortion, her desires, preferences, interests and rights as a person versus a fetus with whatever interests and rights it possesses.

Thus, Coady (2002) posed the following questions: Does a fetus have the moral status of a human being? Is it a being of equivalent moral significance to the woman in whose body it resides? If it does not possess equivalent moral status, does it instead possess some form of partial moral status, perhaps based on its potential to be a fully-fledged moral agent? Alternatively, does a fetus have no moral status at all? Lotz (2012) stated that the main argument against abortion maintains that a fetus does have moral status, and perhaps even moral rights, and on those grounds termination of pregnancy (TOP) is morally impermissible. This argument is based on the widely held assumption of the sanctity of human life.

**Views of moral status.** Jones and Chaloner (2007) stated that by applying the process of deductive reasoning the most common anti-abortion argument goes as follows:

Premise A— The fetus is an innocent human being.

Premise B— It is morally wrong to kill an innocent human being.

Conclusion— Therefore, it is morally wrong to kill a fetus.

On the other hand, such reasoning can also be applied to support a pro-abortion viewpoint:

Premise A— The fetus has no moral status.

Premise B— It is not morally wrong to destroy something that has no moral status.

Conclusion— Therefore, it is not morally wrong to destroy a fetus.

Jones and Chaloner (2007) asked the questions, when does the fetus acquire moral value and, beyond this point, is it wrong to interfere with it. A difficulty in choosing a point during the process of conception to birth beyond which abortion should not be permissible is that pregnancy is a continuous developmental process and there is no clear point of distinction other than birth.

Similarly, Coady (2002) asked; on what basis, and at which point, might a fetus be granted moral status? At one end of the spectrum of possible answers to this question are accounts of the fetus as having moral status from the moment of conception (Fasouliotis, & Schenker, 2000; Oduncu, et al., 2003); to accounts at the extreme opposite end of the spectrum that it has none until after its birth, even well into infancy (Oduncu, et al., 2003) . Several distinct positions occupy the considerable space in between these two views (Lotz, 2012). The most prevailing positions will be discussed next.

The first view, held primarily by traditional religious perspectives, considers the earliest point at which to attribute moral status is at the point of conception, or very close to it. The moral status is acquired at conception because that is the point of ensoulment, when the soul enters the 'body' (Coady, 2002; Fasouliotis, & Schenker, 2000). As Holland (1990) writes "You and I are human beings. There is only one concept of 'human being'- the biological one" (p. 35). Lugosi (2005) contends that a human life is a person from the time of conception. He defines a person as a living organism of the species *Homo sapiens*. His definition applies to all persons living both inside and outside the womb.

Accepting this argument requires accepting the religious views that underlie it, in particular concerning the existence of souls. Noonan (1991) proposed that the process of human genetic coding, in which the zygote receives the full 23 pairs of chromosomes that make up its human genetic code, should be considered the point at which a human being with a right to life comes into existence. However, many are unable to accept the view that a zygote which is a single cell, is a human being with full moral status and a right to life. As critics have pointed out, any human cell has the full genetic coding of a human being, yet surely we would not want to say that any human cell has the full moral status of a human being. The view that full

personhood and consequently moral status is established at the point of conception faces some significant challenges. Liberationists argue that the unborn are not human beings because they do not possess the characteristics of human beings (Lugosi, 2005). Other accounts locate the threshold for moral status at a certain point following conception. For example, for some, the demarcation point has been quickening, the first time a pregnant woman feels the independent movement of the foetus (Noonan, 1991). This view will lead us to the fetal viability standpoints.

White (1991) proposed that threshold for moral status is viability, the time at which the fetus becomes capable of surviving outside of the woman's body. However, a number of points must be kept in mind. First, the point of viability is debated, as reached at between twenty and twenty-eight weeks of pregnancy, and continues to shift as neonatal medical technology and knowledge develops. The main problem with the viability criterion is that it is entirely dependent on the technological skills (Gillon, 2001). Technological advancement in artificial incubation may in due course make ex-utero survival of a fetus possible significantly earlier than is currently the case. Furthermore, it is claimed that a fetus' point of viability depends upon other factors and circumstances, such as its weight and even its ethnic origins (Lotz, 2012). Finally, care needs to be taken with any notion of 'capacity for independent survival', since that term relies upon a stark contrast being drawn between dependence upon uterine support and dependence upon technological support. A fetus born at 24 weeks gestation is in no real sense capable of surviving independently, unless by 'independently' we simply mean 'outside the uterine environment' (and this would reduce the argument to the claim that a fetus should be accorded moral status once it can survive outside the uterine environment because it can survive outside the uterine environment) (Lotz, 2012).



**Sentience.** One influential argument maintains that it is the emergence of actual consciousness and sentience that marks the dividing line between beings with moral status and those without. Only a being that is conscious and capable of experiencing pleasure and pain can be said to have interests, in pleasure and the avoidance of pain (White, 1991) for example, and may on that basis be accorded rights to protect those interests (Feinberg, 1984; Singer & Kuhse, 1986; Steinbock, 1992).

Science does not yet permit an exact identification of the point at which consciousness and sentience are manifested in human beings. Many neurophysiologists believe that the human fetus begins to possess a rudimentary capacity for sentience at some stage in the second trimester of pregnancy (Warren, 1993). It is concluded that the basic neuronal substrate required to transmit somato-sensory information develops by mid-gestation (between 18 to 25 weeks gestation), however, the functional capacity of the neural circuitry is limited by the immaturity of the system. Thus, between 18 to 25 weeks gestation is considered the earliest stage at which the lower boundary of sentience could be placed. At this stage of fetal development, however, there is little evidence for the central processing of somato-sensory information. Before 30 weeks gestational age, EEG activity is extremely limited and somato-sensory evoked potentials are immature, lacking components which correlate with information processing within the cerebral cortex. Thus, 30 weeks is considered a more plausible stage of fetal development at which the lower boundary for sentience could be placed (Tawia, 1992).

Warren (1993) argues that it is widely believed that prior to that stage the fetus manifests only unconscious reflexes and not the behaviours and responses suggestive of sentience. There are important implications of the sentience criterion for the question of the moral permissibility of TOPs. On the one hand, a TOP at an early stage of fetal development presents no serious

moral problem in terms of the impact upon the fetus itself. According to this view, an early term fetus is not a being with an interest in its own continued life. If left to develop normally, the fetus will develop into a sentient being and therefore a morally significant being, one with an interest in continued life and perhaps a right to life. However, until the fetus has become sentient it does not have such an interest, and cannot therefore have such a right either.

Late term TOPs, on the other hand, do pose a moral problem according to the sentience account. However, it is important to note that the sentience criterion does not entail that a late term TOP is morally impermissible. Warren (1993) argued that it does not follow that late term abortion is morally equivalent to murder of an existing person. As she stated, “the principle of respect for the interests of sentient beings does not imply that all sentient beings have an equal right to life” (p. 309).

More recently, Lotz (2012) argued that to retain the sentience criterion, an alternative to the ‘equal moral status’ view is to distinguish between different sentient beings on the grounds of differing degrees or intensities of experiences such as suffering. For example, it might be claimed that while mice and human beings are both sentient, and therefore both have moral status, a human being’s capacity to suffer is greater than that of a mouse’. Since human beings possess capacities such as foreknowledge, fear, anticipation, and fuller recognition of dangers and of their own interests, the prospect of death and dying is a more intense experience for a human being than for a mouse, and human beings therefore suffer more. The fact that human beings typically have more projects, aspirations and plans than many other sentient beings, also means that they have a richer set of interests than many other sentient beings, and this in turn means that they have a greater chance to their interests being obstructed and experiencing suffering. Considerations such as these have lead some philosophers to posit a kind of hierarchy

of moral status, still based firmly upon the sentience criterion, but which avoids some of the serious problems faced by an equalizing sentience ethic.

Lotz (2012) indicated an implication for the abortion debate, especially concerning late term TOPs, is that a sentient fetus may be accorded lesser moral significance than the sentient adult human being in whose body it gestates, on the grounds that it lacks the equivalent capacity to suffer and have its interests prevented. She claimed that the suffering experienced by a sentient late term fetus terminated through abortion, would be less than the suffering experienced by the pregnant woman were she forced to continue with the pregnancy. Lotz (2012) stated that for example, if the woman's own life is endangered by the pregnancy, or would be by carrying the unborn child to full term and give birth, it may not be too difficult to assess the suffering and possible death of the woman as a greater evil than the suffering and death of the fetus. However, in other cases, the calculation will be more difficult. How, for example, are we to compare the emotional, psychological and physical suffering of a woman who is forced to bear, give birth to, and rear or relinquish an unwanted child or a child with disability, with the suffering of a late term sentient fetus terminated by abortion? Problems such as this have motivated some philosophers to move beyond the sentience criterion for moral status to the personhood criteria.

**Personhood.** According to Feinberg (1984), Singer and Kuhse (1986) and Steinbock (1992), the moral status of a fetus in their view is based on the notion of personhood. Certain beings typically possess not only a capacity for sentience but also for more complex mental activities like reasoning, self-awareness, social interaction and sense of responsibility. Personhood is generally defined in terms of the possession of characteristics and capacities such as consciousness, ability to reason, self-motivated activity, communication, and possession of a concept of the self (Tooley, 1972). Thomson (2000) assumes that a fetus is a human being and a

person from the moment of conception. Nonetheless, she defends abortion, arguing no woman has the moral obligation to carry her unborn fetus to term. Tooley (1999) in support of searching for a moral justification of abortion and infanticide asks, “what properties must something have to be a person . . . at what point in the development of the species *Homo sapiens* does the organism possess the properties that make it a person?”(p. 21). Tooley uses the analogy of human slavery to make the point that most people would find slavery of adult human beings morally unacceptable because, at a minimum, adults have experiences and are capable of expressing thought with language. Tooley (1999) argues that an embryo, fetus or newborn infant has none of these properties and therefore, cannot be regarded as a person. Tooley adds that an organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity. This is known as the “self-conscious” requirement (1999, P.24). Lotz (2012) concluded the personhood argument in defence of abortion starts from the view that because persons possess these morally significant characteristics and capacities, they are able to value their own lives, and the lives of other persons, to a greater extent than those beings who lack these mental and social capacities. For these reasons it is more seriously immoral to kill a person than a non-person, even a sentient non-person.

Lotz (2012) argued that although some conservative thinkers have claimed that since the fetus is a person, abortion must be morally wrong, such an argument is based on a misuse of the term ‘person’. It is confirmed that the full capacities and characteristics necessary for personhood are not manifest in the fetal stages of human development. An early stage fetus possesses little if anything in the way of consciousness, self-conceptualization, and reasoning and communication abilities. Even late-stage fetuses fail to meet the full conditions for

personhood, and for that reason the permissibility of abortion on the personhood account is not significantly altered by the stage in a pregnancy at which a termination would take place.

Hence more moderate versions of the personhood view claim that since fetuses are not yet persons their interests and rights, cannot outweigh the interests and rights of actually existing full-fledged persons (Warren, 1993, cited in Singer, 1993). In short, the greatest moral consideration and weight must be accorded to persons over non-persons. Thus the interests, preferences and rights of the biological mother must take precedence in determining whether abortion is morally permissible (Lotz, 2012).

**The potentiality argument.** Lotz (2012) stated that an attempt to base moral status on the possession of potential rather than actual, full-fledged personhood, enables the claim that fetuses are potential persons and thus potential personhood can be used in an argument against abortion.

Warren (1993) argued that there are at least three serious problems that contradict the potentiality view of moral status. First, Warren argued that it is not acceptable to treat a being's potential to reach a particular status as sufficient for establishing the rights that go along with actually reaching the status. Lotz (2012) explained that by example, in case of potential drivers, we do not on the basis of that potentiality grant persons under the age of 17 the right to a driving license.

A second problem concerns where to draw the line for potentiality. If a fetus is a potential person, then a fertilized ovum and possibly an unfertilized ovum and viable spermatozoon, could be regarded as a potential persons. Yet, as Warren (1993) pointed out, few would suggest that these entities ought to have moral status equivalent to that of full-fledged

human beings. It would be difficult to find a basis on which to extend the potential personhood account to include fetuses but exclude fertilized and unfertilized ova and spermatozoa.

According to Warren (1993) the third serious problem with use of the potentiality argument against abortion is how to weigh the interests and possible rights of merely potential persons against those of actual full-fledged persons. It would be difficult to claim that the future interests and rights of currently merely potential persons should outweigh the present interests and rights of actually existing persons. Yet it seems the potentiality argument against abortion could succeed only by defending just that view, since it would suggest that a fetus' future interests and rights should be given precedence over a pregnant woman's current interests and rights in relation to TOP. Most philosophers regard this to be implausible, and its implications for other aspects of life and morality to be undesirable and unreasonable (Warren, 1993). Therefore, fully-fledged persons, with their actual interests and rights, ought always to be accorded greater moral significance than merely potential persons and non-persons.

Lotz (2012) stated that for most philosophers from a personhood or rights-based tradition, the view that a fetus is not a person and cannot properly be said to have interests, autonomy or rights resolves the most difficult question: there exists only one being with interests, preferences and rights, including a right to autonomy, to take account of. Singer (2001) stated that we may have duties and obligations towards the fetus, even though it is a non-person; but whatever those duties and obligations are, they are unlikely to impose stronger obligations on us than the obligation to respect the interests, autonomy and rights of the woman. This argument will lead us to the next discussion on the autonomy and rights of women

**The autonomy and rights of women.** According to this view, this argument claims that even if we were to grant that a fetus is equivalent to a fully-fledged person, this would not mean that abortion is never morally justifiable. The argument was made famous by philosopher Judith Jarvis Thomson in her article 'A Defense of Abortion'. Thomson (1971) presents a thought experiment in which you are asked to imagine finding yourself connected by medical equipment to a famous but unconscious violinist with a kidney disease. The only way he can survive is for his circulatory system to be connected to someone with the same blood type. As you are the only person available, a society of music lovers has kidnapped you, had the connecting operation performed, and had you placed in hospital. You can, if you choose, order a doctor to disconnect you from the violinist, but if you do so the violinist will certainly die. On the other hand, if you remain connected for nine months, the violinist will have recovered and you can be unplugged without endangering him or yourself. The central question posed by the thought experiment is whether you have a right to unplug yourself from the violinist, or instead have an obligation to remain connected for the nine months necessary to prevent his death. Important points to note are that the violinist is a fully-fledged person with moral status equivalent to your own; and that you became attached to the violinist by no decision or intended action of your own. To be analogous to a case involving abortion, then, we need to imagine that the fetus is likewise granted full personhood status and a full right to life, and that the pregnancy is not intended.

Lotz (2012) argued that most reject the idea that you are morally required to make the substantial sacrifice to your freedom and bodily integrity that keeping the violinist alive would require. While the violinist has a need to be connected to you, his need does not entail that he has a right to be connected to you, or that you have a duty to remain connected to him. As

Thomson (1971) suggests, you have a right to refuse to make such a sacrifice. While it might be morally kind and generous of you to volunteer to make the sacrifice, it would not be immoral of you to refuse to do so, and suggesting otherwise imposes unreasonable moral demands.

In this argument the focus has shifted from the moral status of the fetus to the rights of the pregnant woman. Even if we assume that the fetus is a person with a right to life, it does not follow that abortions are never morally justified. The central claim of the argument is that respect for the rights of the pregnant woman, most importantly her right to control what happens in and to her body, justifies abortion in cases like rape, contraceptive failure, and also where there would be considerable risk of harm to the woman resulting from a continuation of the pregnancy.

Consideration of the woman's right to autonomy and liberty also suggests that in cases of serious fetal impairment and potential disability of the future child, abortion may be justified if the woman wishes (Tooley, 1972, cited in Singer, 2001). To force a woman to give birth to a child with a disability would infringe on her right to refuse to consent to substantial sacrifice of her liberty, autonomy and bodily integrity. However, the disability rights movement is arguing that abortion on the grounds of fetal abnormality is morally and legally objectionable in discriminating against people with disability and in manifesting and encouraging disrespect, hostility and contempt for these people (Gillon, 2001). Gillon argued that the argument is closely sealed if it is agreed that human fetuses are people or complete fledged-persons, and thus that fetuses with disabling abnormalities are disabled people. If that is the starting point then the argument is impeccable, and to abort, that is, to kill fetuses on the grounds that they have abnormalities that are disabling is as morally repulsive as it would be to kill adults who have disabling abnormalities. However, are people who justify abortion for sufficient benefit and who



therefore must reject the claim that fetuses are people or persons with full moral status including a right to life, to be found guilty of such discrimination if they justify abortion on the grounds of fetal abnormality? The answer is clearly no! (Gillon, 2001, p. ii8 ). What Gillon (2001) sought to justify was availability of choice to pregnant women to prevent the creation of people with disability by aborting fetuses with abnormalities that would disable the people they would become. If the response to this argument is that such fetuses already have a right to life, disabled or not, then the response is, as noted above, logically impeccable but begs the question about the moral status of the fetus by asserting that it has full moral standing. If that assertion were accepted then, as noted above, it is as morally wrong to kill a fetus with abnormalities as to kill a child or adult with disabilities, and as wrong to abort a normal fetus as it would be to kill a normal child or adult. If, however, the fetus is held not to have full moral status and not to have a right to life, then aborting a fetus with abnormality shows no more disrespect or hostility to people with disabilities than aborting a normal fetus shows disrespect or hostility to people who do not have disability. To permit people to have abortions in order to allow them to choose not to bring a person with disability into being in no way entails any undermining of our obligations to look after and care for, respect and be fair to people with disabilities who do exist. Parens and Asch (2000) concluded that although disability rights activists concerned about the abortion of fetuses with disability traits, they recognize explicitly the importance of women being able to make these reproductive decisions for themselves. In conclusion, if fetuses with disability do not yet have full moral status including a right to life, then there is simply no logical connection between making abortion available to prevent the creation of a person with disability and discriminating against people with special needs.

Lotz (2012) explained that this argument has gained considerable support amongst philosophers, particularly feminist philosophers. While many do not actually agree that a fetus is a person, the argument shows that even if everyone agreed that fetuses are persons, it would not establish the immorality of abortion. The fetus may be a person, but abortion involves a conflict between two persons, the woman and the fetus. Appealing to the different capacities of the two persons in question, most agree that there are scant grounds for according greater moral consideration to the fetus than to the woman. Unlike a woman, a fetus does not yet possess autonomy, a desire and interest in continued existence, a right to make decisions about its own body and the like; and it is difficult to argue that the mere potential for such capacities outweighs actual possession of them (Lotz, 2012).

### **Summary**

This chapter provided some basic arguments concerning the moral permissibility of abortion. Two broad arguments have discussed. The first argument provided the claimed views on the moral status of the fetus and whether it is a sentient being, a person or a potential person. The second argument discussed the woman's autonomy and rights versus the fetus's autonomy and rights.

## CHAPTER FOUR

### Research Methodology and Methods

This chapter presents the methodology and methods used to explore women's experience of termination of pregnancy for fetal abnormalities. I describe the research sample, the setting, data collection, data management and analysis strategies and ethical considerations. Finally a discussion that addresses rigor is presented.

The purpose of this study was to understand the long-term life experience of women after elective second trimester termination of pregnancy (TOPFA) for fetal abnormalities from the perspective of the women. I sought to gain an in-depth understanding of the meaning of women's lived experience of TOPFA more than five years earlier. To guide my research I asked: what is the lived experience of women who have gone through an elective second trimester termination of pregnancy for fetal abnormalities more than five years ago? What does having experienced TOP mean to women in the long term?

The study supported a qualitative approach that focused on human experience and subjectivity rather than objectivity. Qualitative methods are particularly useful when describing a phenomenon from an individual perspective, that is, the perspective of the woman who has experienced a pregnancy termination for fetal abnormality. A qualitative approach involves the systematic collection and analysis of more subjective narrative materials using procedures in which there is minimal researcher-imposed control (Polit & Hungler, 1993). Qualitative researchers emphasize the dynamic, holistic, and individual aspects of the human experience and attempt to capture those aspects in their entirety within the context of those who are experiencing them (Polit & Hungler, 1993). Since I sought to uncover the meaning of the lived experience of

these women, phenomenology, founded in the interpretive paradigm, was considered a suitable approach for my research (Holloway & Wheeler, 2002).

Lived experience is the starting and end point of phenomenological research (van Manen, 1997). Phenomenology explores the way people think, perceive, and interpret interactions, how they live and talk about everyday-life events and interactions, and assign meaning to them (Goffman, 1995; Lincoln & Guba, 1985; Marshall & Rossman, 1999; Sheehan & Craig, 1998). Phenomenological researchers search to find a deeper understanding of the meaning of everyday lived experiences (van Manen, 1984; Creswell, 2007). The phenomenologist's centre of attention is the way humans experience the world (van Manen, 1997). Phenomenology moves inquiry beyond the public appearance of phenomena (what is taken-for-granted) to attain a deeper and authentic understanding of an individual's lived experience through rich description and interpretation.

### **Historical Background of Phenomenology**

In adopting phenomenology as a research approach in this study, it is important to have a historical overview of the development of phenomenology as a philosophy. Historically, phenomenology developed into two primary schools of thought in the early 1900s. These two schools are: transcendental and hermeneutic/existential. Edmund Husserl's philosophy (1859-1938) formed the basic constructs of transcendental phenomenology. His student, Martin Heidegger (1889-1976), differed philosophically from Husserl and formed the foundation of hermeneutic/existential phenomenology.

The philosophical tradition that was shaped by Edmund Husserl, a German philosopher was a radical departure from the classical Western philosophy of that era (Benner, 1994). Philosophers such as the logical positivists described the nature of knowledge as being that

which can be perceived and quantified by the physical senses (Guba & Lincoln, 2005). In contrast, Husserl (1913/1931) assumed that all truths cannot be measured by a mathematical-based instrument without a concern for the subjective experience. He argued against this bias toward objective existence, as it presupposed the world. Husserl's (1913/1931) writings led to the development of transcendental phenomenology, a conceptual approach used to describe a phenomenon as it is experienced (Rapport & Wainwright, 2006). Husserl (1913/1931) claimed that by describing the way we perceive the world, we can determine the meaning of phenomena in the world. This exploration is based on putting the researcher's assumptions and previous experiences on hold so that what is examined will have a firm grounding in perception (Husserl, 1913/1931; Rapport & Wainwright, 2006).

Husserl (1913/1931) described that all preconceived ideas need to be set aside in order to clearly see the world. In the state of pure consciousness, the mind can focus on objects of consciousness, whether they are physical or abstract concepts (Husserl, 1913/1931; Rapport & Wainwright, 2006). Husserl (1970) envisioned phenomenology to be a process whereby describing the lived experience would take into account three essential notions: intentionality, essences, and phenomenological reduction, otherwise known as bracketing.

**Intentionality.** According to Husserl's theory of intentionality (1969), our consciousness is always aware of an object or directedness toward an object. The concept of intentionality lays the foundation of Husserl's phenomenological philosophy. "For phenomenology, consciousness is intentional which means that acts of consciousness are always directed to objects that transcend the acts in which they appear" (Giorgi, 1988, 171). Object is used as a generic term referring to entities in the external world such as facts, emotions, dreams, concepts, or anything that presents itself to the consciousness (Hein & Austin, 2001; Paley, 1997).

**Essence.** The essence of a phenomenon as defined by Husserl (1913/1931) is understood when the basic structure, or parts, are viewed untarnished in our pure consciousness (Husserl, 1931; Rapport & Wainwright, 2006). Husserl (1913/1931) wrote that the essence of a phenomenon is discovered when its basic structure is clear and complete. The essential structure (essence) identifies what a phenomenon is and what it is not.

**Phenomenological reduction.** Phenomenological reduction is the process of putting on hold all assumptions of the natural attitude (Husserl, 1913/1931). Phenomenological reduction is a return to original awareness regarding the phenomenon under investigation. Husserl specified how to describe, with the scientific exactness, the life of consciousness in its original encounter with the world through phenomenological reduction (Husserl, 1970). He challenged individuals to go back to things themselves to recover the original awareness. He believed that in order to achieve description in its purest form, one must practice phenomenological reduction through bracketing. He claimed that by using bracketing, which is holding in abeyance one's presuppositions or theories, and by deep reflection, one could seek the roots or beginning of knowledge in the subjective processes (Husserl, 1970). Although the origins of phenomenological inquiry can be traced back to the philosophy of Husserl (1970) and the study of consciousness, the phenomenological tradition has been hermeneutically shaped by the foundational writings of philosophers such as Heidegger (1962), Gadamer (1989), and Merleau-Ponty (1962).

The work of Heidegger (1962), a student of Husserl, formed the foundation of hermeneutic/existential phenomenology. Phenomenology was reinterpreted as hermeneutical, or interpretive, phenomenology by Heidegger (1889-1976). Whereas Husserlian phenomenology tries to describe essences, hermeneutic phenomenology is designed to uncover

and understand the structures, that is, the internal meaning structure of the phenomenon (van Manen, 1997). Existentialism is a school of philosophy with a focus on the state of existence or the experience of being. The philosophical framework of existentialism was introduced to Western philosophy by Soren Aabye Kierkegaard (1843/1885). The continued development of the philosophical concepts of 20th century existentialism grew from the work of Heidegger and the post WWII French philosophers Jean-Paul Sartre and Maurice Merleau-Ponty (Benner, 1994).

Heidegger had a different epistemological focus than Husserl. He adopted an ontological perspective where the form and nature of reality and being are stressed (Heidegger, 1982). Heidegger sought to answer the question of the meaning of being and one's situatedness in the world (Koch, 1995). He believed that humans are hermeneutic (interpretive) beings capable of finding significance and meaning in their own lives. Heidegger's book (1962) *Being and Time*, focuses on the individual within the lifeworld.

**Lifeworld, or being-in-the-world.** Humans construct meanings of their everyday experience that cannot be separated from the world in which they live. Heidegger (1962) introduced the concept of *dasein* (the human way of being in the world) to emphasize that individuals cannot abstract themselves from various contexts that influence their choices and give meanings to the lived experience. A central tenet of Heidegger's (1962) thought was that the relation of the individual to his lifeworld should be the focus of phenomenological inquiry. Heidegger used the term lifeworld to express the idea that individuals' realities are invariably influenced by the world in which they live. Another term, *being-in-the-world*, was used by Heidegger to emphasize that humans cannot abstract themselves from the world. Interpretation

is a natural part of what humans do to understand and make meaning of the world and is fundamental to being-in-the-world (Heidegger, 1927/1962).

**Fore-structure.** The assumptions of *dasein* and situatedness form the basis for preunderstanding or, as Heidegger (1962) called it, a forestructure of understanding. It is a prior awareness and anticipated meaning used during the process of interpretation. The fore-structure of understanding consists of: fore-having, which means all individuals come to a situation with practical familiarity or background practices from their own world that make interpretation possible and refers to the taken-for-granted background; fore-sight, which means that the sociocultural background provides a point of view from which to make an interpretation; fore-conception, which means that sociocultural background provides a basis for anticipation of what might be found in an investigation. Heidegger (1962) declares nothing can be encountered without reference to the person's background, understanding, and every encounter entails an interpretation based on the person's background, in its "historicality".

**Time.** Interpretation cannot be achieved unless it is grounded in time, a fundamental structure of human existence according to Heidegger. Time can take many forms, such as the time on a clock or calendar time. For Heidegger, time is the horizon for all understanding of Being and a way to interpret it. Time is experienced and given meaning within the life of the person in-the-world. A person is temporally situated in-the-world. Temporality allows for past, present and future to be experienced as a unity, which means that what is experienced in the past is related to what is expected to be experienced in the future and that awareness is as one, in the present. When conducting interpretive Heideggerian phenomenology researchers must situate themselves, the participants and their experiences in time so that ontological understanding can be achieved (Mackey, 2005).



**Space.** Spatiality grounds the person in a specific location. This relates to being-in-the-world because everything in the world belongs somewhere, or as Heidegger referred to it "the there" (Heidegger, 1962). Being in "the there" results in one bringing something close to him/her at this point or experiencing it as distant. Space can also be experienced in terms of horizons. What is brought into the foreground of the horizon of space and what is kept in the back-ground depends on the where the individual is situated in-the-world. This concept of space requires the researcher to listen to what the participant is describing, specifically picking out what is brought into the foreground and what is experienced as remote. This process allows the researcher to describe, analyze, and reflect up the state of concern (Mackey, 2005). Heidegger developed the concept of the hermeneutic circle to illustrate an interpretative process that involves a back and forth movement between parts and whole, between a person's forestructure of understanding and what is experienced (Moran, 2000; Wojnar & Swanson, 2007).

Gadamer (1989), Heidegger's student, further elaborated on existential ontological hermeneutics. The hermeneutic circle from Heidegger was taken to describe the experience of moving dialectically between the part and the whole of an experience. Gadamer (1989) affirmed the position of researcher in the hermeneutic circle and placed a stronger emphasis on language and text. Gadamer claimed language and history supply the shared sphere in the hermeneutic circle. Gadamer (1989) described the hermeneutic circle as the fusion of horizons. In order to understand the meaning of things being studied, Gadamer argued that one remains open to and also embraces the meaning held by the text. To Gadamer (1989), the real meaning of the text is not just that which is understood by the original author; each interpreter places context within the new interpretation. Each reader produces a somewhat new interpretation based on his/her context. Gadamer (1989) indicated that there is no finality of interpretation and there is no

absolute truth. Continuous reinterpretation is a part of what Gadamer called the “fusion of horizon”. A horizon in nature is not an immovable boundary, it moves and one is invited to move with it. This is similar for hermeneutic phenomenology. The horizons of experience, before, after, and in the present, are continually fused as people self-interpret or are interpreted by others. Each part of the fusion brings with it context and history (Gadamer, 1989).

Gadamer (1989) built upon Heidegger’s work by stressing that the observer cannot be separated from the meaning of the experience being studied since the interpretation of the experience and the language that is used are germane to its meaning. Gadamer (1989) claimed that the researcher becomes an instrument in the data collection process and is intertwined with the interpretation of acquired information and its meaning.

van Manen (1997) and Merleau-Ponty (1945/1962), were influenced by Husserl and share parallel ideas on the definition of phenomenology. Phenomenology according to Merleau-Ponty (1962) is the study of essences. Thus, an appropriate topic for phenomenological inquiry is determined by the questioning of the essential nature of a lived experience. Phenomenology as explained by van Manen (1997), “asks for the very nature of a phenomenon, for that which makes a “something what it is- and without which it could not be what it is” (p.10). The experiences of individuals as they are lived in the world, and the meanings derived from the lived experience are the essence of the phenomenon.

Merleau-Ponty’s philosophy was a phenomenology of perception. According to Merleau-Ponty (1962), experience and perception are our original modes of consciousness. Perception is defined as “access to experience in the world” (p.4). We are in the world bodily and the act of perceiving takes place through the body. Perception of an object depends on the context in which that object is experienced for interpretation and meaning. Phenomenology from this

perspective describes the lived experience through one's perception of the world, which Merleau-Ponty termed the "primacy of perception" (Merleau-Ponty, 1962).

Merleau-Ponty (1962) posited that all humans experience the world through four fundamental existential themes: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality). Spatiality is the perception or feelings created by the space around us (Merleau-Ponty, 1962; van Manen, 1997). Corporeality refers to the fact that we are always physically or bodily a part of the world (Munhall, 2007; van Manen, 1997). Temporality refers to "subjective time as opposed to clock time or objective time" (van Manen, 1997, p.104). It might be well described by the expression "time flies when we're having fun." Finally, relationality is the interpersonal space we share with others.

Fundamentally, these four existentials provide a window to how a person experiences the world. van Manen (1997) wrote,

This is not difficult to understand, since about any experience we can always ask the fundamental questions that correspond to these four lifeworld existentials. Therefore, spatiality, corporeality, temporality, and relationality are productive categories for the process of phenomenological question posing, reflecting and writing" (p.102).

Max van Manen was deeply influenced by Merleau-Ponty's writing on embodiment. Rooted in the philosophy of Merleau-Ponty, the core concept of embodiment—"how we live in and experience the world through our bodies, especially through perception, emotion, language, movement in space, time and sexuality" (Wilde, 1999, p.27). For Merleau-Ponty (1962), the body becomes the vehicle by which human beings engage in the world. Embodiment also means being situated within the world, and being affected by social, cultural, political, and holistic forces (Wilde, 1999). With Merleau-Ponty's belief in the sacredness of the body, he explained

that when the relationship between body and world is disturbed, a person's existence is shaken (Merleau-Ponty, 1962). The concept of embodiment was relevant to this research study.

Applying the concept of embodiment while researching the experience of termination of pregnancy for fetal abnormality (TOPFA) will be helpful in understanding this experience.

Pregnant embodiment involves the woman experiencing her body as herself yet not solely herself (Young, 1984). The physical growth and movements of the fetus within the mother's body depicts a notion of separateness. Yet the pregnancy experience, Bergum (1997) suggests, involves a relationship as "one with the other" (p.144) rather than being two separate opposing entities. The fetus presence is not detached from the mother's being, but is part of the mother's lived experience of her pregnant body. Rothman (2000) describes pregnancy as a physical, social and emotional relationship between the mother and her fetus.

When a woman learns she is pregnant, she can give the physical changes in her body a place in her life. She begins to experience a change in her bodily relation with self and others. The symptoms she has noticed are not just discrete, unrelated bodily behaviours but together they add up to something, a new kind of self-knowledge (Young, 1984; Van der Zalm, 1999). In one sense, the wholeness of her pregnant body- pregnant self works as a "being with child" process. In another sense, she recognizes that she carries another being within her, one that is separate from her, yet, part of her (Van der Zalm, 1999). Bergum (1989) called the pregnancy as the time of being with child "a primordial relationship, "a mysterious union", "a commingling, an entangling, an interlacing that goes beyond companionship", where mother and unborn child are one, "an indissoluble whole, yet two, a mother and a child" (1989, p. 53). To be with child is to grow at the centre: to harbour a developing child at the core of one's embodied being (Van der Zalm, 1999). When the fetus moves, the woman feels the baby's touch from within, she begins to

find its being and that is when she distinguishes her pregnant self from the self that she was before. By feeling the baby touch her from inside, she knows that the baby is separate from her, yet enclosed within her body (Van der Zalm, n.d.).

Hermeneutics/existential phenomenology involves going beyond a simple description of a phenomenon as taken from narrative (Dowling, 2007) and argued by the reductionis method adopted by Husserl (1970), to understand the lived experience through bracketing one's pre-suppositions. Heidegger (1962) argued against the ability to describe a phenomenon without an understanding of the ontological view of participants and their context and called for the utilization of appropriate contextual interpretation.

### **van Manen's Research Approach**

Max van Manen, a contemporary scholar was influenced by the work of Heidegger, Gadamer, and Merleau-Ponty. His type of phenomenology is located in what is termed the Dutch school, as it is a combination of descriptive and interpretive phenomenology. He uses the term description to include both interpretive (hermeneutic) as well as descriptive phenomenological element (Dowling, 2007). van Manen (1997) stated that some philosophers make distinctions between phenomenology as a pure description of lived experience and hermeneutics as interpretation of experience via a written text or some other symbolic form such as art, yet others argue that all description is ultimately an interpretation of that which has been described.

As indicated by van Manen (1997), a good phenomenological description is collected by lived experience, is validated by lived experience and it validates lived experience. van Manen stated that phenomenology is the systematic attempt to uncover and describe the structures, the internal meanings structures, of lived experience. van Manen (1990, 1997) has defined

phenomenology as “the study of the lifeworld- the world as we immediately experience it pre-reflectively rather than as we conceptualize, or reflect on it” (p.9). The aim of phenomenology for van Manen is to bring deeper understanding of the nature or meaning of each person’s everyday experience. The text developed from phenomenology is both a reflective re-living and a reflective appropriation of something that holds meaning, rather than an introspective retelling of the experience (van Manen, 1997). van Manen’s approach attempts to explore the structure of the human life world. The structure of the human life world as described by van Manen (1997) consists of four fundamental life worlds or four existentials, namely, lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality).

The lived experience of women who experienced TOPFA was explored based on the philosophical inquiry of a hermeneutic/interpretive and phenomenological nature as articulated by Heidegger (1962) and van Manen (1997). This study aimed to both describe and interpret the nature of women's lived experience of TOP for fetal abnormality. van Manen’s (1997) approach was utilized as the methodological framework to guide this study. van Manen described hermeneutic phenomenological research as a dynamic interplay among six research activities of human science, namely:

**Turning to the nature of lived experience.** van Manen (1997) describes that phenomenological research is driven by a commitment of turning to an abiding concern. Turning to the phenomenon of interest will offer the researcher the full thought of wholeness of life and the sense of certain aspect of human existence. The researcher will gain deep understanding of the essential nature of the phenomenon by asking in-depth questions and describe it with insightfulness.

**Investigating experience as we live it.** van Manen (1997) provides the importance of investigating experience that phenomenological research believes that the practical wisdom is in the understanding of the nature of lived experience itself. "Being experienced is a wisdom of the practice of living which results from having lived life deeply" (p. 32). van Manen suggests the researcher actively explore the lived experience and conduct personal description of a lived experience as a starting point of the study.

**Reflecting on the essential themes that characterize the phenomenon.** van Manen (1997) states that "phenomenological research, unlike any other kind of research, makes a distinction between appearance and essence, between the things of our experience and that which grounds the things of our experience" (p. 32). He further proposes that true reflection on lived experience is achieved by asking "What is it that constitutes the nature of this lived experience?" (p. 32). van Manen (1990) asserts that hermeneutic phenomenological human science research attempts to explore the structure of the human lifeworld. The structure of the human lifeworld as described by van Manen: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality) was used as a guide for reflection in this research process. I was trying to understand and uncover the meaning of lived space for the study participants. Sense of place, what makes place (home/hospital) negative or positive to the participants was explored. The meaning of the lived body for the participants was explored. The relationship of the participants' bodies with their surroundings and perception of body prior to, during and after the experience of TOP was examined. Lived time is time as it is perceived in relation to circumstances. How participants gave meaning to the time spent prior to, during and after the TOP experience was explored. Lived relations, the relationships between the participants and their families, friends, and healthcare providers were explored.

**Describing the phenomenon through the art of writing and re-writing.** van Manen (1997) suggests that to do research in a phenomenological sense is rendering something into language. In order to do this, writing and re-writing was undertaken. Language and responsiveness to phenomena was used to transform the phenomena precisely as it showed itself. I wrote and re-wrote as further, reflection; so that through expressing the meaning, or the essences of the women's experiences, it was better known through illuminating the meaning of the women's lived experience of TOPFA.

**Maintaining a strong and oriented relation to phenomenon.** Through this activity van Manen (1997) indicates that the researcher should remain strongly related to the research question and the phenomenon under study in order to guard against aimlessness. Being fully oriented in relation to the phenomenon assisted me to gain full and human insight. By being focused on the main structure of the experience and being attentive to the goals of my research, I was able to avoid being pulled away by unneeded details.

**Balancing the research context by considering parts and whole.** van Manen (1997) suggests that the researcher needs to constantly measure the overall design of the study in order to maintain the balance of all the parts in the total structure. It is necessary to step back and look at the totality of the text to consider how each of the parts contributes towards the whole.

## **Recruitment**

Using a purposive sampling approach permitted me to purposefully select women who had terminated their pregnancy for fetal abnormality allowing me to deepen my understanding of this experience. All participants needed to be conversant in English and had experienced an elective second trimester termination of pregnancy for fetal abnormalities more than five years ago. Research on traumatic grief reveals that emotional suffering can be prolonged well beyond



two years (Sprang & McNeil, 1995). Five years post termination was chosen as a cut-off point to distance this study from previous research which has focused primarily on the first two years post pregnancy termination.

To access eligible women, a letter was sent to hospitals, perinatal clinics, public places, and community health services facilities explaining the research study and asking to place the poster of the study to be available for their visitors. Participants were recruited through posters, online announcements, and by word of mouth. Posters introduced the research study to the potential participants and included the researcher's contact information in order for the participants to contact the researcher. To access eligible women I provided my phone number and email on the posters, or via the referring individual or online. Interested participants were asked to contact me directly by phone or email on a private and secure phone line. Posters about the study were placed in the Western University bulletin boards, hospitals, walk-in clinics, laundromats, malls and libraries. Moreover, a website message including the notice regarding the study was posted to World Wide Web support groups. Recruitment continued until data saturation occurred. Saturation was considered to occur when study participants described the experience in similar terms, and no new dimensions were detailed (Parahoo, 1997).

### **The study sample**

Ten women who had experienced elective second trimester termination of pregnancy for fetal abnormality 5 or more years earlier comprised the study sample. The age of the participants ranged between 31 and 51 years. Due to including the Internet participants, geographic variety was present. Three women were from Canada, six were from United States of America (USA) and one Canadian woman who lived in USA. Seven participants were recruited from online support groups, one woman was recruited by word of mouth through a shared friend and two

women were recruited through the study poster. All the women identified their ethnic origin as Caucasian or Northern European. Nine women were married and one was divorced. The sample had a high educational level with all reporting having, or working on, a postsecondary degree. Two women were employed in the medical field, four were employed in different fields and four were stay at home moms. In terms of current religious preference, two endorsed Catholicism, four were Protestant denomination, one was Agnostic, and three denied a current religious preference. The TOPFA occurred between five and 19 years prior to the interview. All of the women had no prior history of fetal abnormalities and had no high risk conditions. The fetal abnormalities included Anencephaly, Spina Bifida, Hydrocephalus, Potter's syndrome, Trisomy 18, Down syndrome, and heart defects. The following table displays the participants' characteristics and contextual data.

Table I

*Participants' characteristics*

Name	Age	Marital status	No. of children	Country of residence	GA	Time since TOPFA	Place of TOPFA	Race/ethnicity	Religion
Nancy	51	Divorced	1	Canadian lives in USA	18 wks	19 yrs	Abortion clinic	Caucasian	Catholic
Paige	39	Married	2	Canada	22 wks	7 yrs	Hospital	Caucasian	Protestant
Jennifer	41	Married	2	Canada	19 wks	8 yrs	Hospital	Caucasian	None
Diana	39	Married	3	Canada	24 wks	6 yrs	Hospital	Northern European	Protestant
Tiffany	31	Married	3	USA		6 yrs	Hospital	Caucasian	Protestant
Susan	47	Married	None	USA	18 wks	7 yrs	Hospital	Caucasian	None
Hillary	48	Married	3	USA	14 wks	5 yrs	Abortion clinic	Caucasian	Catholic
Lizzie	37	Married	3	USA	19 wks	5 yrs	Hospital	Caucasian	Protestant
Lucy	43	Married	3	USA	19 wks	5 yrs	Abortion clinic	Caucasian	None
Jessica	37	Married	1	USA	19 wks	5 yrs	Hospital	Caucasian	Agnostic

## **Data collection methods**

A brief explanation of the study was provided through a telephone call or through an email message to women who had contacted the researcher and expressed an interest in the study. A letter of information was sent via email to all women who agreed on participation (Appendix A). Women who met the study criteria and were interested in participating were invited to a private interview at a mutually accepted time and location in case of face-to-face interviews, and accepted time in case of telephone interviews. The location of the face-to-face interviews varied and included, participants' home and work place. In eight cases, face-to-face interviews were not feasible and telephone interviews were conducted. Informed consent was obtained and signed at the beginning of the first interview (Appendix B), and in case of telephone interview, the consent form was read to the participants and agreement was taped-recorded. The interviews were conducted over a nine month period from January 2012 until September 2012 and were the primary data collection strategy used. The length of the interviews was between 1 to 2 hours and they were conducted in a conversational style. All interviews were audio-taped and transcribed verbatim with the participants' permission.

Data collection included in-depth semi-structured interviews utilizing administration of a demographic questionnaire included current occupation, years of education, current religious preference and obstetric history (Appendix C) and an interview guide (Appendix D & E). Two interviews were conducted. Broad, open-ended questions were used to help me gain in-depth, holistic understanding of the women's experience of TOPFA. A general question about the women's life before the pregnancy was posed to start the dialogue followed by some guiding questions. To continue the conversation I asked a general question: "Tell me about having TOPFA experience"; "What this has been like for you?". Additional probing questions were

used to clarify statements a participant made and to allow for further understanding of the experience. Many women talked freely with little need for direct verbal involvement or probing from me. When a conversation needed prompting I would use non-verbal cues such as nodding my head. Sometimes I used verbal probes asking for clarification such as "Can you explain a bit more ? Can you give me an example, or what do you mean by that?". A conscious effort was made by the researcher to refrain from asking questions that might pressure the participant to respond in a particular way.

At the beginning of each interview, I introduced the general theme of the investigation, responses to TOPFA that being explored. Using open-ended questions elicited detailed accounts about long-term experience of termination of pregnancy for fetal abnormality and helped to focus the participant's thoughts, while providing opportunities for expression of individual impressions. I conducted the interviews using a conversational style to help women tell their story freely without interference from my side. I relied on the spontaneous generation of clarifying questions as they told their story.

Silence was also employed to encourage the participant to continue expressing their thoughts and to garner a deep and rich understanding of the experience. During the interviews, I attempted to be sensitive to the emotions the participants were expressing. The participants in several interviews became tearful; at this moment, the interview was stopped and resumed only when the participant indicated her readiness to continue. At the end of the interview, none of these participants mentioned being upset or anxious. Field notes were kept, describing the researcher's notes during the conversation and also the off-tape comments that were made by the participants. According to Cohen and colleagues (2000), field notes reflect "body language, tone of voice, environment distraction, the dress and demeanour of the participants, and the important

symbols that are hanging on the walls or standing on tables and bookshelves" (Cohen, Kahn, & Steeves, 2000, p. 65). Tone changes, restlessness, silence periods, and facial expression were examples of some observed behaviours that were recorded in the field notes during and immediately after the interview.

At the conclusion of the interview, I offered to email the support services should the interview trigger emotions that they wished to discuss. These resources included, "Family Services Thames Valley", Bereaved Families of Ontario", "The London Crisis Pregnancy Center", and online support groups. A follow-up phone call or email was made with the participants' permission to make sure they did not have any emotional troubles.

During the follow-up phone call, I asked participants for permission to make a second contact to review the emerging themes. In the beginning of the second interview the participants were provided with a preliminary outline of the emerging themes. Opportunity was provided for any expansion or redirection of the data. The second interview was conducted to share the emerging themes with the participants and to reflect together, the participants and myself, on the meaning of themes. I shared the preliminary themes with two participants who were available for the second interview. Opportunities were provided to the women to reflect on the themes that emerged from the previous interview in order to aim for as much interpretive insight as possible (van Manen, 1997). Both the participants and I attempted to interpret the significance of the preliminary themes in the light of the research questions. I asked myself and the participants "Is this what the experience is really like?". Time was given for participants to carefully read the themes. A semi-structured interview guide was used in guiding the second interview (Appendix E). This second interview provided the opportunity for member checking

and allowed me, and the participants, to engage in interpretative conversation reflecting together on the emerging themes.

### **Data Analysis**

The purpose of analysis in hermeneutic phenomenological research is to explicate the meaning found in the lived experience of the participants; this was done by finding the essential or invariant themes in the text that comprise the experience and the language that capture meaning of these themes.

According to van Manen (1997), “Phenomenological themes may be understood as the structure of experience, so when analyzing a phenomenon, we are trying to determine what the themes are, the experiential structures that make up the experience” (pp. 78-79). To develop the themes, the researcher first engages in a dialogue with the research participants who are interpreting their experience and whose experience is being interpreted by the researcher. Next, the researcher engages in a dialogue with the full text that is comprised of all the separate interviews and interprets the totality of the experience from all participants. As Gadamer (1986) says, “When we interpret the meaning of something we actually interpret an interpretation” (p. 68) or an interpretation of many interpretations.

van Manen’s (1997) hermeneutic phenomenological approach was used in the process of data analysis. There are four processes in this approach, namely isolating themes, reflecting on the four lived worlds, formulating thematic categories, and phenomenological writing. Thematic analysis refers to the “process recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work” (van Manen, 1998, p.78). This process included uncovering thematic aspects, isolating thematic statements, and composing linguistic transformations. Thematic aspects were discovered by repeatedly reviewing the transcripts in an

attempt to find significant statements and understand the meanings of the experiences. In hermeneutic phenomenology, data collection and data analysis occur simultaneously, rather than sequentially, to capture the whole structure of the phenomenon. In order to heighten my own awareness of presuppositions, assumptions, and bias, I undertook the process of preliminary reflection upon my own personal experience and the literature reviewed, by journaling and creating an initial written description of the phenomenon. When reflective journaling, the researcher maintains an ongoing record of personal insights gained on the topic under study (van Manen, 1997). Cohen and colleagues indicated that maintaining a journal promotes continued awareness of biases, leading to a more rigorous study (Cohen, et al., 2000). Keeping memos were utilized throughout the analysis process. Memos are notes that describe the researcher's insights as the analysis proceeds (Cohen, et al., 2000). As I listened and read I made reflective notes about any observation such as laughter, silences, or changes in the tone of voice. I recorded my thoughts, ideas, and evolving insights as the research proceeds.

Following my first interview with each woman I began a reflective process in an attempt to fully understand each woman's TOPFA experience. I asked some questions to help me understand the meaning of the woman's experience: "What is this woman trying to tell me about her experience? What does she talk about? What stories are being told? What words does she use to describe her experience?". Immediately following my conversation with each woman, I listened to each audiotape for clarity. A trained transcriptionist transcribed all the interviews. After transcribing, I listened to the tapes and compared the voice recording to the transcribed interviews to identify any mismatch or discrepancies.

Themes were isolated from the transcripts by a wholistic and highlighting approach as suggested by van Manen (1997). By following the wholistic approach, after each interview, I



listened to the taped interview and read and re-read each written transcript to capture the experience as a whole. After reading a transcript several times, I used the highlight approach to identify words, significant phrases and statements and coded these pieces of text. Coding is the process of assigning tentative themes to phrases or statements (Cohen, et al., 2000). The transcripts were analysed line by line and initial coding was conducted by highlighting key words and phrases that were repeating throughout each transcript. These initial codes were organized and collapsed into common categories and finally themes. As I read the text as a whole, it became clear how each story characterized a particular theme. Further reflection revealed commonalities between the women's stories. Listening to the tapes and re-reading the interview texts many times, I generated several potential themes and sub-themes. It was necessary to determine the themes that can be seen as meaningful to the phenomenon. To do this, differentiation between essential themes or themes that relate to the phenomenon, and themes that are of less significance to the phenomenon were made. To make a distinction between these two types of themes, I asked myself: "Is this experience still the same if we conceptually change or delete this theme from the experience? Does the experience without this theme lose its fundamental meaning?" (van Manen, 1997, p. 107). If it was found that a theme could affect the meaning of the experience when changed or deleted, the theme was considered to be an essential theme.

When the initial thematic structure of the phenomenon was formulated, I started writing and rewriting the descriptions of meanings within each thematic category or essential theme. I wrote, rewrote, and revised the thematic categories. In this process, I used aesthetic materials such as poems and media stories to assist me to fully understand the phenomenon (van Manen, 1997). The end result was to describe and interpret the possible

experience of women who had experienced termination of pregnancy for fetal abnormality (van Manen, 1997). This description and interpretation, co-created by the researcher, resulted in the development of the final themes of this study. Ultimately, six themes were revealed as essential to understanding the phenomenon of TOPFA experience, that is, these themes point to what makes the experience what it is for the women.

### **Credibility and Authenticity of Interpretive Phenomenology**

The criteria, credibility and authenticity, as described by Guba and Lincoln, were used to address the quality and robustness of this interpretive phenomenological research study (Guba & Lincoln, 1989, 2005). Credibility refers to the extent to which the interpretations reflect the lived experience of the participants (Lincoln & Guba, 1985). Van Manen (1997) described a credible study as one that is an adequate revelation of the lived experience and, “resonates with our sense of lived life” (p. 27). Authenticity addresses method as well as outcome, and negotiation criteria within the interpretive inquiry (Guba & Lincoln, 1989, 2005). Authenticity supports the tenets of interpretive phenomenology in that it is evidenced by data that reflect the multiple instances and meanings of individual realities. The main assumption of interpretive phenomenology is that reality is temporal, contextual, and dynamic over time, thus authenticity addresses the multiplicity of realities within individual and collective interpretations of lived experiences (Corben, 1999; Guba & Lincoln, 1989; Marshall & Rossman, 1995; Tobin & Bagely, 2004).

**Credibility criteria.** Credibility addresses the truth value of the data and it was achieved by prolonged engagement, persistent observation, triangulation, peer debriefing, and member checking (Guba & Lincoln, 1989; Lincoln & Guba, 1985). Prolonged engagement is the investment of sufficient time to achieve certain purposes: learning the participants’ perspectives,

testing for misinformation introduced by distortions either of the self or of the participants and building trust (Lincoln & Guba, 1985). I was able to develop rapport with the study participants through conducting extensive, semi-structured, face-to-face interviews and forming a relationship with the participants. Prolonged engagement required the researcher to be involved with the study participants sufficiently during data collection activities to understand the perspectives of the participants (Lincoln & Guba, 1985). Prolonged engagement through lengthy interviews was achieved through the in-depth interviews, continuous interaction with the participants, the analysis process of the study and the complete immersion of the researcher in the data. Time was given for reflection and analysis of the audiotapes and transcripts. Field notes including researcher's observations and contextual description were recorded. A reflexive journal and memos were kept to record the researcher's thoughts, feelings, and perceptions throughout the research process.

Persistent observation provided thick and rich data to enhance the scope obtained by prolonged engagement (Lincoln & Guba, 1985). While prolonged engagement served to temper distortion caused by the researcher's presence, persistent observation accentuated that presence by actively seeking out sources of data identified by the researcher's own emergent design (Erlandson, Harris, Skipper, and Allan, 1993). This technique enabled the researcher to "identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued and to focus on them in detail" (Lincoln & Guba, 1985, p. 304). Persistent observation according to Lincoln and Guba (1985) added salience to a study that otherwise might appear to be no more than a mindless immersion; "if prolonged engagement provides scope, persistent observation provides depth" (p. 304). This was accomplished by writing, consulting with research supervisor and committee advisory members and most importantly, listening to

their advice. Rewriting, reformulating and reorganizing constituted the activities of this process of tentative identification and detailed exploration.

Triangulation of sources was used to further demonstrate credibility (Brink, 1991; Lincoln & Guba, 1985; Patton, 1990). It is achieved by using different or multiple sources of data, including time, space, and person; different methods such as observations, interviews, verbatim transcription of audio-taping, videotapes, photographs, and documents (Denzin, 1978). The researcher used data sources such as poetry and actual media stories to enhance understanding. The use of triangulated data sources helped in an expansion of meanings because the experiences were interpreted from different vantage points.

Peer debriefing involves utilizing colleagues who are not part of the research, but who had a general understanding of the study methodology. These persons helped the researcher to think out loud, and provided alternative explanations (Erlandson, et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985). This activity was accomplished through informal conversations with colleagues knowledgeable about the research methodology but not directly engaged in the study (Guba & Lincoln, 1989; Lincoln & Guba, 1985).

Member checking is a “process of continuous, informal testing of information by soliciting reactions of participants to the researcher’s reconstruction of what he or she has been told or otherwise found out and to the constructions offered by other participants or sources” (Lincoln & Guba, 1986, p. 77). The determination of credibility was accomplished by taking the preliminary themes back to the participants to see if the results accurately revealed their experiences (Appleton, 1995). Follow-up interviews were conducted with two participants to verify the emerged themes and there was a considerable agreement on most of the themes.

**Authenticity criteria.** Authenticity involves fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Guba & Lincoln, 1989, 2005). Authenticity commits the researcher to a set of actions such as balance of perspectives, learning by the researcher and participants, shared knowledge, and social action.

The first criterion of authenticity is fairness. This criterion maintains that different constructions of reality must emerge from persons with different value and belief systems (Lincoln & Guba, 1986). It is a quality of balance that all participants' views, perspectives, claims, concerns, and voices should be apparent in the text and all participants feel honoured in the process (Guba & Lincoln, 2005). Fairness was achieved through informed consent, member checking, and reflexivity. Informed consent considerations included the consent form (Lincoln & Guba, 1986), pseudonym use, research finding distribution, use of direct quotes, and limits of participation. In order to achieve this criterion, as a researcher I provided full information regarding the purpose of the study, and incorporated measures to ensure confidentiality to all participants. Identification of participants in interview transcripts remained anonymous with the selection of pseudonyms by the participants.

During member checking, participants were given the opportunity to discuss and negotiate findings and the conclusion of the study. According to Manning (1997) member checking is more than assuring that the researcher got it right, it is about representing participants' voices. Member checking is part of the collaborative process of negotiating outcomes that assures that the themes emerging throughout the study arise from the participants (Manning, 1997).

Reflexivity is related to "positionality or standpoint epistemology, which recognizes that texts are always partial and incomplete; socially, culturally, historically, racially, and sexually

located” (Lincoln, 1995, p. 280). The researcher’s perspectives cannot be ignored on the assumption that they will not influence the study. These beliefs and values should be made explicit by the researcher so that the participants of the research know the context in which the research will be conducted (Belgrave & Smith, 1995). The intent of reflexivity is to support and verify the research process through description of how the researcher’s experience and knowledge affect interpretation and understanding of the study findings. The researcher employed reflexivity throughout the research process (Sandelowski, 1986; Todres & Wheeler, 2001) to reflect on the assumptions of the researcher, how these assumptions may have changed over the course of the study and why, ongoing reflection on what is going on/happening in the study, the nature of co-creation of study findings, and how these findings may change according to changing context of the study. The researcher included a self reflection on her assumptions, beliefs, and personal experience regarding the experience of pregnancy termination for fetal abnormality and this self reflection was placed in the beginning of the dissertation . Furthermore, the researcher kept field notes and memos to help in achieving reflexivity. Field notes were used as a method of data collection and were taken throughout the research study to record the setting, non-verbal cues from the participants, tone of the voice, and observations the researcher had made. Memos were written to capture the outflow of ideas, insights, and meaning derived from the data.

Ontological authenticity is critical for determining a raised level of awareness by individual research participants (Guba & Lincoln, 2005). It refers to the extent to which participants’ own constructions are improved, matured, expanded, and elaborated (Guba & Lincoln, 1989). It is, “improvement in the individual’s conscious experiencing of the world” (Lincoln & Guba, 1986). Ontological authenticity was achieved through dialogical

conversations characterized by openness and collaboration between the researcher and participants. Confidentiality and openness regarding the research purposes further built a climate where dialogical, open conversations were possible (Manning, 1997). Ontological authenticity is indicated when participants make statements attributing growth to the research process (Erlandson, et al., 1993). Member checking and reflexive journaling are other means to meet this criterion.

Educative authenticity refers to the ability of this research study to facilitate the appreciation of other's constructions of their world (Guba & Lincoln, 1989; Guba & Lincoln, 2005). This criterion requires participants to recognize values and belief systems outside their own reference group. Educative authenticity is accomplished through dialogue during the interviewing process, member checking and the reflexive journals. An opportunity was created for both me and the study participants to appreciate the worldview of others through dialogue. Further, through member checking the participants viewed emerged themes of the study, allowing them to see perspectives other than their own, creating a more informed experience.

Catalytic and tactical authenticities are concerned with empowering, stimulating, and facilitating action (Lincoln, 1986). Catalytic authenticity refers to the ability of the research study to stimulate human action, and tactical authenticity refers to the ability of the research study to increase the participants' empowerment to act (Guba & Lincoln, 2005). New insight and understanding that might be gained through participating in this research study may include potential for change. As Schwandt (1994) suggests one's thoughts and beliefs are challenged when we become aware of new information. In an attempt to achieve these two criteria, the researcher created an open informal environment during the interview process. Through applying member checking, participants were involved in decision-making regarding the

negotiation of the emerged themes of the study. Finally, as a co-researcher in this study, I plan to take action and create change by sharing the new insights that I gained through publications.

### **Research Ethics**

Ethical approval was obtained from the Research Ethics Board at Western University. Participation in this study was voluntary and participants could withdraw at any time without penalty. However, no one withdrew from the study. A letter of information including a comprehensive description of the study was provided to all eligible participants (Appendix A). Informed consent was obtained after participants' acceptance of invitation for inclusion and prior to the conduct of the study (Appendix B). A consent form was read and signed prior to the first interview sessions. Both the researcher and participant signed and dated the consent form. In case of a telephone interview, the consent form was read to the participant and her agreement to participate was audio-taped. Participants were informed of possible risks and benefits of participation to ensure safety. For example, the letter of information included a note about potential psychological distress, explaining that the experience of TOPFA is distressful for some women. Some participants might find that reliving that time of their life will cause emotional stress for them. If this was the case, and the stress was great, participants could ask to stop and resume the interview at later time. Should participants have experienced a level of stress that required professional help, support services were recommended and a list of the existing services and resources was given to participants (Appendix J). I did not initiate contact with any potential participant directly but provided my contact information. Thus participants were always the one to decide when, where, and how contacts were made. To insure privacy, all the interviews were conducted where only the participant and the investigator were present except if the participant requested someone to be in attendance.



Confidentiality was maintained for each participant by: 1) a code system used so that participants could not be identified on any of the transcripts and post data collection, all identifiers were removed and a predetermined code replaced participants' names. ; 2) all identifying information, audio-taped materials and transcripts were securely stored and kept in a locked cabinet in the researcher's office. Only the primary student researcher, supervisor and committee members had access to the data. The interviews were digitally recorded, and the files were saved on a password-protected computer. Upon completion of the study all consent forms, tapes, transcriptions and other documentation will be sealed in a box and secured for a period of seven years and then destroyed.

### **Summary**

This hermeneutic phenomenological study was designed to gain an understanding of what it is like to experience termination of pregnancy for fetal abnormality. Data were gathered through semi-structured interviews, demographic questionnaires and field notes. Analysis was guided by van Manen's (1997) approach. The establishment of methodological rigor and ethical considerations was considered and described.

## CHAPTER FIVE

### **Women's Voiced Experiences of Pregnancy Termination**

“The essence or nature of an experience has been adequately described in language when the description re-awakens or shows us the lived meaning or significance of the experience in a fuller or deeper meaning” (van Manen, 1984, p.38).

This chapter provides a brief description of each of the participants and highlights some of the key areas uncovered about the experiences described as being meaningful in the lives of the women who terminated their pregnancies because of a diagnosed fetal abnormalities. The voices of ten women who engaged with the researcher during the course of the study are presented. A brief description of each woman who participated in the study and shared their stories is provided in the first section. The second section presents emergent themes and subthemes from the women's storied experiences of TOPFA.

Ten women described their experiences of pregnancy termination for fetal abnormality by telling their stories and expressing their voices. For the purpose of anonymity each woman was given a fictitious name. The methodology of interpretive phenomenology enabled me to gather these women's accounts of their lived experience of termination of pregnancy for fetal abnormality (TOPFA), enabling their voices to be distinct and eliciting the experience from their perspective (Heidegger, 1962). By listening to the women and hearing their individual stories, it becomes possible to come close to their experience "as they live it rather than as we conceptualize it, categorize or theorize about it" (van Manen, 1984, p. 1). In this way the uncovering and capturing an understanding of the nature or meaning of the TOPFA experience as an everyday experience and its aftermath many years later was made possible. From listening to these women's stories, it was clear that although they had experienced TOPFA many years

earlier, they still had very strong emotions concerning their experience. They had vivid memories and described some events in a detailed manner. After many years removed from their experience, their reflections were no longer affected by the rawness of their experience and they had a more clear-minded reflection that helped to delineate the negative and positive aspects of their experience. Although each of the women's pregnancy termination experience is recognized as unique, similarities emerged. Commonalities in women's stories are represented through six shared themes. Together these themes captured the essence of the women's lived experience of TOPFA: encountering the unexpected, making sense of the unexpected, facing the inevitable decision, living with the decision, lacking support, and changing perspectives.

### **Participants' Profiles**

Profiles of each participant were crafted to provide insight into the women who informed this study. Each participant's words were used to create her profile. I selected passages from each participant interview, meaningful to me, and integrated the passages to form a narrative that represents the meaning of the lived experience of pregnancy termination from the women's perspective. Each woman's profile is introduced with a direct quote to relate her lived experience to the emergent themes that will be presented in the next section.

#### ***Nancy "Everybody that I spoke to seemed very much in support"***

Nancy's first pregnancy was terminated for fetal abnormality (anencephaly) a couple of decades ago. She described her first trimester as "*fine I did not have any problems medically*". Later, after prenatal testing she was informed of the anomaly and had to make a decision about her pregnancy. After learning about the lethality of her fetus abnormality, she was given two options. "*I was told the baby may survive a couple of hours after birth but that would be it. If I wanted to continue on with the pregnancy or if I wanted to have a therapeutic abortion.* Her

decision on what to do had to be made *"fairly quickly at that point"* and when she realized that the child was not going to live she decided to terminate. Nancy terminated her pregnancy in an abortion clinic. She described her experience going to the clinic as *"scary"* and *"traumatic"* especially when she encountered antiabortion protestors. *"It was kind of scary just to go into clinic when there's protestors, to have to go through this before you are having something done that's very difficult to do. It was very traumatic at that point"*. The support she received from her husband, family, friends and her church helped her throughout the whole experience. Everybody she asked supported her decision to terminate her pregnancy and was reassuring. Describing her positive experience with the health care professionals Nancy stated: *"Everything went really smoothly, really well, the doctor was very well very good and explained everything and my specialist explained everything to me too before I went, so that was very reassuring"*. Nancy's religion was very important to her so the involvement of her church during her experience of pregnancy termination made her feel better supported. *"The assistant pastor came down that day and sat with us in the clinic awaiting room. I knew my faith was very important and just through prayer, that was what I needed to do at that time"*. Nancy felt supported by family and friends, *"We had a lot of family support, both from my family, friends and my husband"*.

**Paige *"It defies everything you believed"***

More than five years ago, Paige's second and only planned pregnancy was terminated due to a genetic abnormality well into her pregnancy. For Paige, a self-proclaimed feminist and pro-choice woman, her decision to terminate her pregnancy was a very traumatic experience as she had never considered that she would ever be in a situation where she would have to do such a *"horrible thing"* about her pregnancy. Paige was faced with a decision she never had to think

about before. *"It really shocked. I think I was naive. I didn't think I was a woman that would ever consider an abortion and I think at that time I even had trouble saying that word"*.

Paige felt having an abortion *"really challenges your identity"*. Working in social services, with a strong tolerance level, Paige expressed a deep feeling of *"shame"* and difficulty for even considering aborting her unborn baby as she already *"looked very pregnant"* and for her, ending a pregnancy *"would be before you're showing and you know it's not really a baby"*. For her *"the baby was a real baby"*. Having to terminate her pregnancy was a direct contradiction of Paige's identity as a woman. She described herself as *"a woman with strong maternal feelings, someone who could easily have lots of children"*. Her beliefs about pregnancy, abortion and being a mother were challenged. *"You kind of have a framework in your mind of who would be in that situation and you don't really think being 32, married with job and really capable of parenting that 's what you are going to do"*. Paige considered herself a strong person who could bear life difficulties. Being faced with the decision to end her pregnancy because of the presence of fetal abnormality confused her *" I think the other thing for me was that I needed a perfect child. That was not or ever something that I really expected and I felt it contradicted who I was"*. Paige described how she initially felt it important to keep her experience of pregnancy termination a secret from others. *"Some people just got the short version of the story...Paige lost the baby. I don't think we consulted a lot of people. The confidentiality was important"*. Terminating her pregnancy and losing her baby was so traumatizing *"I was so traumatized, you're in shock-physically, emotionally, intellectually"*. At the time of the pregnancy termination her feelings of shame regarding her decision prevented her from revealing pregnancy experience to others *"You feel so ashamed of your decision, you don't even have vocabulary really what is*

*happening to articulate that you feel like you are the only person in the world that is doing this really horrible thing".*

**Jennifer "*I had nobody to understand*"**

Jennifer was a stay at home mom. She was healthy and already had a healthy child when she became pregnant. Jennifer had terminated her second pregnancy almost a decade ago after her fetus was diagnosed with spina bifida and hydrocephalus at 18 weeks gestation. Jennifer did not expect anything to go wrong with her pregnancy. *"You don't think anything is going to happen to you cause these things don't happen to you they happen to other people"*. After many medical consultations, Paige and her husband decided to terminate their pregnancy. She felt devastated and overwhelmed the moment she discovered her fetus's condition. *"I remember walking down the hall leaving the hospital and my husband saying don't cry, don't cry. I was just like done. I was overwhelmed"*. Jennifer needed support to express her feelings and to talk about what happened with other people. She felt alone throughout her experience and was frustrated by her husband's reaction regarding the pregnancy termination. Jennifer thought about naming her baby but she felt neglected by her husband *"He was not too fond of knowing the sex or naming the baby, he just let me take control of it, he didn't cry a lot, he didn't express too much emotion which was a whole part of my experience"*. Her encounter with the health care professionals during the time of her pregnancy termination made her feel even more alone. *"They put me outside the operation room on a gurney and they leave me there and I'm by myself"*. Jennifer felt unsupported by the health care professionals who provided care during the pregnancy termination procedure. *" They're like laughing and talking to each other like just another day at work"*. She described that time as *"just no compassion, nothing was expressed"*. Her experience with the health care professionals increased her feelings of loneliness and

alienation. *"I had nobody to go to and say I know what you are going through and it sucks and I totally understand what you are going through".*

**Diana *"We do still need to talk about our baby"***

Diana was a married mother, who terminated her third pregnancy more than five years ago after her fetus was diagnosed with severe multiple abnormalities. She was shocked on knowing the severity of her unborn baby's condition. *"I guess it kind of hit me and I thought oh my god, like this is really serious. It's not a heart defect, it's a whole system and there's a syndrome".* Diana wanted to be supported by others but she realized that other people did not understand the magnitude of her grief. She recalled one friend's comment about her grief reactions.

You're still upset about that and I know she didn't mean it in such a negative way but I just felt like she had stabbed me in the heart. Oh my God it's only been a month. Like friends sort of figured you know I went 24 weeks without showing but to them I'd just lost a pregnancy and not a baby. It was sort of oh well ok you should mourn for a week and then you move on.

Diana wished for people understanding and willingness to listen to her, *"I just need to talk about it and to feel it".*

**Tiffany *"It was really just one choice"***

Tiffany is a mother with a medical background. Since she had never lost anyone close to her to death, she was naive about her first pregnancy experience, which was terminated more than five years ago. Her unborn baby was diagnosed with a severe lethal abnormality. She never thought that anything could go wrong with her pregnancy. *"I started out my pregnancy just expecting to have a baby at the end ...really excited".* Because of her medical background

and understanding of the diagnosed anomaly she realized that her pregnancy would not end with a live baby. *"I really understood exactly what was going on. I knew that the levels you know people can survive without kidneys, but because there was no fluid the baby's lungs were never going to develop, so you can't live without lungs"*. Tiffany described her situation as not having an alternative option; her unborn baby would die whether she continued to term or terminated her pregnancy. *"It was really just only one choice, do I want to stop the pregnancy now or do I want to continue to term and basically watch the baby suffocate and so for me the right decision was to stop"*. This realization of outcome was devastating for her. *"I was devastated, I don't think I've ever been that devastated by anything in my life. I was very upset"*. Tiffany was fortunate that she had an understanding and supportive husband. *"I was lucky my husband was very supportive, he and I were equally devastated"*.

**Susan *"I was angry with the world, I was angry with God"***

Susan has been married for 30 years. She terminated her pregnancy for Down syndrome, heart and digestive system defects seven years ago. She had been on birth control for 20 years before she and her husband decided to try for a baby. Dealing with endometriosis and infertility, Susan thought that her chance of becoming pregnant was weak. Susan remembered her reaction when she first knew she was pregnant *"I was overjoyed. It was a miracle"*.

Because of her advanced maternal age, Susan underwent amniocentesis. She was a little concerned as her brother-in-law had a daughter with a severe congenital anomaly. *"My family strongly suggested that if the baby had severe problems we should consider termination because they struggle so hard with the baby, her medical needs and special needs are just a huge toll on them"*. Susan remembered feeling devastated when she was told that her expected baby had abnormalities. She said *"The doctor called back and said it is a girl and she does have Down*



*syndrome, heart and digestive defects, at that point I remember the worst wail I have ever uttered in my life. I was devastated". Susan 's decision to terminate her pregnancy was based on her personal experience of having a relative with a disability. "My husband and I had already agreed that if there was a problem, that we would terminate. It was not something that we could handle and we didn't want our daughter, our child to suffer". Susan described her feelings after the termination "I was angry, I was angry with the world. I was angry with God. I mean here God had finally given me the child that I wanted and she was so sick so she wouldn't live". Susan felt that her hope to have children was lost and that made her angry "I was angry that I can never have children. But the only child that I would have ever had was so sick she probably wouldn't have lived".*

### **Hillary "I was blindsided"**

Hillary was a stay at home mom. After her second child, Hillary and her husband decided to try for another baby. It took Hillary about a year and a half to get pregnant. Despite giving birth late in her life, Hillary experienced no problems with her two previous pregnancies. Since she was healthy Hillary was not expecting anything could go wrong with her pregnancy. *"I had no problems, no complications. I'm healthy. Everything up until that point was normal I'd never in my wildest dreams would have thought that something horrible would have happened".*

She terminated her third pregnancy for Trisomy 18 more than five years ago. Although she had a medical background, Hillary was hit unexpectedly with a fetal abnormality that she did not know anything about it. *"I was really kind of blindsided by the whole thing".* Although being supportive of pro-choice she never thought of women deciding to terminate a pregnancy of a fetal abnormality. *"I've always been pro-choice because I believe that women have a right over their own body, but I never sort of, honestly I never even thought about terminating for*

*medical reasons".* Going through the experience of pregnancy termination changed Susan's perspective about ending a pregnancy. *"I never thought about that people are terminating their pregnancy because they have terrible things that have happened".* It was a "learning experience" for her. *"There's so many things that I've learned about. People always think Down syndrome, but I am thinking to myself my God that's like the least of people's worries".*

**Lizzie "I knew that I had made the right decision"**

Lizzie was married with other children. She terminated her pregnancy after her fetus was diagnosed with multicystic and dysplastic kidneys five years ago. Her third pregnancy was not planned but she had always wanted another child. When her pregnancy was confirmed, she and her husband were happy about it. She remembered when she first learned something was wrong with the fetus and making the decision to terminate the pregnancy. *"They were checking everything and she didn't get very far into it, she said there's something wrong with the kidneys. They confirmed that it was 100 percent fatal, there were no lungs".* The genetics counselor provided them with two options to think about. *"We had a decision to make and no decision would be easy and she said we could terminate or we could carry to term. Lizzie thought of what she would have to do in case she continued her pregnancy. "I can't continue to go on pregnant with my living son having to explain to everybody what was happening".* She also thought of what was best for her son and unborn baby. Lizzie did not want her baby to suffer, *"I didn't think it was fair to my baby that I was carrying that he was basically being pushed by not having amniotic fluid and so we decided to terminate".*

When she was prepared for the termination, a nurse gave her a book to read so she could know what was expected to happen. She decided to birth her baby vaginally and have a chance to see and hold him. She appreciated the time she had with her baby and other family members.

"My mother was with me and my husband and we all held the baby". Seeing the apparent fetal abnormalities assured her that she made the right decision. *"I took the blanket off and counted all his toes and his fingers and his ears. His skin was still transparent and you could see just how large his kidneys had gone up into his chest cavity"*. Although she experienced depression for a while afterward, she felt content knowing she had made the right decision.

I knew I had made the right decision. It wouldn't have been fair to continue on and I battled with depression for a little bit. I off and on had gone on antidepressants but for the most part I'm at peace.

**Lucy "What kind of quality of life would she have?"**

Lucy was a married mother who had terminated her pregnancy for a fetal diagnosis of Down syndrome and heart defects more than five years earlier. Lucy described herself as self-proclaimed pro-choice, but never thought that she would ever have to take a decision to end a pregnancy herself. She and her husband believed that since she had healthy children and uncomplicated pregnancies, nothing would go wrong. She remembered how she felt when first told about her unborn baby's condition during a routine prenatal ultrasound. She was shocked at the news because for her the ultrasound was a way to connect with her baby. *"I was just thinking we were going in to take pictures of the baby and announce the gender and the fun stuff"*. Lucy described her initial feelings when the doctor told her about the details of the diagnosis, *"It was horrible. I mean completely surprising out of left field and just feel like you'd been smashed off your feet and the world was spinning because you had no idea what was coming"*.

Lucy and her husband initially were hesitant to consider termination, refusing to make such a difficult decision. However, after doing further research and learning about the possible problems that could arise as their baby grew, Lucy and her husband decided to go ahead with the

termination. *"Initially we were actually thinking we weren't going to terminate, but the more they were able to tell about the problems we started thinking long term".* Lucy's main concern was her baby's quality of life and what kind of life her baby would lead if she continued her pregnancy. *"It was a lot speculation basically on how and what the effect would be. Had they been able to say she's going to be ok. She's going to be fully functioning; then we would have continued the pregnancy".* Since both Lucy and her husband were in their thirties, they were concerned about who would look after their baby if something happened to them *"We were thinking how is this baby going to be cared for when she's adult if something happens to us".* Lucy wondered about her baby's quality of life after researching the health problems associated with Down syndrome and what would be in her baby's best interests. *"Since there's such a variation with Down syndrome and the medical issues she had. We didn't know how severe those were going to be".* She questioned her choices, *"Do we leave that burden to our other children who aren't even the same gender so couldn't really take care of her completely if she needed physical care?".* Lucy felt it would be selfish of her to give birth to the baby, knowing the possible problems that her child would have. *"We went on to search more and saw the problems the health issues that were associated with Down syndrome, we started really questioning whether it would be fair, and how and what kind of quality of life would she have".*

**Jessica *"I was in like this weird little sadness bubble that nobody really understood"***

Jessica was a married woman with a young child. She terminated her first pregnancy for severe spina bifida and hydrocephalus more than five years ago. Jessica had been struggling with infertility for a long time. She was informed of her baby's abnormality during a routine ultrasound performed at 20 weeks gestation. She remembers facing the severity of the anomaly and what it might mean in terms of her child's quality of life. *"Like at best you'll be dealing with*

*somebody who has significant deficit but can still at least be interactive and at worst you will be dealing with somebody who won't ever have any quality of life basically". After her pregnancy termination she felt that nobody understood her intense feelings of loss and grief at having to make the decision to end her pregnancy. "I think like any loss whether it's your parent or whatever it knocks you into this really dark place. I think the added dimension of having to make a decision to basically end your child's life is really hard". Jessica found it difficult to inform people who were aware of her pregnancy of the loss of her baby. "Telling people that it happened and specially since a lot of people knew we had been struggling to get pregnant and we were very excited that we were pregnant and then to have to say oh my gosh". Knowing people's negative views on abortion, Jessica felt "If anybody had criticized me...I probably would have just like gone totally around the bend".*

Accessing support from others was difficult for Jessica and her husband. *"It was just kind of felt I was in like this weird little sadness bubble that nobody else except my husband really understood at all".* Jessica described the support she had from family and friends and how it ended very quickly while she was still in need to be supported.

There's this initial rush of sympathy and empathy from people and we got all these cards and people sent flowers and brought food and then after a week or two that petered off but we were still very much in the hole. Her need for support forced her to seek further support by herself. *"We did a lot of things, we realized pretty quickly that we probably would want to talk to somebody just to help us process it".*

### **Participants' Themes**

Six major themes emerged from the women's interviews that together articulated the meaning of women's experiences undergoing a pregnancy termination for fetal abnormality. The

lived experience of pregnancy termination for fetal abnormality will be revealed through the six themes and their related sub-themes to capture the women's meaning of their lived experiences. All the women in this study wanted their pregnancy however for some, it was not planned. All of them were expecting to birth a healthy baby. The women initially found out there was a problem with their fetus through routine prenatal screenings conducted between 12 to 20 weeks, by either a non-invasive alpha-fetoprotein (AFP) test and/or ultrasound respectively.

The women immediately faced the unexpected when told the results of their prenatal screening tests. Their perception of the initial prenatal screening tests was to confirm their baby was healthy rather than to identify a suspected abnormality. These early screenings led to more invasive prenatal tests, such as amniocentesis or chorionic villus sampling (CVS). Upon confirmation of a fetal abnormality, women were faced with two options; to continue to term or to terminate their pregnancy. While they were trying to understand and make sense of the magnitude of the fetal diagnosis and what it meant for them, their family and their baby, women found themselves not fully-prepared for making such a decision, especially with the limited time and information they had.

Their decision to terminate the pregnancy in the second trimester was associated with much ambivalence and uncertainty. Deciding to end a pregnancy contradicted their maternal identity and beliefs of protecting their unborn child from harm and left them feeling confused. Women who had a fetus with a lethal abnormality realized that terminating their pregnancy was indeed their only choice. For other women who had a fetus with severe abnormality who could live after birth, the decision to terminate was more complicated and complex. Their main concern was the quality of life of their baby. These women's decision to terminate the pregnancy

was altruistic to prevent pain and suffering of their baby and for some to avoid a dismal future regarding long term consequences for their baby, themselves and their family.

Struggling with the loss of a wanted baby and dealing with heightened emotions, women had many contradictory feelings trying to live with their pregnancy termination decision. Throughout their experience of pregnancy termination, women had a pressing need for social support and seeking support from others was a major focus. Reflecting on their experience many years later, women realized that it was a life-changing experience that changed their perspective about life situations. Table II displays the main themes with the sub-themes that emerged from the women's stories about experiencing a TOPFA more than five years ago.

Table II

*Participants' Themes and Sub-themes*


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Theme I	Encountering the unexpected
Theme II	Making sense of the unexpected
Theme III	Facing the inevitable decision
	Conceptualizing the decision
	Decision paradoxes
	Persistent unresolved issues
Theme IV	Living with the decision
	The challenges
	Moving on
	Remembering and acknowledging the baby
	Becoming pregnant
Theme V	Feeling supported
	Women's needs
	Relating with others
	Seeking support
Theme VI	Changing perspectives

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**Theme I Encountering the Unexpected**

Women entered their pregnancy expecting at the end that they will give birth to a healthy baby. They followed routine prenatal care and underwent prenatal testing as recommended by



their physicians. They were also encouraged to get prenatal screenings by their family. Many women perceived these tests would provide them with reassurance about their unborn baby's health and well being. Undergoing ultrasound was an opportunity for them to see their fetus and discover the sex. They did not consider at the time that prenatal screenings could result in detecting fetal abnormalities. Women underwent their screening tests not worried that something would be found wrong with the fetus.

After receiving the news about a fetal anomaly, they encountered the unexpected. For these women the diagnosis of a fetal abnormality came without warning. Since they did not have any known risk factor or previous health history that could lead to fetal abnormality, they expected to have a healthy pregnancy outcome. The unexpected discovery of fetal abnormality left women with feelings of shock, devastation and uncertainty. All the women were diagnosed with a severe fetal abnormality in their second trimester of pregnancy. Women believed that if they were healthy, followed a healthy life style, and completed their first trimester without any problems, there was nothing to worry about and they would end up with a healthy baby. Nancy stated: *"The first three months, it was fine I didn't have any problems medically, everything in the pregnancy was going fine, um I was doing fine, I mean I was actually in a pretty good healthy state"*. Similarly Hillary noted *"I had absolutely no problems, no complications. I'm healthy"*.

The women expected a normal pregnancy since they had previously experienced healthy uneventful pregnancies and had healthy children. Lucy explained *"Even though I was 38 I just kind of assumed since I'd had you know 2 children who were perfectly healthy before that that we wouldn't have any problems"*. Most women went into pregnancy similar to Tiffany:

I never really considered the possibility that something would go wrong with my pregnancy. I just kind of assumed that we would get pregnant and we would have a healthy baby. I mean up and till that point my life had been very um very tragedy free.

I was very fortunate that I hadn't lost really anyone very close to me and I started out my pregnancy just expecting to have a baby at the end and being really excited.

For some women, although they had relatives with fetal abnormality, they did not expect their unborn child to have any severe conditions and if they had problems, it would be something they could deal with. Paige remarked "*I do have a cousin that uh....was born with spina bifida, it was fairly low. Um...I don't think we were expecting um, a diagnosis that worse than Down syndrome*".

All women were in a stable relationship and a well-established stage in their lives. Women described their life circumstances as perfect for having a new baby and they were prepared for either having their first child or for a new addition to their family. Most had planned and wanted their pregnancy and felt it was the right time for them to become pregnant. They were healthy, maintaining a healthy life style, and financially stable. Hillary said "*We wanted to have children and we saved up what was a planned pregnancy. We both worked, we were both professional people, I would say really smart people*". Most of them described their lives as being "*pretty standard*", and "*pretty typical*". They did not expect anything could go wrong and were experiencing normal uneventful pregnancies. Two women's pregnancies were unplanned, yet they welcomed being pregnant and were excited about their pregnancies. Nancy said "*Although it was unplanned pregnancy I really did want the baby. I've always wanted to have a baby*". Susan who had been treated for infertility for long time described her excitement about being pregnant "*I was overjoyed, it was a miracle*".

By adopting a healthy life style, following the advice of others, and adhering to the norms of prenatal self-management, all the women underwent the recommended prenatal screening tests without questioning. For them, undergoing prenatal screenings, such as an ultrasound and blood tests was considered a normative practice and a matter of "routine". *"You just kind of do it, ok the doctor recommends it, you should do this whatever, but you don't have to do it, you're given your options, I just I guess just did it, my mom thought I should do it"*.(Jennifer). Paige stated *"There was some screening in my standard blood work, which is a normal part of pregnancy screening"*.

Rather than to determine if something was wrong with their fetus, most women underwent prenatal screening to be reassured of their unborn baby's health and well being or to potentially discover its sex . Most participants described themselves as being "naive" and "blindsided" when first informed of their prenatal test results. Many underwent the screening procedures with a positive attitude thinking nothing could go wrong. Although Hillary knew her advanced age increased her risk for chromosome abnormalities, since she had an uneventful pregnancy and healthy child previously her prenatal screening test results were totally unexpected. *"Everybody assumes their going to come out normal, but you know I assumed it"*. The women were not fully informed on what they should expect from these tests. As Jennifer stated *"They [doctors] don't think anything is going to be wrong"*. Some women underwent prenatal screenings with little consideration about their intended medical purpose, that being to rule out any potential fetal abnormalities. Hillary described *"I went there thinking woo hoo, I'm going to find out you know let's see if we can see girl and then you're hit with this"*.

The women underwent a second trimester prenatal ultrasound with the excitement of seeing their fetus for the first time and potentially knowing its gender but not expecting to

discover something was wrong with the fetus. Although the women expected to have a healthy baby, some worried about the wellbeing of their unborn child and wondered if something was wrong. When sensing there might be a problem with their fetus, they sought reassurance from their physician and as they had been reassured they ignored their concerns and fears. *"He [her doctor] said that you know the baby is growing so I said ok I'm being paranoid. [laugh] these things don't happen to you they happen to other people".* (Jennifer).

The unexpected discovery of the fetal abnormality combined with the fact that the pregnancy was wanted, was overwhelming. The women had vivid memories of when they were first informed of their positive prenatal test results and described the experience as traumatizing. Women were stunned and shocked to hear of the fetal diagnosis because there was no indication that anything was wrong during their first trimester of pregnancy. Paige expressed her feeling at that time, *"I was so traumatized"*. Jennifer recalled, *"I start crying and I am like you know and just kind of go numb, this is a lot of information, I was just like done. I was just overwhelmed"*. Another woman who suffered from endometriosis and infertility was devastated when hearing about her unborn baby having Down's syndrome. Susan remembered *"At that point I remember the worst wail I have ever uttered in my life. Just devastated, I wanted this baby and so did my husband"*. Lucy described the time when the fetal diagnosis was confirmed as *"the horrible moment"*.

### **Theme II Engaging in sense making of the unexpected**

After the discovery of a possible fetal abnormality, some women found themselves encountering some medical conditions they had never heard of before. *"The genetic counsellor said the baby's tests are showing that the baby had spina bifida and hydrocephalus, and I was like what is hydrocephalus, like this is all new for me"* (Jennifer). Many women did not know

what to expect. *"You had no idea what was coming"* (Lucy). Some women expressed that for some conditions, even health care professionals had insufficient information about them. *"They really gave me limited information, it was very upsetting"* (Hillary). Paige described her unborn baby's abnormality as being rare and *"was difficult to pinpoint. It was difficult for genetic counsellor too"*. Other women expressed not knowing how to react when they initially heard about their baby's abnormality since there was little known about the condition and associated consequences. *"I didn't know anything, what that was or what it meant, I didn't even know if I should be upset or not upset"*. (Jennifer).

Acquiring knowledge about the anomaly and what it means became an important need for all the women. They sought information about the fetal diagnosis from a variety of sources including health care professionals, books, the Internet, and from individuals who have been in similar situations. They needed as much information as possible regarding their unborn baby's abnormality, its magnitude, and what it meant for their baby's well-being and health.

For some women, the first warning that something was wrong with their fetus was identified through an alpha-fetoprotein (AFP) blood test, for other women the fetal abnormality was detected through a routine ultrasound. All the women had the diagnosis of fetal anomaly confirmed with more advanced tests such as chorionic villus sampling (CVS) and/or amniocentesis. Confirming the diagnosis they had been given about their unborn baby was crucial to the women. As a result they underwent more testing as recommended by their physicians. Tiffany explained *"They sent me to a maternal fetal specialist and he diagnosed it as Potter's syndrome"*. Hillary said *"We decided to go for Chorionic Villus Sampling (CVS)"*. Lucy whose fetus had a possible diagnosis of Down's syndrome said *"The only way we can find out for sure is to have an amniocentesis"*.

After the fetal diagnosis was confirmed, most women felt that they needed to know more about their unborn baby's abnormality before making any decision regarding their pregnancy. Many women felt that the health care professionals did not give them enough information to prepare them for making a justifiable decision. All the women were suddenly faced with making the decision on whether to continue their pregnancy to term or to terminate the pregnancy. In order to make this difficult decision, they needed to understand and make sense of their unborn baby's abnormality and what it meant for their baby's future well being, themselves and their family. Paige said "*I think at that time I don't think we knew at that moment what we would do, we weren't comfortable not having the information*". Hillary expressed "*I tried to do as much research as I can on what the truth is out there, what my child would be faced with*". She explained

I was worried, I was very focused on if I didn't terminate what would happen to this baby if I decided not to and carry through the pregnancy when she was born like I was more afraid of, this sounds terrible.

Paige stated "*There was no textbook that you could open up and say 'Can we cope with this?' 'can she cope with this'? um....you know, 'is she likely to survive'? 'is she not to survive'? we didn't have any statistics*". Women considered the lack of information as "*unfair*" as it was crucial for them to understand everything about their unborn baby's abnormality to assist them in the decision making process regarding what to do about the pregnancy. It was important for them to understand the risks, benefits, and consequences of the choice they were required to make. Lucy explained "*They didn't give us any pamphlets or any literature or anything like that on Down's syndrome. It was all pretty they were you know it was all a lot of speculation basically on how and what the effect would be*".

In trying to grasp the importance of why women's understanding of their situation was paramount, I made an etymological look at the word "understand". Barnhart (1995) gives the historical background of "understand" in the "Old English" (before 899), understand, comprehend, grasp the idea of; literally, stand in the midst of, stand between" (p. 846). According to Beauchamp and Childress (2001) there was not a standard definition of understanding, however they indicated, " Persons understand if they have acquired pertinent information and have justified, relevant beliefs about the nature and consequences of their actions" (p. 88). Most of the women found themselves initially lacking information about the condition of their unborn babies and did not fully understand what it meant for their child to have this abnormality if they decided to continue with their pregnancies. This lack of information played a part of their expressed ambivalence, uncertainty and unrest throughout their decision making process.

To lessen their perceived uncertainty associated with the lack of information about the implications of their unborn baby's abnormality, women sought more information through further testing, searching for other's experiences with the same diagnosis, consulting specialists, and searching the Internet. Using the Internet as a strategy to gain more information was evident in women's stories. Some women went directly to the Internet searching for specific information about their unborn baby's condition. Others connected online with other women who had experienced similar fetal abnormalities. Paige stated:

I went on the Internet and looked at other children who had missing- who were missing genetic material. I may be looked at about 30, and I think..out of 30 maybe five children has died. I think between 3 to 5 children has some approximated quality of life and I would say the remaining 20 did not fall in the good quality of life category as I define it.

Jessica who was pregnant after dealing with infertility expressed "*We were googling ourselves to death about everything, it was kind of good because it gave us a lot of time to think about what we were willing to deal with and what we weren't*". When women felt that they lacked the information they felt uncertain about their decision of whether to continue or to terminate their pregnancy. The lack of information about the nature and consequences of the fetal abnormality and the limitations of the diagnostic procedures made the women feel uncertain and ambivalent about their decisions. Paige explained "*Their information was fairly inadequate, science couldn't give us a lot of information about what was happening with her*". Although they tried to gain as much information as possible the women still felt ill informed with insufficient knowledge to make their decision and to feel "*at peace*" about it. They felt confused and astray. Lucy said "*I felt a little lost*". Some women expressed that if they had been provided with more information about the condition of their fetus, they might have made a different decision. "*Had they [specialists] been able to say she's going to be ok. She's going to be fully functioning, she's going to be able to lead a relatively normal life, then we would have continued the pregnancy*" (Lucy). Susan said "*I really wish that our doctors would have been able to give us more information, I feel I don't know if I would make the same decision*".

Women wondered "*what if*", and they asked themselves "*what if they [doctors] are wrong*", "*what if they made a mistake*", "*What if he [the baby] did survive*". Lack of information about their unborn baby's abnormality, the lack of definitive answers for their inquiries and the inability to predict the outcomes accurately led to feelings of uncertainty and unrest about their impending decision. In an effort to decrease their sense of uncertainty the women sought external sources of information to help them reaching a decision they could live with.



### **Theme III Facing the Inevitable Decision**

After the fetal abnormality was confirmed, women commenced the decision making process on whether to terminate or to continue their pregnancy. Lucy explained "*We had a decision to make and no decision would be easy*". Facing the unexpected situation of having a baby with abnormalities and having to make the decision concerning pregnancy termination was excruciating for all participants especially with the limited time they were given to make their decision. Two options were presented to all the women by their obstetricians in collaboration with high risk perinatologists and /or genetic counselors, to terminate the pregnancy or to continue to term. The inevitability of having to make the decision in addition to the perceived sense of responsibility and accountability as an expectant mother made the decision very difficult for the women. Nancy explained, "*He [the doctor] told us we had to make some quick decisions*". Similarly, Paige added, "*The genetic people called us in for meetings and said we had to make decisions*".

One factor that contributed to the women's difficulty in deciding to terminate the pregnancy was the perceived time constraints. Women felt that time took on different meaning as they found themselves moving from the time of joy, happiness, and good expectations to a time full of stress, ambivalence, confusion, and sadness. During their decision making process, with limited information about the diagnosis and their late gestational age, the time available for the women to make a decision about the pregnancy felt constrained. The women stressed that they needed more time to decide what to do. Paige said "*I had a very short...period of time to make the decision because I was so far along, I had 24 hours. It was really short*". Nancy remembered "*They wanted some decisions fairly quickly at that point, it is just the urgency of having to make a decision pretty quick that was a hard thing to do*". After they made the

decision to terminate the pregnancy, the women's perception of lived time continued to change. For example, the women described the time for scheduling the termination as proceeding slowly and painfully. Waiting until the time of the termination was unbearable for the women because they could feel fetal movements and realize the fetus impending death. Jennifer remembered *"That was really hard and that's one of the biggest challenges I go through feeling the baby and then knowing what is the end result having to wait a whole week for that was just suffering"*. In describing the psychological impact of the experience Paige explained: *"...is it better for the gangplank to be shorter or longer? If you had to do something horrendous, do you wanaa..move forward and move through it or you know that anticipation of death coming is really awful"*.

The decision to terminate the pregnancy was described by the majority of women as difficult and complicated by many contradictory issues. They were dealing with a lot of unresolved issues that were still bothering some women at the time of their interview.

In the following section, three sub-themes identified within the third theme "Facing the inevitable decision" are described; conceptualizing the decision, decision paradoxes, and persistent unresolved issues.

**Conceptualizing the decision.** As previously explained, the women's perceived feeling of responsibility and accountability regarding their pregnancy increased the difficulty they experienced in making the decision to terminate the pregnancy. The women perceived their husbands as being supportive in whatever decision they would made. In describing her husband Lizzie explains, *"From the beginning he told me that he couldn't make the decision for me, that it was my body I had to make the decision ultimately, but he would stand by me and be there and he was"*. Although the women's partners shared the responsibility with them, the women appeared to be primarily responsible for the final decision regarding the pregnancy termination.

Three women had fetuses diagnosed with lethal abnormalities which involved certain death either before term (in utero) or immediately after birth. For these women, the decision to terminate the pregnancy was perceived to be less difficult than if the fetal diagnosis was nonlethal. For them, the termination of pregnancy was their only option because their unborn baby would die either way. Their decision to terminate seemed the only choice they had which made their decision easier and lessened their sense of accountability because the decision appeared to have already been made for them. Lizzie remembered "*They confirmed that it was 100 percent fatal, Um, there were no lungs but so he wouldn't develop lungs*". Tiffany expressed "*It was really just a choice of um you know do I want to stop the pregnancy now or do I want to continue to term and basically watch the baby suffocate*". Hillary, whose unborn baby suffered from Trisomy 18, described her decision saying "*The choice was easier because it was not a grey area, the more I researched about it the more I...it was easier for me in a way to make my decision*".

Other women who had a diagnosis of severe abnormality with the possibility of a live baby with variable degrees of disability, felt having a role in the decision to end their pregnancy complicated the decision making process. The women's active role in deciding on the life or death of their unborn baby was described as an added burden. "*I think the added dimension is having to make a decision to basically end your child's life is really hard*" (Jessica).

All the women saw their decision to terminate being made without any viable alternative options available. Some women who had lethal fetal abnormalities expressed an absence of choice in their decision to terminate. They perceived their unborn baby had no chance to survive whether they ended the pregnancy or not. "*It was really just one choice*" (Tiffany). These women perceived their decision to terminate as easier because there was no choice for them

except to terminate; the fetal abnormality was lethal and incompatible with life. For women whose fetuses had severe but non lethal abnormalities and who could give birth to a live baby who has a chance to survive, the decision to terminate was more complex than women with lethal fetal abnormalities but still they believed that they also did not really have a choice.

It is something that really stays with you for a long time especially If the diagnosis isn't a terminal one, it's may be not quite as hard if you get a terminal diagnosis because it would have ended the same way eventually" (Lucy).

Women facing a pregnancy with non lethal fetal abnormalities were presented with two alternatives, to terminate or to continue their pregnancy to term. For these women the process of decision-making was complicated by the reality that the baby could live. Hillary explained that she did not really have a choice and she wanted to save herself the difficulty of having to make the decision to terminate. *"If I was guaranteed that she [her baby] would have died at birth I might not have terminated"*. She did not want to feel responsible for making the decision to end the life of her baby. For Hillary, if she was certain that her unborn baby would die at birth, she might have continued her pregnancy to term and would not be compelled to make this difficult decision.

Although some women identified an alternative option, to continue their pregnancy to term, this was considered something they could not do. The decision to continue the pregnancy to term would have entailed dealing with babies with poor quality of life and caring for severely disabled children. Women realized choosing that option would subject their babies to suffering and pain. Concerns about suffering and what was best for the baby were frequently expressed by the women. Susan said, *"We didn't want her to have to go through that much pain. She wouldn't have understood at an infant age putting her through that kind of pain and suffering"*. Diana

considered her decision to terminate her pregnancy an act of parental love, intended to end the baby's suffering even if it was at a great sacrifice to her:

I don't think this is fair, we can't bring this baby here only for her to go through endless open heart surgeries and with the possibility that she was going to die after each surgery and then on top of it she probably it looked like going to be having leg amputation and so I just can't imagine doing that to a child. It seems so inhumane to me. I couldn't watch our child being tortured just sort of make ourselves better.

Although some women had thought about continuing their pregnancy but when they considered the suffering and pain that their baby, themselves and their family would endure, their decision to terminate superseded their initial thoughts of continuing the pregnancy to term. Lucy explained "*Initially we were actually thinking we weren't going to terminate, but the more they were able to tell about the problems the more we think of termination*".

Women decided to terminate their pregnancy based on their expectations of how their baby's quality of life would be affected. They reflected on what would be best for their unborn child and what type of life their baby would likely have in the future. Jessica and Lucy whose fetuses had a diagnosis of spina bifida and Down syndrome described how some diagnoses could be placed in a "*grey area*" in which they are not fatal but are associated with a poor quality of life. They wanted to protect their child from experiencing a poor quality of life. As a mother, Hillary explains, "*It's your instinct to want to protect your kids from anything bad*". Jennifer's understanding of the quality of life was based on how her baby would function normally. "*I didn't want to bring it a baby into the world to exist never to be able to smile or laugh or learn or play*". Hillary's concept of quality of life was based on the normal development of her baby and the accomplishment of important developmental milestones. "*To me seeing a child that's*

*confined to a bed or is unable to function like a child it's just completely selfish and unfair".*

Continuing the pregnancy and giving birth to the baby despite the presence of fetal abnormalities was seen as unfair and selfish. Women decided to have their pregnancy terminated by being altruistic and giving up their motherhood to save their baby a poor quality life. Women described quality of life as being able to take part in and enjoy day to day basic activities. Paige expressed:

Being able to play a game, you know kind of being aware of their surroundings, being able to eat food-cus those really basic activities. Not being able to walk, not being able to talk, not being able to eat independently, all those things, things were a present for them. So looked pretty bleak at that point.

Some women were concerned about the long-term care of their child when they are no longer around to provide care. *"Um, we were thinking how is this baby going to be cared for when she's an adult if something happens to us"* (Lucy). In thinking about caring for her child Hillary explained, *"We didn't want to think about putting a child in a home, we were concerned about how she was going to be taken care of if she didn't live with us"*. Susan who had a family member suffering from a severe genetic abnormality took into account the effect of raising a child with severe disability. She drew on personal experience stating:

We agreed that we would terminate because we knew the struggle it was for my family for my brother-in-law, they struggle so hard with the baby, she is not a baby anymore she's a full grown, but they struggle so hard and her medical and her special needs are just a huge toll on the family.

Some other women made their decision based on the best interest of their baby and of themselves, their family, and their other children. Tiffany, when she has been asked whether she had made her decision for the sake of her unborn baby said:

You know people are very excited when they see a pregnant woman and knowing you know psychologically the impact that would have on you having people be excited for you and having to tell them that your baby wasn't going to survive so, it was for me as well as for the baby.

Other women recognized their limitations and capabilities in raising and caring for a child with special needs and enduring that child's suffering. Jessica explained that, in addition to thinking about what is best for the child you need to consider "*what you are able to handle and you know this certainly a baby who is going to require 24-7 care*". Some women made their decision thinking about their family and their other children. As Lucy who had two boys wondered "*whether it would be fair to the baby and to our other children ...um to do this ...to go forward*". Jennifer thought about the burden of having a child with special needs on her other living child:

Then we had to think about our son, our first born son who you know we had to take care of and how much time that would take away taking care of the second baby take away from the first child's experience in the world.

After receiving the fetal diagnosis some women hoped that their baby would quickly die in utero since the decision to terminate would be easier if the fetus had already died and the wait to make the inevitable decision decreased. For others, having a fetus with a non lethal abnormality with which the fetus is likely to survive up to birth or for a variable time after birth, led to them struggling with the perceived inevitable suffering for both their unborn baby and themselves. Their decision to terminate the pregnancy was to end their baby's suffering and pain and to save

their baby a poor quality of life as they conceptualized it. These women were concerned about not whether their babies are going to live, but how well they would live.

**Decision paradoxes.** The meaning of the word "paradox" refers to a conflicting situation. A definition includes "a person, thing, or situation, exhibiting apparently contradictory nature", "an opinion that contradicts with common belief", or "a person or thing having qualities that seem to be opposites" (Merriam-Webster Dictionary, 1997). The women's decision-making process uncovered many paradoxical aspects of their experience. For example, the women found the decision to terminate their pregnancy contradicted their previous values and beliefs about pregnancy, motherhood and abortion.

Some women explained that hearing their baby's heart beats, seeing its picture on ultrasound and feeling its movements made the baby real for them which led to the decision to end the pregnancy being very complicated and difficult. Paige said "*At that point, I could feel the baby move, uh, the baby was a real baby, um, so it was just really difficult*". Embracing the maternal role of keeping her unborn baby unharmed and safe contradicted Jennifer's decision to end her baby's life. She recalled knowing her decision to terminate the pregnancy will kill her baby "*I remember feeling the baby move and knowing that I was going to kill my baby, that was really hard and that's one of the biggest challenges I went through*". Making the decision to end her pregnancy at 22 weeks gestation made a huge impact on Jessica. "*I felt I had bigger issues, I was feeling my baby kicking and all that kind of stuff*".

Women saw the pregnancy termination as a way to avoid suffering for the unborn baby, their other living children and their family, including themselves. The role of a mother involves making choices for the best interest of her children hoping to protect them from future suffering and pain. Jennifer remembered immediately before the dilatation and evacuation (D&E)



procedure speaking to her unborn child *"I always remember talking to the baby telling her I loved her and that I was doing this for her and rubbing my belly and knowing that's the last time she was going to be with me"*. Although to end a pregnancy may seem contradictory to the normative role of being a mother, to terminate the life of a fetus in order to keep him/her from suffering in the future presents another aspect of the maternal-child relationship that seems to override or transform the paradoxical ideas of choosing death to avoid possible future suffering for the anticipated child.

Some women found themselves ambivalent about being in the position of making a decision to terminate their pregnancy, even though they considered themselves as a pro-choice. Women believed that adopting a pro-choice stance would strengthen their attitude toward their experience of pregnancy termination. However, their decision to terminate made them question their beliefs about pro-choice. *"It really challenges your identity, who you think you are and what you choose to do, I don't think they match up very well. I was a pro-choice..but for other people, right? I wasn't really conscious about that until I was in that spot"* (Paige). The women exclaimed not finding terminating a pregnancy to be problematic when talking hypothetically about other women. But when they were personally facing this situation their feelings about termination took a different meaning. Being personally faced with a moral decision that involve a life and death situations of their unborn baby, even if they were pro-choice, contradicted and challenged their underlying values and beliefs. *"I'm a pro-choice person but when you're faced with something like that I mean it's everything against the grain of choosing to terminate your baby that you wanted so badly"* (Hillary).

Most women expressed difficulty in having their experience of pregnancy termination referred to as an abortion. Furthermore, they did not consider their pregnancy termination as an

abortion. Most participants believed that abortion is performed on women who have an unwanted pregnancy, no mature or stable relationship, young age, low socioeconomic status or very early in gestation. They did not view themselves as matching with this description. Abortion carried negative connotations for all the women. Consequently, they did not want to think of themselves as someone who had an abortion nor did they want others to think of them as someone who had an abortion. No matter what terms the women in this study used to label their experience, "*genetic loss*", "*pregnancy termination*", "*medical termination*", "*pregnancy induction*", or "*therapeutic termination*", nearly all women articulated that the stigma attached to abortion, influenced their decision-making and grieving experience in some way. These women, who had plans and dreams for their wanted child, explained that deciding to terminate their pregnancy did not equate with willingly choosing to have an abortion. These women found themselves in a situation of making decisions about their pregnancy and fate of their unborn child which they never thought they would encounter. At the same time they were dealing with many contradictory issues and stigma associated with pregnancy termination, even if they feel it would be the best option for their babies, themselves and their families. Lizzie did not like the idea of terminating her pregnancy at an abortion clinic as she did not view her decision to end the pregnancy as an abortion. She was shocked on having her experience described as an abortion.

I didn't think about it as an abortion. I just thought I was you know inducing my pregnancy and that was that and then when my OB um...when she had called to apologize for the doctor not coming in to start my induction he said something about well you know some people just really are against abortions, and that's when it hit me, oh my gosh.

That's exactly what I am doing, I am having an abortion!!

Lizzie explained, "*It took me a while to even be able to say that yes that's what I did. Um, uh...you know for a while it was just a medical termination*". Most of the women did not accept the notion that they have made a choice to abort their baby. For these women, their pregnancies were wanted and for them abortion refers to the decision to terminate an unwanted pregnancy. Even for women with lethal abnormalities, they considered their termination as "*therapeutic abortion*" or "*medical termination*" that entails a medical condition that needed intervention. "*I really didn't at that point think about it, I thought that medically that was I needed to do*" (Nancy). It was important for them to see their pregnancy termination as being different from an abortion.

A major issue surrounding these women's experiences involved the social stigma regarding pregnancy termination and the women's fear of other people's judgement of them. The women commented that others could not possibly understand what they had been through. Susan described her experience with the reactions of other people to her decision to terminate the pregnancy:

I think it's the stigma of termination. The fact that people judge you because you are making decision that's based on normally the best for you child and in many cases that is not letting your child suffer I think there is such a stigma on abortion termination that people don't realize that the choice between letting your child suffer or ending their suffering before they can even feel pain.

Most participants felt stigmatized by their decision to terminate their pregnancy. Even if pro-choice, when faced with the decision to terminate their affected pregnancies the women expressed having contradictory feelings about making such a decision. They discovered that although they claimed themselves as pro-choice, when they experienced the situation to

terminate a pregnancy it was difficult to go through it without an internal struggle. They struggled with their moral beliefs and societal views about abortion. Paige explained: *"I even had trouble saying that word [abortion], there was a lot of shame, I did think about how are other people going to respond to our decision? Will they support us? Will they judge us"*. The societal controversy and stigma about abortion led women to fear social disapproval of the decision they made. Women were cautious about revealing the nature of their loss to others from the fear of being judged. *"Let's say I just no matter or whatever, I tell them my story, in the back of my mind I worry that they are judging me"* (Jennifer). The women expressed anger, irritability and annoyance and were hesitated to reveal what happened because of the negative reactions they felt they would likely receive.

It really angers me when people are judging people for having abortions, that's what makes me angry is that those people are out there and they can have their beliefs and that's fine, but I don't go around dictating to people well you should just do this" (Jennifer).

Although some women did disclose to some people about their pregnancy loss they chose not to provide the actual reasons behind what happened. Susan expressed that she preferred to tell her friends and co-workers her pregnancy loss was a miscarriage instead of telling them the real reasons. *"I didn't feel comfortable sharing the reasons um....that I lost the child. I just told her that I lost the baby, not how I lost it, I think it's the stigma of termination"*. Some women did not share their experience openly with others and if they did disclose, they chose the people carefully. Jessica explained *"We told kind of a select inner circle of friends, I mean everybody knew that we lost the baby, not everybody knew what happened"*. Susan explained that she always had to be on guard because she lived in a small town with negative views on abortion. *"I*

*did not disclose the nature of how we lost our child to anyone, I was so very guarded about it".*

The impact of feeling stigmatized was so great for Lucy that she moved from her neighbourhood

*"We moved and since then I've made a whole new group of friends".*

Some women felt uncomfortable when they went to an abortion clinic to terminate their pregnancy. Their reasons for terminating the pregnancy were perceived as different from women who were ending pregnancies for reasons other than fetal abnormalities. Lucy expressed *"I was 20 weeks along and had really wanted the baby and planned the pregnancy and just gotten a diagnosis that was bad"*. Lucy felt the stigma associated with abortion and wanted to be treated in a different way than a woman who terminated an unwanted pregnancy.

Some neonatal health conditions will lead to adverse health outcomes requiring long term high technical medical care to maintain bodily functions. For some women it was not that they wanted perfect babies, rather it was that they do not want to submit their unborn child, their loved ones and themselves to undue suffering and pain. For Paige, who considered herself pro-choice and a feminist, it was conflicting to make the decision to terminate her pregnancy because of a confirmed disability. She felt wanting a healthy baby contradicted what she believed about herself as a feminist:

I think the other really complication for me was that I needed really a perfect child..that was not even something that I really needed or expected even..but..um..but being in social services and a feminist and being very accepting and being part of my personal philosophy that being a tolerant and all of those things. I felt it contradicted who I was. Jessica commented that protecting people with disabilities is the role of the society, however there is a lack of understanding of the difficulties that arise when caring for people with a

disability. She explained *"I have friends who have siblings with Downs and I can see firsthand that it is not all sunshine and roses as many people portray it to be"*.

**Persistent unresolved issues.** Facing the unexpected diagnosis of fetal abnormality and dealing with the numerous paradoxes underlying the decision to terminate a pregnancy for fetal abnormality, these women described having to deal with many unresolved issues concerning their experience. Unresolved issues involved anything that the women identified as still being troubled by or still wondering about. For example, most women commented about having, unanswered questions, guilt, anger, and lack of support. These issues remained part of their continuing experience and were present at the time of interviews.

Some women explained the lack of information about the fetal diagnosis remained troublesome. Hillary considered having more information about the fetal diagnosis would have been helpful and thus she did not feel supported with the limited information and resources she was given. *"They are lacking information and support, like I should have been given support right from my doctor's office about the diagnosis and resources"*. Paige felt that if she had been given sufficient information she would have asked more questions. *"As far as I mean looking back certain questions I guess I could have asked which I didn't even think to ask which weren't provided to me like the size of lesion"*. Hillary still felt irritated about the lack of information regarding prenatal screenings many years after her pregnancy termination. She stated that she was not well informed by health providers before she underwent the various prenatal tests. *"You can't do these things without interpreting it to people"*. Some women expressed being upset with the lack of information regarding the pregnancy termination procedures, the grieving process and how to deal with their baby after the termination. *"...there really no information out there for the grieving process, I wish I had known to ask questions like do I need to get my baby's remains,*

*about getting a footprint, or handprint, those kind of things"* (Susan). Lucy described not being well-informed about her two options of pregnancy termination and what each option would entail. *"One thing that has bothered me over time is that I mean it was vaguely glossed over during my perinatal visits that you can go through labor and delivery or D& E"*. Paige's limited knowledge about what to do with her baby's remains after the termination was *"disorienting, we just had no idea, I remember that-going, oh my gosh, we had no idea"*.

For some women the care received from health care professionals' (HCPs) was described as inadequate. Painful memories of the pregnancy termination were still bothering them at the time of the interviews. Jennifer described her experience with HCPs during her termination procedure. *"Still the hardest time for me is just remembering that one part outside the operation room and just no compassion. Nothing was expressed"*. She expressed feeling neglected by the social worker who did not provide her with any support services after her pregnancy termination. *"She's like well we can call you. I never get a call, never, they basically leave you hanging"*. Jessica described her frustration accessing social support. *"I had a lot of frustration like finding resources, sometimes I felt like I had done more research than the person that was supposed to be helping me"*. Having follow-up care and support services were very important to these women and when they were deprived of this care they felt abandoned and frustrated. Many described HCPs as ill prepared to offer the support services they needed. *"I think doctors are not equipped to give the follow-up and follow through care"* (Hillary). The women expressed unresolved feelings of regret, blame, and anger. Susan was still feeling angry towards the whole experience of losing her baby because of fetal abnormality.

I was angry with the world, angry with God, I mean here God had finally given me the child that I wanted and she was so sick she wouldn't live, angry that I had to go through

all of that, that I can never have children, and I still feel angry, the counsellors and the psychologist couldn't help me with the anger.

Susan also had an unresolved feeling of self-blame related to not trying to get pregnant earlier in her life. She explained, "*If I had known how difficult it was going to be for me to have children I would have tried much earlier in my life*". Diana was dealing with her regret of choosing D&E over labor and delivery and missing the opportunity of seeing her baby. "*I wish that I had if I could go back and do it again I would have a labor and delivery and just to have held her and [crying] seen her*".

Some women expressed they were still experiencing some doubts about their decision to terminate related to the uncertainty and lack of information surrounding fetal anomalies. Lucy stated, "*Knowing that there is a possibility that the baby could have lived a relatively typical life that makes it harder, it makes you second guess yourself more afterwards*".

Some women spoke about the process by which they resolved or determined to live with the unresolved issues associated with their pregnancy termination years before. They acknowledged a painful sense of short-coming and regarded the situation with a more accepting attitude that took in account the magnitude of the difficult decision and the impossibility to have all information you need before making such decisions. The women considered that in the end they had made the best decision they could based on the information they had at the time and while under extreme painful circumstances. As voiced by one of the participants, "*But knowing what I knew at the time, I did the best I could, I did what I really thought I should do*". (Lucy).



#### **Theme IV Living with the Decision**

After deciding to terminate their pregnancy, the women encountered many challenges in their efforts to live with the decision they had made and move on. Women described feelings of deep sadness and loss during and after making the decision to terminate.

**The challenges.** Many challenging feelings were experienced by these women. Feelings such as loss, devastation, pain, void, grief, and regret were frequently described. Participants described holding their feelings inside until they made their decision to terminate their pregnancy. Paige gave an analogy that described her feeling at that time:

It's sort of like ...you know I had to go with my children a couple of times, because they have had pneumonia-which is scary as a parent...scaring for them but scary as a parent too. And you're in the Emerg room and it's the sickest you've ever seen them and they are checking their oxygen levels and they are low and ..and..but but because you want to be that steady-calm, steady presence for your child, you don't get upset. You just are calm and steady and you just go through it-you do- you just talk to the nurses and you negotiate and you tell them the information. You've very, you know....I mean, you function like staff functioning really. You..um...and then you get the antibiotics rolling and you get your child home and you get them into bed and you see they are getting a little better, you go somewhere and have a big cry.

In describing her everyday life shortly after terminating her pregnancy Jennifer stated, *"Everything after that was hell. I cried every day. It was just bad. Every year is hard for me. This has never gone away"*. Nancy commented on how she felt broken after the termination saying, *"I believe the hardest part was probably the next month when everything was over and you kind of have to pick up the pieces and go on with your life"*. Tiffany expressed, *"I was devastated I*

*don't think I've ever been that devastated by anything in my life. I was very upset. The blanket that they had her wrapped in, I slept with, you know probably a week afterwards "*. Lizzie suffered from depression after her pregnancy termination *"I battled with depression for a little bit. I off and on had gone on antidepressants"*. The women's many expressions of sadness during the interviews were evidence of women's ongoing grief. Tears, difficulty talking, as well as verbal affirmation of sadness revealed the extent of this continuing grief. All the women expressed experiencing ongoing loss.

Since all the participants had terminated their pregnancy in the second trimester, had seen the baby's image in the ultrasound and most influentially, had felt the baby's movements, they had physically experienced the fetus as a real entity. The women considered the baby they lost as a real baby and used words such as *"my child"*, *"my baby"*, *"him"* or *"her"*, or referred to the baby by name. They talked about having bonded physically and emotionally with the baby. They all wanted and wished for their anticipated baby. The meaning they had constructed about their baby as a real entity contributed to their feeling of loss and void. Jennifer stated, *"I have a definite part of me that died"*. Paige noted, *"There is that feeling, I'll always have this feeling like we are missing someone, I don't have any expectations that it will ever go away"*. Hillary described her ongoing feeling of missing something. *"I feel there's always going to be an empty spot. I had a picture next to my bed of my boys, and when I look at that picture you know what I see...I see a picture with a missing piece"*. Diana explained, *"I never will ever forget her"*. Lizzie stated, *"There is always part of me missing, I'll say I have 4 boys, I have one in heaven"*. Jessica explained *"There is always this sort of dark period in my life which is never going to go away"*. Using words such as *"never"* and *"always"* when describing their feelings of loss indicated the intense impact the experience of pregnancy termination for fetal abnormalities

continued to have on the women's lives. The women all expressed how much they loved their babies and that their feelings of loss would last forever.

Most participants experienced feeling of emptiness, and void physically and emotionally. Their loss differed from any kind of other losses that they had experienced previously. Susan described her feelings saying "*I just wanted a baby so badly and I missed my baby so badly. There was that huge void there, I need to try and fill*".

Paige had a memory that explained how empty she had felt after TOPFA,

I remembered after she died, going up to [Mall] to pick something up and I heard a baby cry and all the milk came out of me....so I am standing in [Mall] with a wet shirt. all I want to do is go and pick up the baby crying cus it's the worst sensation leaving the hospital without your baby. You are feeling empty. Like it's a very physical trauma too....I felt like my whole chest was empty like there was supposed to being a baby in my arms and my chest, so the void feels, I dunno, like a thousand miles long.

The women's immense grief over the loss of their unborn baby was described as being unrecognized and unacknowledged by those around them including health care professionals. Some women commented that their grief was also ignored by others leaving them feeling alone and not understood. Diana explained, "*It was hard because like friends sort of figured you know I went 24 weeks without showing but to them I'd just lost a pregnancy and not a baby*". Jessica described her feelings as, "*It was just kind of I felt like I was in like this weird little sadness bubble that nobody else really understood*". Jennifer expressed her disappointment at some people who were not aware of the nature of her loss and dismissed its significance:

They have no idea, I think it's like if you had a stillborn, like a woman who goes a long and say at 5 months gives birth and it's just premature and the baby dies, you are going

to get more empathy from somebody than who at 5 months terminates a pregnancy because of a medical condition.

Although the feeling of anger at the whole experience was mentioned by only one participant [Susan], who was the only childless participant in the study, it is important to discuss because it was very strong and it could be common especially among women who have experienced infertility. Susan was dealing with a long history of infertility and was terminating the only possible pregnancy that she could ever have. She described her experience had an impact on her religious beliefs, *"Angry, furious with God. Um, in fact I lost my religion, it was not just because of my termination it was because of the several losses after my termination and the subsequent IVS"*.

For many of the women the death of their anticipated child was accompanied with several other felt losses. Participants experienced multiple losses such as loss of hopes, dreams, and plans for the future; loss of faith and loss of feeling secure. For Jennifer *"It's a loss of a child and a loss of a dream and a loss of a future that you like planned or that you thought about"*. She felt more pessimistic and had thoughts of her own mortality. *"I have more paranoia. I was really afraid of dying because if I die who's going to take care of my kids, whereas before I wouldn't think bad things are going to just happen"*. Some women had fears of adverse pregnancy outcomes for themselves or others. Lizzie stated, *"I have a fear of pregnancy for anybody now. Every time I heard a friend is pregnant I worry more than probably should because I know that the outcome of pregnancy usually is not a happy ending"*. Paige had fears about facing this kind of ethical decision in the future. *"I still have fears that, um...I will someday have a parent who will have a stroke and it will be a really bad stroke and I will be*

*faced with making that decision about..quality of life". She added, "Unfortunately, I think I will ever have an anxiety free pregnancy again"*

Some participants talked about their feeling of loss of innocence, because their TOPFA experience was the first experience of loss they have ever encountered. Feeling the loss of innocence was pervasive, affecting not only future pregnancies but other areas of their lives. Hillary lamented *"There are so many horrible things that can happen. In fact you were innocent, you were not innocent any more"*.

**Moving on.** The women described their endeavours to overcome the many challenges they encountered in the aftermath of terminating their wanted pregnancies. Some women begin a comprehensive search for information from the moment they first learned about their baby's diagnosis. Others tried to use strategies to move on after their termination such as returning to work immediately, getting busy with their other children, getting pregnant, and involving themselves in activities that honor their babies to move on after their termination . A few women revealed they were still, currently, having some troubles to move on. *"It does not get better with time, every year it's hard for me, this has never gone away"* (Jennifer).

**Remembering and acknowledging the baby.** The time spent with the baby after the delivery, although short, was valued by the participants who had their labour induced. They appreciated the opportunity for the family to spend some time with the baby. The women described being able to make memories, *"have keepsakes"* and *"take pictures"*. Tiffany mentioned, *"having someone come and baptize the baby after she was born. We were able to take pictures. So we have all the keepsakes that we keep you know in a I have a box of stuff related to her"*. The women valued experiencing the labor and delivery process because it gave them the opportunity to see their baby.

The women who went through a D & E missed the only time they would have seen their baby and as a consequence tried to create their own memories. Not having tangible mementos of their baby's physical being caused the women to feel the baby never existed and that was painful because they needed to remember their baby and acknowledge its existence. Jessica described not having a funeral for her baby as *"It just seemed like too much on top of everything else. And um, so there's no physical reminder really"*. Diana regretted her choice to go through a D & E because it prevented her from seeing her baby. She lamented, *"I wish that I'd had the opportunity to even, if she'd [The nurse] just been able to put a hat on her or something I just wish I had some mementos from her like the footprints"*. Susan did not have tangible reminders of her baby and tried to get her ultrasound pictures from the hospital. She stated, *"I wanted those ultrasounds it was the only thing I had of my daughter"*. Many women created memory boxes in honor of their babies including scrapbooks, photo albums, ultrasound pictures, framed pictures, and other mementos. Tiffany stated, *"We did something to remember her by um we both had rings made with her birthstone and the only time I've taken it off since I've had it it's for my 3 subsequent deliveries when they made me"*.

Paige prepared her memory box before the interview and showed me its content explaining everything inside it. She stated, *"All my kids have memory box. But .....[the baby's name] I thought needs one too because just she's not alive does not mean that she didn't exist"*.

Women reported doing special activities or having rituals for their babies, particularly on special days such as anniversaries of birth or death dates. Paige remembered, *"We made just a small service in the Church, we brought her ashes to the Church and he helped us with a small service and our families attended, just immediate family which I thought were helpful"*. Jennifer

recalled, *"She was due in my birthday, I want to go out to the grave and I want to release balloons or do something significant, so we did it. I went out and got the balloons"*.

Most participants felt a need to honor the memory of their child and keep their memory alive in the family. Many women told their other children about their lost sibling and some planned to tell them when they were older, more mature and could better understand the situation. All the women agreed that their other children should know about this loss. Jennifer confirmed, *"I find it very important for me to keep her existence going so I take the kids to her grave"*. Paige stated, *"both kids were there when we spread the ashes so I think that was okay, It felt okay with them talk about that"*.

Some participants had their baby cremated and spread the ashes in a very special place. Paige kept her baby's ashes for long time *"I had her ashes beside my bed and I'm glad I waited and didn't rush to feel like I had to spread the ashes right away, she is actually in the place that I dreamed about"*. Although it has been six years since the termination Lizzie still keeps her baby's ashes on her dresser, *"One day may be I'll be ready to spread his ashes but right now I'm content with him just being with us"*.

***Becoming pregnant.*** All the women desired to have a subsequent pregnancy and another baby as soon as possible after the termination. They wanted to fill the physical and emotional void that existed from losing their baby. For them the transition to becoming a mother had been interrupted and incomplete. They did not consider another pregnancy was a replacement baby, but a desire to regain their motherhood, their hope for a healthy baby, and to overcome their feeling of loss and grief. Susan and Hillary described their feelings as, *"I felt like a mother without a child"*. Referring to her subsequent pregnancy, Nancy explained, *"Until I had my son born...I mean every ...you know things were still hard and I always remember the past, but like*

*once I had my son things just started to get much better". Lucy who became pregnant again stated, "Even though it didn't replace the other baby, it really filled the void".*

Most participants emphasized that becoming pregnant again and giving birth to a subsequent child was a very important part of their healing process. Lucy stated, *"I really didn't feel like I'd healed and if I hadn't been able to get pregnant again, I don't know how long it would have taken because that was really the only thing that did it for me"*. Hillary noted:

I would have done anything to have a baby, anything, if you told to do drugs and I would get pregnant, I would do it. That's the way I felt like. I think you just feel so empty. So what ended up happening to me was immediately I became involved with the reproductive endocrinologist.

For other women their need to become pregnant as quickly as possible was their way to move on with their life. Diana explained, *"I ended up getting pregnant right away. I knew like in my mind heart I had to get pregnant right away, I felt like to move forward I needed to be pregnant"*.

Some women described an intense need to become pregnant. *"We were so desperate to have a child"*. (Tiffany).

### **Theme V Feeling Supported**

The women expressed an ongoing desire to have others approve and support their decision to terminate the pregnancy. Although they avoided telling others about the termination for fear of being judged, they continued to seek approval and understanding from others.

Women often felt isolated and alone when they were unable to tell others about their decision and experience.

**Women's needs.** The women described having unfulfilled needs such as talking about their experience, be listened to, be understood and acknowledged, and be supported. As Lucy



expressed, *"I think the healing would have been a lot faster if I'd gone and talk to someone, nobody really wanted to talk about it, I mean they [family, friends] were sympathetic, they didn't really want to talk about it"*. Many women found family and friends avoided talking about what happened. Lizzie expressed, *"They [family] weren't talking about it, they were afraid to mention it around me"*. Women mentioned not having anyone to talk to who could really understand what they were going through. Jennifer added, *"I had nobody. I had nobody to go to and say I know what you are going through and it sucks and I totally understand what you are going through"*. Jessica reflected, *"it's also a burden you kind of have to bear on your own and nobody can really say anything to make you feel better"*.

Women needed other people to understand their experience, to understand their suffering and pain. Jennifer explained, *"This isn't something that I want to do. I hope you realize, I need you people to know that this was not something that was going to be, this was a baby that I wanted"*. They believed they were good mothers and needed to let others know that they terminated their affected pregnancy for the best interest of their baby. Lucy tried to convince herself and others that she is a good mother *"People terminating for medical reasons aren't doing this because they don't love their children. It's because we do love them"*.

Jennifer remembered when she was alone waiting outside the operation room talking with her unborn baby explaining to her how much she loved her. The women wanted people to know they made their decision to end their pregnancy to protect the fetus from pain and suffering. *"I think once you find out that something fatal like that is going to happen to your child it's your instinct to want to protect your kids from anything bad"* (Hillary). Similarly Susan stated *"Your making a decision that is based on normally the best for your child, you have to make the compassionate choice"*.

Although some women felt that their experience of deciding to terminate their pregnancy was understood by some people, the majority did not. Women described their feelings of frustration about being judged by others. Jessica stated:

One of my relatives called my dad and said he was going to send me a giant bottle of folic acid so it wouldn't happen again next time. And I had one person who was like well didn't you take your folic acid, I couldn't believe they had said that.

The fear of being judged by others interfered with the women needs and desires to talk about their experiences with TOPFA. Paige stated, "*Women don't really talk about it until they know someone who may be would be open to listening to them or and wouldn't be judgemental to them*".

Women needed to talk openly about their experience and wished that people could do the same and understand their reasons for terminating their wanted pregnancy. Doing so would help others to appreciate and understand what they have experienced. Lizzie explained, "*I just feel the more it is talked about and the better the people might have a better understanding of it*".

Diana stated:

I guess I just hope that people realize that we're not as fragile as they might think and that we do still need to talk about our babies and that they are part of our family part of our heart and that we just try to do the best we could for them with the information we had.

All the women needed to be acknowledged by others as being good mothers, for them, they believed that they made this difficult decision and unselfish one for the best interest of their baby. They let go a wanted and loved baby for a better life for him/her. Diana explained, "*I think that in my heart I know I made the right decision that to let her go and just be where she*

*needed to be free from a body that was so unhealthy and unwell".* Susan expressed her need for understanding regarding why she made the decision to terminate her pregnancy. *"The choice between letting your child suffer or ending the suffering before they can even feel pain, you have to make the compassionate choice".* Regarding her decision to terminate pregnancy, Lucy added *"We are trying to make a decision on whether we think that their lives are going to be good for them or not".* They gave up their motherhood for saving their baby from a life full of suffering and pain. For them they were protecting their baby.

**Relating with others.** The women needed to find individuals who would be "there" for them, show concern and understanding, provide ongoing support, and offer opportunities to share and connect. The participants often felt alienated and alone when they did not get the support they hoped for. The women described receiving limited support from their personal social networks. Although some participants received support from husbands, family members, friends and health care professionals, the majority did not. Interactions with others often invalidated the significance of their experience through inattention, oversight, or just not "*being there*". Their lived relations with others were very important to them as they all sought support, understanding, and empathy from health care professionals, family and friends.

Most women appreciated their husbands' support and "*being there*" for them. They described the unique bond they shared which arose from caring, sharing, and standing by them. Susan said, *"My best friend has always been my husband, he's always been my rock".* However for some women, how their husbands reacted to the experience of pregnancy termination created tension in their relationship. Hillary said, *"I was irritated with him initially because I was going to a support group meeting that people and their husbands went to and he had no interest in going. He was over it pretty quick".* Paige described the different reaction of her husband to the

loss of the pregnancy. *"He went to bed and slept, sort of has the more flight response, uh, this is overwhelming and I am going to withdraw"*. She expressed the *"need to protect my child' kind of response"*. The couple experienced some marital problems and needed professional help to resolve these difficulties.

Women sought support through relating with others. Some women described their encounters with others as being supportive from the time they made the decision until the termination had occurred. Susan appreciated her family's understanding and sharing *"All my family, my husband's family, my sister who is very religious and but she cried with me and supported me, everybody in my family did and everybody in my husband's family especially his mother"*. Other women wondered about and missed the understanding and support of others. Women commented that some family members and friends displayed lack of acknowledgement, minimized the experience, or made insensitive remarks. Lizzie described the support she had from her family and friends as more of physical presence but it only lasted for short time. *"They just were there physically. If I needed anything, they were not talking about it, they were afraid to mention it around me "*. Diana found people expected her *"to move on and stop being upset"* within the first couple of weeks after having terminated her pregnancy. Other women encountered insensitive remarks, such as, *"oh, you are still upset about that"* and *"I just don't feel like there's even a real baby"*, which interfered with their desire to ask for support.

Women sought empathic understanding, support, and acknowledgement for their painful experience from health care professionals. Some women described their interaction with the health care providers as complicating their experience. Jessica remembered, *" The supervisor nurse was kind of brusque and not very friendly and I unfortunately remember that quite clearly"*. Lucy described her experience in the abortion clinic, *"It was really hard. There was no*

*compassion*". Support and understanding from nurses and other health care providers was often lacking. Women expressed the support they needed included providing them with information, resources, appreciating their suffering and pain, and empathetic understanding.

The women mentioned that some of the hospital practices associated with their experiences of TOPFA increased their stress and anxiety. For example, many women upon learning about the fetal abnormality had already decided to terminate but had to wait a long time to be scheduled for the procedure. The waiting period was an extremely difficult time emotionally for the women. Being with the fetus and feeling its movements after having made the decision to end their pregnancy was extremely painful and stressful. In a normal uneventful pregnancy, feeling the baby's movements is often exciting and pleasurable and helps to strengthen the mother-child relationship. For these women, when they decided to terminate their pregnancy for fetal abnormality, these usual pregnancy events turned into nagging reminders that happy thoughts about this expected child were no longer available, only thoughts of their impending decision. The felt movements of the fetus made it impossible for the women to distance themselves from their unborn baby and constantly reminded them of their difficult decision. Jennifer remembered the many tests she underwent before receiving a definitive diagnosis. *"I continued with my regular, being as normal as I possibly could, I mean you're trying to just live and get through it. Not think about it every second"*. Then she had to wait again another week for her termination time. She lamented, *"knowing that I was going to kill my baby and I could feel the baby and then knowing what the end result having to wait a whole week for that like that was just suffering"*. She continued blaming the hospital practice. *"I don't know why it took a week, it was hard, I think that they should try to do that fairly quickly, it should be a priority"*.

The lack of understanding of their pregnancy termination experience by the health care professionals was evident in the women's encounters. Women spoke about painful experiences they encountered with healthcare professionals while being in the hospital setting before, during and after their termination experience. Providers were described as "*very stand-offish*", uncompassionate, and uncaring in their interactions with them. The women felt ashamed and stigmatized by their decision to terminate the pregnancy. They felt hurt when they encountered insensitivity from HCPs. Paige described the staff who attended her pregnancy termination procedure and how they conveyed messages of dissatisfaction about what was happening. "*The doctor didn't have great bedside manners with me, I mean being even a little insensitive feels so abrasive and horrible. You could just feel it when someone is uncomfortable and that made me feel horrible*". Jennifer's encounter with health care providers was particularly painful:

They put me on the gurney, obviously, I'm on the gurney and they leave me there and I'm by myself and all I'm doing is hearing all these people in the operation room setting up. got ready and their like laughing and talking to each other like just another day at work, and I'm out there by myself with nobody around just scared scared scared.

Some women commented that fixing their problem and making sure that they are medically stable was all that health care professionals cared about. Jennifer said, "*It's just like ok we've solved your problem now they don't treat it as this is your child, they, oh....you solved the problem, ok. We solved it for you see you later, off you go*". Caring for the women physically seemed to be the first concern of HCPs. The women described their encounters with health care providers and hospital system as very clinical, detached and basically, "*getting the procedure done*". Lucy explained how clinical the pregnancy termination experience felt for her, "*They were just trying to get us in and out*". The women described insensitivity and negligence by

HCPs and hospital practices in addressing the psychological and emotional aspects of their experience. Lucy stated "*There was no compassion. I'm not sure you felt like they were not concerned about your wellbeing other than getting you out there without anything bad happening, it felt like nobody really care*". Tiffany expressed, "*My OB didn't really offer anything, any kind of follow up, she never asked me anything about psychological response to termination*". Lack of empathetic understanding from health providers made the women feel frustrated. Jennifer described her psychological and support needs after her pregnancy termination not being acknowledged:

I asked the social worker I said so are there groups or somebody that you know is there, something I can go to that the other people have gone through this. I never get a call. Never, they basically leave you hanging. And it was frustrating and I'll tell you even up to 2 years ago I called back to the genetics counselor because having a hard time, feeling the need to talk to other people that have gone through this and seeing how they are coping..., cause I'm thinking here I'm 6 years along and I still feel this was. Why is this happening. Am I normal or am I abnormal. The lady takes a week to call me back, leaves me a message, so I called back, leave a message and never heard again.

The women's unfulfilled needs of support through interacting with others left them feeling neglected. Having the immediate support by health care professionals was very important for these women. Feelings of alienation and abandonment by HCPs, who were expected to provide the needed support, were expressed. The women still felt frustrated many years later not having received the adequate support they expected from their health care professionals.

Placing women with other women who were having healthy deliveries, leaving them waiting in public waiting areas, and showing disregard to their emotional state were considered

hurtful and frustrating. Diana recalled a hurtful memory while in the hospital getting ready for her termination. *"I'm walking in there visibly pregnant and it's all done in the same place where women are having C-sections and you know,...you can hear other women and they're having their babies"*. Tiffany remembered meeting the nursing staff at her follow-up visit who were unaware that she was no longer pregnant. *" When I came in for my postpartum follow up, they hadn't bothered write anything on my chart about the termination itself, and were asking me questions about pregnancy and if I was feeling fetal movement"*.

Experiencing pregnancy termination for fetal abnormality made the women felt ashamed and stigmatized and needed to keep their experience as a secret. Ensuring strict confidentiality was an important part of their experience. Jessica felt *"uncomfortable"* having to reveal her pregnancy termination to others.

The nurse who admitting me into the surgical suite was like,..so what are we here for today and I was in this sort of open surgical intake area where I had to say I'm here for a D&E. I felt kind of exposed and really uncomfortable.

Although, most women experienced a lack of support from health care providers and the hospital system, some women felt positively about individual encounters they had with health providers. Jessica stated, *"They had like a social worker that they connected us with to um...give us resources, they're very non-judgemental"*. Susan recalled, *"One of the kindest people during the whole process was the anaesthesiologist who held my hand and said he understood and that I was making the right choice. The nurses were fantastic they were very kind and considerate and non-judgemental"*. Having the understanding of others, especially from HCPs, was considered comforting, and supportive of the women's decision to terminate their pregnancy. When HCPs were non- judgemental, the women felt reassured that they made the right decision. Hospital



practices that showed empathetic understanding and support were identified as helpful. Lizzie remembered:

The hospital was wonderful, they put a white flower on my door, I didn't know it at the time. My mom later told me they put a white flower on my door to let them know that I was not leaving with a baby.

Being there for the women and engaging with them physically and psychologically was appreciated. Lizzie remembered, "*The nurse was very caring, stayed with me most of the time, explained things as they were happening, asked me questions of things that I wouldn't have thought of,...she kept the communication open*". Not being physically present for the women was considered hurtful and not caring. Jennifer expressed, "*Being left alone, don't leave somebody alone that's going through this, just stand beside them*". Lizzie had a positive caring experience with a nurse who prepared her for the termination process:

That nurse actually gave me a book called 'Empty Arms' and my husband and I both read it front to back several times during the four days, I told him that you know I wanted to name him. I thought I wanted to hold him.

**Seeking support.** After their pregnancy termination experience, some women took positive actions and sought professional help by themselves and others were referred by their physicians. Susan sought some psychological therapy to help overcoming her anger "*I was very angry and I needed to know and so I reached out and got help*". Jessica expressed her need for some help immediately after the pregnancy termination. "*We realized pretty quickly that we probably want to talk to like a counselor just to help us process it, there was just so much, it happened so fast, from the diagnosis to ending... just so many emotions*".

Although most of the women found consulting psychologists and therapists was helpful, they also expressed the need to be connected with women who had similar experiences as they had. There was a sense that people who had been in this position would know or understand what they were going through. Hillary stated, "*I didn't want to just work it out with someone who didn't know what I was going through. I wanted to work it out with other people who knew what I was going through*". Support groups are described as important because they provided emotional support for women who had faced similar situations.

Being involved in general perinatal loss support groups was not considered to be that helpful to these women. They felt their experience of pregnancy termination for fetal abnormality was different and more complex than other types of perinatal loss. In describing one perinatal loss support group Diana stated:

I kind of felt a little bit uncomfortable being there as somebody who had chosen to terminate, I felt like each women had their children taken from them without them signing the 'x' and I thought maybe being here is hurtful to them.

Most of the women found that on-line support groups offered a beneficial and safe place to share their feelings and connect with other women who had the same experience. There was a sense of secrecy with online discussion groups that uphold the importance of confidentiality and anonymity, which were very important for the women. "*They administer it very carefully, and so you don't get any crazy people wandering in there*". (Jessica). Although, for some women there was the fear of being judged by others. "*How do I know that if I go to one of those and I get judged you know. I can't go in there*"(Jennifer). Other women appreciated being able to join online support groups because of their availability and accessibility in the time of need. Jessica said:

That was kind of a life saver, somebody was always there because there's people on there from all over the world so if you're having a moment of insomnia and was up in the middle of the night I could log on and there would be somebody to talk to.

Participating in online group allowed the women to talk freely about their experiences and "*just let anything and everything out*". As they began receiving the support they needed, some women were moved to reach out to help other women who had experienced a TOPFA. "*I'm on there every day, support people, just to let them know what they are going through, and kind of direct them to other boards depending on what their diagnosis*". Seeking support through online support groups allowed the women to connect with other women and share their experiences openly and discuss their feelings. Reading and writing about their experiences helped and supported women throughout their pregnancy termination experience and provided them with the feeling that they are not alone.

### **Theme VI Changing Perspectives**

These women had experienced pregnancy termination for fetal abnormality many years ago. With the passage of time since the termination, most women had gained different or broader perspectives on their pregnancy termination experience and the influence it had on their lives. The women attempted to make sense of their pregnancy experience and the subsequent loss of their baby. Some women spoke about having learned more about themselves and developing different perspectives on life events.

You just look at things differently, like I believe in some way that was meant to be for me, and I don't know at the time, I didn't see that but I learned a lot about myself, I learned a lot about my husband too (Hillary).

Some women found new meaning about life from having had experienced TOPFA many years ago. They realized that their pregnancy termination experience had brought many changes into their lives. As years passed they begin to see the positive aspects left behind by the loss of their baby; whether it is in their new found strength and ability to be there for others experiencing something similar or in the new understanding of self. Some women expressed changes in their way of thinking through their life experiences. They described becoming "*more caring*", "*less judgemental*", "*more sympathetic*", " and "*less critical*". Going through this experience made the women see shades of gray in situations which, in the past, were quickly judged. "*I used to be more like a black and white person and I'm not anymore*" (Jennifer). They became more compassionate and aware that no one can truly walk in another's shoes but everybody must try to understand. "*You never know what you're going to do until you're in that situation*" (Hillary).

Some women have made an "*altering life decision*" based on their new understanding of doing what one loves to do and what is important in life. The priorities in their lives were seen differently now. Jessica changed her career after her experience.

At the time I was in a job I just didn't really enjoy it and I think having this happen made me think a lot about reprioritizing my life and like I had so much stress and sadness in my life already.

In her desire to help other women who had similar experience as hers, Lizzie changed her career to be in health care and studied ultrasound. "*I just completely changed my career focus to sort of I don't know give back in a way to everything happened to me, I feel like it's good thing*".

Some women realized their inability to control life situations. Hillary expressed, "*There's no guarantees in life, there's no controlling things*". Diana stated, "*I'd say it's just kind of changed how I perceive the world and how much more precious life is and how fleeting life can*

be". They appreciated their life and enjoyed it as it is. Paige stated "*there are no guarantees and...so what do I want to do and how I want to make it beautiful. It just puts life into perspective and what is important, not worry about small stuff anymore*". Some women developed a sense of appreciation of the birth of healthy children and valued being parents. "*I think I'm more appreciative of my children and how I parent them*" (Diana).

Some women described their experience as a "growing", "learning" experience that "*strengthened you*". Going through this experience made some women feel stronger than before. "*It's a horrible drop in the road and I was able to claim out of that hole, and I'm still here, I'm ok*" (Lizzie). Their experience changed their life worldview. "*You just realize how fragile life is and sometimes you get more appreciation of life*" (Nancy). For other women, they became more aware about life and death situations. "*I'm much more aware and in tune around the issues around death, I think we live in a death denying society and I'm not a part of that anymore*"(Paige). Being faced with a diagnosis of a fetal abnormality made some women more cognizant of the people with disabilities and "*I have more compassion for them and their families*" (Lucy).

### Summary

The findings of this interpretive phenomenological study uncovered what was like for women to experience pregnancy termination for fetal abnormality more than five years ago. Encountering the unexpected, making sense of the unexpected, facing the inevitable decision, feeling supported, and changing perspectives were six themes that emerged from the women's stories. Women experiences revealed that they unexpectedly encountered fetal abnormality and experienced shock and trauma of learning that their wanted baby had severe abnormality. Their endeavour to understand their baby's conditions were wrenched with much uncertainty and lack

of information. The inevitable decision to terminate their pregnancy contradicted the women's personal values and beliefs regarding pregnancy, motherhood, abortion, disabilities, and choices. Living with the decision to terminate the pregnancy revealed the women's attempts to move on with their life with their perceived lack of support. They revealed the need to share their stories of grief and loss and to be understood and not judged by others. The experience of pregnancy termination for fetal abnormality was a pivotal changing experience for the women who gained new perspectives on life and deeper understanding regarding self and others. The next chapter will discuss what we can learn from the women. The implications and limitations of this study will be explored. Recommendations for practice and future research that come out of what the women said and the new gained understanding of their experiences will be discussed.

## **CHAPTER SIX**

### **What Can We Learn?**

The findings of this phenomenological study provide an understanding of the essence and meaning of the long-term lived experiences of women who terminated their pregnancy for fetal abnormality. It is readily apparent from listening to these women's stories that this was a very complex experience. Ten women who had pregnancy termination in the second trimester recounted their life stories in relation to their pregnancy termination experience during in-depth interviews. Six themes were uncovered through hermeneutic analysis of the women's interviews. These themes were; encountering the unexpected, making sense of the unexpected, facing the inevitable decision, living with the decision, feeling supported, and changing perspectives. In this chapter the study findings are discussed and integrated with the existing research to identify what they support and add to the existing body of knowledge on termination of pregnancy for fetal abnormalities. The findings are summarized and discussed in terms of the existing literature. Additionally, implications for clinical practice and future research are presented along with the study's strengths and limitations.

#### **Violation of Expectations**

Women reported how they felt when a normal uneventful pregnancy quickly transformed into a serious situation for themselves and their unborn baby. The pregnancy outcome did not unfold exactly in the way that the women had anticipated or hoped for. After the diagnosis of a fetal abnormality was confirmed, all the women's expectations about their pregnancy and its outcomes were violated. At the time of being diagnosed with a fetal abnormality, the women were not expecting anything to go wrong with their pregnancies. They had not considered prenatal screening tests as a means to detect problems with the fetus. Initially, the women

perceived that they did not need to worry about their pregnancies or the well being of their fetus. They believed that as long as they were healthy, taking care of themselves, and did not have any previous risks that their pregnancy will result in a healthy baby. These findings are supported by McCoyd's (2003) mythic expectations that provide women with reassurance leading to the sense that nothing can really go wrong during pregnancy. McCoyd's qualitative study focused on the bereavement process that women who terminated desired pregnancies in the second trimester after the discovery of fetal anomaly underwent. McCoyd (2003) found that all women in her study basically believed that if they were healthy and "followed the rules" then all will go well. She stated that women enter pregnancy with many expectations which are supported by societal beliefs and norms. These expectations include a belief that if a woman is relatively young and healthy and becomes pregnant, a healthy baby should be born after nine months. Furthermore, a belief that women will likely not be diagnosed with an anomaly which in turn reflects societal ignorance about the primary purpose of prenatal screening tests. McCoyd (2003) indicated that believing this myth leads people to experience pain and anguish when this myth is of what constitutes a uneventful normal pregnancy is shattered. Women in this study believed in this identified myth regarding pregnancy. This myth created a backdrop for the pregnancy and enhanced the women's expectations of having a healthy baby.

The women in the current study seemed to hold the myth identified in McCoyd's study but their beliefs were violated when they learned about the fetal abnormality and this violation contributed to their initial shock and devastation when they received the diagnosis of their fetus. Although some women had relatives who had experienced a pregnancy with fetal abnormality, the myth of pregnancy being uneventful and ending with a healthy baby was embraced. There are advertisements directed to women that perpetuate the myth of that all is fine during



pregnancy leading to the settlement of this myth in the women's mind. For example, Eistenberg and colleagues (1991) clearly state that the intent of her book "What to expect when you're expecting" is to reassure women that they do not need to worry during pregnancy. "Our goal is simple and single-minded: to bring reassurance to expectant parents" (Eistenberg, Murkhoff, & Hathaway, 1991, p.xx). This reassurance might enforce women's sense that nothing can really go wrong in case of uneventful pregnancy.

The diagnosis of fetal abnormality was not anticipated or expected by the women in this study. How something so serious could really be happening to them when they felt their pregnancy was progressing normally was a common thought. The women were shocked to be confronting the unexpected diagnosis of having fetal abnormalities.

### **Perception of Prenatal Screenings**

Women reacted very emotionally when they first learned of the diagnosis of the fetus because they were not well-informed on what to expect from undergoing prenatal screenings. Women's goals of having the ultrasound scan done were to gain reassurance about their fetus's well being and have an opportunity to see their unborn baby. They considered the ultrasound as a fun or enjoyable opportunity to see and get picture of their unborn baby and to potentially learn its sex. Similar findings were found in a qualitative study which examined how women perceived ultrasound when they received unexpected abnormal findings (Mitchell, 2004). Drawing from qualitative anthropological content analysis of semi-structured interviews with 42 Canadian women, results revealed that women experienced considerable disjuncture between their expectations for a pleasurable picture of the baby and the anxiety, grief and anger of unexpected ultrasound results (Mitchell, 2004). Reid, Sinclair, Barr, Dobbs, and Crealey (2009) described the women's experiences when they have been told about the diagnosis of a fetal

abnormality after an ultrasound scan as "Treading on dreams" (p. 1570). Reid and colleagues (2009) indicated that women were wishing to see the baby and being reassured about its health and their dreams were crashed on hearing the diagnosis of an abnormality.

Suter (2002) indicated that prenatal screening tests have become normalized. Women undergo these tests without questioning. They play a passive role during pregnancy due to the medicalization of pregnancy. Prosen and Krajnc (2013) stated that pregnancy and childbirth were considered to be a natural phenomenon at the beginning of the 20th century. In the second half of the 20th century, which coincides with more intense development of gynecology and obstetrics and the related technology, pregnancy and childbirth became the subject of the authority of medicine (Johanson, Newburn, & Macfarlane, 2002). Pregnancy and childbirth has become increasingly influenced by the advancement in medical technology, and medical intervention during pregnancy is the norm in most Western countries (Johanson, et al., 2002). Conrad (1992) defined medicalization as "a process by which non-medical problems become defined as medical, which is also related to the implementation of medical interventions" (Conrad, 1992 as cited in Prosen, & Krajnc, 2013, p. 251; ). As risks and complications that might occur during pregnancy and childbirth were emphasized in health care, the process became a focus of attention for the medical authority and gradually fell under medical surveillance (Riessman, 1983). Oakley (1986) indicated that pregnancy has been transformed by today's health care system into a highly technical process in need of external authority and control to help identify and reduce any associated risk. Young (1998) stated that within medicalization, the needs and desires of the pregnant woman are rarely heard. Women in this study described undergoing prenatal screening tests because they had been recommended by their health care professionals. Prenatal screening tests have become normalized in prenatal management. women

undergo these tests without questioning. They play a passive role during pregnancy due to the medicalization of pregnancy.

Remminnick (2006) reported that expert authority is considered an influential element toward the routinization of screenings. It appears that pregnant women's acceptance of prenatal screenings comes from the strong endorsement by their physicians as they represent the expert authority which is built upon trust and knowledge. Similarly, Brown and Webster (2004) have pointed to the importance of trust in the health provider expert-woman relationship and indicated that routinization of screening is not possible when trust fails. The unlimited trust which some women placed in the health provider as expert is captured by the comments of one participant in Heyman's et al., (2006) study "*But you just..basically trust (Doctor's name), and whatever is to be done, then just do it*". (p. 2364). This previous comment reveals the hegemony of the medical model and the medical professionals which distinguished them as the people of knowledge and expertise.

Women's lack of information about prenatal screening and its implications was evident in this narratives. When prenatal testing was first offered, it was recommended for only high risk women with the possibility that fetal abnormalities might be diagnosed (Suter, 2002). Prenatal testing is currently recommended to be offered to all pregnant women as a routine practice, including low-risk pregnant women, yet the likelihood detecting the presence of a fetal abnormality remains low. Farrant (1985) as cited in Statham (2002) first drew attention to the dichotomy in attitudes towards prenatal testing between HCPs, who saw testing as a means to detect abnormalities, and women who sought reassurance about the absence of these abnormalities. Farrant's view is supported by the findings of this current study. Most of the

women underwent prenatal screening not expecting to discover something wrong, but were seeking reassurance about the health and well being of the fetus.

The routinization and widespread use of prenatal screening tests may lead to a different perception of the goal of the tests between women and health care professionals. While women's goal for undergoing these screenings is to be reassured about the health of their baby, the health care professionals' goal is to detect abnormalities and treat, if necessary. Pilnick, Fraser, and James (2004) who conducted a qualitative study in the UK investigating pregnant women's decision to undergo prenatal ultrasound screening reported that women engaged in prenatal screening expecting to receive reassurance about the health and well-being of the baby. For the women, pregnancy perceived as a normal uneventful event with a positive outcome. As indicated in another qualitative study which examined the responses of couples to genetic amniocentesis, the women reported being totally ignorant of the fact that having the diagnosis of fetal abnormality could ever happen to them (Jones, et al., 1984). This is consistent with the findings of Rapp's (1997) anthropological research study on the social impact and cultural meaning of prenatal diagnosis. He concluded that in contrast to a medical model approach to examining this phenomenon of prenatal diagnosis, mothers often took these measures to obtain confirmation that their baby was in fact normal or healthy rather than to confirm a suspected diagnosis. In a number of previous studies, investigators reported that the majority of pregnant women were not familiar with the purpose and the procedures of prenatal screening and/or diagnostic tests (Cederholm, et al., 1999; Chilaka, Konjie, Stewart, Narayan, & Taylor, 2001; Faden et al., 1985; Freda, De Vore, Valentine-Adams, Bombard, & Merkatz, 1998; Mulvey & Wallace, 2000).

Women in this study did not have detailed information on the prenatal screenings and its consequences. Information can help prepare women for tests such as Alpha fetoprotein (AFP) and prenatal screening as well as provide them with an opportunity practice informed choice to interpret subsequent experiences. They explained that they were not well-informed about the purpose of prenatal screening by their health care professionals whether they are family physicians, midwives and/or obstetricians. Evidence has indicated that pregnant women are usually provided with very little information about the prenatal screening and consent is sometimes assumed rather than explicitly sought (Fearn, et al., 1982; Freda, et al., 1998; Lobel, Dias & Mayer, 2005; Marteau, Slack, Kidd, & Shaw, 1992; Press & Brown, 1994; Taylor & Clark, 1985).

Findings of this study revealed that the prenatal screening tests were often presented as a routine type of blood work, or a test of unspecified abnormalities. Some health care professionals do not describe the specific conditions screened for, the failure rate of the test, or the manner and time frame for providing test results for fear of alarming pregnant women unnecessarily since the majority receive normal test results (Rowe, Fisher, & Quinlivan, 2006). Moreover, there is a disjuncture in the women's perception and understanding of the prenatal screening purpose and the health care professionals' purpose of the prenatal screening tests.

Gammeltoft and Nguyen (2007), Harrison and Colleagues (2004) and Lippman (1991) reported that the introduction of obstetrical ultrasound scanning has occurred in an ad hoc and haphazard fashion, driven by individual initiatives and professional fascination rather than by decisions rooted in health policy. In a study of 49 women in Montreal undergoing their first routine ultrasound, none of the women reported having had pre-scan counseling, being asked if they wanted an ultrasound, or being told what ultrasound could or could not detect. Mitchell

(2001) indicated that ultrasound's meaning in women's lives as both a device for, and a social ritual of communication and pleasure makes it a distinctive form of prenatal testing. The social meaning of ultrasound dominates its medical uses (Mitchell, 2001). Detecting a fetal abnormality by ultrasound is unexpected, not only because the unpredicted nature of the abnormality and the low likelihood of a problem resulting but also because the social meanings in which ultrasound is provided to and experienced by women. Chisholm (2011) indicated that there has been a shift in the use of prenatal ultrasound technology over the last fifteen years in North America. Non-diagnostic clinics have opened across Canada and the United States for the purpose of producing ultrasound images and videos as keepsake items for pregnant women and their families. Private or non-diagnostic ultrasound clinics are those that operate outside the purview of the medical setting, whose services are marketed to pregnant women and their families as a way to bond with their fetus. In this setting, seeing the fetus is fostered as a social and cultural ritual not as a scientific or medical image that could reveal problems, such as fetal abnormalities.

A national survey of ultrasound provision in Ireland (Lalor, Devane, & McParland, 2006; 2007) has demonstrated that availability of both written and verbal information in relation to routine ultrasound in pregnancy is poor, yet uptakes for ultrasound screening programs by pregnant women are almost 100 percent. This lack of explicit information on the purpose of the ultrasound reinforced its non-threatening aspect, leaving women to look forward to the scan with anticipation. These findings are in consistent with the current study. When women underwent prenatal screening tests they did not realize the relationship between performing these tests, detecting a fetal abnormality and the possible decision to terminate the pregnancy. The women were not associating the prenatal screening tests with the potential of detecting a fetal

abnormality which could lead them to having to make the decision to terminate their pregnancy. Findings of previous studies about women's insufficient knowledge of screening tests and the way screening tests are offered in antenatal care question the soundness of women's informed choice regarding prenatal screening tests (Browner & Press, 1996; Faden, et al., 1985; Marteau, et al., 1988, 1992; Press & Browner, 1993; Santalahi, et al., 1998).

Press and Browner (1993) analyzed the decisions of an ethnically and socioeconomically diverse group of women to accept or refuse a prenatal diagnostic test. They found that how women were informed about the test and the kind of information they were given determined their decisions more than their ethnic or social class background. They argued that women and their health care professionals have created a "collective fiction" (p.100), which situates the prenatal screening for abnormalities within the domain of routine prenatal care and denies its central connection to selective abortion. In fact, the offer and the appearance of these tests within the context of being routine, regular, and normal seem to favour consent and mitigate against refusal (Press & Browner, 1993). Green (1994) stated that the 'shock' couples repeatedly described as their initial response to learning that something was wrong with their baby was intensified by this de-medicalization or 'non-event' orientation to prenatal testing (p. 44). In addition, Schneider (1998) stated that health care professionals need to acquire the skills necessary to provide an adequate level of counseling about common conditions and routinely used testing strategies. Furthermore, the SOGC recommendations concerning the pre-counseling information that should be provided to pregnant women prior to a screening test are:

Details about the conditions being screened, the likelihood of detection, the method of screening, the meaning of a screen-positive result and a screen negative-result, the

choices following a positive diagnosis and details as to how further information can be obtained (SOGC,2012).

This disconnection between health and illness is evident in women's experiences whereby ultrasound of pregnancy has been normalised to just another aspect of routine antenatal care. The women in this study anticipated that their fetus would be healthy and did not perceive themselves to be in a risk category for the occurrence of a fetal abnormality. They underwent prenatal screening to determine fetal well-being and not to detect if there was an abnormality. Some women, who acknowledged the capabilities of the examination to detect an abnormality, believed that their previous experience of normal findings had influenced their participation in screening this time around, and being in good health was an additional factor associated with the likelihood of a positive pregnancy outcome. The women's past experience with previous uneventful pregnancies and their overall perceived general health informed their perception of prenatal tests and their expectations of that nothing would go wrong with the fetus or the pregnancy.

It is interesting to note that although these previous studies were conducted in different time periods (in the 80's, 90's, and 2000's), the findings of these previous studies are quite similar and supported by this current study's results. The findings of these previous studies revealed the information that needs to be provided to pregnant women before undergoing prenatal screenings was lacking. This indicates that the application of prenatal screening as well as informed consent practices are not adequately applied despite the passage of many years of research in this area.

### **Dealing with Uncertainty**

When first learning about the possible diagnosis of fetal abnormalities the women in this current study felt confused, ambivalent, shocked and lacking information about the diagnosis as



well as the prognosis of their fetus 'condition. They wanted more information and needed to understand what outcomes were expected if they continued their pregnancy. Their felt need for information was pervasive especially when they were required to make a difficult decision to continue or to terminate their wanted pregnancy. What was striking from the women's accounts was their sense of being uninformed and unprepared for these decisions. The women often indicated that they have not received any information about potential adverse results from prenatal screening or forewarning of the choices they would have to make in the event abnormalities were discovered.

The need to search for information once a fetal abnormality has been diagnosed implies that the HCPs involved in the women's care had not provided the appropriate or sufficient verbal or written information to the women. This is reflected in the efforts that the women took to obtain further information. The women went through further testing to confirm the fetal abnormality, its severity and the prognosis. Although most of the women trusted the diagnosis they were given, they went for more testing to gain an increased understanding concerning the fate of their fetus. Women described their effort in seeking information to clarify, for themselves, the meaning of the diagnosis. Although the women consented to undergo prenatal testing, or did not refuse it, it was often without the full understanding of it as comprising procedures that, like other screening and diagnostic procedures, was intended to look for something wrong. According to Browner and Press (1996), women accept prenatal screening tests and follow biomedical advice uncritically, because these technologies are culturally regarded as being accurate and incontrovertible allowing women to feel they are doing all they should do to assure the fetus's well being. As Press and Browner (1993) commented, "prenatal testing seemed less like a medical procedure than a new pregnancy ritual of reassurance" (p.

105). However, some studies have reported that there is denial and some skeptical thoughts among pregnant women about the accuracy of the diagnosis. Kenyon and colleagues (1988) investigated the effect of an immediate counseling session on women's feeling of support when they first learned about a fetal anomaly during a routine ultrasound. Rillstone (1999) utilized a grounded theory approach to investigate the social and psychological problem of women having a subsequent pregnancy after TOPFA. Both studies reported that some parents were skeptical and uncertain about the diagnosis and had fears that the medical professionals were wrong. Similar findings were reported in the current study.

Dealing with the uncertainty associated with the lack of information about the fetal abnormality was evident in the women's stories especially when they were asked to decide on the fate of their pregnancy. Uncertainty has been defined as "the inability to determine the meanings of events and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and /or is unable to accurately predict events" (Mishel & Braden, 1988, p. 98). For the women in this study, their lives changed suddenly and unexpectedly at the time of being diagnosed with a fetal abnormality. Their good expectations about the "taken for granted pregnancy" were violated leading them to feel uncertain about their fetus's prognosis. In addition, their lack of information about prenatal screening, the meaning of their baby's condition and how the severity of the abnormality could change their life increased their sense of uncertainty. The prognosis of the fetal abnormality was often left not known. Women were dealing with speculations, rather than actual knowledge of potential future problems. They needed information about what are the long term outcomes for their fetus. The decision-making process regarding whether to terminate the pregnancy or not accompanied with feelings of uncertainty was difficult for the women. Their experience of being diagnosed with fetal

abnormality, the diagnosis and its consequences on their lives were characterized by many unknowns including potential pregnancy outcomes, health condition of their baby in case they continued the pregnancy, and the long-term quality of life of their baby. A sense of unrest and persistent concerns about having made the right decision emerged in women's thoughts and continued many years later. The sense of being uncertain about the future of their unborn baby led to feelings of frustration and unrest. Not having the needed information that could help in making a difficult decision complicated the women's experiences of choosing between continuing or ending their pregnancy. The consequences of this state of uncertainty are implied by Skirton (2001) when she discusses individuals' need for certainty to prepare for the future, to understand the present and principally for "peace of mind".

The women in the current study reported feelings of stress and anxiety in many occasions throughout their experience of TOPFA. For example, the prolonged waiting time for scheduling their diagnostic tests and obtaining the test results were stressful for the women. Hsieh (2009) conducted a randomized controlled research study to assess and compare the effects of an individualized versus a non-individualized prenatal genetic education program on uncertainty in pregnant women prior to their prenatal genetic counseling and /or testing appointments. The results indicated that pregnant women experience uncertainty while waiting to undergo their prenatal counseling sessions in part due to the unfamiliar situation and the lack of information to help them become familiar with this event. Similarly, other studies investigated the impact of waiting periods before different medical procedures and found that patients experience increased uncertainty during the waiting period before medical treatments or diagnostic procedures (Calvin & Lane, 1999; McCormick et al., 2006). These findings indicate that uncertainty occurs when

patients have insufficient information to understand their situations and treatment options during any diagnostic or therapeutic procedure.

The time provided to the women to make their decision on the fate of their fetus was perceived as very limited. Time constraints contributed to increasing women's sense of uncertainty. They felt they did not have adequate time to be comfortable with their decision. Lived time as defined by van Manen (1997), relates to the various ways we experience time and locates us time-wise personally, chronologically, and historically in relation to our world. Women in this study experienced time differently. The women perceived time as having stopped when they were first informed with their fetal diagnosis, they did not have any sense of the time, time was lost. They felt numb and traumatized. In addition, the waiting associated with being scheduled for more confirming investigations or the time period until they received the test results was full of uncertainties. Having to wait was considered threatening and stressful. They felt the time stretched out and longer than usual. Again, after they made their decision to terminate the pregnancy, the lived time until the procedure had to be done felt irritating, prolonged, stagnant, slow, and unbearable and that is because they already made their decision to end their pregnancy and it was excruciating for them to feel the movement of their fetus while deciding to end its life.

Experiencing uncertainty, women expressed a critical need to know as much as they could about their unborn baby's condition. An easy-accessible source for the women to get information on their diagnosis was using the Internet. They searched the Internet for information to understand the prognosis of their fetal conditions and to seek out parents with similar experiences. Similar findings were reported in a phenomenological study conducted by Vantine (2000) utilizing a narrative analysis method with three women who had chosen to terminate their

pregnancy for possible fetal abnormalities. Vantine (2000) reported the Internet had an impact on the women's decision regarding pregnancy termination. She added that women have an easy access to as much information as their doctors do and have the time and interest to look deeply into their particular problem. Criticism of health information access through social media such as the internet is lack of regulation on the information that is provided online. Unlike refereed medical journals, anyone can print anything they want on a subject on the Internet, and it is up to the individual's interpretation. Additionally, it may give the women false hope or on the other side, it may give them a complicated and hopeless picture. However, Internet played a very important role in getting information and support for the participants of this study.

### **Perceived Decisional Dilemmas**

The decision to terminate the pregnancy was perceived by the women as a complicated and difficult decision. A difficult decision is the one that is hard to make or carry out, and hard to understand (Merriam-Webster, 1997). A complicated decision is consisted of many interconnecting parts or elements and involving complications (Merriam-Webster, 1997). The women's lack of information accompanied with the restricted time given to make their decision contributed to the perceived difficulty of the decision. Moreover, the intricate aspects of the decisions and the perceived challenges and consequences contributed to its complexity. There were several elements associated with the difficulties the women experienced in deciding to terminate their pregnancy. The women lacked the opportunity to make an informed choice, as they lacked information on the full meaning of the diagnosis, and for some faced uncertainty about future of their unborn baby if they continue the pregnancy. All women in this study indicated that in the end they had to make a choice. Most of them perceived their decision as for the "*best interest of the baby*". Previous research has indicated that decisions concerning

termination of pregnancy for fetal abnormality are complex and many factors are involved (Kramer, et al., 1998; Browner, et al., 1999; Moyer, et al., 1999; Bell & Stoneman, 2000; Britt, et al., 2000; Zlotogora, 2002).

In the current study, both the women who had a fetal diagnosis of lethal abnormalities and those who had a diagnosis of severe fetal abnormality with a possibility of a living baby, perceived their decision to terminate the pregnancy as the only choice they could make. Sandelowski and Jones (1996) concluded that women who had been diagnosed with lethal fetal abnormality or abnormality that would lead to fetal death shortly after birth realized that they would lose their baby anyway so their choice might have been less complicated. They called this choice as "Nature's choice" (p. 357). They stated that these women terminating pregnancy saw themselves as having had no choice in effecting that outcome. They had either suffered fetal demises or had fetuses with ultimately lethal abnormalities, such as anencephaly and Trisomy 18. Given the fact that their baby would die anyway, they perceived their choice to terminate the pregnancy as having been made for them. The lethality of their fetus' condition was the most evident reason for their decision to terminate (Sandelowski & Jones, 1996). Evans and colleagues (1996) in a study of 310 chromosomal abnormalities diagnosed after invasive prenatal diagnosis demonstrated that parental decisions for termination of pregnancy for fetal abnormality were mainly determined by the severity of the disorder.

Women in the current study who had been diagnosed with severe fetal abnormality that could end with a live baby chose to terminate the pregnancy for altruistic reasons to avoid pain and suffering for the baby or a dismal future and poor quality of life for the child as well as for themselves. These women perceived their decision also as the "*only choice*" they could make. They were faced with choosing between two evil alternatives, they can either deliver a baby with

severe disability or end their baby's life to spare him/her further suffering. Sandelowski and Barroso (2005) suggest for couples receiving positive prenatal diagnosis, the experience was one of both "chosen losses" and "lost choices" (p. 314). This metaphor revealed the dilemma of the women's choice of pregnancy termination for fetal abnormality. "Lost choices" referred to the paradoxical lack of choice and "chosen losses" referred to the pregnancy termination decision in the face of fetal abnormality.

Being faced with choosing between two undesirable alternatives brings women into a moral dilemma. Keller (1985) indicated that dilemma is a difficult situation in which strong reasons can be given for and against the same action. Furthermore, a dilemma may also be defined as a situation which involves a choice between equally unsatisfactory alternatives. Keller (1985) concluded that if at least some of the reasons for the actions, or reasons why an alternative is unsatisfactory are moral reasons, the situation is a moral dilemma. Therefore, women who were faced with the decision to terminate their pregnancy for fetal abnormality, are faced with several moral dilemmas.

One dilemma the women were faced with could be sketched as follow: because there is no therapy available, on receiving the diagnosis of fetal abnormality women were confronted with moral dilemma concerning their perceived concept of "mothering". Women's concept of mothering involved accepting their children unconditionally and protecting their lives as well as protecting them from suffering and pain. The women reported that the most important reason for termination was the perceived quality of life and the long term suffering primarily for their child, but also for themselves and family. These findings are supported by Bell and Stoneman (2000) and Benute, Nomura, Liao, Brizot, de Lucia and Zugaib (2012) who investigated the factors associated with the decision to either terminate or continue a pregnancy when the fetus

was diagnosed with disability or chronic illness. They found the most recurrent reason for women to terminate their pregnancy was the perceived quality of life of the child. Additionally, Benute and colleagues (2012) report the reason for the pregnancy termination was to reduce suffering in all of them (baby, mother, and family).

Deciding to terminate their pregnancy for fetal abnormality challenged the women's pre-existing values and beliefs regarding being a "good" mother, abortion and disability. Their decision to end their baby's life contradicts their understanding of being a mother, who is supposed to protect their children from harm. Being pregnant in the second trimester and feeling fetal movements was one of the several aspects that complicated the women's experiences. The women considered the fetus growing inside of them as a life, as their baby. Hence, their decision to terminate the pregnancy was a decision to end a life. As Vantine (2000) pointed out, women are caught between the following: seeing the termination as an act of love versus an act of killing. Sandelowski and Barroso (2005) stated that positive prenatal diagnosis made the embodiment that defines pregnancy as a uniquely female experience a source of anguish for women choosing to terminate their pregnancies. The termination decision was profoundly contradicting the fetal life women experienced while pregnant, and the signs of fetal life after termination (e.g., breasts leaking milk). Pregnancy embodiment complicates a woman's decision to terminate the pregnancy. McCook (1999) indicated pregnant women who come to recognize, accept and embrace their status as pregnant are said to have a maternal identity and realized that they are potential mothers. Motherhood identity in pregnancy has been defined as the ability to recognize, accept and have an emotional bond with the child that is being carried within the womb (Marzoni, 1983).



Previous research indicates motherhood identity is primarily linked to gestational age, and becomes stronger as women get closer to being full term (Leifer, 1977; Lumley, 1980; Kirkley-Best, 1981; Marzoni, 1983; Muir-Jonusan, 1983). Motherhood is also considered a social phenomenon. As Russo (1979) stated, "The centrality of motherhood to women's identity is characterized as a mandate that is built into our social institutions as well as our psyche" (p.7). Motherhood is on a qualitatively different level than other gender roles for women in the society. Woollett and Marshall (2001) articulated that, "Motherhood is often considered the key aspect of women's adult identity". Rogers and White (1998) propose that, with respect to identity, motherhood is more powerful than either marital status or occupation. Marshall (1991) and Parker (1995) stated that motherhood is not only a direct tie to a woman's primary or sole identity; it is also constructed as a major source of well-being, emotional satisfaction, and fulfillment. Moreover, Forcey (1994, p. 375) defined motherhood as "a socially constructed set of activities and relationships involved in nurturing and caring for people". While Forcy's definition hints to the caring and nurturing aspects of mothering, most other definitions expand upon these practices to reflect selflessness and total sacrifice of mothers for their children.

Phoenix, Woollett and Lloyd (1991) represented motherhood as multifaceted and complex, representing what often is characterized as the epitome of devotion. The mother portrayed in this ideology is devoted to the care of her family; she is sacrificing and "not a subject with her own needs and interests" (Bassin, Haney, & Kaplan, 1994, p. 2). In turn, this woman is the good mother (Ribbens, 1994; Thurer, 1993). The notion of a "good mother" also creates the notion of the unspoken and undefined "bad mother", which becomes everything outside of total sacrifice and devotion. Therefore, women who see themselves deviating from this norm could perceive themselves as a "bad mother". Women in this study felt that they have

chosen to lose their motherhood as a result of their decision to terminate their pregnancy. They had contradictory feelings about whether they are good or bad mothers. They as mothers, are supposed to protect the life of their unborn baby and sacrifice their interest for their baby's interest. On the other hand, they are supposed to protect their unborn baby from a future full of pain and suffering because of their severe abnormality. These contradictory feelings impacted the women's healing process and grief and contribute to their perceived moral dilemma.

Another moral dilemma associated with the women's decision to terminate their pregnancy concerned their beliefs about abortion and ending their pregnancy. All the women wanted and welcomed their pregnancies, even though for some, it was not planned. It is interesting to note that the women did not define their termination as an abortion. They perceived abortion differently. No matter what the women in this study decided to call their experience, nearly all were able to articulate that the societal views of abortion influenced their decision making and grieving process in some way. Many of the women worked to dissociate themselves from the stereotype of women who have abortions. Most did not envision people electing to terminate for social reasons having the same kind of experience. The women were aware of the societal views and negative judgement for abortions and feared that might be applied to them. Rothman (1993a) explained a mother's decision to terminate a wanted pregnancy after positive prenatal diagnosis:

Abortions to prevent the birth of a disabled child may be more socially acceptable, but they are not in any sense easier..the meaning of the abortion lies in the meanings the pregnancy holds for the woman. If the woman see the pregnancy as an accident-if for example, her pregnancy is a by-product of contraception that did not work-then in her definition the fetus is not a person and not meant to be one. The abortion is the solution to

the problem of failed contraception. But if the fetus is to be her child, if she has chosen to have this- chosen by a consciously and purposefully becoming pregnant, or by willing or openly accepting an unintended pregnancy-then she consider the fetus to be a person. It is her baby. She means it to be her baby. To abort an accident is one thing. To abort your baby, even your very imperfect baby, is something else again (pp. 5-6).

This description of terminating a wanted pregnancy concurs with the women's dilemma in this study. The women believed they had made the right decision by terminating their pregnancy, rationalizing they were sparing their anticipated baby from future suffering and protecting themselves and other family members from additional anguish as well. However, they did not want to be compared to the abortion stereotype held in societal norms that includes women who abort are uncaring, disrespectful and dismissive of their responsibilities towards their child. They were stressed from the societal views of abortion and needed to explain their reasons for making this decision. In support of this view Vantine (2000) indicated, women understand that while others might categorize their pregnancy termination as abortion, they most definitely did not understand their termination as such. All the women in her study saw their TOPFA as something different from what they understand an abortion to be. On mentioning their reasons to participate in this study most of the women stated that this topic is a "*taboo*" and they needed it to be discussed more openly. They said that people needs to know and to understand their position of why they terminated their pregnancy.

Another moral dilemma the women were faced with is the dilemma of the meaning of disability. The women's perception of disability and the low quality of life associated with it impacted their decision to terminate their pregnancy. In addition, their perception of their abilities to care for a child with a disability, the lack of resources necessary for caring for these

children, and the impact of other family members contributed to their decision to end their pregnancy. They concluded that they could not afford to take care of a baby with special needs. They weighed their decision to terminate and examined their options from their baby's point of view, their own, and their other children. They dealt with a moral conflict that arose from their decision to terminate because of an anticipated disability. They felt that although they appreciated the families that are raising children with disabilities, they pitied them when they realized that they live in a society in denial of the many difficulties entailed in raising children with disabilities. The main reason given for seeking to prevent the birth of a child with disability is that in preventing such birth one is eliminating suffering, which is morally desirable. Harris's (2000, 1998, 1982 ) view as cited in Edwards (2001) is that a person does wrong if they intentionally bring a child with a disability into the world. The wrong done in such cases is "deliberately choosing to increase the suffering in the world when one could have avoided so doing" (2001, p.380). In giving birth to a child with disability one is responsible for the infliction of "needless suffering" (p.380).

The social views and stereotypes regarding disability were not explicitly described by women as reasons for their termination. However, many studies indicated that societal views of disabilities have influenced the women's decision to terminate the pregnancy. For example, Sandelowski and Jones (1996) indicated that the socio-cultural milieu has a major influence on the women's decision to terminate a pregnancy for fetal abnormality as it is characterized by negative views of disability (p.359). As Rothman (1993b) indicated, the "decision to continue or terminate a pregnancy are never medical decisions. They are always social decisions" (p.63). McCoyd (2003) indicated that some women felt having a child with disability as a challenge for them because of the child's poor quality of life and the life changes that having a disabled child

would entail. Their perception is accompanied with their lack of information about resources and families with children with disabilities. Their choice to terminate was based on the societal disability stereotypes. These stereotypes as Block ( n.d. ) indicated are: people with disabilities are different from fully human people; they are partial or limited people in an "other" and less category; and the burden of disability is unending. To understand the women's decision to terminate their pregnancy because of future disability, the following two stories told by people who lived and first hand experienced disability are discussed. These two stories may give us some reasons why the women chose to terminate their pregnancies and the moral dilemma they encountered.

**Tommy's story.** I have read a story written by Chloe Ashton in the CHATELAINE magazine, July 2013 called Tommy's story. Chloe was confessing in her story "*Three years ago, I did something*". She continued, "*I had never imagined myself doing: I chose to end my pregnancy at 19 weeks*". Her unborn baby boy [Tommy] was diagnosed as having Down's syndrome. She remembered the hard time she and her husband went through to decide what to do. She said:

A defining moment came during a family dinner, when I had all of those I loved the most in the world around me. I was worried about discussing it, as I have a sister with a physical disability. How could I tell her that I was contemplating ending a pregnancy because of a disability? But she looked at me directly and said, I've lived with disability for most of my life, and I wouldn't wish it on any one. Please think hard about what you are doing to this child if you choose to bring it into the world.

**Walker's story.** Another story of a family who has a child with a very rare genetic mutation condition called CFC who suffers from severe mental, physical, and developmental disabilities. The father, Ian Brown is a writer and he wrote his story in The Globe And Mail.

"I'm glad I never had to decide whether my strange, lonely boy ought to exist"

Ian Brown, (2011)

His son, Walker suffers from CFC, an impossibly rare affliction (150 known cases, globally) caused by a completely random genetic mutation. He is 15 now, looks 10 and has the mind of a two-year-old. He always will. Walker's father said, *"He is an often charming, and fantastic companion, but he can't speak, or live on his own, or manage the toilet, or eat without a tube, or go for long without smashing his ears flat and ugly with his fists"*.

He continued *"We raised him on our own for 10 years, and the experience almost shattered everything I valued-my family, my marriage, my health daughter's life, my finances, my friendships, life as I wanted to live it"*.

Walker's father described *"In the early years of my son's life, before I understood how far outside the norm his disabilities took us, I was always astonished to hear a parent say, I wouldn't change my disabled child for anything"*. He described his wife, Johanna as an exceptionally compassionate person, and a terrific mother, and she never made such statements. Ian Brown recounted Johanna's words while they were lying on bed, talking in the night on a rare occasions Walker fell asleep, she said:

But I would. I would trade walker, If I could push a button, for the most average child in the world, who got C's in school. I would trade him in an instant. I wouldn't trade him for my sake, for our sake, but I would trade him for his sake. I think Walker has a very, very, hard life.

Although Walker's parents lead a very difficult life taking care of him, his father said *"I'm glad I never had to decide whether my strange, lonely boy ought to exist"*. He once asked his wife, Walker's mother *"Would you have taken the test and had an abortion,"* She said,

If there had been one? It was his loneliness I couldn't bear, the boy's own sad sense of how different he was. Somehow he knew that. If there had been a test when I was pregnant that revealed what Walker's life would have been like, I would have had the abortion.

Then the husband said *"But then you wouldn't have had Walker,"* Suddenly Johanna began to move around the kitchen a little faster. *"You can't say that after I've known Walker – would I have done something to get rid of him? It's one thing to abort an anonymous fetus. It's another to murder Walker. A fetus wouldn't be Walker."*

The parents in the previous two stories were in close contact with people with disabilities who lived very hard lives. The first story, Tommy's mother has a sister with a life-long physical disability who told her that she wished no one lived the life that she has lived. The second story, Walker's mother wished that she could trade him instantly if she had the chance to do that for the sake of him. She also thought that If there had been a test when she was pregnant that revealed what Walker's life would have been like, she would have had the abortion. It is a very conflicting dilemma, because now she already had her son and she knew him, loved him, and cared for him. So currently, she could not be certain what she would do if she had the choice to terminate her pregnancy because during pregnancy, the fetus is a potential baby but at the moment she had been asked, her son was a reality that she has always lived with. These two stories are supporting what the women in the current study went through thinking of the impact of severe disability on their lives and considering the poor quality of life their baby will suffer .

## Dealing with Complicated Grief

Research and clinical reports suggest that termination of pregnancy for fetal abnormality involves profound loss and grief for many women (Donnai, Charles, & Harris, 1981; Leon, 1995; Lloyd & Laurence, 1985; Rothman, 1986; Van Putte, 1988; Black, 1989; Zeanah, Dailey, Rosenblatt, & Saller, 1993;). Kruszewski (1999) conceptualized grief as:

Grief is a human process with characteristic responses that change over time. The antecedents of grief is loss of something that is valued. Grief is influenced by characteristics of the griever, of the environment and of the loss. Consequences of grief can include changes in physical, social, and psychological functioning, changes in relationship to that which is lost, and changes in health (p. 6).

The women in this study described their TOPFA as a major loss. They grieved their loss profoundly and primarily alone. Women's grief was not understood and acknowledged by others (husbands, families, HCPs). According to Gilbert (2011), Rando (1986) and Zeanah, Danis, Hisshberg, and Dietz (1995), compared to other types of mourning, such as the loss of a parent or a sibling, the loss of a child is associated with a grief experience that is particularly severe, long-lasting, and complicated with symptoms that fluctuate in intensity and duration. Women in this study experienced severe, ongoing grief which went unacknowledged by others. These characteristics are in agreement with the concept of disenfranchised grief. Doka (1989) defined disenfranchised grief as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (p.4). Being unsanctioned by society, this kind of grief creates an additional hurdles for the grief process because of limited or non-existent sources of support (Doka, 1989, 2002).



In addition to the negligence of the loss by the women's social network, their grieving process was complicated by several other elements; the trauma emerged from learning about the diagnosis of fetal abnormality followed by the decision to terminate a wanted pregnancy, their role in the decision making, and the stigmatizing circumstances of the pregnancy termination. These elements are discussed in the next section.

First, the women's sense of responsibility for the loss was evident in this study. The sense of being responsible for their perinatal loss felt as a burden because of the women's active role in terminating their pregnancy. As a result of their perceived responsibility for the decision to terminate their pregnancy, they felt ashamed and isolated. Similarly, women in (white-van Mourik, et al., 1992) reported an "overwhelming sense of responsibility" and shame as they chose to terminate their pregnancy.

Second, women in the current study reported feeling shocked and traumatized as a result of learning their fetus's diagnosis and making the pregnancy termination decision. Kersting and colleagues (2007) reported the diagnosis of fetal abnormality and the decision to terminate the pregnancy would confront any woman with a traumatic event, one which is hard to cope with and entails an inherently high-risk of the grieving process having a complicated course (Kersting, et al., 2007). According to the American Psychiatric Association (APA, 1994), a traumatic event has a number of characteristics: it happens suddenly and unexpectedly, it disrupts beliefs, values, and one's basic assumptions about the world. In this study, being informed of their fetus's diagnosis was sudden and unexpected without any previous suspicious of disease or abnormality. According to this definition, the women's experience when learning about their fetal abnormality could be considered a traumatic experience. Aite and colleagues (2011) conducted a qualitative study in Italy with 165 prospective mothers and 91 prospective fathers being interviewed after

communication of fetal abnormality diagnosis to assess if the communication of diagnosis of a congenital anomaly in the fetus is traumatic and meets APA criterion for trauma. They found that all women in their study felt numb and did not know how to respond. Aite and colleagues' findings indicated the women upon learning about the diagnosis of their fetus responded with anger or emotional release and/or concern or loss and/or hyperarousal. These findings comply with the APA criterion for trauma which states the individual has to experience the event as sudden and unexpected. In consistent with Aite and colleagues (2011), the women in this study had expectations of normal pregnancy and giving birth to a healthy baby. Most of the women had planned their pregnancies and wanted the pregnancy and had dreams and hopes for their unborn baby. As revealed in their stories, discovering a fetal abnormality causes the loss of the expected healthy baby as well as the loss of future plans of being parents of a normal healthy child, disrupting their assumptions regarding pregnancy outcomes. This is in agreement with the APA criterion for which the experience is traumatic, if it disrupts the individual's beliefs and basic assumptions about life.

The women's experiences of TOPFA reveal that they are still troubled by what happened to them and their pregnancy so many years ago. They are dealing with a long term impact of traumatic event. Late pregnancy termination of fetal abnormality has been reported to be associated with intensified grief, depression, and greater psychological morbidity (Salverson, et al., 1997; Zeanah, et al., 1993). In addition, Davies and colleagues (2005) reported that women with second trimester termination for fetal anomalies had high levels of posttraumatic stress disorder (PTSD) symptoms (Davis, Gledhill, McFadyyn, Whitlow, & Economides, 2005). Consistently, other studies examined the symptoms of posttraumatic stress up to 7 years after the event. Findings showed that the participants had high levels of posttraumatic stress symptoms

(Kersting, et al., 2005; Kersting, et al., 2007; Korenromp, et al., 2005). Furthermore, Christiansen and colleagues (2013) in a quantitative study conducted in Denmark examined chronic PTSD symptoms up to 18 years after late pregnancy loss reported an estimated PTSD prevalence of 12.3% in their sample.

Third, the current debate around abortion that was perceived by the women caused them to feel stigmatized by their decision to terminate their pregnancy. The women were ashamed of their decision because it involved abortion and disability and both have attached negative societal stereotypes. The feelings of shame reported by some women in this study were similar to those reported by White Van-Mourik et al., (1992). Having a baby with disability and terminating the pregnancy makes these women different from the norm. As Rillstone (1999) stated "the stigma regarding termination is a reflection of our culture and ...socio-political situation" (p.85). A major issue surrounding the stigma of pregnancy termination concerned the fear of judgement by others. The women believed other people could not possibly understand what they had been through. They feared to be accused of killing their own child. Concerns about fear of judgement were consistent with what is reported in the literature (Bryar, 1997; Gregg, 1993; Rillstone, 1999). Some women preferred to leave others think of their loss as a miscarriage or stillbirth for the fear of condemnation. The stigma of pregnancy termination for fetal abnormality caused the women to live their experience in silence. Women felt isolated and alone because they could not tell people freely what exactly happened. Most women tended not to share their pregnancy experience and if they did share their experience, they chose the people to whom they disclosed carefully. These findings were consistent with the findings of several other studies (Green, 1994; Gregg, 1993; Hodge, 1989; Rillstone, 1999; Suslak, 1995). One nurse in (Rillstone, 1999)'s study said "the people won't understand, almost universally, you

know. Here we allow [the parent] technologic information to force them into a decision society does not understand or support. It is very hard for them" (p. 84).

### **Perceived Support**

The women's storied experience of TOPFA indicated that its effects on their lives was profound and long lasting. The women needed adequate time and space to grieve while being offered support from family and friends, the community and HCPs. The grief experience is a personal response, which needs to be acknowledged and respected by all who communicate with these women. The support the women needed included: having information about (their diagnosis, grieving process, termination procedures and supportive resources); being able to talk, tell and retell their story; having empathetic interaction; and prolonged time of support. Lasker and Toedter (1991) reported social support is critical to coping with spontaneous perinatal loss, so it is logical to assume that a lack of social support following TOPFA will complicate the grieving process. The women in the current study reported a need to talk about their experience with other people who can understand their feelings. Talking about their experience validated their loss and helped them deal with their grief. The need to talk has been supported by other studies as Stieman (1987) who examined the emotional aspects of perinatal loss, Wallerstedt and Higgins (1996) who investigated the perinatal grief reaction in mothers and fathers and Watkins (2001) who conducted a phenomenological study exploring women's lived experience with perinatal loss.

Goffman (1963) as cited in Rillstone (1999) discussed two types of individuals who were considered as a source of support for stigmatized parents. These included the "own" (p.87), who share the stigma, or in this situation have been through a similar circumstances, for example, a partner, a family member or other family with similar experience and the "wise..whose special

situation has made them intimately privy to secret life of the stigmatized individual and sympathetic with it" (p.87), such as some health care professionals.

Similar to the current study's results, Sanguesa (1995) stated that women who terminated their pregnancy for fetal abnormality are often neglected by their social support network as family and friends who are also inadequately prepared to help. Moreover, this lack of personal support is confounded by that the institutional support that is available may not be familiar to women, and may be underutilized, not recommended or not accessed at all. Most of the women in this current study felt disappointed by their encounters with the health care professionals throughout their TOPFA experience. The women's stories revealed that although the involvement of HCPs sometimes facilitated them working through their grief, frequently the HCPs actions compounded their grief response. They felt that HCPs dealt with their experience as a medical problem that needed to be fixed by terminating it. They had a sense that their experience was a problem and it was fixed. Lang, Fleiszer, Duhamel, Sword, Gilbert and Corsini-Munt (2011) similarly concluded that HCPs were often perceived by women as minimizing their loss by treating it as a medical event and not recognizing it as the loss of their baby. Women felt that some HCPs's attitudes reflected that this type of loss was less important or significant than other types of loss. Recognition of the loss by the women's social network was important to women in the current study. The importance of recognition following perinatal loss has been documented in the literature (Lang, et al., 2011; Swanson, 1991; Swanson-Kauffman, 1986; Watkins, 2001).

Although some women indicated that they had adequate support from husbands, families and friends, the majority did not. The women in this current study reported that their husbands were their main source of support, although they had different grieving styles than their wives

which might cause difficulties in the healing process. In consistent, Peggy (1996) in a qualitative study examined parents' experiences of a subsequent pregnancy after perinatal loss, indicated that in an effort to protect their wives, spouses did not wish to communicate about the loss. Similar to the current study's results, the women in Peggy's study commented on their husbands' grieving styles; they were generally less expressive of their sadness, wish to deny the loss and simply move on, returning to work and going on their normal daily activities. In this current study, in spite of the differences in responses to grief, most women reported that loss had strengthened their marital relationship.

Most women initially distanced themselves from others immediately following the loss. Women withdraw from their social world to avoid painful questions or comments from others. Refraining from contact to avoid painful remarks or other uneasiness with perinatal loss was reported by de Montigny, Beaudet, and Dumas (1999) and Watkins (2001). Similarly, some women perceived others avoided them when they were not comfortable in confronting the loss. At times, this led to feelings of isolation and frustration. It seems that, even though some women deliberately avoided others, they did not want to avoid them. Women realized that people around them might not know how to respond sensitively and empathetically so they say as little as possible or nothing at all, or they express the sympathy by their physical presence but not mentioning the issue at all. The women wanted others to recognize their loss and grief. Feelings of avoidance and abandonment have been reported by other researchers (Banson & Stevens, 1992; Cecil, 1994; de Montigny, et al., 1999; Rajan, 1994; Stierman, 1987; Watkins, 2001). Having to endure and deal with insensitive remarks from others was a finding in this current study that has been consistently documented in the literature (Banson & Stevens, 1992; de Montigny, et al., 1999; Kavanaugh, 1997; Smith & Borger, 1988; Stierman, 1987, Swanson-

Kauffman, 1986). Women needed to feel that their baby's existence was acknowledged and their grief was understood by others. Similarly, Keyser (2002) noted that a necessary component in order for a "sense of recovery to be felt, to have the meaning of their baby's life validated and their grief empathetically understood by others is the heart of healing" (p.240).

Humans are social beings, and as such we can be greatly influenced by the social world in which we live. Bereaved women make or find meaning in their experiences through their interpersonal contact with others. The women experienced the world through their relationships with others (Family, friends, HCPs). van Manen (1997)'s lived relations indicated that human beings have searched in this experience of the other, the communal, the social for a sense of purpose in life, meaningfulness, and grounds for living. Lived relations, including positive and negative influences, were experienced by the women. Most women experienced isolation due to perceived lack of support and lack of understanding while relating with family, friends, and HCPs.

Women needed to share their lived experience of TOPFA with other women who could understand their experience. They successfully found their way through going online and joining online support groups. Online support groups were perceived as a significant facet of their lived experience because it helped them to connect and relate with women experiencing similar feelings and challenges. Patterson (2013) confirmed that the solidarity of a group provides the strongest antidote to traumatic experiences. The online place is also related to van Manen's lived space. As van Manen (1997) indicated, "We became the space we are in" (p.102). It is perceived as a safe place for the women to communicate freely, safely and privately. In other occasions, the lived space for these women was experienced negatively. Being in a place like waiting rooms, operating theatres, ultrasound setting alone without empathetic care, women felt lonely,

exposed, and even neglected. For some women who terminated their pregnancy in abortion clinic, the lived space there made them feel ashamed and stigmatized.

When the social response to the bereaved women's grief includes silence, insensitive response or un-empathetic understanding, they are affected deeply and their grief can become "extraordinary complicated" (Attig, 2002, p. 15). In this current study the perceived lack of support and grief recognition by the women's social networks complicated their grief experience and left them feel isolated and made their grief not validated. Women went to the online support groups to address their unfulfilled need to talk to others and to be understood. They looked for other women with similar experiences through a safe environment that protect them from being judged and provide them with an opportunity to talk, to be understood and to be acknowledged.

In support of the findings of this current study, Van der Houwen, Stroebe, Schut, Stroebe, and van den Bout (2010) explaining the use of online support groups, indicated that compared to individuals who lose an adult, bereaved parents might be less likely to find peers with a similar loss history among their usual social contact, or their typical social support is less forthcoming with support over a prolonged period of grief. The women in this study expressed that their feelings of safety and privacy were met by joining the online support group. These findings are in consistent with the findings of Gold and colleagues (2012) and van Uden-Kraan and colleagues (2008). Gold and colleagues noted that message boards helped women to feel less isolated in their loss and grief. They appreciated the unique aspects of Internet communication such as convenience, access, anonymity, and privacy (Gold, Boggs, Mugisha, & Palladino, 2012). van Uden-Kraan and colleagues found that visiting online support groups has an empowering impact on patients. Patients reported being better informed, feeling more confident,



improved acceptance, and enhanced social wellbeing from engaging in online discussion groups (van Uden-Kraan, Drossaert, Taal, Seydel & van de Laar, 2008).

The value of being able to share feelings with others who had a similar loss experience was evident in this study. In addition, noting a positive aspect of the experience of TOPFA, women in the current study found themselves reaching out to other women with similar experience to assist and support them with their grief. Reaching out to other women was perceived as a positive outcome of this traumatic experience. Support groups were very important to the women because of their need to have others to talk to who could possibly understand what they were going through. Almost all became involved with a support group either face-to-face or via the Internet.

In the current study women adopted some supportive activities in an effort to reduce their feelings of loss and grief. Keeping their baby's memory alive and acknowledging their existence, as well as becoming pregnant, were evident to have a positive influence on the women's healing. Most of women recognized that they had to acknowledge their grief somehow and for many acknowledgement came through their use of various rituals or memorials designed to remember their lost baby. Examples of some rituals were giving the baby a name, baptizing the baby, cremating or burying the baby's remains and creating a memory box to keep their baby's mementos.

Findings of the current study indicated that some women who had a labor and delivery (L&D) experienced seeing and holding the baby for a short time after birth, while others who had dilatation and evacuation (D&E) did not have this opportunity. Not having had the opportunity to see or hold the baby was met by regret for some women. Choosing to hold or view the baby may be as it makes the baby more real and having a concrete image of the baby

may help in the grieving process. For two women, seeing their baby's abnormality was reassuring that they made the right decision. Women valued the time spent with their babies and appreciated the motherly feeling even if it was for short time. Radestad, Saflund, Wredling, Onelov, and Steineek (2009) conducted a quantitative study using a questionnaire to examine mothers' feelings when holding their stillborn baby. Similarly, their findings indicated that women felt tenderness and warmth when they held their dead baby. Holding the baby gives the mother an opportunity to nurture her baby, a chance for her to care for the baby, which can be seen as a motherly natural reaction after giving birth. Christoffersen (2008) reported that parents who had both seen and hold their stillborn baby during the first 30 minutes after birth said that this was the most valuable time they had with their baby. Other activity that supported the healing process for the women was to pursue a new pregnancy. Becoming pregnant as soon as they were physically ready was a strong motive for the women in this study. Becoming pregnant again was a means to address their intense feelings of emptiness and void after losing their baby for fetal abnormality. The following excerpt of a poem by Anne Morrow Lindbergh depicts a feeling of void that a woman experiences alone after losing her fetus. It reminds me of the women's expressions of emptiness and void after their TOPFA experience.

For whom  
The milk ungiven in the breast  
When the child is gone  
For whom  
The love locked up in the heat  
That is felt alone

Anne Morrow Lindbergh, (1972).

The maternal-fetal relationship could be explained by van Manen's lived body which refers to the phenomenological fact that "we are always bodily in the world". The women in this study were in their second trimester of pregnancy. They had developed all the physical symptoms of being pregnant. They experienced the world around them through their pregnant body. Matulaite (2012) described the embodied relationship with the baby within in the second trimester saying "I've got you under my skin" (p.1). Matulaite (2012) stated that the second trimester is a time when a pregnant woman is playing with a confusing concept; she is seeking to digest whether her baby is actually a part of her or a separate human being. Women considered themselves in a relationship with another human being within them. The second trimester is also a time when women realize that the baby is separate human being, yet still a part of them. Losing the baby unexpectedly for fetal abnormality disrupted this embodied relationship. All the women experienced huge feelings of void and emptiness and all of them eventually opted for another pregnancy.

Peggy (1996) and Korenromp and colleagues (1992) indicated that it has been a general recommendation that women wait until at least six months before pursuing pregnancy again so as to allow themselves adequate time to mourn their loss and distinguish between children, rather than risk viewing the subsequent child as a replacement for the lost one. In spite of such recommendations, all women in this study turned their attention to the pursuit of another pregnancy. They believed that a new pregnancy would be helpful in managing their grief and healing process. They did not think of their subsequent pregnancy as a replacement for their dead baby.

The use of subsequent pregnancy as a mechanism for coping with perinatal loss is controversial. In earlier research, mothers had been advised to seek a "replacement" pregnancy

quickly and distract themselves with another child to diminish their sense of pain; to resolve their grief (Brost & Kenney, 1992; Lewis & Page, 1978; Peppers & Knapp, 1980; Zeanah, 1989).

However, great concern has been voiced that a rapid subsequent pregnancy (within a year) may be an indicator to disordered mourning (Zeanah, 1989). Pregnancy might inhibit or delay the grieving process and healing until the time of birth, at which point it may interfere with the relationship between the mother and subsequent child. Other evidence suggests that waiting to pursue pregnancy is an asset to the healing process (physically and emotionally), facilitating greater enjoyment of a subsequent baby (Davis, 1991). In support of our findings, Korenromp and colleagues (1992), Peppers and Knapp (1980) and Theut and colleagues (1989; 1992) reported that the birth of a viable, healthy child has been seen to aid in grief resolution.

## CHAPTER SEVEN

### Conclusion

When I began this research, I thought that I had fairly good understanding of women's experience of terminating a pregnancy for fetal abnormality. As I have worked and cared for women who had been diagnosed with fetal abnormality, I believed that I could understand what they went through. However, in my previous nursing practice I did not meet any woman after her pregnancy termination was performed. When I have been faced with the possibility of having to make the decision to terminate one of my pregnancies, I felt a pressing need to deepen my understanding of this experience and uncover all the aspects around it. When I finished this research, I was surprised to discover how complex and difficult it is to go through this experience. I discovered that this experience involves many paradoxical aspects related to the women's decision to terminate a pregnancy and their experiences of its aftermath that I previously did not know or understand. The first finding that surprised me was the faulty belief of the "taking-for-granted healthy pregnancy" that was adopted by me and by the participants in this study. All the women including myself expected to have a normal uneventful pregnancy with healthy outcomes.

Secondly, I discovered how prenatal screenings were frequently perceived as routine tests for the purpose of reassurance of fetal health status and general well-being. There was no in-depth preparation for these women regarding what to expect when undergoing prenatal screening tests. No one talked with a health care professional about the main purpose of these screening tests before were offered. This appeared to be more of an inattention or misunderstanding on the part of HCPs, rather than an intention to keep people not well-informed about these tests and their implications. The findings of the study indicate that women agree to

undergo prenatal screenings as part of their routine prenatal care, particularly ultrasound screening, without full understanding of the tests, their purpose, and what they would do if they have a positive test results.

Another discovered aspect of this experience, is the women's intense and complicated feelings of loss and grief after the decision to end the pregnancy had been made. I discovered that the decision to terminate a pregnancy for fetal abnormality is full of paradoxes and dilemmas that complicated the grieving process and healing experiences for women in the long term. The pregnancy for these women was wanted, hoped-for and as a result of the discovery of a fetal abnormality, women were forced to actively participate in a decision to end this wanted pregnancy and end their fetus's life. These women had never thought they would have to make this complicated decision about their pregnancy which entailed several dilemmas; those concerning their abortion views, disability views, and their maternal identity. They have been left with many persistent unresolved issues as a consequence of this experience.

Another area surprised me was the lack of social support these women experienced during and after their pregnancy termination experiences. They conceptualized the support they needed as, having adequate information provided throughout the whole experience, receiving empathetic care from others, and having people's understanding to the extent of their loss. I was amazed by the women's crucial need to talk and explain themselves and their need to make others understand their situation. Through listening to these women's stories I discovered how pregnancy termination is still considered a "Taboo" subject. I was struck by the women's fears of being judged by others and how much this contributed to their feelings of isolation and loneliness. I was impressed by how important it was to women to dissociate their experiences of pregnancy termination from an abortion because of their feelings of shame and stigma. Finally,

as reflecting on their experiences, women were able to see positive aspects of their past experience with TOPFA. They have grown and developed a greater sense of self and world realities.

### **The Limitation of the Research**

There are limitations to this study. First, the participants were all Caucasian, middle class, and well-educated. Women from other socio-economic, ethnic, and cultural groups have not been represented in this study. Second, the study findings and interpretation must be considered within the context of the research design and methodology. As in most qualitative research, the sample size was small. The findings of this study only reflect the study participants' experiences. However, by using rich and in-depth interviews of few participants, I am able to get a more thorough and new understanding of women's experiences of terminating a pregnancy for fetal abnormality. Care should be taken not to make generalization to other women based on this study alone.

Although using the World Wide Web as one of the methods of recruiting the sample was helpful in accessing more participants, recruiting women from two different legal and contextual systems (USA , Canada) might have some influence on the interpretation of the data, however, care was taken to focus my interpretation on the commonalities of the women's experiences.

This research's results may be limited as all the participants were volunteers. It is possible that the kind of women who would volunteer for this type of research might be experiencing more struggle, dilemma, and more psychological problems than the majority of women who terminated their pregnancies for fetal abnormalities.

Finally, interviewing most of the women through a telephone conversation may be seen as a limitation. It can be challenging because it is more difficult to gain rapport with the participants because their non-verbal reactions and cues could be missed.

### **Strengths of the Research**

This study contributes to the current understanding of the TOPFA experience and provides new insights to aid in the counseling and care of these women. This study attempts to address the women's needs for; information regarding prenatal screening and testing procedures, empathetic understanding and supportive care, and increasing public awareness by the complex nature of this experience.

### **Implications for Nursing Practice**

During the course of this study it became evident that women who experienced the diagnosis of fetal abnormality and decided to terminate their pregnancy struggled in the most part of their experience with lack of information. The lack of information concerning pregnancy outcomes and prenatal screening and testing was one of the major sources of anxiety and uncertainty.

The findings revealed that women entered into pregnancy with some mythic expectations about the normality of pregnancy. When they were faced with the diagnosis of a fetal abnormality, their expectations of a normal pregnancy and having a healthy baby were violated. Raising the awareness of and educating pregnant women regarding the pregnancy outcomes and the possibility of fetal problems is crucial because of the advancement in prenatal screening technology that will lead to increase detection of fetal abnormalities. Educating women could be provided through pre-conceptual counseling that encourage women to prepare actively for pregnancy prior marriage. Through antenatal care women should be provided with sufficient



information concerning possible risks for fetal anomalies, prenatal screening tests, and pregnancy management in case of possible risks.

The findings raise questions around informed choice, informed consent and prenatal screening tests. It is evident from the women's accounts that they were uninformed and unprepared for undergoing prenatal screening tests and the pregnancy termination decisions that followed their participation in these tests. Women indicated that they have not received adequate information about prenatal screenings or forewarning of the choices they would have to make if an anomaly was discovered. Therefore, the prenatal screening practice guidelines and how they are applied in the clinical setting should be reviewed and enhanced to provide women with the necessary information about the method of screening, the conditions being screened for, meaning of the results, and pregnancy management in case of detection of abnormality before introducing these tests to enable the women to make informed decisions. It is imperative to explore the existing prenatal counseling available to women who undergo prenatal screenings for HCPs to be better able to design, implement, or expand upon counseling services for pregnant women. By understanding the actual prenatal practice and the women utilization of knowledge, HCPs would be able to improve the quality of their practice.

In the light of the findings, health care professionals need to pay more attention to the way informed choice and informed consent regarding prenatal screening tests and determine whether women who see screening as a means of reassurance are making an informed choice about undergoing tests. How information about prenatal screening is presented to pregnant women and if they understand the information needs to be addressed. Health care professionals need to ensure when dealing with prenatal screenings and its consequences, that their participants have sufficient knowledge and understanding of these technologies. HCPs should confirm with

the women that the information is understood by asking the women questions such as; what will they do if the tests revealed a fetal abnormality?, will they consider pregnancy termination?, what do they feel about pregnancy termination? Providers should consider the women's individual values and enable women to comprehend the information given well enough to allow it to inform their value-based decision making about their pregnancy (Harris, Washington, Feeny, & Kuppermann, 2001). Health care professionals need to ensure informed choice by providing opportunities for women to ask questions, to learn about the screening tests' limitations, and to confront the small but real possibility of detecting a fetal abnormality which necessitates them making a difficult decision about the pregnancy. Increased awareness of the diagnostic aspects of prenatal screening tests might encourage women to discuss the ramifications of parenting a child with disabilities and knowing the available resources for support to these children. Referring women to associations of parents of children with disabilities could support them in making their decisions.

The findings indicated that women's decision-making process regarding TOPFA was complicated and raised many dilemmas. The ethical and moral aspects of the pregnancy termination decision must be considered when caring for these women. Efforts to develop better decision-making support tools for this complex decision are recommended to meet the needs of the women who anticipate making this complex decision in the future. In order for individuals to make decisions that will affect their future, HCPs are charged with bringing their patients to a level of understanding where they can appreciate the consequences of a particular decision. As a result, patients are then able to make an informed choice. For example, providing women with adequate information and evidenced-based resources about their fetal diagnosis through pamphlets, written materials, web sites, and support groups. Informed choice in medical

decision-making stems from the Western bioethics' value of respecting individual's autonomy. All western HCP codes of ethics and a number of legal acts hold that informed choice must be obtained prior to any substantial intervention (Beauchamp & Childress, 2001). Freedman (1999) stated, "the patient must be informed so that he/she will know what he is getting into, what he/she may expect from the procedure, what his likely alternatives are and what the procedure will mean" (p. 172). When these steps are applied to the women's decision-making to terminate or not to terminate their pregnancy, the situation is overwhelmingly complex and involves multiple moral dilemmas as revealed in the findings of this study; dilemma of maternal identity as women wondered if they are good mothers or bad mothers, abortion and disability views dilemmas with being. Women's intense emotions and the lack of time can make this decision difficult especially with the shock the women experience due to the unexpected nature of diagnosis. In this situation, HCPs must engage with women to address their ethical and moral dilemmas. They should develop new strategies to understand the uniqueness of each individual women situation, as well as how ethical dilemmas are understood by each woman. HCPs should assess women's values and beliefs and deal with the experiences in a holistic approach. Strategies that could be applied by HCPs could include prolonged counseling time in order to convey sufficiently full information and provide women with opportunity to ask questions. Several successive counselling sessions could be provided by HCPs in order to provide adequate time for women for reflection on the alternatives they have in the light of the given information. Therapeutic relationship should be enhanced to help women during the process of decision-making. Providing women with space and time to talk about their needs, values and concerns and listening to them empathetically and sensitively are important strategies to enhance decision-making process.

Similar to what has been reported in the literature (Aite, et al., 2006; Aite, et al., 2011; Korenromp, et al., 2007; Kresting, et al., 2005; Kresting et al., 2007; Lalor, Begley, & Galavan, 2009; Skari, et al., 2006), this study's findings indicated that learning about the fetal abnormality as well as making the decision to terminate a pregnancy for fetal abnormality is a traumatic experience for women. Debriefing is standard clinical practice after traumatic events (Aite, 2006; Aite, et al., 2011; Skari, et al., 2006) and should be considered by HCPs. Women who undergo a TOPFA could be asked whether they need to see a trauma specialist to help them processing their feelings and managing their stress.

Nurses and health care professionals need to acknowledge and appreciate the complex nature of women's experiences of TOPFA and its long-lasting and profound effects. They have an important role in understanding this experience and provide adequate support for these women. Women need time and space to grieve their loss while being offered support from family, friends, community, as well as HCPs. Women's feelings of loss and grief do not diminish rapidly. The grief experience is a personal response, which needs to be acknowledged and respected by all who encounter these women. Nurses and other HCPs need to be aware of the immediate need of support for these women. The experience of TOPFA is traumatizing for women and often challenging and sometimes difficult for the professionals involved. However, education, ongoing training and staff support will improve the services offered to these women. These women require empathetic and sensitive presence from the HCPs who provide care throughout TOPFA experience. Providing health care professionals who work in the area of reproductive health with training programs concerning ethical decision making could help them supporting these women during the decision making process. In addition, creating training programs about grief for HCPs could help in recognizing the importance of touching and

comforting their patients in a compassionate way, showing warmth and human connection. Moreover, there is a need to establish bereavement programs that are geared to meeting the unique needs of these women. Bereavement services may help to reduce immediate emotional trauma and may reduce long-term consequences associated with grief experience after the discovery of a fetal abnormality and the termination of pregnancy. The women's reported feelings of ongoing loss need to be followed up by long-term support services that could be accessible at any time of need.

Nurses can provide important and cost effective support services for women. Some participants reported having a positive experience with nurses and appreciated talking with them. Building time into the nurses' work schedule to follow up with these women would allow the women the opportunity to talk and to gain satisfaction from further contact. Community health nurses could be easily accessed to these women and they could guide women to other support services in the community. Nurses could encourage using the Internet as a source of support for these women by providing them with some online support groups concerning TOPFA experience. One of the important aspects in providing psychosocial support for these women is to establish a therapeutic relationship between the HCPs, especially nurses. HCPs need to be highly sensitive to these women's needs. Women recognized their grief as ongoing, severe and unacknowledged by others. HCPs were often perceived by women as minimizing the loss by treating it as a medical event while not recognizing it as a loss of their baby. It was revealed from women's stories that they lacked understanding from HCPs and other people like family and friends of the nature of their grief. They were sensitive to other people's insensitive remarks, looks and attitudes even if unintentional. Providing empathetic care will help in easing the women's stress and enhancing their grieving and healing processes. By asking the women about

their needs and exploring supportive interactions during and immediately after the termination, For example, HCPs could help reduce some stressful moments during the hospitalization. For example, providing women with detailed information on the available methods of termination and providing them with the opportunity to decide on the method they prefer; discussing with women the procedures of dealing with their baby's remains; exploring the women's readiness to view their baby and have their pictures taken could have a positive influence on the women's grieving and healing process later on.

Moreover, adopting a family-centered care approach will lead to a better support to these women. The women reported that the most source of support was their husbands and family. HCPs should involve women's family in their care. The philosophy of family centered care recognizes the family as the constant in a person's life and any person in health care services must support, respect, encourage and enhance the strength and competence of the family in their natural care giving and decision-making roles.

### **Implications for Policy**

In my exploration of the women's lived experience of TOPFA, I have identified a policy implication with regard to the meaning that women give to abortion. Based on findings from this study, it was apparent that the legal definition of abortion possesses a great deal of stigma. Women who selectively chose to terminate their pregnancy in the second trimester are, by law, choosing to abort. However, for these women abortion had different meaning. Most of them did not use the term 'abortion' to describe their pregnancy termination. Women used terms as "*genetic termination*", "*genetic loss*" or "*therapeutic termination*". They tend to associate abortion with unwanted pregnancy, and for them their experience of pregnancy termination is different. They desperately wanted their children, they wanted them to live. Thus, women who

chose termination do not consider themselves within the abortion category as society might categorize them. They made their choice to end their pregnancy for the best interest for all involved. Care should be taken not to label these women as 'aborters' because for them, they suffered the loss of a wanted pregnancy. It is important to address this issue as a policy implication, because the choice women elected dictated the hospital they could utilize and subsequently impact the extent of bereavement support services offered and provided. It should not be assumed that because a woman chooses termination that she did not want her child or does not mourn that loss. Another policy implication for hospital practice is the routine admission and discharge procedures for these women. Maintaining the privacy and confidentiality of these women during the admission procedures is crucial. The reason for admission should not be explored in public, as this can make the women feel exposed and stigmatized. Also admitting women in the same area where birthing women with their normal newborns are, should be avoided.

It was found that women experienced feelings of shame and stigmatization after having had their pregnancy terminated for fetal abnormality because of the societal views and debate around abortion. A policy implication concerning Being faced with anti-abortion demonstrations could add more difficulties for these women. Establishing rules and regulations regarding anti-abortion demonstrations should be a policy implication. For example, these demonstrations should not be arranged in or near residential areas, protestors anti-abortion signs should not include any hurtful pictures or comments, and access areas to hospitals or health clinics should be cleared from protestors.

## **Implications for Future Research**

With regard to future research on the experience of TOPFA, there are many areas needing further exploration. It is imperative to explore the existing prenatal screening and prenatal counseling practices and assess how they are applied in order to further examine the gaps and inconsistencies that were evident in this research study. In addition, it would be important, both in research and in clinical practice to pay more attention to the way informed consent is presented to people and how they take up the information given. There should be research studies to evaluate women's knowledge and satisfaction when providing prenatal screenings and tests to ensure that the participants have sufficient knowledge and understanding of these technologies. If prenatal screening tests continue to be offered as a routine practice, future research should concentrate more on perception of disability amongst potential parents and health care professionals and on how best inform women about the lives of children with disabilities and their families.

Future research studies should be directed to explore existing bereavement support services available to women who choose to terminate for fetal abnormality and to evaluate their quality and accessibility. By understanding the support available, HCPs would be able to design, implement, or expand upon services for this population of women.

An important area for future research is the decision-making process regarding TOPFA. As revealed in the findings, many women described feelings of uncertainty during the decision-making process. Supportive interventions that could assist women with decision-making could be developed and tested through research studies. In addition, the ongoing feelings of grief and loss experienced by most women in this study showed a need for a program offering ongoing emotional support whose effectiveness could be evaluated through longitudinal research studies.



The role of the Internet in searching for information and in getting the informational as well as emotional support was evident in these women's lived experiences. All the women in this study were well-educated and good users for computers. They went immediately to search for their lacked needs for information and support. They connected with online support group to share their experience with women they believed they could understand their suffering. Further research studies are needed to assess the role of online support groups in supporting these women and what are the positive and negative aspects of this kind of support for women who terminated their pregnancy for fetal abnormality.

### **Summary**

This interpretive phenomenological research study on the women's lived experience of termination of pregnancy for fetal abnormality used van Manen's (1997) method to explore the question: What is the lived experience of women who have terminated their pregnancies through an elective second trimester termination for fetal abnormalities more than five years ago? From the data collected, six themes were emerged and captured the women's meaning of this experience. Based on the themes, findings were discussed in the light of the related literature on the experience of TOPFA. Implications for nursing practice, policy, and research were presented as well as the limitations and strengths of the study.

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## Appendix A

### Organization Request Letter

University of Western Ontario, School of Nursing,  
Health sciences addition Building  
1151 Richmond Street.  
London, ON N6A 5B8

Attention:  
Address:  
Dear Sir/Madam,

My name is Heba Hassan, I am a nursing doctoral candidate currently studying at the Nursing Doctoral Program at the University of Western Ontario, School of Nursing, London, Ontario. I am commencing a research study as part of the requirements for completion of this degree, under the supervision of Dr. Marilyn Evans, thesis supervisor.

The purpose of this study is to understand the long-term life experience of women after elective second trimester pregnancy terminations due to fetal abnormalities. I am requesting your assistance in recruiting participants for my research. Specifically, I am requesting your assistance by placing posters announcing the study in your place and by giving the eligible women a copy of the information letter.

I have included a copy of the poster and letter of information for your scrutiny. You may contact Dr. Marilyn Evans at the School of Nursing at xxxxxxxx ext. xxxxx or at xxxxxxxx as necessary. I can be reached at xxxxxx or at xxxxxx for any additional questions or concerns you may have. I look forward to hearing from you on this matter.  
Thank you for your time and assistance.

Sincerely,

Heba Hassan, BScN, MScN, PhD candidate  
UWO, School of Nursing



## Appendix B

### Poster

Did you know?

- Continued use of prenatal screening and diagnostic testing has led to increasing the number of pregnancy termination due to fetal abnormality.
- Some problems and consequences due to this experience may affect your physical and mental health.

Are you a woman who has experienced a pregnancy termination due to fetal abnormality more than five years ago?

### And

Would you be willing to share information about your experience?

### Why.....

Limited information is available about women who have experienced pregnancy termination due to fetal abnormality. I am seeking your individual experiences and stories to inform health care providers and to develop resources for you and other women to be able to understand what happens after this experience and what helpful things can be done that may improve your overall health.

### Interview:

- Complete of a short demographic questionnaire.
- Face-to-face audiotaped interview.
- An option to participate through a phone call interview will be available.
- Participation involves two interviews.

### Are You Interested?

If you are interested or know someone who might be, please contact:

Heba Hassan, PhD(c)

@

XXXXXXXXXX

or

[XXXXXXXXXX](#)

## Appendix C

### WEB Research Study Announcement

Volunteers needed for the following research study:

#### Termination of pregnancy for fetal abnormality

##### Do the following apply to you?

- Have you experienced termination of pregnancy due to discovery of fetal abnormality more than five years ago?
- Are you between the age of 25-60 years?
- Are you willing to talk about and share your experience with a doctoral nursing student from the University of Western Ontario?

**If so**, you may qualify to participate in this study. Participation involves two interviews.

##### Compensation will be provided

To see if you qualify and for further information please contact Heba Hassan at xxxxxxxxxx or at [xxxxxxxxxxx](mailto:xxxxxxxxxxx)

## **Appendix D**

### **Letter of Information**

Women's Long-Term Life Experience after Pregnancy Termination for Fetal Abnormality:

Interpretive Phenomenological Study

Principal Investigator: Dr. Marilyn Evans, RN, PhD

Associate Professor, Arthur Labatt School of Nursing, University of Western  
Ontario

Co-Supervisor: Dr. Cheryl Forchuk RN PhD

Professor, Arthur Labatt School of Nursing, University of Western Ontario,

Co- Investigator: Heba Hassan, BScN, MScN, PhD student.

Arthur Labatt School of Nursing, University of Western, Ontario

### **Introduction**

You are invited to take part in a research study about women's experiences after having terminated a pregnancy for a fetal abnormality. The purpose of this research study is to gain a better understanding about the experience of women who have gone through an elective second trimester termination of pregnancy for fetal abnormality more than five years ago.

The researcher's name is Heba Hassan. The researcher is a doctoral candidate in the Arthur Labatt School of Nursing, the University of Western Ontario. The researcher's speciality is in Maternal- Newborn Health Nursing. As a requirement of the doctoral program, the researcher is conducting a research study to understand the long term life experience of women who have had pregnancy terminations for fetal abnormality. While some women are known to experience short-term distressful effects from the experience of pregnancy termination for fetal abnormality, the research literature lacks information about the long-term effects this experience

has had on women and how women have integrated the pregnancy termination into their lives. Your role in this research is to describe what your experience of pregnancy termination for fetal abnormality was like, what effects it has had on your life and what meaning you attach to it at the present time.

### **Procedures**

If you take part in this study, you will be asked to participate in 1-2 interviews with the researcher. You will be asked to complete a demographic questionnaire in the beginning of the interview. You will be interviewed privately in your home or another mutually agreed upon place and once again in two to three weeks time for verification of the findings. Each interview will last approximately 60-90 minutes and would take place at a time convenient to you. You will be able to choose if the interviews are in person or by telephone. The interviews will be audiotaped recorded as this method would allow the researcher to accurately recall the conversation. The audiotape will be transcribed into a written format. In appreciation of your assistance and time with the study, you will be offered \$25 as an honorarium at the end of each interview. In case of telephone interview, the honorarium sum will be mailed to your address by cheque. In the event you are not able to complete the study your compensation will be pro-rated accordingly. Each participant will be interviewed twice when possible. A follow up call will be made three days after the interview to make sure that everything is fine with you and you do not feel sad, upset, or anxious. During this follow up call, a time for the second interview will be determined if you want.

### **Benefits of Participation in the Study**

There may be several potential benefits to your participation. By talking about things that have happened to you, you may begin to understand them in a different way, make sense of

what happened to you, and learn from your past experiences. As well, the information and knowledge that will be gained from this study may help other women who have chosen to terminate their pregnancies to learn from your experience and instruct health care professionals how to better care for women who have gone through this experience.

### **Risks of Participation in the Study**

No immediate or long-range risks are foreseen from participating in this study. However, the discussion of the experience of termination of pregnancy for fetal abnormality is distressful for some women. You may find that reliving that time of your life causes emotional stress for you. If this is the case for you, and the stress is too great, you may ask to stop and resume at a later time. Should you experience a level of stress that requires professional help, support services can be recommended. You will be contacted by phone three days after the interview to determine if you are okay or you experience some feelings such as sadness, upset or anxiety and you would like any further help. A list of the existing services and resources will be given to you to get support if required.

### **Voluntary Nature of Participation**

Your participation in this study is completely voluntary. You are free to refuse to answer any specific question(s), to stop the interview, and to withdraw from the study at any time.

### **Confidentiality**

Your name will not appear on the demographic questionnaire but the questionnaire will be assigned an anonymous identity code. This code will be the same one attached to the audio-taped information and the transcription of the interview. If you participate, the written transcripts and audiotapes will be kept confidential and only accessible by the research team. The interviews will be digitally recorded, and the files will be saved on a password-protected

computer. Neither your name nor any other identifying information will appear in the report of the study or in any written or verbal reports associated with the study. You will not be identified in any publications of the study results. At the completion of the research study, the list of the research code numbers with the corresponding participant identifying information will be destroyed. If the research ends for any reason or the participant changes her mind and decides she doesn't want to be in the study, all data and recordings will be destroyed. If you would be interested, a summary of the study results will be made available to you at the completion of the study.

### **Contacts and Questions**

If you have any questions about the study you may contact Dr. Marilyn Evans (Principal Investigator) or Dr. Cheryl Forchuk (Co-supervisor) or Heba Hassan (Co-investigator conducting this study) as mentioned in the beginning of this letter. If you have any questions about your rights as a research participant or the conduct of the study you may contact:

The Office of Research Ethics

University of Western Ontario

This letter is yours to keep for future reference. Thank you for your interest.

**Appendix E**  
**Consent Form**

Study Title: Women's Life Experience after Pregnancy Termination for Fetal Abnormality:  
Interpretive Phenomenological Study

Principal Investigator: Dr Marilyn Evans

Co-investigator: Heba Hassan

I have read the letter of information describing the study or have had it read to me, have had the nature of study explained to me, and I consent to participate in this study. I have received answers to questions asked.

Name of Participant (Print)

Signature

Date

Name of Person Obtaining Consent

Signature

## Appendix F

### Demographic Questionnaire

Study Title: Women's Life Experience after Pregnancy Termination for Fetal Abnormality:

Interpretive Phenomenological Study

Identity code:

**For the following questions, check the applicable answer:**

Present marital status:

Single

Married

Divorced

Separated

Engaged

Common law

Marital status at time of pregnancy termination

Single

Married

Divorced

Separated

Engaged

Common law

Present occupation

Student

Employed (describe)



Unemployed

Stay at home mother

Occupation at time of pregnancy termination

Student

Employed (describe)

Unemployed

Full time mother

Others

Highest level of education completed

Elementary school

High school

Post secondary

Ethnic origin

African-American

Caucasian

Hispanic

Asian

First Nation

African

Middle-East

Others

Religious affiliation at the time of Pregnancy termination

Catholic

Protestant

Muslim

Hindu

Jewish

Buddhist

None

Others

Present religious affiliation

Catholic

Protestant

Muslim

Hindu

Jewish

Buddhist

None

Others

**Reproductive history:**

Number of pregnancies:

Number of living children:

Number of miscarriages:

Number of deceased children:

Number of termination of pregnancy for fetal abnormality:

**Chronological description of reproductive history:**

Outcome of your first pregnancy: live birth (full term/premature), stillbirth, miscarriage, therapeutic abortion

Outcome of your second pregnancy:

Outcome of third pregnancy:

Outcome of fourth pregnancy:

Outcome of fifth pregnancy:

What was your age when you had pregnancy termination for fetal abnormality?

What year did you have the pregnancy termination?

What kind of abnormality did your baby have?

## **Appendix G**

### **Interview guide**

#### First Interview

- 1- How would you describe your life before the experience of pregnancy termination?
- 2- How does it feel to experience having fetal abnormality?
- 3- How your life has been since the termination of pregnancy for fetal abnormality?
  - What in your life has changed since TOP?
  - What are the main things that make this experience positive or negative for you?
  - What supported your healing?
  - What responses and actions of others considered caring and helpful?
  - How health care professionals impacted your life before, during and since the pregnancy termination?
- 4- What meaning do you give to this event in your life at the present?
- 5- How do you integrate the event and its meaning into your life?
  - How this choice affects you, your relationships, and your life decisions?

**Appendix H**  
**List of Services and Resources**

Family Service Thames Valley (519) 433-0183

Bereaved Families of Ontario (519) 686-1573

The London Crisis Pregnancy Centre (519) 432- 2073

## **Appendix I**

### **Interview Guide**

#### Second Interview

- 1- What come to mind in reviewing the themes of the interview?
- 2- Can we look at each one of the themes together and talk about our interpretation?
- 3- How well do themes reflect your story?

## Appendix J



### Use of Human Participants - Ethics Approval Notice

**Principal Investigator:** Dr. Marilyn Evans  
**Review Number:** 18537E  
**Review Level:** Delegated  
**Approved Local Adult Participants:** 10  
**Approved Local Minor Participants:** 0  
**Protocol Title:** Women's Long-Term Life Experience after Pregnancy Termination for Fetal Abnormality: Interpretive Phenomenological Study  
**Department & Institution:** Nursing, University of Western Ontario  
**Sponsor:**  
**Ethics Approval Date:** November 29, 2011      **Expiry Date:** December 31, 2012  
**Documents Reviewed & Approved & Documents Received for information:**

Document Name	Comments	Version Date
UWO Protocol		
Letter of Information & Consent		2011/09/01
Advertisement	Newspaper Advertisement	
Advertisement	Poster	
Advertisement	WEB Research Study Announcement	
Other	Follow up Telephone Script	
Other	Initial phone call script	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines, and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00009940.

Signature \_\_\_\_\_

#### Ethics Officer to Contact for Further Information

[redacted] (jsthebe@uwo.ca)	[redacted] (grace.kelly@uwo.ca)	[redacted] (emalcott@uwo.ca)
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*This is an official document. Please retain the original in your files.*

**The University of Western Ontario**  
 Office of Research Ethics  
 Support Services Building Room 5150 • London, Ontario • CANADA - N6G 1G9  
 PH: 519-661-3036 • F: 519-850-2466 • ethics@uwo.ca • www.uwo.ca/research/ethics

## CURRICULUM VITAE

**Name:** **Heba A. Hassan**

**Post-Secondary** The University of western Ontario

**Education** London, Ontario, Canada

**And Degrees:** 2011-2014, PhD Candidate

The University of western Ontario

London, Ontario, Canada

2006-2011, PhD student

Cairo University-Faculty of Nursing

Cairo, Egypt

M.Sc.N. in Maternal Newborn Health Nursing (1997-2003)

Cairo University-Faculty of Nursing

Cairo, Egypt

B.Sc.N. in Nursing (1990-1993)

**Honours and Awards:** International Doctoral Scholarship for PhD (2004)

Inductee, Sigma Theta Tau, International Honor Society of Nursing, Iota Omicron Chapter (2006)

Graduate Thesis Research Award, UWO (2011)



Iota Omicron Chapter Research Grant (2011)

Teaching Award Nomination, 2003

Teaching Award Nomination, 2002

Teaching Award Nomination, 1998

**Related Work Experience**

Research Assistant,

The University of Western Ontario,

2006

Graduate Teaching Assistant,

The University of Western Ontario,

2008-2013

Assistant Lecturer,

Faculty of Nursing, Cairo University, Egypt.

2003-2006

Clinical Instructor,

Maternity-Newborn Nursing, Faculty of Nursing, Cairo, Egypt.

1995-2003

Internship,

Faculty of Nursing, Cairo University, Egypt,

1993-1994

Head Nurse, Intensive care Unit

El Amal Hospital, Giza, Egypt,  
1993-1996

**Publications:**

**Hassan H, A, & Evans M, K. (2011).** *Women's life experience after termination of pregnancy for fetal abnormality.* The Faculty of Health Sciences Research Day, The University of Western Ontario, London, Ontario, March, 2011. (Poster presentation).

Hassan, H. (2010). *Women's long-term life experience after pregnancy termination for fetal abnormality: research proposal.* The 23<sup>rd</sup> Annual Research Conference, School of Nursing and Iota Omicron Chapter, Ontario- Canada – April, 2010. (Abstract accepted for oral presentation)

Hassan, H. (2010). *Women's long-term life experience after pregnancy termination for fetal abnormality.* The 22<sup>nd</sup> Annual Congress Conference, Orlando, USA.–July, 2010. (Abstract accepted for poster presentation).

**Hassan H, A, & Evans M, K. (2010).** *Women's life experience after termination of pregnancy for fetal abnormality: A research proposal.* Toronto Women's Mental Health Conference, Centre for Addiction and Mental Health (CAMH), Toronto, Ontario, September 1, 2010. (Poster presentation).

**Hassan, H., Sayed, Y., & Hassan, S. (2004).** *Relationship between iron deficiency anemia and course of labor, mode of delivery and neonatal outcome.* The Congress of the German Society of Obstetrics and Gynecology, Hamburg, 14 – 17. 09. 2004.(Oral presentation).

Hassan, H. (2003). *Relationship between iron deficiency anemia and course of labor, mode of delivery and neonatal outcome.* The 1<sup>st</sup> International Scientific Annual Conference of Maternal and Newborn Nursing Department. “Discovering Women and Family Health Reality: A Road for Nursing Success. 19 – 20 Feb, 2003. Cairo- Egypt. (Paper presentation).