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Exploring parental experiences and decision-making processes following a fetal anomaly diagnosis

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Graduate Program in Health and Rehabilitation Sciences
A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy
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**EXPLORING PARENTAL EXPERIENCES AND DECISION-MAKING PROCESSES
FOLLOWING A FETAL ANOMALY DIAGNOSIS**

(Thesis format: Integrated-Article)

by

Graduate Program in Health Professional Education

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

Often the first indication that something may be wrong in a seemingly normal pregnancy occurs during the first detailed ultrasound appointment between 16 and 20 weeks gestation. Even the most tentative suspicions of fetal anomalies are jarring. Parent's default reality of a normal pregnancy and a 'perfect child' changes to one of risk factors and the possibility of an 'unhealthy child'. This study begins with the realization of this first loss in a series of losses that follow for parents as they grapple with diagnostic information to be able to make informed medical decisions regarding their fetus and pregnancy. The study aims to explore the gap between clinical/professional knowledge and the private worldviews of parents when they return home to process the information and make decisions.

This study was situated within a Canadian healthcare context that provides prenatal screening and medical care within a socialized medicine system. Using Grounded Theory methodology, this study bridges the disciplinary boundaries of Thanatology, Psychology, Bioethics and Reproductive medicine to explore the lived experience and the processes of personal/emotional decision making of parents, as well as a patient-informed needs assessment of services.

The process of inquiry and the results are discussed with relevance to scholars and clinicians on the context of end-of-life decision making that occurs within the prenatal context. Theoretical lenses also examine the multiple death related and non-death losses as well as the reframed identity of parents and their unborn babies following a diagnosis of fetal anomalies.

Keywords:

Fetal anomalies, grief, loss, prenatal screening, decision-making, prenatal attachment, Grounded Theory, Participant-Observation, Foucault, biopolitics, ethics

Dedication

For Josh, my partner in all things

In remembrance:

Tristan, Zoe & April

With much gratitude

To all the little babies in this study - in honour of huge legacies in their tiny lives

Acknowledgments

A study such as this requires many people without whose guidance and vision such an endeavor is not possible. I have come to appreciate that it takes a whole village to bring a PhD candidate to this point of growth and a dissertation to fruition. While it is not possible to name each individual specifically, I sincerely hope that all who have shared this journey know that they have my deepest gratitude.

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Dr. Renato Natale & Dr. Jeff Nisker – my advisory committee, they are undoubtedly visionary people who saw the possibilities of interdisciplinary work and championed the need for such a topic at the highest administrative echelons to open access to the phenomenon.

Special thanks to the many clinicians, staff and administrators of St. Joseph's Healthcare London & London Health Sciences Centre, and in particular, Sandra Letton, Janice Gorodzinsky, Dr. Kevin Coughlin, Rusty McRae & Ciaran McKenna. Thanks also to Tanya Weiler & Dr. Jim Sanders for their many years of encouragement and reading several drafts of this dissertation. Finally, my deepest gratitude to the participants in this study who shared so generously in the hopes of improving clinical care for others, their legacy is tremendous.

Table of Contents

Preliminary pages

| | |
|-----------------------|-----|
| Abstract | ii |
| Dedication | iii |
| Acknowledgments | iv |

Introduction

| | |
|-------------------------------------|----|
| Background | 1 |
| Purpose and Relevance of Study..... | 4 |
| Bridging disciplines | 7 |
| Operational Definitions..... | 9 |
| Organization of Paper | 13 |
| References | 16 |

Chapter 1: Review of the Literature

| | |
|---|----|
| <i>Significance of Fetal Anomalies</i> | 17 |
| Historical and current fetal health surveillance programs | 17 |
| Trends and prevalence of fetal anomalies in Canada | 18 |
| Limitations of fetal surveillance..... | 20 |
| <i>Prenatal Screening and Prenatal Genetic Diagnosis</i> | 24 |
| Defining prenatal screening | 25 |
| Typical procedures and timelines | 28 |

| | |
|--|----|
| Non-invasive testing | 29 |
| Invasive testing | 30 |
| Genetic screening | 31 |
| Criticisms of prenatal screening | 32 |
| <i>Initial review of the literature on fetal anomalies</i> | 35 |
| Grief & coping following a fetal anomaly diagnosis | 35 |
| Provision of health services for fetal anomalies | 39 |
| Decision factors | 41 |
| References | 42 |
| | |
| Chapter 2: Methodology | |
| Philosophical & Theoretical orientations | 49 |
| Methodology choice | 53 |
| Methodology rationale | 58 |
| Rationale for Grounded Theory | 60 |
| Rationale for Grounded Theory version | 64 |
| Rigour & credibility in Ground Theory | 70 |
| Stages of Inquiry..... | 78 |
| | |
| <i>Methods</i> | |
| Phase 1: Understanding the scope of the phenomenon..... | 79 |
| Method rationale | 82 |
| Credibility | 85 |

| | |
|------------------------------------|----|
| Procedure | 87 |
| Phase 2: Research Interviews | 89 |
| Participants & setting..... | 90 |
| Procedure | 91 |
| Analysis | 91 |
| References | 94 |

Chapter 3: Results

Phase 1: Understanding the scope of the phenomenon

| | |
|--|-----|
| Overview of the clinical environment..... | 97 |
| Situational context | 98 |
| Typical day in the clinic..... | 99 |
| Summary of the clinical context..... | 104 |
| Revision of the final research questions | 117 |
| Theoretical sampling..... | 118 |

Phase 2: Research Interviews

| | |
|-----------------------------------|-----|
| Participant demographics..... | 119 |
| Procedures | 123 |
| Analysis | 124 |
| Analysis of codes and themes..... | 126 |
| Qualitative Themes: | |
| 1) Prenatal Screening..... | 129 |

| | |
|--|-----|
| 2) Diagnosis & prognosis | 130 |
| 3) Making Decisions | 132 |
| 4) Navigating through the system | 137 |
| 5) Information & communication | 140 |
| 6) About the pregnancy & baby | 142 |
| 7) Relational & post-loss experiences..... | 144 |
| 8) Intrapersonal factors & experiences | 147 |
| Conclusions & limitations | 149 |

Chapter 4: Discussion

Theoretical Orientation

| | |
|---|-----|
| Nature of Grief & Bereavement in Reproductive Loss..... | 152 |
| Historical frameworks | 153 |
| Fetal anomalies as a distinct type of reproductive loss | 158 |
| Anticipatory Grief | 158 |
| Disenfranchised Grief | 161 |
| Prenatal Attachment | 163 |
| Effects of Technology on Relationship & Attachment | 165 |
| Torn between hope and acceptance | 167 |
| Ambiguous and Non-Finite loss | 168 |
| Conceptual framework for prenatal palliative model | 171 |
| References | 179 |

Chapter 5: Philosophical Discussion

| | |
|--|-----|
| Biopolitics: A Foucauldian framework..... | 184 |
| Prenatal screening as a way of seeing..... | 187 |
| The subject and object in prenatal screening..... | 188 |
| Foucault’s Biopolitics & the Clinical Gaze | 191 |
| Techniques of the clinical gaze | 194 |
| The confessional narrative & anatomo-politics of the body | 201 |
| Prenatal surveillance & the ‘disciplining of the body’ | 206 |
| Biopower as the ‘investment in life’ | 211 |
| Economic motivations of biopower | 216 |
| References | 220 |

Chapter 6: Concluding reflections

| | |
|--|-----|
| Reflexivity as rigour and quality in qualitative research | 223 |
| Locating the researcher: methodological & practical considerations of | |
| Interdisciplinary work | 227 |
| Frameworks for reflection, reflexivity & reflective practices | 234 |
| Researcher’s journey, challenges & transformations | 238 |
| Considerations for ‘sensitive research’ with ‘vulnerable people’ | 249 |
| Implications for clinical practice..... | 252 |
| References | 257 |

List of Tables & Figures

| | |
|---|-----|
| Table 1: Prenatal Screening | 28 |
| Table 2: Number of fetal anomalies (FA) and maternal factors (MF) | 106 |
| Table 3: Frequency of fetal anomalies noted per case..... | 106 |
| Table 4: Total Maternal factors noted | 106 |
| Table 5: Fetal anomaly systems | 107 |
| Table 6: Cranial anomalies | 108 |
| Table 7: Facial, Neck and Central Nervous system anomalies | 108 |
| Table 8: Cardiovascular anomalies | 109 |
| Table 9: Gastrointestinal anomalies | 109 |
| Table 10: Renal anomalies | 110 |
| Table 11: Musculoskeletal anomalies | 110 |
| Table 12: Growth & other factors | 111 |
| Table 13: Maternal factors | 112 |
| Table 14: Maternal & gestational ages | 113 |
| Table 15: maternal age | 113 |
| Table 16: Gestational ages | 114 |
| Table 17: Attending/referring specialist | 114 |
| Table 18: General location..... | 115 |

| | |
|---|-----|
| Table 19: Prenatal screening..... | 115 |
| Table 20: Prenatal screening type..... | 116 |
| Table 21: Obstetrical history..... | 116 |
| Table 22: Demographics and reproductive histories..... | 122 |
| Table 23: Frequencies of theme codes & interview data contexts..... | 125 |
| Figure 1: Revision of the final research questions | 117 |
| Figure 2: Concept map - Theoretical sampling..... | 118 |
| | |
| Appendices | |
| Appendix 1: Medical terminology | 262 |
| Appendix 2: Examples of fetal anomalies | 265 |
| Appendix 3: Letter of Information | 267 |
| Appendix 4: Research Ethics Board Approval | 269 |
| Appendix 5: Interview Schedule | 270 |
| | |
| Vita | 271 |

**Exploring parental experiences and processes of decision-making following a
diagnosis of fetal anomalies**

For most parents who have been planning a family, pregnancy is a time of celebration. Most people assume that their unborn fetus/ child is perfect and healthy; this is the default nature of reality for most expectant parents. This default belief is based on an assumption of safety and, therefore, constructs an assumptive worldview. Assumptive beliefs about safety in the world persist until such time that an external reality alters the course of a taken-for-granted premise to the point when confronted with a reality that all may not be well in their pregnancy. Often the first indication that something may be wrong, in a seemingly normal pregnancy, occurs during the first detailed ultrasound appointment between 16 and 20 weeks gestation, when the physical development of the fetus and the organs can be well visualized. Even the most tentative suspicion of ‘problems’ can be jarring. Suddenly, the default reality of a ‘perfect child’ changes to one of risk factors and the possibility of an ‘unhealthy child.’ The aim of this study is to understand the lived experiences and decision making processes of parents as they grapple with diagnoses of fetal anomalies.

Background

With the advent of increasingly sophisticated reproductive technologies, the nature of reproductive loss is no longer a phenomenon narrowly construed as one of continued pregnancy versus miscarriage or abortion. Although a broad umbrella of

‘reproductive or perinatal loss’ as a conceptual frame is useful, issues regarding infertility, pregnancy loss following infertility, pre-implantation genetic diagnosis, multi-fetal reductions, and fetal anomalies constitute unique contexts for the phenomenon of reproductive loss. Contexts that warrant further study based on the unique precipitating factors as distinctions, rather than a binary category of ‘healthy pregnancies’ versus ‘reproductive losses.’

This study is an extension of a previous study concerning women’s lived experiences with pregnancy loss. The earlier study included women who had experienced ‘unintended’ pregnancy losses and was limited to those who had conceived without assisted reproductive technology (Fernandez, Harris & Leschied, 2011). Although the results of this study examined unintended pregnancy loss broadly, they did not distinguish whether the nature of the loss was spontaneous or resulted from complications arising from fetal anomalies. Two participants from this study had perinatal losses as a result of pregnancies complicated by fetal anomalies, which posed a qualitatively unique set of circumstances when compared to those with spontaneous loss. In both cases, the post- loss characteristics were congruent with the other participants, and hence, the resultant themes were coherent for post-loss coping and healing. The precipitating factors, however, and the incident of loss itself were different.

These two cases were significantly and qualitatively different, in that routine prenatal screening during pregnancy revealed the fetal anomalies and the fatal prognosis. Both women were well into their second trimester and had anticipated healthy normal pregnancies. Thus, the diagnosis of lethal fetal anomalies was a jarring deviation from their anticipated life trajectory that altered their expectations of pregnancy in at least two fundamental ways. First, that the pregnancy was redefined by risks. Second, was the confrontation of the reality of the imminent or impending death of their fetus. In comparison, those who had spontaneous miscarriages realized their loss either during the event of miscarrying or after the fetal death and thus accepted the irreversibility and finality of death from the moment of realization. By contrast, in the two cases involving fetal anomalies, the awareness of impending death brought the semblance of death vigil and the anticipation of death that could not be prevented.

Furthermore, both cases involved lethal fetal anomalies and the prognosis of imminent death during pregnancy. Following prescriptive medical management, both women were counselled regarding the options available to remove the fetus from the woman's body. The awareness and anticipation of death, coupled with the requirement to make medical decisions regarding the obstetrical management of their own bodies presented two distinctive criteria distinguishing these two cases from the other participants. In the interview narratives, both participants spoke of the struggle and feelings of emotional culpability that this anticipated knowledge of death and the requirements of decision-making imposed upon their existential reality. The

requirements of medical decision-making redefined the narrative of loss based on linguistic use and recast the story as an issue of “choice” and “options” regarding the outcome of the pregnancy. As a result, it redefined the perception of women and their partners as active agents rather than the unfortunate and tragic realization of a lethal diagnosis in the narrative of their losses. The public perception of “choice” and “options” in the issues of reproductive health are multi-layered and intersect with individual’s private reality of coming to terms with the meaning of loss.

Although the results of the research illuminated the post-loss grief process, it also revealed that fetal anomalies posed a unique interpretation in pregnancy loss that could not sufficiently be explained at the time solely by the results of the study or existing theory. The interview narratives revealed that the mere surface of the fetal anomaly loss phenomenon and hinted that the struggles embedded in the lived experience were not solely confined to an individual’s worldview, but rather situated within a social context of entrenched metanarratives that added to the complexity of the lived experience.

Purpose of the current study

In our current age of technological imaging and diagnostic technology, highly detailed 2D and 3D ultrasounds provide physicians with detailed anatomical visualizations of the internal structure, organs and functions of the fetus in ways that were not possible a generation ago. Furthermore, rapid innovations at the genomic

level and technologically, have enhanced the ability to provide prenatal genetic diagnoses at the constituent DNA level of the fetus. In addition, the experimental frontiers of fetal therapies and surgeries promise new hopes and new challenges for this population, both for parents and clinicians.

There are multiple reasons that warrant research on the topic of fetal anomalies- medical, psychological, social or health policy. Following from our previous study, our motivations are directed towards the psycho-social aspects of healthcare practice and service for this population. More specifically, the private experiences where the parents' internal values and beliefs of their worldview intersect with the harsh reality of an unexpected and undesirable health crisis for their unborn fetus and the resulting dilemma between facts and undergirding medical decisions.

Professionals are not explicitly privy to the private emotions and intrapersonal factors that influence how people absorb, process, and cope with such news and the dynamics of negotiating such decisions once families leave the clinical setting. Much of evidence-based science focuses on what is objective, observable, and testable. This research aimed to uncover those aspects of dealing with life, crisis and existential trauma that can only be known from the subjective reality of the individual whom it affects. In the absence of this knowledge, medical advice may be highly influenced by anecdotal clinical knowledge and interpretative assumptions made by professionals, albeit informed by how previous patients have responded. Although there is value in

using such assumptions in the absence of empirical knowledge, what needs to be ascertained is whether these assumptions are accurate and to whom they are transferable.

The limited research in this area does not adequately reflect a detailed mapping of how parents personally experience and navigate such crises. I use the word “navigate” deliberately, because from clinical observations there seems to be a back and forth process between rational and value-based/emotional decision making. As well, these decisions are situated within family and professional contexts. Hence, these decisions are made collaboratively and in consultation with numerous people, some of whom are spouses, children, grandparents-to-be, extended family, and family of choice, as well as professionals.

The value in understanding the lived experiences and the process of navigating decisions informs health care providers about how service to this population can be delivered within a supportive holistic context, while acknowledging the multiple challenges for parents and their families. It is also relevant and important to understand these personal factors as it informs the ongoing continuity of care; particularly the losses in the aftermath of ‘bad news’; decisions about future family planning and supportive care in subsequent pregnancies.

The previous study illuminated a facet that bears acknowledgment for shaping a fundamental assumption embedded in the researcher's worldview at the outset of this project - "Every reproductive event after a loss is shaped by the previous loss because the assumptions about normal pregnancy, childbirth and parenting are fundamentally altered" (Fernandez, 2008, p. 66).

Bridging disciplines – through interdisciplinary lenses

This study explores the experience of fetal anomalies from the theoretical perspective of five intersecting disciplines. Each of these disciplines provides a theoretical framework to illuminate a particular facet of this phenomenon. Taken together, it is the goal that this interdisciplinary richness expands the understandings that are possible by allowing the phenomenon to be examined from multiple viewpoints and disciplinary perspectives.

The rationale for an interdisciplinary approach stems from a clinical practice orientation. Specifically, the clinical reality of providing care for this population involves multi-disciplinary healthcare teams. Each profession is socialized to espouse particular values about knowledge claims. Although, there may be points of divergence, collectively as a healthcare team they are represented by multiple constructions of ontology, epistemology and theoretical views and language of discourse that collectively serve the needs of this population. Thus, the implicit scholarly goal of this research inquiry is that an interdisciplinary lens will better facilitate both the richness

of the inquiry as well as dissemination of knowledge construction and translation in a manner that resembles the clinical contexts for smoother knowledge translation.

There are five disciplinary perspectives:

A) *Counselling psychology/ social work* - for the understanding of the psychosocial factors that surround the individuals at the heart of their lived experience and the interplay of these factors as they relate to therapeutic relevance. In particular, the aspects that inform clinicians around interpersonal and familial factors of loss, risk, coping, healing, resilience and how people make sense of such crisis in their life-worlds.

B) *Thanatology* - which is the study of death and dying, life and living, and the existential dimensions in the processes of grief, bereavement, and healing.

C) *Reproductive Medicine* - as the forefront stage upon which these issues first come to be known, the site of intervention and precisely the cusp of the tensions between the advance of technological science and the limits of human life and reproduction. Maternal-Fetal medicine, a particular specialty within this discipline, contends with the dilemmas that arise at the cusp of the perinatal threshold, between the status of 'personhood' and the '*non-dum*' ('not- yet') personhood of the fetus and represent the dual interests of both the pregnant woman and the fetus as patients.

D) *Bioethics* – Such a topic is highly entrenched in ethical dilemmas. Hence, the perspective of bioethical theory is central and deeply woven throughout. Dilemmas in these contexts, while numerous, can be relegated to the tensions surrounding two key issues: the highly charged debate about personhood and competing rights of the

mother versus the fetus; and the tensions of advancing technology that push the limits of human reproduction to new frontiers of diagnosis and intervention, thereby pushing the limits at the cusp of the perinatal threshold. This then calls into question new examinations of what is possible and permissible in the threshold between pregnancy and birth. This arena will draw broadly from ethical theory, and feminist theoretical lenses to add a theoretical frame with which to appreciate the relevance and significance embedded in this discussion.

E) *Biopolitics* – Together with the ethical dilemmas, the social constructions of fetal health, the health promotion of the future generations layer some significant socio-political debates that center on managing the health of individuals and therefore, the health of the population. Although, a critical theoretical framework was not initially considered, the predominant themes of stigma and controversy that were recurring events in the early years of the research necessitated a theoretical framework within which to examine and appreciate the reasons and challenges of fetal anomalies.

The bridging of multiple lenses was not limited to theoretical or philosophical parameters; the inclusion and melding of these lenses was also significantly important for the methodological choices.

Operational definitions

This topic is fraught with political metanarratives that require some transparency about the intentions behind the choice of language and embedded

meaning of linguistic definitions. Given the interdisciplinary methodology of this research and collaboration, there is an open appreciation that certain words carry implicit assumptions in each discipline. The following clarification provides a conscious consideration of the assumptions made with the following words.

Parents -The word 'parents' is used purposefully, even though it can be argued that parenthood is likened to a goal attained upon the delivery of a living child. Pregnancy loss and reproductive losses as a whole are highly stigmatized in society, and these losses are often silenced, dismissed, and disenfranchised with the parents themselves marginalized. Disenfranchised loss is 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). The word 'parents' is used deliberately to acknowledge the existence of the life-form upon whom parents have placed wishes, hopes and dreams, a relationship, and the attachment to the 'child' that are recognized as losses, which then qualifies these individuals as bereaved parents/ expectant parents. With the intent of being inclusive of who is considered 'parent,' this definition will encompass the parties who identify themselves as the intended parents of the fetus, whether biologically related or not, as they are also actively invested in the decision-making process.

Patient/ Client - For the purpose of this paper, the working theoretical definition will be that the 'patient/client' is a collective entity consisting of the fetus and mother

as patient, for while the woman is pregnant she is both patient and expectant parent. The medical discipline utilizes this definition when providing care to pregnant women under the paradigm of maternal-fetal medicine. The words 'patient' and 'client' are used synonymously and interchangeably in this context to reflect the multi-disciplinary nature of teams, as some professions use the word 'patient' while others use 'client.'

The unborn – The words "fetus", "baby", "child" or "unborn child" are used collectively to reflect the essence of the unborn but conceived human life-form at any stage of gestation. Given the awareness that the choice of word is often central in debates about reproductive rights, ethics and feminist perspectives, these words collectively and albeit sometimes interchangeably reflect various perspectives – feminist rights, bioethics, medical professions, and the voice and identification of the expectant parents in how they view the unborn.

Family - The extension of this working definition consists of 'family' as defined by whomever the parents choose to consider within their understanding of who represents members of their family, whether the members are biologically related or a family of choice. Parents, both mothers and fathers, are potentially disenfranchised, by extension there also needs to be recognition of the losses and impact upon the family system - siblings, grandparents, aunts, uncles, and anyone else who may have invested and celebrated the anticipation of a relationship with the unborn child is also impacted. Even though this research is focused on parents, it is not meant to exclude the validity

of other's grief. Even professionals who work with these families often share in such grief with families.

Anomaly - Finally, the word 'anomaly' is used rather than 'birth defect,' 'abnormality,' or 'malformation.' While all these terms are synonymous in relating outcome, the long history of certain terminology to marginalize those that do not conform to societal perceptions of 'normal' has left a checkered and disturbing history. Thus, with particular awareness and sensitivity to the historicity of language, the term fetal anomaly is used. Specifically to create a distinction between the medical condition and the identification of the personhood of the fetus or parents if the condition is also genetic, as words such as defect, malformation, and abnormality tend to carry connotations that may imply blame, judgment, or which may be further stigmatizing, however unintentional. With this growing awareness, the term fetal anomaly has been more widely accepted as perhaps more neutral and more therapeutically sensitive in clinical work.

Fetal anomaly – Although congenital anomalies is the preferred term for citing population based epidemiological data, the term congenital anomalies represents all anomalies whether identified in the prenatal, neonatal periods or at a later time in lifespan of the individual. Since this particular research study is concerned with the identification of anomalies in the prenatal period the term 'fetal anomalies' will be

used instead to focus on those anomalies identified in the prenatal/fetal period through prenatal screening and ultrasound technologies.

Prenatal Screening- For the purposes of this dissertation, the term ‘prenatal screening’ is used to collectively include the various technologies used in ascertaining the status of health and the presence of fetal anomalies during the prenatal period. Although, each technology has a specific use and nuanced meaning, for the purposes of a common denominator when referring to these technologies, the umbrella term ‘prenatal screening’ is used. These technologies represent the standard routine prenatal care offered to women in Ontario (such as Ultrasound scans and blood based tests) as well as options that may be offered to those women with elevated risks (such as amniocentesis, MRI, 3D Ultrasound scans). As prototypical, prenatal screening in this paper could include some of the following technologies: Ultrasounds- regular and 3D; Nuchal translucency measurements; Integrated Prenatal Screening (IPS); Maternal Serum Screening (MSS); Chorionic Villus Sampling (CVS); Amniocentesis; Prenatal genetic testing/counseling and pre-implantation genetic diagnosis (PGD). The appendices provide a glossary for medical terminology (Appendix 1) and examples of fetal anomaly conditions (Appendix 2).

Organization of the dissertation

The dissertation is formatted in the integrated-article manuscript style. As such, each section represents a portion of understanding from either a particular theoretical

or a methodological framework. While no one section is an exhaustive analysis of the topic, together they bring together pieces of the puzzle. Following this introduction:

The first chapter provides a review of the literature on fetal anomalies that explores the existing knowledge base about the phenomenon, the scope and context of prior research investigations on this topic.

The second chapter provides the philosophical orientation and assumptions of the proposed methodology; the context and explicitly stated research questions; the rationale of the chosen methodology and an explication of the methods to be employed in carrying out the research.

The third chapter provides the results of the data inquiry process. The first section of this chapter provides an overview of clinical context and the researcher's observations and understanding of the scope of the phenomenon that informed the breadth of theoretical sampling. The second section of this chapter provides the analysis and resultant themes that arose from interviews with patient participants, and the discussion of these findings.

The fourth chapter discusses and applies a variety of theoretical views from thanatology and counseling psychology that offer explanations to some of the multi-layered facets of reproductive loss. This chapter examines what existing theory may offer as theoretical or conceptual explanations.

The fifth chapter of the dissertation examines, from a bio-political perspective, prenatal screening and diagnostic technology as a changing landscape with implications for ethical and sociological issues. Surrounding the metanarratives of reproduction,

concerns and critiques are raised at a philosophical level about the hopes and dilemmas that such technology manifests. The second section of this chapter considers the ethical dilemmas and provides a comparative framework to relate how professionals process and resolve ethical dilemmas codified by practice guidelines versus the value based moral reasoning of parents that require decision making to balance high emotional stakes.

The sixth chapter, in keeping with the spirit of qualitative research, is a critical reflection of the researcher's located/ situated awareness; the critical incidents and events that shaped the journey, and views of the researcher(s) and the ensuing methodological decisions.

The concluding section summarizes the conclusions of the research study and addresses the challenges and limitations of the project, the implications for clinicians, scholars and future research.

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Chapter 1: Review of the Literature

Significance of the topic and Prevalence of Fetal Anomalies

The concept of perinatal health surveillance is a population-based health promotion exercise to ascertain the health and vitality of the population. Beyond tracking the rates of births and deaths, perinatal surveillance programs also seek to ascertain the determinants of health and risk factors.

Historical and current fetal health surveillance programs

The Canadian Congenital Anomalies Surveillance System (CCASS) is a nationwide initiative established in 1966 in response to the thalidomide incidents around the world (Congenital Anomalies in Canada, 2002, p. vii). Thalidomide was, at the time of use, an unknown teratogen which resulted in physical congenital deformities of the limbs. Congenital anomalies, birth defects, and congenital malformations are synonymous terms used to describe an abnormality of structure, function, or metabolism that is present at birth, even if not diagnosed until later in life. (Canadian Perinatal Health Report, 2003, p. 100).

In 2010, the Congenital Anomalies Surveillance in Canada report identified 19 perinatal surveillance programs initiated across the country, representing one each in Newfoundland & Labrador, Prince Edward Island, New Brunswick, Quebec, Manitoba, Saskatchewan, Alberta, Yukon, Northwest Territories and Nunavut; two each in Nova Scotia and British Columbia; and five in Ontario.

In 2004, the Fetal Alert Network was established as in order to document the epidemiological context of fetal anomalies in Ontario, Canada, and as a fetal surveillance program, it reflects a province – wide representation of birth defects in Ontario including under-serviced areas such as communities in Northern Ontario. It was initially supported by the Ontario Ministry of Health and Long-term Care and the Hospital for Sick Children and Mount Sinai Hospital. Every major hospital center that has a way to identify fetal anomalies through testing or ultrasound was connected to this network (n =18 centers). The five, major hospital centers that have maternal-fetal medicine programs (London, Hamilton, Toronto, Kingston and Ottawa) are specialized centers. Their website (now de-activated) claimed to be “the first mandatory tracking & reporting system in Ontario to monitor the incidence, prevalence and outcomes for infants born with birth defects” (Fetal Alert Network, n.d., deactivate). The Fetal Alert Network, along with the other four Ontario perinatal surveillance programs, have since been incorporated under a new umbrella called BORN Ontario, which is housed at Ottawa’s Children’s Hospital of Eastern Ontario (CHEO) (Kim, Walker & Beduz, 2006; BORN Ontario (n.d.).

Trends and prevalence of fetal anomalies in Canada

The Congenital Anomalies Surveillance in Canada program, a division of the Public Health Agency of Canada, estimated in 2002 that, “Of the approximately 350,000 children born in Canada each year, most are born healthy and at term. However, 2%-3% of these babies are born with a serious congenital anomaly” (Congenital Anomalies

in Canada, 2002, pg. xi). The agency had also noted that the epidemiological prevalence indicated that 3% of those pregnancies did not necessarily stem from known family histories or other known systemic/ environmental risk factors for congenital anomalies. What they did establish was that, “infant mortality due to major congenital anomalies has decreased significantly in Canada, from 3.1 per 1,000 live births in 1981 to 1.9 per 1,000 live births in 1995.” (Congenital Anomalies in Canada, 2002, p. xi).

In their most recent publication of 2010, the prevalence of congenital anomalies (including live born and stillborn babies with at least one congenital anomaly) was 4.8%. This data was based on the results of a 2006-2007 survey of 16 responding programs that retain records of congenital anomalies. These programs or data sources were broadly categorized as: administrative databases; perinatal database programs; and fetal anomalies and congenital anomalies surveillance programs (Congenital Anomalies Surveillance in Canada, 2010, p. 3).

To put Canadian statistics on fetal anomalies into context within the global population, The World Health Organization (WHO) places the prevalence of congenital anomalies as 1 in 33 infants representing a global population of “3.2 million birth defect related disabilities every year” (WHO, 2012, No. 370). Of the 3.1 million neonatal deaths reported from 193 countries (data gathered in 2010), they estimate that approximately 270,000 infants die due to complications from congenital anomalies as

the underlying cause of death within the first 28 days of life/ birth (WHO, 2012, No. 370).

Limitations of fetal surveillance

The 2010 report (Congenital Anomalies Surveillance in Canada) also recognized the limitations of ascertaining data as each provincial or territorial region may have had different data recording practices. This lack of consistency in a standard format or even the minimum data variables for mandatory reporting represents a significant limitation to accurately identifying the trends and prevalence of fetal anomalies in the Canadian population.

By similar extension, ascertaining the risk factors has also been a challenge. In 2002, it was estimated that approximately “15%-25% are due to recognized genetic conditions reflected in chromosomal and single gene causes, 8%-12% to environmental factors such as maternal-related conditions, drug or chemical exposures, and 20%-25% to multifactorial inheritance, while the majority, 40%-60% of congenital anomalies, have unexplained causes” (Congenital Anomalies in Canada, 2002, p. xii). The World Health Organization places the proportion of unexplained causes as 50% (WHO, 2012, No. 370).

Of special significance is the fact that 40% to 60% of such conditions have unexplained causes, which has a profound impact on parents who need answers or are

left to wonder about the same risks in subsequent pregnancies. In 2010, the Canadian Congenital Anomalies Surveillance in Canada report listed the following risk factors: maternal age, maternal obesity, pre-pregnancy diabetes and those conceived through Assisted Human Reproduction Technologies (ART) although the etiology could not be established (pp. 4-6). At the same time, primary intervention efforts have been credited for the reduction in neural tube defects, particularly the introduction of foods fortified with folic acid (Congenital anomalies in Canada, 2010, pp. 4-6) with the 2008 Canadian Perinatal Health Report citing a 42% decrease in anomalies involving neural tube defects (p. 54).

Nevertheless, major congenital anomalies remain a leading cause of death among Canadian infants in both the neonatal and post neonatal periods (Congenital Anomalies in Canada, 2002, pg. xi). Although, early prenatal screening and treatment innovations have increased the life expectancy for some conditions (which several decades earlier had a dramatically poorer prognosis), the 2010 report of the Congenital Anomalies in Canada now has a broader definition of health that the presence of congenital anomalies represents a “first chronic disease,” and thus calls for an appreciation of the conditions of health or illness that become defining as early as the prenatal period. (p. 4)

One of the primary challenges in adopting the framework of prevalence is the potentially misleading idea that such anomalies are uniformly prevalent conditions.

Some conditions receive more attention in the public media or through advocacy. They, therefore, may seem more prevalent. Other conditions are more actively screened and can be diagnosed through sensitive testing, and, thus a better idea of prevalence will be determined. Some conditions such as Down's syndrome are prevalent in 1 out of 800 live births (Congenital Anomalies in Canada, 2002, p. 1), whereas other conditions, such as anencephaly, may be quite rare. For example, the report *Congenital Anomalies in Canada* (2002) indicated that "In 1999 in Canada (excluding Nova Scotia), the birth prevalence of anencephaly was 0.9 per 10,000 total births or 31 cases" (p. 8).

Another consideration related to rates of prevalence is the influence of early prenatal screening and diagnostic technology. The increasing technological innovations are a potentially significant confounding factor in assessing population-based perinatal health outcomes. In particular, early identification of congenital anomalies through prenatal screening allows for decisions regarding continuing or terminating the pregnancy prior to the border of viability. In Canada, the registration of stillbirths included all fetal deaths greater or equal to 500 grams or with a gestational age greater or equal to 20 weeks gestation (Canadian Perinatal Health Report, 2008, p. 11).

The Canadian Perinatal Health Report (2008) defines the borderline of viability fetal weight at 500grams. Live births at this borderline of viability (<500g) increased from 4.1 per 10,000 in 1985 to 12.4 per 10,000 in 2003 (p. 10). The obvious implications of increased risk of infant mortality at this gestational age & weight also factor into the trends. In similar comparison for the same time period (1985 vs. 2003), the rates of

stillbirths (<500g) also increased from 12.8% of all stillbirths in 1985 to 29.4% in 2003. The report further specifies that stillbirth due to congenital anomalies or pregnancy termination represented 11.6% of all stillbirths in 1985 as compared to 40.4% of all stillbirths in 2003.

Just as the 2010 Congenital Anomalies in Canada report identified inconsistencies in reporting practices for surveillance of anomalies, the Canadian Perinatal Health Report (2008) also noted that the cause of death was not always clearly reported, as to whether it was due to pregnancy termination or congenital anomalies.

“ Note the change in the cause of death coding of stillbirths <500 g that (presumably) resulted from pregnancy termination following prenatal diagnosis—from the mid-1990s onwards, such deaths have been increasingly assigned pregnancy termination as the cause of death, rather than congenital anomaly” (Canadian Perinatal Health Report, 2008, p. 11).

Indeed, there may be some pregnancies that these are discrete causes of death but it could also represent subsets wherein the deaths resulted from a decision to terminate for reasons related to the anomalies – lethal and non-lethal conditions; the lethality of the congenital anomaly, itself, or wherein the congenital anomaly was not identified prior to death.

Prenatal Testing & Screening

As technological advancements and knowledge regarding genomics progresses, it is increasingly possible to identify fetal/ congenital anomalies earlier in gestation with greater detail regarding diagnoses and prognostic outcomes. However, the process of diagnosing anomalies remains a complex process replete with uncertainty for parents.

At the outset of this research study, the initial question that differentiated this study from my previous research on perinatal loss was an attempt to understand the unique phenomenon of loss or grief due to fetal anomalies as distinct from other reproductive losses. However, before that question could be considered, an understanding of the concepts and medical contexts was required. Hence the two initial guiding questions that lay the foundation for the cohesion of the subsequent 'research questions' were: what are fetal anomalies? And how do we know an anomalous fetal condition exists?

Prenatal screening as a method of ascertaining risks and probabilities of such anomalies became identified through observation and consultation with medical colleagues as the logical starting point. This section explores some of the normative prenatal screening methods afforded to parents in Canada. However, as a caveat, these are basic understandings to situate the context and terminology of the phenomenon rather than a technical critique of specific methods of screening; limited by my non-medical training.

Defining Prenatal Screening

'Prenatal' is defined as the period of pregnancy until birth (Alderson et al. 2001) and the Society of Obstetricians and Gynecologists of Canada (SOGC) provides the following definition for (prenatal) screening:

"Screening is the process of surveying a population, using a specific marker or markers and defined screening cut-off levels, to identify the individuals in the population at higher risk for a particular disorder. Screening is applicable to a population; diagnosis is applied at the individual patient level" (Cuckle & Wald, 2000 as cited in Summers, Langlois, Wyatt & Wilson, 2007, p. 147)

Although commonly referred to as 'prenatal screening' reflecting the umbrella term, Alderson et al. (2001) further distinguish the terminology of 'genetic screening', 'prenatal screening', 'prenatal scanning' and 'prenatal testing'. They elaborate that while 'genetic screening' is specific to heritable conditions, 'prenatal screening' is:

"The systematic search for a specific condition among a large, asymptomatic subpopulation selected by demographic characteristics such as age, sex or ethnicity. Screening typically identifies at-risk groups for further diagnostic testing." (p. 232)

Alderson, et al. (2001) propose that Ultrasounds although often referred to as a screening method should be considered as a testing method. "The process of scanning would classify it as screening, but the outcomes of scanning would often classify it as testing" (p. 232). The conceptual distinction of prenatal testing or diagnosis as opposed to screening or scanning appears to be demarcated by the level of invasiveness and

iatrogenic risks, therefore 'prenatal testing' such as amniocentesis and chorionic villus sampling (CVS) may be viewed a diagnostic method and due to its level of invasiveness and risks for fetal loss and therefore should be reserved for those whom initial screening identifies to be at 'higher risk' (Alderson et al, 2001; Trent, 1995).

Although now viewed in some wealthier nations as 'routine' prenatal care and public health practices, the underlying aim of prenatal screening and testing is ultimately to mitigate the risks of 'high risk pregnancy' and the 'health of fetuses' through the identification of fetal anomalies, congenital birth defects and maternal complications that pose a threat to maternal and infant mortality (Arulkumaran, Sivanesaratnam, Chatterjee & Kumar, 2004; Trent, 1995; WHO, 2012, no. 370; Nisker, Baylis, Karpin, McLeod & Mykitiuk, 2010; Summers, et al., 2007; Chitayat, Langlois, & Wilson, 2011).

Considerations for the use of screening or testing methods are determined by the safety of the diagnostic tests for mother and fetus; effectiveness of the testing method as determined by the *sensitivity* and *specificity*; the ability to accurately identify the probabilities of risk for a given condition; while balancing the risks of invasive methods that may contribute to miscarriage or fetal death, infection or other complications for mother and fetus; including anxiety induced by testing, uncertainty or inaccurate testing results known as 'false positives' and 'false negatives'. Further considerations may also take into account known family history of heritable genetic conditions, consanguinity, previous recurrent pregnancy losses, or previous

pregnancies where a fetal anomaly or congenital birth defect was identified, and advanced maternal age of 35 years or older (WHO, 2012, no. 370; Alderson et al., 2001; Anderson & Brown, 2009; Cartier & Murphy-Kaulbeck, 2012; Summers, et al., 2007); Trent, 1995)

Typical procedures & timelines

Table 1: Prenatal Screening

| Procedure/ Diagnostic Test | Test time (gestation age-weeks) | Timing (results - weeks) | Invasive | Iatrogenic risks | Detection rate (D) False positives (FP) (normed Trisomy 21) | Cut off risk probability |
|--|--|--|---|--|--|---|
| CVS | 11-13 weeks ^a | 13-15 weeks ^a | Invasive (placental) | 1/100 ^e 5% (fetal loss – natural +test risk) ^b (miscarriage, fetal injury, spotting, infection) ^b | D- 97.8% ^g FP- 1-2% ^g | |
| Amniocentesis | 15-22 weeks ^a | 17-24 weeks ^a | Invasive (amniotic fluid) | 1/200 ^b 1/100 – 1/175 ^e 3.5% (natural + test risk) ^b (miscarriage, amniotic fluid leak, spotting, cramping, infection & fetal injury) ^b | D- 99.4% ^g FP- 0.1-0.6% ^g | |
| Integrated Prenatal Screening (IPS) - 1 st blood sample - NT ultrasound - 2 nd blood sample | 11-14 weeks ^a 11-14 weeks ^a 15-20 weeks ^a | 16-21 weeks ^a | Minimal (blood sampling) Non-invasive (Ultrasound) | N/A | D - 85-90% ^a D- 87% ^{c,d,e} D- 90% ^f D- 94-96% ^g FP- 2-4% ^a FP – 1.9% ^{c,d,e} FP- 5% ^f FP- less than 3-5% ^g | 1/200 ^{c,d,e} T21: 1/200 ^b T 13 & T18: 1/100 ^b |
| Serum Integrated Prenatal Screening (SIPS) - 1 st blood sample - 2 nd blood sample | 11-14 weeks ^a 15-20 weeks ^a | 16-21 weeks ^a | Minimal (blood sampling) | N/A | D- 80-90% ^a D- 85% ^{c,d,e} D- 85-88% ^g FP - 2-7% ^a FP- 4.4% ^{c,d,e} FP- less than 3-5% ^g | 1/200 ^{c,d,e} |
| Ultrasound - Dating - NT - anatomy | 6-10 11-14 16-20 | Local timelines (immediate-few weeks) | Non-invasive | N/A | NT D- ~80% ^f NT D – 70-71% ^g NT FP- 5% ^f NT FP- 3.5-5% ^g | |

Referenced sources in Table:

^a Prenatal screening Ontario; ^b Mount Sinai Hospital Toronto; ^c SOGC 2007; ^d SOGC 2011; ^e SOGC 2012; ^f Arulkumaran, Sivanesaratnam, Chatterjee & Kumar, 2004 ; ^g Anderson & Brown 2009

Non-invasive testing methods

In an attempt to provide earlier testing in pregnancy and to mitigate the risk of more invasive testing, the concept of Maternal Serum Screening (MSS) and Multiple Marker Screening (MMS) “uses a combination of maternal age and two or more biochemical tests, with or without an ultrasound examination, to produce a single result for risk of Down syndrome, trisomy 18, and ONTDs” (open neural tube defects) (Summers, et al., 2007; Chitayat, Langlois, & Wilson, 2011; Cartier & Murphy-Kaulbeck, 2012)

IPS and SIPS - In terms of routine non-invasive screening, the first blood test based screening combined with early first trimester ultrasound scanning, commonly referred to in Ontario Canada as the Integrated Prenatal Screening (IPS) or Serum Integrated Prenatal Screening (SIPS) is possible at approximately 11 to 14 weeks gestation. Assuming that there has been no medical need for ultrasound prior to this point, this is also the usual time that a first brief ultrasound is done to check the gestational age, fetal size from a crown-rump measurement and to check the Nuchal Translucency (NT), which is the skin fold at the back of the fetal neck (as cited in Congenital Anomalies in Canada, 2002, pg. 38).

Anatomical Ultrasound Scan - Between 15 to 17 weeks gestation, additional blood test based screening is conducted. Between 16 to 20 weeks gestation the first detailed anatomical ultrasound is conducted. This ultrasound carefully examines and records measurements for fetal growth, nuchal translucency, amounts of amniotic fluid

and specific details of every organ, limb and basic bodily functions such as swallowing and discharge, movements etc. (Fetal Alert Network, n.d., de-activate). The detailed ultrasound scan at approximately 16-20 weeks gestation provides visualization of the fetal organs (specific to millimeters) and checks for the presence of 'soft markers' which highlight a pattern or constellation of anomalous signs and symptoms that aid in diagnostic and prognostic conclusions (Twining, McHugo, & Pilling, 2007). In medical communities with specialist Maternal Fetal Medicine programs, additional diagnostic methods such as fetal echocardiography, fetal Doppler, and MRI may also be employed to aid in diagnosis where fetal anomalies are suspected.

Invasive testing methods

Invasive prenatal testing involves entering the uterus which carries with it a risk of miscarriage/ fetal death or injury that must be weighed against the other risk factors, testing results and potential benefits. Chorionic Villus Sampling (CVS) is the earliest genetic test of the fetus and can be done as early as the 10th week of gestation. Amniocentesis can be done as early as the 16th week of gestation. Although amniocentesis boasts a significantly high risk of accuracy, the risk of losing the pregnancy is often quoted by clinicians as 1/100 to 1/200 usually resulting from pre-term labour (Cartier & Murphy-Kaulbeck, 2012; Mount Sinai hospital, n.d.). The risks to the fetus include the possibility of injury and fetal death/ spontaneous pregnancy loss due to the nature of testing that punctures the amniotic sac. Additional maternal risks may also include leaking amniotic fluid, the risks for infection, bleeding, and cramping

(Cartier & Murphy-Kaulbeck, 2012; Mount Sinai hospital, n.d.). Furthermore, because fetal viability at 16 weeks gestation leaves poor prognosis for fetal survival physicians balance the other testing results (risk probabilities) against the odds of fetal death or pre-term complications due to invasive methods when they counsel parents. Arguably, the decision whether to pursue invasive testing is a difficult one to make. The clinical practice guidelines from the Society of Obstetricians and Gynecologists of Canada (SOGC) now strongly advise against invasive testing procedures except where there is an elevated risk for aneuploidy (chromosomal abnormality) as established by MMS results; ultrasound; conception using in vitro fertilization with intracytoplasmic sperm injection; or where there is a known history of genetic familial risk or previous pregnancy involving fetal anomalies (Chitayat, Langlois, & Wilson, 2011).

Genetic counseling

Although not a testing method per se, in addition to prenatal screening and testing, there are options for couples to have preconception genetic testing where they have known familial risks for heritable diseases or for couples who have previous pregnancies/ children with congenital anomalies. Preconception genetic counseling may also be considered for women of advanced maternal age (over 35) who wish to consider their age related risks for conditions such as Down's syndrome (Congenital Anomalies in Canada, 2002, p. 36; Anderson & Brown, 2009).

Criticisms of Prenatal Screening

Psychological factor – “Some women reject screening in order to avoid the psychosocial and medical risks associated with higher risk status, or because they rule out pregnancy termination” as an option for personal reasons (Heyman, Hundt, Sandall, Spencer, Williams, Grieller & Pitson, 2006, p. 2). The study by Heyman et al. (2006) examined the reactions to being placed at higher risk, identifying that such placement is viewed as a ‘probability of risk’ rather than stated as a ‘diagnosis’. Although these results of probability odds was intended as precautionary to enable informed choices about decision-making, it appeared to also be associated with distress that was not easily dismissed even after chromosomal anomalies were ruled out (Heyman et al, 2006). Maternal/ parental anxiety or distress induced by testing should arguably be balanced as a potential psychological factor that needs to be taken into consideration along with other physical risk factors.

Implicit assumptions – There is a concern cited in the literature that the implicit assumptions about what tests can or cannot reveal are not always readily understood by the general public, the majority of who do not have medical training. The rapid technological advancements in the field of genomics also means that current diagnostic methods may not have existed in the same format in previous decades or generations and hence even anecdotal experiential knowledge for public consumption is limited.

Finally, the question of how the risk probabilities are understood and interpreted by parents, more specifically what such numbers mean to parents who are

considering the evaluation of the well-being of their child and child's lifespan are inadequately addressed in the literature. Some scholars have raised debate that arguably, without adequate information about what living with a given condition would look like on a daily basis, women and parents, might be presented with these probability risks in such a way that highlights either questionable viability, a life of disability, foreshortened life, or a picture of medical fragility defined by single traits; or a choice between termination or continuation of pregnancy (Lippman, 1993 as cited in Nisker et al., 2010; Nisker, 2010; Asch & Wasserman, 2010; Alderson et al. 2001; Rapp, 2000; Rothschild, 2005; Parens & Asch, 2000; Heyman et al. (2006)

“Assumptions that genetics means Mendelian heritance patterns can increase fears misleadingly: i) into worries about a kind of family infection or inadequacy, ii) into guilt when parents feel they should somehow predict and prevent affected births and iii) into an implied or explicit overemphasis on biological determinism which can undermine confidence in human agency and social opportunities.” (Alderson et al., 2001, p. 232)

Recommendations

SOGC (2012) recommends that physicians and genetic counsellors include in their discussions with patients clear information about what conditions are able to be screened for with accuracy and reliability by explaining in common language, aspects such as detection rates, false positives, and false negatives and that a 'screen positive' represents a probability cut off rather than a conclusive verdict (Cartier & Murphy-

Kaulbeck, 2012). Furthermore, health care providers should aim to use “non-directive” language and “show respect for the needs and quality of life of persons with disabilities”, and support for informed choices including the decisions to pursue or decline testing (Summers, et al., 2007).

Even the most tentative suspicions change the reality of what it means to have a perfect and healthy child. This is often the first loss in a series of losses to follow for parents facing a suspected fetal anomaly are the loss of the idealized ‘perfect child’ and the loss of a ‘healthy pregnancy’.

Initial review on fetal anomalies

In keeping with Grounded Theory methodology, the literature review has been ongoing in response to questions following the data trail of the previous study and emerging questions and themes directed from observational clues in the field.

Grief & coping following a fetal anomaly diagnosis

Following logically from the previous study (Fernandez, Harris, Leschied, 2011), an initial consideration for review of the literature centered on bereavement and coping responses following fetal anomalies as that is my professional background. As is frequently the focus in the professional and clinical practice literature, the initial review yielded outcome based analysis of coping and were heavily inclined to viewing the loss as a psychological morbidity. Conversations with clinicians in the field also supported this view and focus – they wanted to know which patients would cope better with ‘bad news’; which treatment options would induce less distress or shorter/lesser periods of acute grieving; and which patients based on the treatment options would be less likely to regret their decisions. Quite reasonably, clinicians who write academic papers on these topics are seeking to answer question directly related to the context of providing care.

Comparison to miscarriage - One study compared the grief of women who had experienced miscarriage and those who had terminated pregnancy for fetal anomalies, and while the study had hypothesized a difference in the existence of a grief reaction, in both sets of circumstances, the loss of a wanted pregnancy produced grief reactions

without a significant difference in 'grief scores' (Keefe-Cooperman, 2005). The two groups were compared on three dimensions: the loss of biological self-esteem; the loss of social self-esteem and the loss of moral self-esteem. With regards to moral self-esteem that impact was, "The woman is aware of her own decision to end her child's life, which may result in guilt. Although, women in either group may have felt guilt, or feelings of responsibility the distinction about the ambiguity or certainty of the cause of death was noted, as termination being associated with the additional burden of guilt. However, those who viewed themselves as somehow 'responsible' either by having to make an active decision to terminate the pregnancy or a more passive reason such as stress, working too hard or not taking vitamins tended to show grief scores indicative of higher levels of grief and distress (Keefe-Cooperman, 2005). Since the hypothesis had failed to provide a conclusive comparative difference in outcomes, they compared the factors contributing to grief yielding six factors for perinatal loss: time since the most recent loss; intervention of counseling; employment outside the home; feeling responsible for the perinatal loss; age of the mother as related to guilt; and gestational length of pregnancy as representing a longer duration for attachment (Keefe-Cooperman, 2005).

Influence of time on grief & coping – Other studies, treated the passage of time as the determining variable in grief outcomes (Korenromp et al., 2007; Korenromp et al., 2009; Korenromp et al., 2005; Kersting et al., 2005; Geerinck-Vercammen & Kanhai (2003)

Korenromp et al. (2005) was among very few studies that factors the experiences of fathers. However, as they had intended to compare the reactions and concordance for both sexes 2-7 years after termination for fetal anomalies, they also excluded 23% of the women from the analysis whose partners did not also participate. Both the proportion of the excluded sample and the results may consequently be skewed in the perception of response rates for men and women in perinatal loss studies. Of the 151 included couples in the analyzed sample, 38 were terminations by Dilation & Evacuation, 112 were Induction of Labour and 1 selective reduction. They concluded that both men & women viewed termination of pregnancy as a psychologically traumatic event and loss, with women showing higher scores on psychological factors and post-traumatic stress although noting that couples tended not to show pathological outcomes simultaneously. They theorized that higher education, good partner support, earlier gestational age, and life-incompatibility of the disorder positively influenced the outcomes, more for women than for men (Korenromp et al., 2005).

Korenromp et al. (2007) conducted a similar study prospectively at 4 months post-termination. Similar to Korenromp et al. (2005) this study predictably showed elevated post-traumatic stress and depression for women as compared to men. They concluded that the following factors influenced adverse outcomes: high level of doubt in the decision period, inadequate partner support, low self-efficacy, and lower parental age, being religious, and advanced gestational age (Korenromp et al., 2007). Interestingly, the type of anomaly did not feature as a cause of distress, regret or

future pregnancies plans, however religious orientation were found to provoke some significance for psychological outcomes Korenromp et al. (2007).

Korenromp et al. (2009) included only women in their longitudinal study evaluating psychological outcomes at 4, 8 and 16 months post termination for fetal anomaly showing a corresponding decrease with the passage of time for post-traumatic distress and depression. Similar to Korenromp et al. (2005) and Korenromp et al. (2009), they found that the predictors were low self-efficacy, high level of doubt during decision making, lack of partner support, being religious, and advanced gestational age (Korenromp et al., 2009). Kersting et al. (2005) similarly supported the conclusion of post-traumatic distress following termination further citing that in their longitudinal study extending 2-7 post loss that in their conclusion “reveals a degree of enduring posttraumatic stress response which is still detectable several years after the event and underlines the severity of the trauma induced in a woman by TOP due to fetal malformation” (p. 12), and in particular, the sequelae of events – unexpected diagnosis, having to make a decision, waiting for labour pains and delivery of a dead fetus to be complicit in the traumatic response induced.

Geerinck-Vercammen & Kanhai (2003) explored coping after termination of pregnancy for a fetal anomaly. 89 couples participated in semi-structured interviews at 3 intervals: prior to delivery, at 6 weeks and 6 months after termination of the pregnancy. Though not explicitly stated, it would seem that these terminations involved Early Induction of Labour. This assumption is made based on the discussion of parents viewing the baby and taking photographs and so on. In a surgical termination

such as Dilation and Evacuation, these aspects would not be an option due to the nature of the procedure. The viewing of the baby's body similarly to a traditional funeral rite, and in particular, being able to witness visible confirmation of the anomalies may be thought to provide validation of the decision. This study is important for the exploration of the experience of couples. Often the focus in this research is on the pregnant woman and the medical context where feelings of doubt, guilt, failure, shame, anger, anxiety, and relief are experienced. Women were noted to score higher on these indices. For couples in general, these characteristics for the period during the first 6 weeks were elevated. Recommendations following from this research included practical directions for professional care providers including the determination for psychosocial bereavement care.

Provision of health services for fetal anomalies

Lalor, Devane, Begley (2007) interviewed thirty eight women who were determined to be at low risk for a fetal abnormality, and who received a diagnosis of a fetal abnormality in a tertiary referral center in Ireland. Because these women were considered low risk, they had anticipated the ultrasound positively, only to be then receiving an unexpected diagnosis of fetal anomaly. In the interactions with healthcare providers six categories in relation to women's encounters emerged: information sharing, timing of referral, getting to see the expert, describing the anomaly, availability of written information, and continuity of caregiver. Once an anomaly was suspected, women wanted information quickly, including prompt referral to the fetal medicine

specialist for confirmation of the diagnosis. These women preferred visual images to aid in the explanations rather than percentile charts and supplementary written information, which were viewed as essential to enhancing an understanding of significant information. Continuity of a caregiver and empathy from staff were valued strongly as fostering a trusting relationship. In comparison to women who are initially screened through prenatal testing as 'high risk' (Heyman et al., 2006) and experiencing high anxiety at the unconfirmed suspicions these women encounter a crisis or traumatic acuity without prior warning. Lalor, Devane, Begley (2007) highlight that particular dissatisfaction was related to communication from healthcare providers: the level of information disclosed, the dismissal or ignoring of patient's questions by the ultrasound technician and waiting without answers for a referral to a specialist. However, the demonstration and validation of supportive gestures such as taking the time to phone, continuity of care and the use of simple non-jargon language aided with visual communication was indicated in the study as especially helpful.

Chitty, Barnes, & Berry, (1996) interviewed five couples for their recommendations about the delivery of service for couples experiencing fetal anomalies. They indicated that options for the continuation and termination of pregnancy should be presented such that: couples can decide together; that the bad news be given personally and sensitively; patients are seen for regular antenatal clinic hours; separate areas are provided within antenatal and post-natal wards such that couples are not confronted with other normal deliveries; there should be training programs for professionals regarding how to deliver such news and provide care in a

sensitive manner; provision of formal counseling facilities; and continuity of care be maintained by a senior doctor and midwife with communication to the general practitioner.

Decision-making factors

This aspect was especially lacking in information, and in particular an absence of focus on generalizable factors and the factors related to the emotional and lived experiences. McCoyd's (2008) study was one of the very few explorations into understanding the factors that contribute to the decision making regarding termination of a pregnancy involving fetal anomalies. The title of the article, "I'm not a saint" was actually a code drawn from a theme from the qualitative analysis. The study involved 30 women with desired pregnancies that would not have been terminated but for the presence of an anomaly. The issues identified from McCoyd's study that are pertinent are: fears of social ostracism for a child with a disability; financial and resource limitations; the impact on marriage, family roles and other children; self-assessment of personal limitations to raise and parent a child with an anomaly. The process is both reflective of rational choice and emotional decision making. Schechtman et al. (2002) found that when a fetal diagnosis included a cognitive impairment, parents were 90% more likely to terminate the pregnancy for the same level of life threat than when there was no cognitive impairment predicted (as cited in McCoyd, 2008).

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Chapter 2: Methodology

Background & Purpose

A preliminary literature review was conducted following the closer examination of this data that hinted at fetal anomalies as a qualitatively unique typology of reproductive/pregnancy loss. The preliminary literature review illuminated the divergent breadth of the topic that spanned the interdisciplinary boundaries of thanatology, psychology, sociology, biopolitics, and bioethics in addition to the traditional forum of reproductive medicine.

Beyond the biomedical sciences that focused on the etiology of fetal anomalies and best practice guidelines for medical management of pregnancies complicated by fetal anomalies, the review illuminated that this topic was highly charged with ethical concerns and metanarratives about the beginnings and ends of life within the politics concerning the abortion debate and euthanasia. Further review of the literature indicated that the scope of the phenomenon was not limited to metanarratives of abortion and euthanasia, but rather a proverbial minefield of social and ethical concerns ranging broadly from debates on status of personhood, feticide, deformity, disability rights, eugenics, concerns about reproductive technologies, genetic selectivity, genetic privacy, prenatal screening practice to environmental and toxicological concerns among others. Despite the breadth of concerns and controversy, however, the private lived experience and how parents wrestle with various factors to arrive at decisions regarding the pregnancy remains obscure, with little research to

date to form consensus about the private experiences of parents and their moral decision-making processes.

In the absence of elucidating what transpires between delivering a diagnosis and the subsequent appointment when a clear decision has been made, clinicians in practice are left to hypothesize, based on their clinical interactions and various assumptions, about medical and social determinants of health. In an age where health care accountability places strong emphasis on 'evidence-based practice,' these assumptions bear critical consideration. Furthermore, if the healthcare system is to adequately address the bio-psycho-social needs of parents facing a diagnosis of fetal anomalies, an in-depth understanding about the multitude of factors and reasons that shape parental deliberation, both the private and the articulated sentiments and decisions, are essential for developing a comprehensive needs based assessment of services.

Hence the initial question beginning this inquiry concerned the lived experience of parents who face a pregnancy complicated by a prenatal diagnosis of a fetal anomaly. In order to understand the phenomenon from the parents' perspective- how they identify their concerns and attempt to reconcile the reality of the diagnosis with their existential and practical realities of daily life. Thus, the *emic* or insider's point of view of the phenomenon was of central value, (Carpenter & Suto, 2008; Neimeyer, 2009), with particular focus on understanding the meanings ascribed by parents.

Gelwick (1977) suggests that “scientific inquiry begins with the sighting of a good problem” (p. 88). The construct of what qualifies this inquiry as a ‘good problem’ is an acknowledgement of the scientific gap that the inquiry seeks to address with particular attention to the implications and potential of the findings to serve both clinical practice and a humanistic appreciation of the ethical dilemma that parents face in an age of advancing reproductive technologies.

Philosophical orientation

The interviews in the prior study hinted at a complex set of connections between the private reality and the social situations but did not provide direction about the subsets specific to the fetal anomaly phenomenon to further direct the inquiry.

Clinicians who attend to this population are required to exercise their expertise towards providing care. In the scientific gaps clinicians draw on a different schema of knowledge – clinically informed knowledge or practice knowledge that is attuned by the reflective practitioner. The assumptions made by clinicians represent propositional or practice- oriented knowledge (Schein, 1987; Carpenter & Suto, 2008, p. 27) and represent a dimension of knowing.

However, from a constructivist orientation, one might acknowledge that although this represents the professional lens, this lens perspective informs ‘a way’ of knowing among multiple perspectives. A caution is raised that it would be a leap to

draw generalized conclusions about the lived reality of parents and the interpretations they may construct without considering the context.

“As everyone knows, different people in different positions may offer as ‘the facts’ very different information about the same subject, and they vary that information considerably when talking to different people. ... Some sociologists see these circumstances as presenting an unbounding relativism of facts –no data is accurate. ... But when different slices of data are submitted to comparative analysis, the result is not unbounding relativism. Instead, it is a proportioned view of the evidence, since, during comparison, biases of particular people and methods tend to reconcile themselves as the analyst discovers the underlying causes of variation” (Glaser & Strauss, 1967, pp. 67-68)

Thus, embedded within the philosophical position of Glaser & Strauss’ Grounded Theory, is an ontological view that ‘reality’ can be relativist but that it also can be ‘discovered’ through careful methodical examination. Michael Foucault’s (1975) text, *‘Birth of the Clinic: An archaeology of medical of medical perception’* illustrates how the botanical model, the mathematical model, as well as the clinical gaze, hold implicitly the premise of a ‘discoverable reality.’ The idea of a ‘discoverable reality’ that moves towards a more relativist position than objectivist realism is an interesting tension that brings together the phenomenological constructions of worldview that impacts upon an observable reality that exists independently from the minds of the individuals.

Regarding the question of how we begin to uncover a discoverable relativist reality, Gelwick (1977) examines Michael Polanyi's suggestion that "scientific inquiry begins with '*anticipatory intuition*'. This anticipatory intuition is a subsidiary awareness of hidden aspects of reality that prompts our imagination to look in a new direction" (p. 88). He explains that Polanyi's theory of scientific discovery, drawing clues from Gestalt psychology, claims that the process of inquiry and the resulting theory is in essence a matter of "integration of certain bits in our perception to form a whole. ... where the researcher is engaged in the problem of trying to find coherence of various pieces of information" (p. 26). The ability to make these connections may not always be explicit but rather tacit knowing. Gelwick (1977) explains that Polanyi's theory of the Tacit Dimension involves the ability to integrate our awareness contexts going back and forth from attending to the clues and attempting to integrate them towards approximating a coherent meaning (p. 55-77, 89).

In the absence of clear understanding about why and how parents make decisions about fetal anomalies, clinicians attend to clues provided within the therapeutic relationships with their patients and attempt to construct propositional or tacit knowledge to guide their clinical practice. Foucault's theory of the clinical gaze (1975) further examines how clinically informed practice knowledge attempts to bridge the gaps by employing the tools of observation, perceptual skills of the clinician,

the botanical model, and the mathematical model towards codifying, classification, and deciphering phenomenon.

Between Polanyi's theories, Foucault's theory of the clinical gaze and Schon's theory of the reflective practitioner we have a model addressing how clinicians make clinically informed decisions about the care of their patients but it does not represent the emic view of the parents. Most significantly, that the parents are making highly emotionally invested decisions. Secondly, unlike clinicians, they (parents) quite often do not have exposure to others in similar circumstances and hence do not have an experiential knowledge in the same way that clinicians experience within their caseloads.

This study attempted to fit within the gap between parents' lived reality, and a health-care providers' practice knowledge in an attempt to draw out in a systematic fashion the clues put forth from the experiential world of the parents and the clues that illuminate the attempts of clinicians to interpret these clues actively or tacitly. While the details remain at the level of tacit awareness, the question about congruence between 'a lived reality' for the parents and 'interpretation' remained difficult to establish and assumptions prevailed without a critical examination of therapeutic fit. For this study, the aim was to explicate both the processes and the details of the experience. Van Manen (1997) notes that the relevant details are in the rich descriptive characteristics of the phenomenon and ascertaining the meaning therein (p. 38). It is

important to show the phenomenon within awareness contexts, such as the universal characteristics, the flow and patterns within the dynamic nature of human relationships and thus the points of divergence and convergence, such as in Glaser & Strauss' seminal work, *The 'Awareness of Dying'*, (1965). "To say what one sees; but also a use involving the foundation and constitution of experience – showing by saying what one sees" (Foucault, 1975, p. 196). Thus, the goal was to make explicit the tacit clues and processes within the parents' experiences and the therapeutic context. In particular, attention to the processes and decisions surrounding prenatal screening, medical decisions, practical, personal and value based decisions that are navigated and negotiated between medical staff and parents and between parents as a family unit.

Methodology choice

Given the dearth of existing knowledge and the personal, emotional nature of the research problem, an inductive qualitative methodology was proposed.

"Knowledge development using inductive approaches begins with the specific, observing particular people in context, and ends with descriptions and concepts that generate new social theories or contribute to and refine existing ones" (Carpenter & Suto, 2008, p. 26).

The methodology for the current study followed within the Grounded Theory tradition to begin with the data itself (Glaser & Strauss, 1967; Glaser, 1978; Charmaz, 2006; Corbin & Strauss, 2008). As with the broad conceptualization of

phenomenological research, the inquiry “begins in the lifeworld” as per Husserl’s edict that engagement must be “original, pre-reflective, pre-theoretical attitude” in open awareness without the imposition of presuppositions and unreflected assumptions (as cited in van Manen, 1997, p. 7, 46-47)

The identification of phenomenon begins the inquiry of the research situation to be explored, rather than through abstracted a priori variables (van Manen, 1997). Quite simply, the relational emotional nature of the topic begged for an appreciation of the subjective awareness contexts enmeshed in the phenomenon in ways that a quantitative view could not feasibly illuminate. An objectivist design required identification of variables that were as yet not fully known or limited by presuppositions. Furthermore, an objectivist design by its methodological rigour demands that the researcher(s) exercise a degree of control over the phenomenon under investigation. It is not only unrealistic for this topic, but proposing a research design where the researcher(s) have any say about what the decision should be, would have been both counterintuitive to the aims of inquiry and highly unethical.

From an ontological position, this study valued a relativist position and multiple constructions of reality and diverse interpretations. This study aligned with the philosophical orientation that assumed that the answers to the research situation may be enriched by considering this context from multiple perspectives (Guba & Lincoln, 1994, p. 106-111).

In the course of engagement with this topic, the particular philosophical lens had been refined as being situated as a relativist constructivist-interpretative ontology and epistemology. However, such a topic that is inherently laden with ethical controversy must also be willing to consider a deliberate and thoughtful critical reflexivity about the constructions, interpretations and knowledge claims as also morally obligatory.

The rationale that this inquiry would be enriched by seeking to explicate ‘thick’ descriptions and drawing out explicitly the interpretations and deliberation processes of parents situated this inquiry within the constructivist-interpretive orientation, thereby shifting “from an ontological realism to ontological relativism” (Guba & Lincoln, 1994, p. 109-111). A philosophical position that spanned the breadth of a continuum from a ‘discoverable reality’ that can be observed, to constructivist inter-subjectivity that privileges the role of the subjective experience may at first appear to present a conundrum of incompatible epistemological and ontological positions. This breadth was not intended to be a methodological identity crisis but rather a result of ongoing critical reflection towards deliberate methodological choices; cognizant of the metanarratives, the sensitivity to the ‘life-worlds’ and meaning construction of participants, and the generation of knowledge that should be useable to the community that serves these populations.

With regards to the rationale of employing a critical lens, the previous study and existing literature raises questions about the intersection between the private life-worlds and the larger social structure, particularly where politico-ethical metanarratives are concerned. Corbin & Strauss (2008) points to the symbolic interaction and pragmatist interactionism schools of thought to justify why attending to the larger social contexts cannot be ignored as extraneous to the understanding of the phenomenon:

“human action, interaction and emotional responses that people have to events and problems they encounter. The nature of human responses creates conditions that impact upon, restrict, limit, and contribute toward restructuring the variety of action/interaction that can be noted in societies. In turn, humans also shape their institutions; they create and change the world around them through action/ interaction” (p. 6)

“McLaren (2005) proposes the following definition of critical theory: ‘a critical theory is concerned in particular with issues of power and justice and the ways that the economy; matters of race, class and gender; ideologies; discourses; education; religion and other social institutions; and cultural dynamics interact to construct a social system’ (p. 306)” (as cited in Carpenter & Suto, 2008, p. 24). Given the politically charged metanarratives that intersect with this topic, the attention to a critical lens is not only appropriate, it can be argued to be obligatory for the need to unpack the value laden and historical realities which shape public and private worldviews about what constitutes a moral decision in this topic area. Although this study did not intend to lay judgements about morality, it is nonetheless a significant personal quandary for

parents as they attempt to reconcile their diagnosis with their moral decisions. In order to understand the factors an appreciation of how parents interpret the diagnosis provided was significant given that “the concept of *interpretation* suggests that all psychological and social activity involves assessments of the meaning that events have for people”(Neimeyer, 2009, p. 25).

Neimeyer (2009) notes that “people live in an interpreted world, one organized as much by their individual and collective categories of meaning as by the structure of an “objective” world of external stimuli” (p. 5). That these constructed realities are relativist is to acknowledge that the product of inquiry bears the marks not just of those who co-construct reality but also the social values that retain politically, socially, historically indelible impressions (Guba & Lincoln, 1994, p. 110-116). With regards to scientific knowledge, Gelwick (1977), drawing on Michael Polanyi’s theories, suggests the view that data can be categorically objective may represent a fallacy, stating instead that

“data require interpretation, and the seeing of pattern and relationship is not inherent in the appearance of the data itself” ... “all data are “theory-laden” and that there is no such thing as uninterpreted facts. Whatever is regarded as fact represents the consensus of scientific opinion at that time” (Gelwick, 1977, p. 80)

The distinction between a constructivist-interpretative position and a critical one is the requirement to go beyond the ‘what’ and ‘why’ of the process and to delve

into those “concepts and practices that aim to emancipate and enlighten individuals and groups, illuminate power relations and the role of economics, and uncover the ideologies that implicitly shape people’s lives” (Carpenter & Suto, 2008, p. 24). In addition to bioethics, Foucault’s ideas about biopower (1990) and the clinical gaze (1975) will be used to provide the critical structural lens for this study.

Methodological rationale

The nature of the research problem directed the initial process of inquiry to an inductive qualitative methodology. Gelwick (1977) identifies a paradigm that “provides metaphors, analogies, explanations and standards for solutions to puzzles. Paradigms are adopted because they both win adherence of followers and are sufficiently open-ended to allow focus upon further research” (p. 55).

Lived Experience - Identifying an inquiry as focusing on ‘lived experience’ tends to direct researchers along the lines of phenomenology as the method of choice, but is not necessarily limited to phenomenology. The philosophical underpinnings of the current study as critical relativist constructivist-interpretivist in ontology and epistemology allowed space for the phenomenological aspects without exclusively committing to phenomenology as a methodology.

The following attributes of hermeneutic phenomenology that were an appealing methodological fit include the orientation to the phenomenon itself, as Husserl states, to return to 'the things themselves'; reflective awareness; inter-subjectivity; attention to language and its role in the construction of meaning; Husserl's concept of 'bracketing' (although controversial whether this is truly possible) and above all, the focus on the existential aspects of human nature (Van Manen, 1997). Although these would appear to provide adequate justification for choosing phenomenology as the methodology, at its core the aim of this study also needed to address the social and critical aspects of the embedded metanarratives. Hence, this study required that we go beyond the individuals' lived experiences, and hold the individual lived experiences in context with the larger social worlds that they inhabited. Thus, this study required a sociological perspective in addition to a phenomenological one. Max Van Manen (1997) addresses the limitations of phenomenology for this stated purpose as:

- 1) "not an empirical analytic science" (pp. 21-22) - that it would not be able to empirically derive generalizations about relationships, interactional dimensions, conditions of the phenomenon and descriptions of the social milieu. Although it might be able to extrapolate a sense from the accounts of lived experience phenomenology is not primarily concerned with these aspects, other than how the participant relates and interprets their relevance to the ascribed meanings.
- 2) Unconcerned with particulars (p. 9-10, 23) – phenomenology does not focus on particulars of the phenomenon at large such as incidence, prevalence, conditions or aspects such as who, what or when of the phenomenon.

Furthermore, attempting to classify, categorize or create a taxonomic analysis that illuminates the flow and pathways of the phenomenon is not a concern for phenomenology, which is more concerned with the pre-reflective experience than its codification. From a constructivist-interpretivist lens the ability to marry the details of the phenomenon at large with the private interpreted meanings of parents is a crucial link.

- 3) "Does not problem solve" (pp. 23-24) - that phenomenology is primarily concerned with the meaning and not with the inherent problems that are within the context. "The process of identifying a taken-for-granted phenomenon and revealing the particular social and economic processes that contribute to it is an example of problematizing, which is central to any critical theory" (Carpenter & Suto, 2008, p. 24). Including a critical lens for this research involves attending to problems/ problematic aspects that go beyond mere philosophizing about existential aspects and requires a space to address them constructively through means of "critical enlightenment" to uncover power relations embedded within the phenomenon and "critical emancipation," which is defined as human agency through empowerment (Carpenter & Suto, 2008, p. 24).

Rationale for Grounded Theory - Although a number of other paradigms and methodologies also seemed suited for this topic, Grounded Theory emerged from the methodological choices as an ideal fit for a number of reasons, as follows:

First and foremost, the methodological permission to begin with the phenomenon and data as the source of inquiry without preconceived *a priori* hypotheses, granted a blank slate, a *tabula rasa*, to open the process of discovery from what emerged naturally (as it occurred) in the real world - an obvious fit to Van Manen's phenomenology of lived experience. This inquiry began by following the data trail of the previous study, wherein the concept of fetal anomalies as a unique phenomenon (separate from other reproductive losses) first came to the researcher's awareness.

Glaser & Strauss (1967) insist that the analysis and ensuing theory or explanation must be 'grounded' in the data with attention to the process of generating this data and therefore the theory. They raise a critique against formulaic verification models that reframe the data to the duality of verifying or nullifying existing 'grand theories' rather than the pursuit of knowledge generation (pp. 1-12). The attention to critical issues for this topic made this a key consideration – that in order to understand the private inner workings of parental decision-making, we need to be open to their version of facts and their interpretation foremost, and layer the theoretical and 'expert' lens subsequently, thereby enriching the understanding rather than channelling it along predetermined conventions.

As an attitude and mindset for the researcher, Glaser & Strauss (1978), require that one employs an active awareness and attention to bracket and put aside preconceived ideas.

“to enter the research setting with as few predetermined ideas as possible...to remain sensitive to the data by being able to record events and detect happenings without first having them filtered through and squared with pre-existing hypotheses and biases.” (Glaser & Strauss, 1978, p. 3)

To explain, what grounded theorists mean when they insist upon ‘starting with the data’, Charmaz (2006) notes that data is constructed “through observations, interactions, and materials that we gather about the topic or setting. We study empirical events and experiences and pursue our hunches and potential analytic ideas about them” (p. 3) – a concept that relates to Polanyi’s ‘*anticipatory intuition*’ (as cited in Gelwick, 1977).

Charmaz (2006) elaborates that rather than waiting, data collection begins early in the inquiry process before theoretical conceptions, and that data gathering and analysis is a simultaneous process with emphasis to what is actually happening (pp. 3-4).

“To describe is to follow the ordering of the manifestations, but it is also to follow the intelligible sequence of their genesis; it is to see and to know at the same time, because saying what one sees, one integrates it spontaneously into knowledge; it is also to learn to see, because it means giving the key of a language that masters the visible” (Foucault, 1975, p. 114).

Secondly, this methodological position values the social interactions between players in the situation drawing attention to how roles, norms, activities and non-

human factors shape the phenomenon- where it lives and how it plays out. It is an open, emergent process and product that is informed through interaction, “both witnessed and lived” (Charmaz, 2006, p. 178). As such, this methodology invites rather than limits the complexity of the phenomenon and hopes to enrich the resultant theory not just with a catalogue of variables but it also accounts for the existential by attempting to make explicit the subtle and tacit ways of knowing and relational factors that shape the phenomenon. While phenomenology is less concerned with generating theory, grounded theory actively makes this a goal (Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin 1990, 1998; Corbin & Strauss, 1990 Charmaz, 2006; Corbin & Strauss, 2008).

Thirdly, this methodology encourages the depth and breadth of exploration by not limiting the variety of tools and theoretical positions from which to engage. Charmaz (2006) notes that this methodological flexibility as a strength. The range of epistemological positions allowed for the ability to engage both from a detached position and as actively engaged in co-constructing the representation of the phenomenon. While this permits a range of awareness, an active critical reflexivity was required to view the vantage points and lenses of the various players and to keep a check on the inherent push-pull of epistemological tensions. At the initial stages this freedom to explore the situation from a broad epistemological position without having to declare upfront a particular philosophical orientation as positivist, interpretivist, and criticalist and so on was an asset towards finding a coherent fit from the linkages rather

than mashing the emerging observations into a predetermined worldview. The ability to utilize methods and theoretical orientations that best fit particular questions allows for methodological congruency and enabled triangulation of emerging data.

Fourth, key grounded theorists have formulated an inductive process into a map for qualitative researchers to guide the inquiry in a coherent, rigorous, and systematic fashion while retaining the freedom to allow the phenomenon to direct the inquiry itself. These methodological frameworks provided direction for the study, reflexive checkpoints and rigour for the quality and credibility of the research design (Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin 1990, 1998; Corbin & Strauss, 1990 Charmaz, 2006; Corbin & Strauss, 2008). While latter versions of Glaserian and Straussian traditions have diverged in their theory generation goals and epistemological identities, the core attributes of the methodology maintained congruence.

Rationale for Grounded Theory version - In Corbin & Strauss (2008), Juliet Corbin acknowledges that Grounded Theory as a methodology has been evolving and labels to lump qualitative methods into epistemological categories are sometimes misleading. She recalls that in earlier versions with her mentor Strauss and his colleague Glaser so much work had been done to separate inductive qualitative methods from the dogmatic structure of the objectivist quantitative paradigm in order to legitimize a space for constructivist perspectives. Glaser & Strauss' *Discovery of Grounded Theory* (1967) demonstrated that there was in fact rigour and credibility to this methodology

by outlining detailed methods for research design and criteria to evaluate the rigour of a research study employing this methodology. Their criteria for credibility reflected the prevailing dominance of the objectivist paradigm, and hence a response to the critiques of the time. However, as Charmaz (2006) and Corbin & Strauss (2008) noted, after the post-modern era, by today's classification the original versions of grounded theory appear to be more post-positivist in light of growing acceptance of interpretative and critical perspectives.

A challenge with the current study was how to draw upon the ideas of different methodologies and versions towards a coherent research design that brings the strengths of this collective knowledge and yet avoids the feel of haphazard method-slurring. Charmaz (2006) identifies that grounded theory's flexibility allows it to function as an emergent inquiry without being narrowly bound to singular epistemologies (p. 178). Rather, the nature of the problem and emerging data directed the methodological decisions for particular methods.

Among the grounded theorists, Glaser & Strauss' approach seemed an ideal fit for this study. Glaser & Strauss' (1965) research, entitled *The Awareness of Dying*, is a seminal text in thanatology about the context surrounding the awareness of death in the social interactions among terminally ill patients, medical staff, and families. The resulting theory illuminated not just the aspects unique to death and dying in hospitals, but also the social contexts and conditions by examining the social culture of what it

means to be a dying patient, family of a terminally ill patient, and health care staff providing care at the end of life. They examined the broader social context about the changing social influences shaping the reality of death that increased the likelihood of dying in hospitals as opposed to homes. Within the hospitals, they examined the organizational culture and environment, the epistemological views of staff and families about disclosing terminal diagnoses, the relationships and interactions that maintained or altered the path trajectory of the phenomenon. With a rigorous method they attempted to both explicate the phenomenon in detail, as well as provide a taxonomic understanding of what variables existed under what conditions for each of the four final awareness contexts.

The methodology employed by Glaser & Strauss in that particular study pioneered the beginnings of ground theory. Although our current research study occurred in the prenatal context, it similarly involved the context of death, the awareness of expectant parents and the social interactions among health care professionals, parents, families, as well as the broader social context that occurred within and without the walls of the hospital environment.

Beyond the obvious fit of researching a topic in the same broad substantive area (thanatology), Glaser & Strauss' grounded theory version (1965 & 1967) was concerned with generating theory about social process and social phenomenon, whereas Max van Manen (1997) was primarily concerned with the pre-reflective

hermeneutic interpretations of the private lived experience. Charmaz (2006, pp. 7, 179-184) distinguished the deviation between subsequent Glaserian and Straussian versions as follows: Glaser proceeded in the direction of codifying social processes towards explanatory models which took on an empirical flavour; while Strauss along with Corbin (Strauss & Corbin 1990, 1998; Corbin & Strauss, 1990) moved towards theory verification and pragmatic technical procedures while valuing a subjectivist position.

Glaser's (1978) notion of Theoretical Sensitivity expanded the process of handling data and analysis in meticulous detail, adding the perspective of structural and social dimensions to understanding social phenomenon. Glaser's (1978) attention to structural conditions, along with the theories of Michael Foucault (1990; 1975) dovetails together towards the critical aims of this current study.

Strauss' direction "assumed that process not structure, was fundamental to human existence; indeed human beings created structures through engaging in processes" (Charmaz, 2006, p. 7). Thus, his stance of valuing the constructed role of subjective, human agency, social meaning, and language aligns more organically with Van Manen's (1997) hermeneutic position.

Charmaz' stance (2006) is primarily a 'constructivist return' of 'classic' grounded theories of Glaser and Strauss with an open embracing of interpretive lenses that creates a way to link the rigour of meticulous abstracted details without divorcing the humanity of relational ways that meaning is made about the way life events, and

temporal, social, historical, linguistic and other factors shape worldviews of the people, social worlds and phenomenon that we study. Charmaz' stance is premised in the following assumptions that honour the original theory but situates it within a constructivist paradigm:

- "the grounded theory research process is fluid, interactive, and open-ended
- The research problem informs initial methodological choices for data collection
- Researchers are part of what they study, not separate from it
- Grounded theory analysis shapes the conceptual content and direction of the study; the emerging analysis may lead to adopting multiple methods of data collection and to pursuing inquiry in several sites
- Successive levels of abstraction through comparative analysis constitute the core of grounded theory analysis
- Analytic directions arise from how researchers interact with and interpret their comparisons and emerging analyses rather than from external prescriptions" (p. 178).

Thus, rather than being viewed as competing paradigms of grounded theory, Charmaz (2006) attempts to bring the strengths of Glaserian and Straussian traditions but "loosens the objectivist foundations" (p. 180). As a constructivist epistemology with a strong value for interpretation, it seemed a way to layer an interpretative lens onto

Glaser & Strauss' original theory, thus utilizing the strengths of their original theory without having to narrowly stake a position in one epistemological camp or the other. Although their subsequent directions further enhanced Glaser or Strauss' divergent views of grounded theory, neither of the subsequent directions seemed to fit this current study as closely as their original 1967 theory. Strauss's later emphasis on verification presents challenges to the current inquiry partly because it directs us back to preconceived notions and conflicts with the aims of both the original tenets of grounded theory and a critical lens. Glaser's subsequent focus on objectivist positivist assumptions tends to aim towards reducing the complexity of the phenomenon and detach the researcher's role in the production of the data and resulting theory. If we are truly employing a critical lens, we must also be willing to direct that lens to how research is generated, who asks and answers the questions, what questions are asked, what is spoken, and what remains silenced. In a constructivist-interpretive-critical paradigm, these assumptions need to be addressed.

As a point of reflexivity, it bears noting that perhaps the draw towards Glaser & Strauss' original theory was two-fold: One, it has a long tradition of demonstrating academic rigour and has been accepted by several epistemological positions including objectivists. Although we would like to believe that research should be judged solely on its quality, in order to be useful research it needs to be accessible within the particular scientific community that will be the recipient of the knowledge claims generated from the inquiry. Second, the familiarity of setting and topic context (thanatology in a

hospital context) enabled a way to imaginatively view how applying their methodology would translate to our study. The attention to studying an emotionally sensitive topic (death) in a health care institutional setting required guidance on how to attend to the multitude of factors and the happenings of the social context. Their 1965 *Awareness of Dying* research spoke to the researcher not only to explain the method and theory but also what it meant to study this topic in a similar setting over an extended period of time. In short, the reflexivity in the text guides a researcher following in their footsteps about lessons learned from experience about the nuances of seeking entry and maintaining access in similar research context.

Rigour and credibility criteria in Grounded Theory

Charmaz' (2006) criteria for rigour or credibility of grounded theory is a comprehensive study of the criteria that both Glaserian and Straussian views have held in various versions of the theory. She defined and synthesized the core attributes that transcend the versions as four core criteria, and provides a detailed reflexive questionnaire for the researcher and evaluators. Charmaz (2006, pp. 182-183):

- 1) Credibility – intimate familiarity, sufficient data for range and depth, systematic comparisons, wide range of empirical observations, logical links and enough demonstrated evidence to allow the reader to evaluate the claims.

- 2) Originality – the extent to which the work expands existing knowledge and generates fresh novel insights about social and theoretical conceptual understandings.
- 3) Resonance – given the limitation that no one theory can claim to be generalizable to all people everywhere, within inductive qualitative methods that the data can ‘speak to’/‘relate’/ ‘echo’ the common experience of humanity such that others can see themselves or imagine themselves in the situation.
- 4) Usefulness – consistent with other methodologies that stress that the research must serve an end towards the contribution of knowledge. Thus researcher must demonstrate the ability to disseminate and make the research accessible and applicable.

Glaser & Strauss (1967) distinguish their methodological tasks as centering around two key aspects: Constant comparative analysis and theoretical sampling. Their version of comparative analysis is distinguished from quantitative paradigms, in that although they appreciate that replication enhances the reliability of the study and agree with this goal, albeit, differently. They contend that replication should not be the sole goal of grounded theory. Furthermore, that the theory generated by their method should not be narrowly limited to a similar sample, group size, or specific population; rather, that the theory can be applied broadly across the phenomenon that the core

substantive area studied (pp. 21-23). The aims of comparative analysis follow thus (Glaser & Strauss, 1967, pp. 23-30):

- 1) Accurate evidence – “to check out whether the initial evidence was correct.”... “In discovering theory, one generates conceptual categories or their properties from evidence; then the evidence from which the category emerged is used to illustrate the concept” (p. 23).

They reason against the criticism of infallible proof by acknowledging that the evidence may not be above all doubt, but that the concept may be “a relevant theoretical abstraction about what is going on in the area studied” (p. 23) Given that they aim for the grounded theory to be used broadly (outside the limited sample group) the ability to conclusively hold evidence as true in all cases sets up unrealistic explanations. In social, phenomenological research that involves interactions, processes, actions, and reactions that number of permutations and combinations cannot be accounted for in its entirety. Therefore, grounded theorists contend that the rigour of the study should be more realistically based on whether or not the theory can help enrich the explanation.

- 2) Empirical generalizations – differentiation and process

“by comparing where the facts are similar or different, we can generate properties of categories that increase the categories’ generality and explanatory power” (p. 24).

- 3) Specifying a concept – to explicate the “dimensions of the concept” such that the distinction to similar units to “insure clear understanding of differential definitions” (pp. 25-26).

- 4) Verifying theory- continual checks as the theory emerges, both explicit and implicit (p. 28).
- 5) Generating theory - “Since accurate evidence is not so crucial for generating theory, the kind of evidence, as well as the number of cases, is also not crucial. A single case can indicate a general conceptual category or property; a few more cases can confirm the indication” (p. 30). The goal is rather to “develop a theory that accounts for much of the relevant behaviour” (p. 30).

The goal in generating theory is both in the categories as well as the properties of each category.

Analysis and generating theory - “Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next, and where to find them, in order to develop his theory as it emerges” (Glaser & Strauss, 1967, p. 45). In keeping with their edict that inquiry should generate fresh understandings and not an endless homage to grand theories, theoretical sampling follows the data trail and the literature is reviewed for theoretical insight rather than directives. They specify the following considerations regarding theoretical sampling (Glaser & Strauss, 1967, pp. 45-65):

- 1) begins “with a partial framework of ‘local’ concepts,” which can be related broadly to the topic area either structurally or procedurally (p. 45).
- 2) researcher must be “sufficiently theoretically sensitive so that he can

conceptualize and formulate a theory as it emerges from the data” (p. 46).

- 3) Utilizing multiple “slices of data” with the rationale that this lends “diverse structural conditions of each group: schedules, restricted areas, work tempos, the different perspectives of people in different positions, and the availability of documents of different kinds” (p. 65).

According to the early grounded theory of Glaser and Strauss (1967), the researcher should be broadly versed with multiple theories, schools of thought, training along with a “personal and temperamental” nature towards insight and using this insight together with the emerging data to formulate conceptual theory (p. 46-47). However, as cautioned by Glaser and Strauss (1967), the researcher should be mindful not to adopt a theoretical stance exclusively such that it precludes discovery in favour of selectively choosing and discarding data that fits with a preconceived theory (Glaser & Strauss, 1967, pp. 46-47). Thus, the role of literature review continually informs the process, by returning to the literature to seek answers and fit from existing theory rather than prescribing theoretical categories upfront.

The question of whom or what is under study is also informed by the emerging data. Although a broad study population is identified at the outset, in order to fully understand the phenomenon, various sub-groups may become identifiable only once their role, purpose, and theoretical relevance becomes established by the emerging data (pp. 47-56).

- 1) For furthering the development of emerging categories – “comparative analysis takes full advantage of the ‘interchangeability’ of indicators, and develops, as it proceeds, a broad range of acceptable indicators for categories and properties” (p. 49).
- 2) Ongoing inclusion of groups – “In research carried out for discovering theory, the sociologist cannot cite the number and types of groups from which he has collected data *until* the research is completed” (p. 50).
- 3) Rationale for comparing groups and sub-groups is threefold at: conceptual level; population scope; for simultaneous comparison of differences and similarities (p. 55). By maximizing the differences among groups, the breadth of the data collected is enhanced. Rather than a verification versus null strategy, the researcher “searches for maximum differences among comparative groups in order to compare them on the basis of many relevant diversities and similarities” (p. 56). By minimizing the difference among groups, the emerging theory is sharpened by narrowing a set of conditions necessary for the category to exist and enhances the theory’s ability to postulate an informed theoretical prediction (p. 56).

Credibility

For their methodology in *Awareness of Dying*, Glaser & Strauss (1965) provide the following four criteria for the rigour of their analysis about their ‘awareness theory’:

1) Fitness – that there must be a close fit between the integrated theory proposed and the substantive area (p. 259-261).

“a substantive theory that is faithful to the everyday realities of the substantive area is one that is carefully *induced* from diverse data gathered over a considerable period of time” (p. 261).

- How the researcher arrived at the concepts and conclusions (p. 291):

“readers will assess the types of data utilized from what is explicitly stated as well as from what can be read between the lines. It is absolutely incumbent to make such judgments about reports based on fieldwork, partly because the publication could conceivably be a complete fabrication, but more usually because any analysis may require some qualification” (p. 291) – Glaser & Strauss refer to this as “discounting process.”

2) Understanding – that the explication of the theory makes practical sense that one can understand the realities as well as apply the theory (p. 262-264).

“The sociologist finds that he has “a feeling for” the everyday realities of the situation, while the person in the situation finds he can master and manage the theory” (pp. 263-264).

- “Feeling for” – “readers would almost literally be able to see and hear the people involved” (p. 264).

- “if a reader becomes sufficiently caught up in the description to feel that vicariously he has been in the field, then he is likely to be more kindly disposed toward the theory than if the description seems flat or unconvincing” (p. 291).

3) Generality - Requires 2 parts: analytic & sensitizing

Analytic – “sufficiently generalized to designate the properties of concrete entities- not the entities themselves” (p. 263).

Sensitizing – “that they yield a meaningful picture with apt illustrations that enable medical and nursing professionals to grasp the reference in terms of their own experiences” (p. 263).

“The presentation of substantive theory, developed through analysis of qualitative data, is often done at a sufficient level of plausibility to satisfy most readers” (p. 292).

4) Control – that the person who applies the generalized concepts of the theory is able to understand not only the theoretical concept but also the interactional dimensions and must include access variables (p. 268-272).

Glaser & Strauss (1967) added that in addition to the ability to “predict, explain, and be relevant” other criteria to judge the quality of a theory should center on the ability of the theory to “fit and work”. Hence elements such as “logical consistency, clarity, parsimony, density, scope, integration” are also relevant within the context that attends to how the data was generated (p. 5). Glaser (1978) further refined the criteria for fitness to include:

- Refit: continually check if it fits all the data it claims to support (p. 4)
- Emergent fit: links new data with pre-existing categories previously established in the research or previous literature, establishing whether they work or not and their relevance(p. 4)
- Modifiability (work) : the need to provide qualification in explaining the theory (p. 5).

Stages of Inquiry

From this methodological lens this study explored the complexity of the phenomenon in two phases of inquiry. At the outset, a participant-observation process engaged and observed the day to day reality as it existed within the general and specialized social contexts. Following this pilot stage, a focused set of interviews with participants attempted to delve into the private lived experience and elicit clues about the multiple factors that parents had to contend with and the unseen processes of emotion and decision making. Thus these stages in the evolution of the research form an iterative process to continually revise and refine the research question in an attempt to explore the phenomenon, the participants' accounts of their experience and the socially situated complexities that form a dialectic between the private subjective world of the parent(s) and the external social reality.

Methods

Phase 1: Understanding the scope of the phenomenon

This study was premised within a socio-cultural context. In keeping with a qualitative grounded theoretical methodology, there were no preconceived / a priori hypotheses. Although Phase 1 was not part of the formal data collection research strategy, it represented a training ground for the researcher's awareness, understanding and appreciation of the nature and context of the phenomenon. While a theoretical understanding can be informed by textbook theory, scholarly journal articles, lectures, and so on, a well-rounded conceptual understanding of the experience of a phenomenon requires a familiarity of both the theoretical and the experiential worldviews. The ability to bear witness to the reality of phenomenon required that the researcher bear some responsibility to critique one's own presuppositions which may be limited by a purely theoretical lens, conditioned by existing assumptive worldviews, may be inaccurate for a variety of reasons, or at the very least limited to an etic view. In order to fulfil the rigour requirements set by grounded theory with a phenomenon that is almost exclusively cloistered away from public, one must enter into the phenomenon to walk amongst the insiders, to hear the language of the discourse, to put words to the things witnessed and to understand empathically what it means for the insiders to live with the reality of the phenomenon. In short, this stage pertained to understanding the humanistic dimensions that cannot often be translated as richly through interviews alone or through text and theory.

As per Tri- Council ethical policy guidelines (2010, pp. 139-141) the primary researcher networked with key gatekeepers to negotiate and facilitate entry to the field and to ascertain the nature and context of the phenomenon to be studied. Preliminary field notes were utilized to engage in reflexivity and serve to facilitate research documentation about the logistics of coordinating the study and to ascertain the parameters of the research scope and question to enable an ethically and emotionally sensitive methodological approach. These field notes were a descriptive analysis of the context of the service and did not focus on an individual or any identifying information.

“Direct involvement in the here and now of people’s daily lives provides both a point of reference for the logic and process of participant observational inquiry and a strategy for gaining access to phenomenon that commonly are obscured from the standpoint of a non-participant” (Jorgenson 1989, p. 9).

As a methodology, Jorgenson (1989) conceptualizes Participant Observation as applicable to a wide range of epistemological orientations that can align with the inductive, exploratory and interpretative qualities of participant observation. As a method for research strategy the epistemological range may be used quite broadly depending on the nature of the problem and the lens for the process of inquiry. As a positivist method it may be used where the goal is to identify concepts in the initial stages which may be treated as variables for further exploration; or as a “humanistic

methodology” (p. 7-13) seeking to explore phenomenon, lived experience, interactions, relationships, meanings and the intricacies of human existence.

The core values underpinning this methodology concerned the following general characteristics and constructs: the nature of existence; the privileged, obscured viewpoint of the insider; and the manifestation of the phenomenon as it occurred in everyday life. From an ontological position, the constructive-interpretative assumptions are less concerned with reducing human existence down to a handful of acceptable generalizations, rather this methodology redirects the focus appropriately to the perspective of the insiders (emic)- seen as possessing the explanation that arises from *a lived reality*. Furthermore, the premise that although the meanings, interpretations and perhaps even the semantics of the participants’ experience are obscured to outsiders, does not make it less valid ontologically. Rather, a concerted effort to “uncover, make accessible, and reveal the meanings (realities) people use to make sense out of their daily lives” enriches theory by permitting a lens to see what might otherwise remain hidden (Jorgenson, 1989, p. 14-15).

Jorgenson (1989) explicitly holds that although this method of participant observation shares the dominant scientific view of generating theory based on “accurate and truthful findings”, he demarcates that with its strong existential perspective it does not presuppose absolute views of reality (p. 26-27). In response to criticisms for more positivist paradigms, Jorgenson (1989) actively “rejects the conventional conception and distinction between subjectivity and objectivity” (p. 27),

and stresses that the truthfulness of the findings requires coming to understand the private experience of another. Thereby, attempting to reconcile the philosophical dichotomy, by marrying observation (standing back, looking in) with participation by engaging with the phenomenon and experiencing it directly (pp. 27-28).

Rationale: Participant-observation when employed (together with Glaser & Strauss' original version of grounded theory) as a method of engagement with the phenomenon naturalistically enriched a more fluid understanding between the 'observable, discoverable reality' and the 'private, interpreted, lived experiences'.

Similar to the rationale of the grounded theory of Glaser and Strauss (1967), participant observation holds that although the abstract broad research question may provoke a research investigation, the nuances of how, why and what of the research method may need to be arrived at inductively. Participant observation therefore advises that for an inductive exploratory inquiry the process is a "logic of discovery" beginning with the "immediate human experience" (Jorgenson, 1989, p. 18). The following key reasons that supported this methodological rationale for the current study were (Jorgenson, 1989, pp. 14-16):

- 1) *The insider's view:* aptly notes that "insiders manage, manipulate, and negotiate meanings in particular situations, intentionally and unintentionally obscuring, hiding or concealing these meanings further from the viewpoint of outsiders" (p. 14).

- 2) *A 'real picture'*: Rather than artificially constructed situations such as experimental groups, participant observation is concerned with daily life and all its minutiae. Drawing an epistemological connection with the paradigmatic views of social interaction theories. Beyond preserving the details of the “ordinary, usual, typical, routine” of the daily existential experience, Jorgenson (1989) advises that being immersed in the participants’ worlds might reduce the problem of social desirability from the players; and that eventually, with sustained involvement the true phenomenon emerges (p. 15).
- 3) *Here and now*: The immediacy of the interactions is critical for two key reasons. First, the identification and refining of the problem are prompted by the critical incidents in the field. The second reason provided is that this is the relational space in which the researcher participates with the phenomenon. (Jorgenson, 1989, pp. 15-16). Perhaps these reflexively important moments that come as surprises, or ‘a-ha’ moments, may only be fully realized for the significance slowly in constant ongoing reflection, they nonetheless, plant a ‘way of knowing’. The characteristics of the researcher are implicit factors in the interactions – what one sees or fails to notice, where one is invited by the insiders, how space is used etc. These factors provide a context to fill in between the lines of who said what to whom and create narratively ‘thick’ descriptions. Furthermore, the recognition that when dealing with systems, the expectation that a baseline level of control is possible, which is a taken for granted assumption in experimental and other designs, proves fallacious. People, organizations and systems are constantly

dynamic, reacting and adapting. Similarly, the researcher is thrust into this current and must constantly evaluate, renegotiate, be creative and go with the flow of the dance between pushing toward further immersion and withdrawing at times.

- 4) *Practical decisions*: “Ultimately, the methodology of participant observation aims to generate practical and theoretical truths about human life grounded in the realities of daily existence” (p. 14). Immersion in the field is crucial for the feasibility of the study, from negotiating access with gatekeepers to refining research questions, ascertaining the best sources of information, times, and spaces. The logical, administrative, and practical details are integral for successful completion.

The justification for Participant-Observation as an ideal method for this study hinged on the following theoretical criteria provided by Jorgenson (1989):

- 1) Little is known about the phenomenon
- 2) The phenomenon is hidden or obscured to outsiders or public view in critical and pertinent ways
- 3) The study is primarily concerned with meanings, interpretations, interactions of human existence embedded within the phenomenon (p. 12-14).

Furthermore, in order to delve into the participants' 'reality' with the aim of generating theory, a feasible method to structure observation is critical towards theoretical credibility. Given that the phenomenon of fetal anomalies is highly personal and biological, a method that reduces the gap between the researcher's outside awareness (which may represent un-reflected presuppositions) and the day to day reality of the phenomenon was essential. Participant-observation in a setting where this phenomenon first enters the worldview of the pregnant parents was the ideal entry point. It not only provided a point of access to the population and phenomenon but it began with the existential worldview shift that is precipitated by the first diagnosis. Hence the following additional criteria supported the methodological rationale for this methodology: ability to access the phenomenon; reasonably limited logistical scope; appropriate questions that can be explored with relatively small samples sizes and qualitative data; the methods and the researcher are able to be flexible enough to follow the trail of data and theoretical sampling; that the field and the researcher are able to act fluidly and interchangeably in multiple membership roles, from observation to participation in order to maintain access and relationships; and above all, that the range of the phenomenon can be directly observable or elucidated by means of participation and interaction (Jorgenson, 1989, pp. 12-14).

Credibility – qualitative researchers have developed specific criteria coherent with the philosophical orientation of the methodology. We no longer hold that qualitative research must be justified by the criteria of quantitative methodology when the aims

and knowledge claims may be fundamentally dissimilar. However, in the 1980's when Jorgenson put forth his methodology of participant observation, rigour was judged by the prevailing rubric of positivist scientific methods and he therefore stated the following criteria as standards of rigour (Jorgenson, 1989, pp. 34-37):

- a) Concepts – are defined descriptively with the indicators involving “a search within the field context for meaning, relevancy, and linkages of key concepts and ideas,” including multiple indications for the idea and to show how they are used (Jorgenson, 1989, pp. 34-35). The latter statement is theoretically consistent with the grounded theory put forth by Glaser & Strauss (1967).
- b) Insider's perspective – this point is overtly stressed, that the researcher must demonstrate the perspective of the insiders, not just in ascribing values to them but to then tell the story as they would, such as using the same keywords, linguistic, cultural labels, and indicators of how the insiders identify and describe their positions and experiences (Jorgenson, 1989, pp. 35-36).
- c) Concept validity –researchers must be able to address whether or not they have “been able to gain direct access to the insider's world or meaning and action”; able to gather multiple sources of indicators (evidence) from various sources and procedures, including advantages and limitations of these procedures; and also be able to “describe conflicts and disagreements over the meanings” among insiders (Jorgenson, 1989, pp. 36-37).

Using more modern qualitative criteria for rigour and quality scholarship, one could address that within a constructivist-interpretivist paradigm, multiple constructions of truth need to be demonstrated along with transparency of method and procedure, methodological and theoretical coherence, credible engagement and immersion with the context and the data, triangulation of data, attention to participant voice, researcher reflexivity, and member checking or verification testing of concepts in the field as appropriate.

Procedure:

Drawing from those theorists who explicate the methods for being a Participant-Observer, the following key tasks map the journey (Jorgenson, 1989; Spradley, 1980, DeWalt & DeWalt, 2011):

- 1) *Defining the problem & research questions* - Although a proposed study may begin with a spark of an idea that is theoretically relevant and that also addresses a gap in the literature, like grounded theorists, Jorgenson (1989) posits that the true research question(s) arise in the field and as the data emerges (pp. 29-30). To begin with the phenomenon itself requires that the researcher hold simultaneously an abstract conceptual idea of why this topic is worth studying, while holding a blank open awareness that avoids prematurely restricting the scope (pp. 29-30). The questions emerge from the experiences, the surprises, and the reflections about what is unfolding. Jorgenson (1989) further advises that some degree of strategic negotiation is needed to refine the

scope of the study and the questions, set logistical and feasible parameters, and negotiate access to sufficiently maximize the depth and breadth of exposure to the phenomenon (pp. 30-34). Thus for the current study, the immersion into the field is necessary in order to be able to see the phenomenon naturalistically, and to identify the scope and parameters that will inform the research question and sub-questions, which is critical to ground theory, as participant-observation facilitates a way of seeing and knowing.

- 2) *Selecting a setting* – In addition to selecting a setting that provides reasonable access to the phenomenon, the researcher ‘maps’ the setting noting the particulars of who is involved, the hierarchies, the relational power structures, the point of entry and exit, and various semiotics of the space, time, resources etc. that are relevant. (Jorgenson, 1989, pp. 40-45; Spradley, 1980, pp. 37-45; DeWalt & DeWalt, 2011, pp. 81-85, 126-127). Spradley (1980) identifies the three key elements for astute observation that pertain to the ‘place’, the ‘actors,’ and the ‘activities’ of the setting (pp. 39-41).
- 3) *Negotiating access with key gatekeepers* – At the outset, the nature of the study methodology determines what kind of access, how much negotiated access is required, and who has the authority to grant access. For the purposes of the current study, the social context of the phenomenon is cloistered from the public view due to the medical nature, vulnerability, and emotional distress of the parents. Quite reasonably, such a setting requires open, honest disclosure of the study aims but also the personal temperament of the researcher. Hence,

negotiating access to the setting is more than the logistics of conducting research; it is the slow gradual building of trust, rapport, cooperation, reciprocity, and sharing of resources is required. (Jorgenson, 1989, pp. 45-49, 69-81; DeWalt & DeWalt, 2011, pp. 41-67).

4) *Establishing relationships* - The process of negotiating access is therefore a continual and ongoing process as opposed to a milestone. DeWalt & DeWalt (2011) represent this process as stages of 'first contact,' 'establishing rapport,' 'breaking through,' 'talking the talk,' 'walking the walk,' and 'making mistakes' (pp. 41-67, 211-226). Jorgenson (1989, pp. 69-81) and DeWalt & DeWalt (2011) also acknowledge that resistance to strangers and defensive or hostile reactions is also common. The roles that the researcher plays within the setting may be on a continuum from a passive detached observer to full participation, and the extent and timeline is contingent upon the acceptance and membership afforded to the researcher.

Phase 2: Research Interviews

In keeping with a methodology that sought to understand the perspectives of the participants, research interviews that elicited the participants' version and narrative account of their lived experience story was critical to the appreciation of the emic view. Very minimally structured (semi-structured) interview questions were provided so as to allow the experience to emerge and be informed from the perspective of the participants. The guiding questions drew focus on the narrative of

events, the relationship between parents, families and professional care providers, and the connections among various contributing factors and resolutions. The narrative of telling the story and the meanings constructed by parents/participants illuminate the processes and criteria of their decision making. Follow up questions followed the data trail - the interview narratives as well as the emerging theoretical codes and themes.

Participants & Setting – Participants for the interviews were parents who had been referred for obstetrical care to a high-risk maternal fetal program. The sole inclusion criterion was that parents must have been referred to this service due to a suspected or confirmed fetal anomaly, regardless of the outcome, interventions or lethality of the condition. The only exclusionary criteria was age (lower limit of 21 years and upper limit of 65 years) and the ability to express free and informed consent to participate in the study. Although the pregnant woman is considered a patient, both the pregnant woman and her partner/ support person were eligible to participate jointly or independent of the other. The sample size is a calculated range that is expected to theoretically achieve depth of saturation, as informed for the review of the literature, the scope of the phenomenon, as illuminated by the previous phase, and the estimate of geographically determined incidence of fetal anomalies. However, in keeping with grounded theory and other qualitative inductive methodologies, the sample size was determined by the point of saturation.

Procedure - Staff at the clinic approached potential participants who meet the basic inclusion/ exclusion criteria. Participants were informed about the study and provided with a letter of information & the researcher's contact information and/or offer introduction to the researcher. Alternately, participants could fill out a form consenting to allow the researcher to contact them with more information before they consented to the study.

Upon acquiring consent, basic demographic data was gathered and participants were interviewed. Interviews were semi-structured, with minimal prompts to allow participants the freedom to share only what they wish. Interviews were audio-taped and transcribed for analysis.

Analysis - Consensual Qualitative Research protocol (CQR) as outlined by Hill, Thompson, & Williams (1997) & Hill, Knox, Thompson, Williams, Hess, & Ladany (2005) was used for the open and axial coding to generate a content analysis of the interview data. Glaser & Strauss' (1965, 1967) constant comparative method was used to refine the codes into categorical ontologies, which helped refine the emerging themes and categories. Glaser & Strauss (1965, 1967) stress this aspect of ground theory and advocate that the credibility of the emerging theory is enhanced by "systematically studying several comparison groups. ...guided by the logic of the emerging analytic framework" (p. 289).

“The constant comparison of many groups rather quickly draws the observer’s attention to many similarities and differences among groups: these contribute to the generation of theoretical categories, to their full range of types or continuum, their dimensions, the conditions under which they exist more or less, and their major consequences. In addition, the observed differences and similarities speedily generate generalized relations among theoretical categories, which in turn become the hypotheses soon integrated into the substantive theory” (p. 290).

Glaser & Strauss (1965) contend that credibility by a comparative model provides rationale by two strokes: replication and prediction:

“First, by detailing precisely the many similarities and differences of the various comparison groups, the researcher knows, better than if he had studied only one or a few groups, under what sets of structural conditions his hypotheses are minimized or maximized; and hence to what kinds of social structures his theory is applicable. ...By using multiple comparison groups, much of this burden of delimiting relevant boundaries for the theory is lifted from the readers’ shoulders. In short, replication is built into the research. A second way that multiple comparison groups maximize credibility is by helping the researcher to calculate where a given order of events or incidents is most likely to occur or not to occur...This calculus provides him with an efficient logical guide to groups whose study will yield more data to fill in gaps in theory and to verify hypotheses” (p. 289-290).

The content analysis method (CQR) helps to track the audit trail of open and axial codes within the context of the interview data. The constant comparative method addresses the criticisms of strong objectivists about not being able to “control” the confounding variables. Although control groups are not feasible (which would be highly unethical even if they were possible), the use of a constant comparative approach addresses the similarities and differences of theoretically constructed groups for the purposes of comparison. In this study, the theoretical groups would be determined by the outcome of the pregnancy and path of that trajectory. For example, was there a difference in variables or process of decision making between two sets of parents facing a similar prognosis that accounts for resulting in different pregnancy outcomes based on the sequence of decisions? The constant comparative approach also allows a bridge to merge the emerging observational data from the first phase with the interview narratives towards theoretical sensitization of themes and theory generation – how do the narratives align with the observations in the field?

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Chapter 3: Results

Phase 1: Understanding the scope of the phenomenon

Overview of the training environment

Although my initial encounter with fetal anomalies first came to awareness in my prior research on reproductive loss and bereavement, my training in this area could best be described as being in the very formative stage. My doctoral advisors recommended that as part of my doctoral training program, I should understand the phenomenon as it presents in the medical context. Facilitated through the collaborations of visionary clinicians and healthcare administrators across several departments, a space was created to allow for me to learn, observe, and engage within a multidisciplinary milieu. My manner of engagement was guided by the principles of Participant-Observation and the nuances of being and behaving 'in the field.'

This thesis is shaped to a considerable extent by the understanding and reflections that have arisen from my direct exposure in the field. The encounters and reflections have opened my eyes to things that cannot be known to outsiders; challenged the taken-for-granted hasty generalizations that pervade public sentiments; illuminated the depth of complexity and uniqueness of each case; and made very real the lives and challenges of those whom this topic touches-- the pregnant women & their fetuses, their partners and families, as well as the many clinicians and

administrative staff who provide care, support, and direct contact in their professional life-worlds.

Situational Context

At the time of my training, the various local hospitals belonged to one of two hospital organizational systems, one secular and the other religiously affiliated with the Catholic Church. The obstetrics and gynecological services within the community were located at three different hospitals each with an emergency department, and all three affiliated with the local university's medical school and designated as teaching hospitals. The maternal-fetal program's high-risk clinic was at the time located within a Catholic affiliated hospital. This program represented one of five specialist centres in the Canadian province at the time.

In the province of Ontario, the Ministry of Health and Long Term Care is divided into 14 Local Health Integration Networks (LHINs). The referral base or geographical catchment area that would direct referrals to this local program, as opposed to the four other centres, are the geographical boundaries of two LHINs. These LHINs represented approximately 11 counties, 41 hospital sites, and a general population of over 1.6 million people. Hence in several cases patients were travelling a considerable distance from out of town to access services through this program.

There are two important considerations for this arrangement of services: First, Canadian healthcare is viewed primarily as a secular, socialized medical model with

espoused separation of church and state. However, mission statements, values, and institutional policies may reflect or belie strong overtones of their affiliations' value systems. Second, at a practical level given the well documented positions and moral objections of the Catholic Church in various reproductive issues, the delivery of services had to be referred, relocated or accommodated across the secular and Catholic sites to meet the needs and autonomy of patients. Furthermore, services that were viewed as being in potential conflict with the moral values of the religious institution had to be vetted by an ethical committee to balance the duties and obligations in the provision of care with the values of the institution. This program and all of the other women's and children's health programs have since been merged and relocated into a state of the art facility at the secular institution.

A typical day at the clinic

In healthcare settings, while events occur on a 24-hour clock, it was not possible or realistic for me to be there around the clock. Rather, I attended when and where I was invited, while being as unobtrusive as possible. I talked and learned from anyone who was willing to help me understand better the functions of the various disciplines. A 'typical day' was minimally structured as I attempted to follow and keep pace with whatever was the established routine or events of the day.

Patients were generally asked to attend at various times during the morning clinic hours so that medical histories, physical exams, ultrasounds, testing, and any

other diagnostics could be done. In the early afternoon, the multidisciplinary team of specialists, consisting of maternal-fetal-medicine obstetricians, neonatologists, radiologists, and their medical residents would gather for 'rounds' to discuss each of the cases with new diagnostic information and strategize on the plan of care. I was invited to come for the afternoons, which also accommodated my regular class schedules. When I arrived, I would go to the clinical area, see if I could find someone I knew or check in with the clinic coordinator or the nurse to find out where I should go.

During the rounds, typically a senior medical resident would begin with an oral history summarizing each case. This summary would include: the reasons for the referral; obstetrical, gynecological and medical history of the patient; any known family history pertinent to the issue; and any psycho-social indicators that had been expressed by the patient, partner/family, or the referring physician. The radiologist would then cue the patient's ultrasound images from that morning and project the images onto two large overhead screens placed side by side taking up the width of the room. Several images showing general anatomy to highly focused 'zoomed in' views of the fetal organs would proceed in succession, often going back and forth and comparing different angles of view on the side-by-side screens. As the images were viewed by the clinicians, each brought their areas of expertise in making observations, asking for specific angles or image details, relating the 'findings' to the research or other clinical evidence cited in journals that indicated potential clues to the 'ranges of normal,' prognosis, and other associated factors. A thorough sweep often covered not

just the suspected fetal anomaly, but typically a head to toe assessment of the fetuses' health and the maternal factors.

When a diagnosis and prognosis was determined, a plan of care was established. This plan of care began with: who would be the first to 'tell the news'; details for obstetrical plans; what considerations the parents should be aware of at delivery, birth, or later; and what the recommendations would be for follow-up visits or continuity of care with other clinicians or community providers.

Each case proceeded in a similar format. After the last case, the order of appointments would be established with considerations given to providing sensitivity and triage. For example: "let's see those with good news first so we can send them home quickly"; "patient X has young children with them/at home needing childcare"; "patient Y is from out of town and has several hours drive to get home" ; "patient Z is highly distressed so let's not make them wait longer than needed".

We would make our way from the 'rounds room' back to the clinical area, often taking stairwells and back hallways that are restricted or known to hospital personnel. During this time I would often ask for clarification about a term, diagnosis, or ethical issue, and / or the correct spelling of certain medical terminology. Initially, I found myself 'out of my depth' and unprepared by my lack of medical knowledge in a highly

specialized area. The medical residents almost always obliged me by offering background information to fill gaps in my knowledge. Often this also included a summary in non-medical terms. In turn, I asked questions that may have been obvious to a trained physician but were completely foreign to me as an outsider. These were also spontaneous moments for all kinds of things, from introductions, one-minute research talks, invitations to observe other things, practical discussion about dress codes and 'loud' footwear, and spontaneous moments where they acknowledged, supported, celebrated, and offered support to each other in various ways. There were also 'heavy' days where several cases were 'bad news' one after the other. These walks back were often then filled with silence-- few words, but knowing glances and sighs.

Back in the clinical area, the meeting with patients occurred in a windowed room with a round heavy wooden table that was too large for the space and chairs around it. The clinicians sat around the table, on one side facing the door. I usually tried to position myself so that I could observe faces and non-verbal language as well. Sometimes, a place at the table was available, at other times I sat perched on the windowsill. On a few occasions when the patient came with several family members, and there were too many people crammed into a tiny room, I excused myself and sat out the session. In those moments, I would stand or walk the hallway stealing a glance in the waiting rooms at either end. One waiting room had people waiting for appointments as well as family and well-wishers with flowers and baby baskets awaiting happy news from the labour and delivery area. The other waiting room was

out of the way and those who waited here were generally for 'the clinic'. People in waiting rooms often seemed to want to appear like just another person waiting for an appointment, but you could almost guess by the worry on a face. Often couples sat in silence, sometimes holding hands, sometimes trying to keep / look busy. I also observed that a woman with a visibly pregnant belly in a waiting room is the recipient of a lot of sideways glances. But patients and couples were not confined to this space. Between the morning and afternoon appointments some left the obstetrical areas and went to the Tim Horton's coffee shop or cafeteria or left the building to find lunch elsewhere and returned for the afternoon session.

During the afternoon sessions, the team stayed in the same room and patients /couples were brought in for the 'patient counselling' on the pre-arranged schedule. In cases when a couple or individual was highly distressed after the communication, the resident would typically offer to take them to an examination room in the corridor so that they could have 'some privacy'. It was often challenging for the team to end a session with bad news and distressed people but knowing that others were in the waiting rooms anxiously waiting as well and a schedule to be maintained.

At the end of the last session, each staff member gathered their things and went off to do their dictation and charting. On some occasions there were moments of unstructured impromptu debriefing or a teaching moment that happened in the room

after the last patient. Sometimes it was to express the reactions of the staff, especially if they had been the focus of a patient's anger, sometimes it was to express value laden thoughts such as "babies having babies" and sometimes it was just the sorrow experienced by the professional after a long day filled with having to be the messenger of bad news. Although this was the end of a typical day in the clinic for me, the staff still had several hours ahead of them.

Summary of observation and learning in the clinical context

In the approximately two years that I spent learning and observing in this environment, I was able to witness 75 cases with 67 different types of fetal anomalies as well as being a witness in the labour and delivery area and surgical areas.

Although this is a qualitative study, the following representation is intended to provide a synopsis of the clinical context. This summary is based on an analysis of the notes that I made to facilitate my learning and observational skills which would later inform both practice knowledge as well as refining the research questions and theoretical concepts for analysis. Hence, a caveat, that these numbers are not an exhaustive epidemiological portrayal but rather a reflection of the kinds of diagnoses and conditions that have informed my understanding.

In the area of maternal-fetal-medicine, the wellbeing of both the mother and the fetus is held together in priority to both. A study that looks at the fetal conditions in this context must therefore also be attentive to the maternal conditions as well.

Table 1 illustrates that among the 75 cases, the frequency of complicating factors in a case ranged from one to ten. Table 2 illustrates the frequency of fetal anomalies involved in all of these cases. While the majority of cases involved one or few anomalies, 10% of the cases had five or more anomalies per pregnancy. Table 3 illustrates the frequency of maternal factors. In 70% of the cases, only fetal conditions as factors were noted without maternal complicating factors.

In one case, no fetal anomaly was identified but there were two high-risk maternal factors. It is possible that either the suspected fetal anomaly had been ruled out as 'normal' prior to the clinic appointment or that the patient was referred to the maternal-fetal program for imminent maternal complications that could potentially compromise the fetus' wellbeing if unresolved.

Table 2: Number of fetal anomalies (FA) and maternal factors (MF) noted per case

| | N | Minimum | Maximum | Mean | Std. Deviation |
|------------------------|----|---------|---------|------|----------------|
| Total FA & MF per case | 75 | 1 | 10 | 2.96 | 2.140 |
| Total FA only | 75 | 1 | 10 | 2.44 | 1.832 |

Table 3: Frequency of fetal anomalies noted per case

| Number of fetal anomalies | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------------------------|-----------|---------|---------------|--------------------|
| 1 | 31 | 41.3 | 41.3 | 41.3 |
| 2 | 17 | 22.7 | 22.7 | 64.0 |
| 3 | 10 | 13.3 | 13.3 | 77.3 |
| 4 | 9 | 12.0 | 12.0 | 89.3 |
| 5 | 4 | 5.3 | 5.3 | 94.7 |
| 7 | 2 | 2.7 | 2.7 | 97.3 |
| 8 | 1 | 1.3 | 1.3 | 98.7 |
| 10 | 1 | 1.3 | 1.3 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

Table 4: Total Maternal factors noted per case

| Number of maternal factors | Frequency | Percent | Valid Percent | Cumulative Percent |
|----------------------------|-----------|---------|---------------|--------------------|
| 0 | 53 | 70.7 | 70.7 | 70.7 |
| 1 | 10 | 13.3 | 13.3 | 84.0 |
| 2 | 9 | 12.0 | 12.0 | 96.0 |
| 3 | 2 | 2.7 | 2.7 | 98.7 |
| 5 | 1 | 1.3 | 1.3 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

For clarity, the 62 fetal anomalies noted are grouped by the physical systems that are involved or impacted: cranial; facial and central nervous system (CNS);

cardiovascular; gastrointestinal; renal; musculoskeletal; growth & other. The maternal factors include a broad conceptualization of health, both the physical as well as psychosocial and lifestyle factors. Tables 6- 13 provide further detail for each system outlining the frequencies for each of the 62 fetal anomalies and 14 maternal factors.

Table 5: Fetal anomaly systems

| System involved | Frequency | Percent | Valid Percent | Cumulative Percent |
|--------------------------|-----------|---------|---------------|--------------------|
| Head- cranial | 13 | 17.3 | 17.3 | 17.3 |
| Head- facial | 3 | 4.0 | 4.0 | 21.3 |
| Cardiovascular | 5 | 6.7 | 6.7 | 28.0 |
| Gastrointestinal | 9 | 12.0 | 12.0 | 40.0 |
| Renal | 11 | 14.7 | 14.7 | 54.7 |
| Musculoskeletal | 4 | 5.3 | 5.3 | 60.0 |
| Soft markers* | 12 | 16.0 | 16.0 | 76.0 |
| Growth | 2 | 2.7 | 2.7 | 78.7 |
| Multi-systemic anomalies | 13 | 17.3 | 17.3 | 96.0 |
| other | 3 | 4.0 | 4.0 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

*Note: Soft markers are distinguished in this table from other systemic anomalies for two reasons. First, as signs and symptoms in their purpose as diagnostic clues and second, because soft markers in and off themselves do not present a significant defect that would compromise the structural or functional abilities of the fetus. Rather they represent part of the constellation of factors that clinicians attend to in the diagnosis, prognosis and treatment of care.

Table 6: Cranial anomalies

| Cranial anomalies | Frequency | Valid Percent |
|-------------------------------|-----------|---------------|
| agenesis | 1 | 1.3 |
| choroid plexus cyst | 7 | 9.3 |
| cisterna magna | 3 | 4.0 |
| Dandy-Walker syndrome | 3 | 4.0 |
| fused thalamus | 1 | 1.3 |
| holoprosencephaly | 2 | 2.7 |
| hydrocephalus | 4 | 5.3 |
| cranial structures/ size | 6 | 8.0 |
| lateral ventricular asymmetry | 2 | 2.7 |
| meningocele/ teratoma | 1 | 1.3 |
| ventriculomegaly | 7 | 9.3 |
| echogenic focus-brain | 1 | 1.3 |
| Total cranial | 38 | |

Table 7: Facial, Neck and Central Nervous system anomalies

| Facial & CNS anomalies | Frequency | Valid Percent |
|-------------------------------|-----------|---------------|
| absent/ abnormal features | 2 | 2.7 |
| cleft lip only | 1 | 1.3 |
| cleft lip and palate | 5 | 6.7 |
| cystic hygroma | 1 | 1.3 |
| NT defects* | 6 | 8.0 |
| Total facial & CNS | 15 | |

* NT is the often used obstetrical and ultrasound radiology shorthand used to refer to Neural Tube defects and to refer to the Nuchal Translucency measure, which is a measurement of the thickness of the nuchal fold behind the fetus' neck. This ultrasound measurement along with blood-work results taken during 11-13 gestational weeks informs early first trimester prenatal screening results.

Table 8: Cardiovascular anomalies

| Cardiovascular anomalies | Frequency | Valid Percent |
|---------------------------------|-----------|---------------|
| atresia-cardiovascular | 2 | 2.7 |
| abnormal heart rhythms | 1 | 1.3 |
| ASD/ VSD/ AVSD* | 5 | 6.7 |
| cardiac position | 5 | 6.7 |
| congenital diaphragmatic hernia | 2 | 2.7 |
| pericardial & plueral effusion | 4 | 5.3 |
| small ventricles or atria | 2 | 2.7 |
| vascular/ lungs/ blood in lungs | 1 | 1.3 |
| echogenic focus- heart | 7 | 9.3 |
| Total cardiovascular | 29 | |

* For spacing in the table above, the often used abbreviated shorthand is shown. These refer to defects in either the atrial or ventricular chambers or both.

ASD - Atrial Septal defect
VSD- Ventricular Septal defect
AVSD- Atrial Ventricular Septal defects

Table 9: Gastrointestinal anomalies

| Gastrointestinal | Frequency | Valid Percent |
|--|-----------|---------------|
| abdominal mass | 2 | 2.7 |
| amniotic fluid band | 1 | 1.3 |
| ascites | 1 | 1.3 |
| atresia, stenosis, distension- abdominal | 2 | 2.7 |
| dilated bowels | 1 | 1.3 |
| bowel / intestinal obstruction | 1 | 1.3 |
| gastroschisis | 4 | 5.3 |
| omphalocele | 3 | 4.0 |
| gallbladder-prominent | 1 | 1.3 |
| fetal stomach- prominent/ small | 3 | 4.0 |
| bowel loop- prominent | 3 | 4.0 |
| echogenic- bowel | 3 | 4.0 |
| Total gastrointestinal | 25 | |

Table 10: Renal anomalies

| Renal | Frequency | Valid Percent |
|---------------------------------------|-----------|---------------|
| agenesis- renal | 1 | 1.3 |
| hydroureters- unilateral or bilateral | 1 | 1.3 |
| hydronephrosis | 5 | 6.7 |
| pyelonephritis | 1 | 1.3 |
| polycystic kidneys | 3 | 4.0 |
| multicystic dysplastic kidney | 2 | 2.7 |
| renal obstruction/ reflux | 5 | 6.7 |
| renal dilation - kidney or pelvic | 10 | 13.3 |
| distended bladder | 2 | 2.7 |
| kidney size - larger or smaller | 4 | 5.3 |
| oligohydramnios | 4 | 5.3 |
| polyhydramnios | 3 | 4.0 |
| Total renal | 41 | |

Table 11: Musculoskeletal anomalies

| Musculoskeletal | Frequency | Valid Percent |
|------------------------------|-----------|---------------|
| achondroplasia | 2 | 2.7 |
| skeletal or spinal dysplasia | 3 | 4.0 |
| thoracic dysplasia | 1 | 1.3 |
| club foot/feet | 4 | 5.3 |
| Total musculoskeletal | 10 | |

Table 12: Growth & other factors

| Growth & Other | Frequency | Valid Percent |
|--|-----------|---------------|
| fetal anemia | 1 | 1.3 |
| cystic structure | 3 | 4.0 |
| growth- (LGA) or (IUGR) for dates* | 11 | 14.7 |
| infection exposure | 1 | 1.3 |
| screen positives** | 1 | 1.3 |
| fetal hydrops | 1 | 1.3 |
| echogenic focus (location not specified) | 2 | 2.7 |
| 2-vessel cord | 3 | 4.0 |
| Total- growth/ other | 23 | |

* IUGR and LGA refer to discrepancies between actual fetal size and the estimated ranges of normal growth at specific gestational ages. IUGR is also known as 'Intrauterine Growth Restriction' which indicates a fetus who is measuring smaller than the normal ranges, conversely LGA refers to 'Large for Gestational Age'

** Screen positive in this table refers to a linguistic communication by a health professional that a prenatal screening test result provided a significantly high probability risk that is interpreted by health professionals as a conclusive diagnosis for a particular condition such as Trisomy.

Table 13: Maternal factors

| Maternal factors | Frequency | Valid Percent |
|---|-----------|---------------|
| placental | 2 | 2.7 |
| pre-eclampsia | 3 | 4.0 |
| gestational diabetes/ diabetes | 2 | 2.7 |
| fibroids | 1 | 1.3 |
| anemia | 1 | 1.3 |
| spotting/ bleeding/ leaking fluid | 4 | 5.3 |
| fetal position / delivery concerns | 4 | 5.3 |
| mental health concerns and/or medications | 5 | 6.7 |
| no prenatal care/ folic acid | 2 | 2.7 |
| smoker | 4 | 5.3 |
| substance use | 1 | 1.3 |
| teen/single mother | 7 | 9.3 |
| unplanned pregnancy | 3 | 4.0 |
| domestic violence/ CAS | 2 | 2.7 |
| Total maternal factors | 41 | |

* Please note: The inclusion of teenage or single mother does not represent a “risk factor” per se. The inclusion of this category in the table represents an appreciation of the additional psycho-social, familial and peer challenges, financial limitations, access to resources and the availability of social support systems. In addition, an unplanned teen pregnancy may also include other factors to be considered, for example, whether they had prenatal folic acid supplements and sought prenatal care.

Demographics

The following demographics illustrate the patient contexts including the maternal and gestational ages, an approximation of the rural or urban localities that patients may come from, and the types of healthcare providers who may encounter and refer high-risk patients to a maternal-fetal program. As well, information concerning whether patients may have participated in prior prenatal screening and previous obstetrical histories is included.

Table 14: Maternal & gestational ages

| | N | Minimum | Maximum | Mean | Std. Deviation |
|-----------------|----|---------|---------|-------|----------------|
| Maternal age | 70 | 17 | 40 | 27.91 | 5.447 |
| Gestational Age | 45 | 13 | 38 | 27.00 | 6.079 |
| Valid N | 41 | | | | |

Table 15: Maternal age

| | | Maternal age | | | |
|---------|--------|--------------|---------|---------------|--------------------|
| | | Frequency | Percent | Valid Percent | Cumulative Percent |
| | 17- 20 | 9 | 12 | 12.9 | 12.9 |
| | 21-25 | 16 | 21.4 | 23 | 35.9 |
| | 26-30 | 21 | 28 | 30.1 | 66 |
| | 31-35 | 18 | 24 | 25.7 | 91.7 |
| | 36-40 | 6 | 8 | 8.6 | 100.0 |
| | Total | 70 | 93.4 | 100.0 | |
| Missing | System | 5 | 6.6 | | |
| Total | | 75 | 100.0 | | |

Table 16: Gestational ages

| Gestational Age | | | | |
|-----------------|-----------|---------|---------------|--------------------|
| | Frequency | Percent | Valid Percent | Cumulative Percent |
| 13-20 | 4 | 5.3 | 8.9 | 8.9 |
| 21-25 | 15 | 20.1 | 33.3 | 42.2 |
| 26-35 | 20 | 26.7 | 44.4 | 86.7 |
| 36-38 | 6 | 7.9 | 13.3 | 100.0 |
| Total | 45 | 60.0 | 100.0 | |
| Missing System | 30 | 40.0 | | |
| Total | 75 | 100.0 | | |

Table 17: Attending/referring specialist

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|------------------|-----------|---------|---------------|--------------------|
| Obstetrician | 27 | 36.0 | 36.0 | 36.0 |
| Family physician | 24 | 32.0 | 32.0 | 68.0 |
| Midwife | 6 | 8.0 | 8.0 | 76.0 |
| Other HCP | 2 | 2.7 | 2.7 | 78.7 |
| unknown | 1 | 1.3 | 1.3 | 80.0 |
| missing | 15 | 20.0 | 20.0 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

Table 18: General location

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|---|-----------|---------|---------------|--------------------|
| London Ontario | 25 | 33.3 | 33.3 | 33.3 |
| St Thomas, Middlesex, Elgin, Norfolk counties | 3 | 4.0 | 4.0 | 37.3 |
| Chatham & Kent county | 5 | 6.7 | 6.7 | 44.0 |
| Windsor & Essex County | 2 | 2.7 | 2.7 | 46.7 |
| Sarnia, Lambton & Huron Counties | 4 | 5.3 | 5.3 | 52.0 |
| Kitchener-Waterloo-Guelph, Perth, Oxford counties | 12 | 16.0 | 16.0 | 68.0 |
| Greater Toronto area | 2 | 2.7 | 2.7 | 70.7 |
| Grey-Bruce & Northern Ontario | 3 | 4.0 | 4.0 | 74.7 |
| unknown/ supressed | 4 | 5.3 | 5.3 | 80.0 |
| missing | 15 | 20.0 | 20.0 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

Table 19: Prenatal screening

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|------------------|-----------|---------|---------------|--------------------|
| yes | 5 | 6.7 | 6.7 | 6.7 |
| no | 4 | 5.3 | 5.3 | 12.0 |
| no -not offered | 1 | 1.3 | 1.3 | 13.3 |
| declined | 10 | 13.3 | 13.3 | 26.7 |
| missing/ unknown | 55 | 73.3 | 73.3 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

Table 20: Prenatal screening type

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|--|-----------|---------|---------------|--------------------|
| IPS or MSS | 10 | 13.3 | 13.3 | 13.3 |
| amniocentesis | 3 | 4.0 | 4.0 | 17.3 |
| MRI | 1 | 1.3 | 1.3 | 18.7 |
| declined screening or no previous result | 1 | 1.3 | 1.3 | 20.0 |
| IPS & amniocentesis | 3 | 4.0 | 4.0 | 24.0 |
| IPS & Ultrasound | 1 | 1.3 | 1.3 | 25.3 |
| missing/unknown | 56 | 74.7 | 74.7 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

Table 21: Obstetrical history

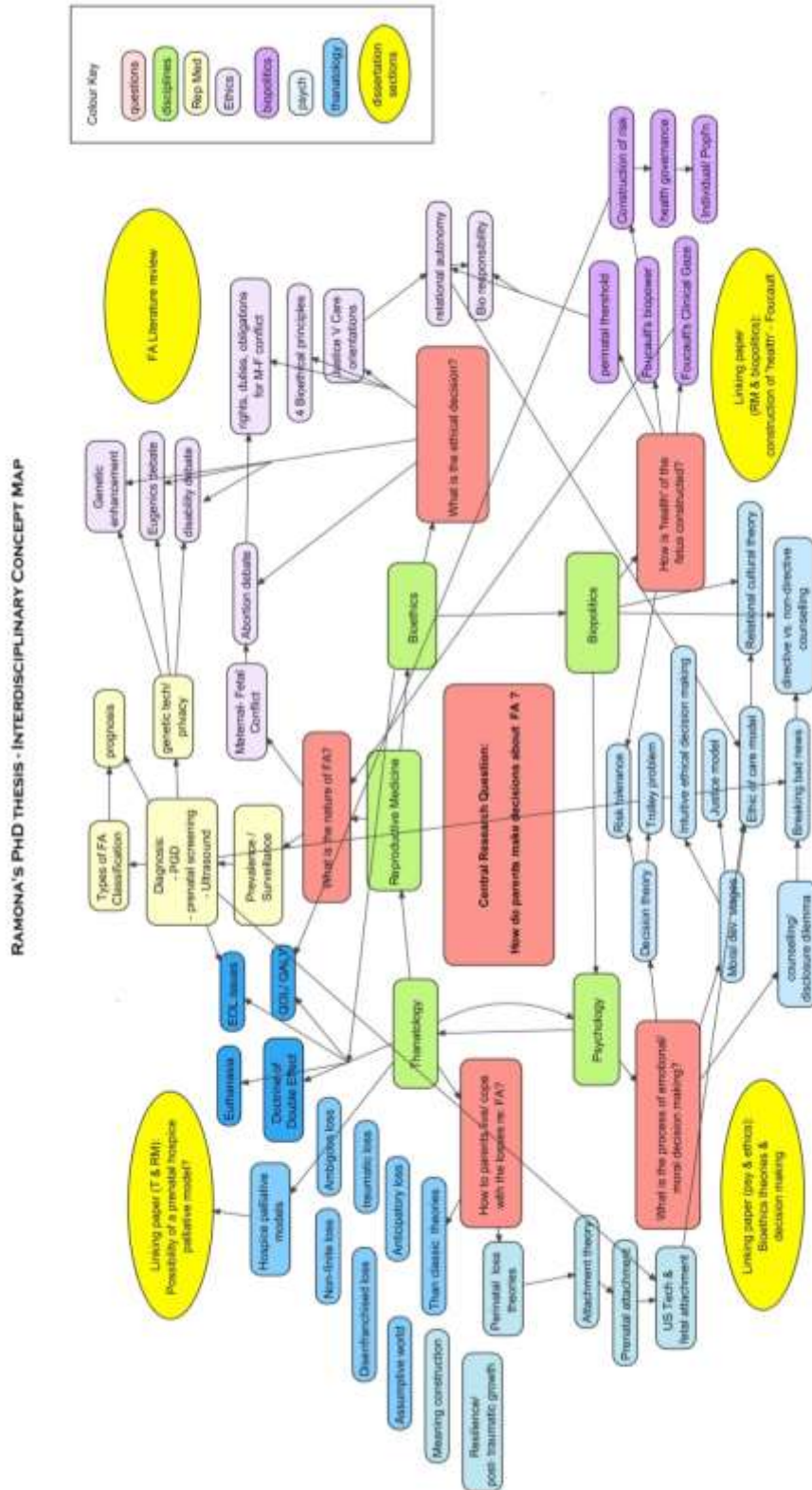
| | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------------------------------------|-----------|---------|---------------|--------------------|
| 1st pregnancy | 5 | 6.7 | 6.7 | 6.7 |
| living children | 10 | 13.3 | 13.3 | 20.0 |
| previous loss | 3 | 4.0 | 4.0 | 24.0 |
| previous loss & living children | 5 | 6.7 | 6.7 | 30.7 |
| family history of FA noted | 8 | 10.7 | 10.7 | 41.3 |
| genetic or consanguinity risk noted | 2 | 2.7 | 2.7 | 44.0 |
| missing/ unknown | 42 | 56.0 | 56.0 | 100.0 |
| Total | 75 | 100.0 | 100.0 | |

Figure 1: Revision of the final research questions



- FA = fetal anomalies

Figure 2: Concept map - Theoretical sampling



Phase 2: Research Interviews

Participants

Seven individuals who had experienced a diagnosis of fetal anomalies participated in the semi-structured qualitative interviews. The participant group comprised of five women and two male partners, representing the stories of five couples and six fetuses. These participants had all experienced a pregnancy complicated by a diagnosis of fetal anomalies within the past one year, some experiencing a loss as recent as two and half months prior to the interviews. Participants are identified by pseudonyms to preserve privacy and confidentiality. Furthermore, the names of the diagnoses have been omitted in the write-up of the results with the recognition of the need for genetic privacy, given that some of the fetal anomalies featured in these narratives are extremely rare, occurring in only a handful of cases each year, and hence participants' confidentiality may become compromised if revealed.

Recruitment - All consenting participants were approached and recruited by the hospital social worker who is affiliated with the specialized programs that provide clinical services to this population. This clinician generally meets with patients of the specialist clinic at the time of ascertaining diagnosis and continues providing ongoing counselling services for an open duration after the medical care has ended. The Research Ethics Board (REB) approval included a provision that participants must be 'prospective' and must be recruited by a health care provider within their circle of care. Hence, these participants met both inclusion criteria as specified by the REB requirements.

Inclusion/ exclusion criteria - Beyond the criteria of a fetal anomaly diagnosis, and sufficient psychological ability to be able to participate without undue distress that may

compromise the participants' wellbeing; there were no other explicit exclusion criteria. In the letter of information, participants were invited with the specific explicit wording that their views as parents were of critical value in helping to inform future clinical services. Given the relatively small prevalence of fetal anomalies amongst the reproductive population (3% of pregnancies), the potential sampling pool within the geographical area and timelines of the research study, and the REB requirements, the only feasible recruitment was purposeful sampling method and hence this is a convenience consenting participant group.

Demographics - The mothers ranged in age from 29 to 34 years of age at the time of the pregnancy (diagnosis/ loss). Their partners ranged in age from 30 to 38 years of age. All the couples in this study were in long-term relationships (married or soon-to-be married) at the time of their diagnosis and time of participation in the study. The educational level ranged from high school completion to graduate masters prepared. All of the couples had participated in some form of prenatal screening early in the pregnancy and throughout the diagnostic period.

Loss History - For three couples the fetal anomalies occurred in the first pregnancies. The other two couples had living children at home, with one couple having one biological child and the other couple having one adopted and one biological child. Two couples had subsequently been able to conceive and were in the second and third trimesters, with lower-risk pregnancies and no identified fetal anomalies in the subsequent pregnancies. For one couple their last pregnancy conceived after 8 years of infertility and many failed treatments, resulted in the intra-uterine death of one twin and a rare lethal anomaly in the second twin, and was also their last reproductive attempt. The total number of pregnancies resulting in a

conception amongst the five couples was 10. The following table illustrates demographics and reproductive histories.

Table 22: Demographics and reproductive histories

| Participants | Age | Education | Marital Status | Reproductive history | Prenatal Screening |
|---------------|----------------|-------------------------------|----------------|---|--|
| Fawn | M- 32 F- 30 | M- college F – high school | Engaged | 1 st pregnancy – unplanned, resulted in FA 2 nd pregnancy – planned (current, 31 weeks) | Yes IPS Amniocentesis Ultrasound Genetic counselling |
| Sophia | M- 29 F- 31 | M- college F- college | Married | 1 st pregnancy – planned, resulted in FA | Yes IPS Amniocentesis Ultrasound Genetic counselling |
| Ellen & Shawn | M- 34 F- 38 | M- university F- college | Married | 8 years of infertility with treatments 1 st pregnancy planned– miscarriage at 7 weeks Adoption – 5 years ago, Daughter age 6.5 Failed IVF converted to IUI – Son age 3.5 IVF* – 2 blastocysts transferred – twins Twin A – spontaneous loss at 7-8 weeks Twin B – FA *Last reproductive attempt | Planned but not completed IPS Ultrasound |
| Yvonne | M- 30 F- 31 | M- university F- college | Married | 1 st pregnancy – Daughter age 2 2 nd pregnancy – planned, resulted in FA | Yes IPS Amniocentesis Ultrasound Genetic counselling |
| Maya & Will | M- 30 F- 32 | M- masters F- high school | Married | 1 st pregnancy – planned, resulted in FA 2 nd pregnancy – planned (current, 17 weeks) | Yes IPS Ultrasound -regular & 3D Genetic counselling |

Procedures

Participants were initially approached about the study by the social worker with whom they had an ongoing existing professional relationship. She invited them on behalf of the researcher, explaining the aims and intentions of the research and facilitating their understanding of what would be involved in participation. Since, the potential participants would not have had a chance to meet the researcher prior to this recruitment, she may also have shared additional information about who the researcher was and answered relational questions that participants may have had to aid their process of giving informed consent. Once participants had given their signed informed consent to be contacted, she facilitated communication between the researcher and the participants by sharing participants' contact information.

The researcher initially contacted participants via email and upon reply phone and in-person meetings were arranged. Three participants met with the researcher to do the interviews in-person at a university office location, with one couple attending the interview together. The remaining four interviews were conducted over the telephone at the participants' request to facilitate convenience, privacy and accommodation of child-care needs.

The interviews were semi-structured to allow participants to share as much or as little as comfortable. The researcher guided the interview minimally with prompt questions around central research questions or with responses to clarify details and ensure a therapeutic rapport and pacing of the interview. Thus, interviews were variable in duration ranging from 42 minutes to 137 minutes of audio recorded length with the average being 87 minutes. The audio-recorded interviews yielded a total of 246 pages of typed single-spaced text (12 point

font size). The transcript lengths ranged from 15 pages to 82 pages with the average length being 41 pages.

In reality, the interviews themselves were longer than the recorded time to account for setting-up of equipment, establishing of trust and rapport; explanations and verbal confirmations of consent prior to the interview and debriefing after the interview. Thus, in reality, participants' actual contributions in terms of time and emotional willingness may be underrepresented by qualifications such as interview length and transcribed page counts.

Analysis

All interviews were audio-recorded and transcribed to facilitate a Grounded Theory analysis. Transcripts were read several times with and without audio accompaniment to allow for data immersion in the coding process. In keeping with Grounded Theory, as outlined in the methodology chapter, the data was analyzed inductively, first for content analysis in line-by-line open coding; followed by refining and organizing into axial codes and finally organization into the final eight thematic areas. MAXQDA 11 a Grounded Theory software program developed by Juliet Corbin was used to aid in the management of data. The analysis yielded a total of 1216 initial codes contributing to the eight themes.

The following table illustrates the frequencies of codes of the eight thematic areas and context data for interview times and length.

Table 23: Frequencies of theme codes & interview data contexts

| Participant | Prenatal screening | Diagnosis | Decisions | Individual Exp | Relational/ Post loss | Pregnancy & Baby | Services | information | Total codes | interview time | transcript pages |
|-------------|--------------------|-----------|-----------|----------------|-----------------------|------------------|----------|-------------|-------------|----------------|------------------|
| Fawn | 12 | 23 | 21 | 11 | 10 | 5 | 22 | 7 | 111 | 42 | 15 |
| Sophia | 13 | 52 | 18 | 39 | 46 | 32 | 33 | 13 | 246 | 81 | 46 |
| Ellen | 1 | 33 | 20 | 29 | 23 | 31 | 20 | 15 | 172 | 99 | 33 |
| Yvonne | 2 | 24 | 16 | 30 | 21 | 17 | 25 | 17 | 152 | 70 | 29 |
| Shawn | 0 | 10 | 10 | 43 | 18 | 13 | 16 | 3 | 113 | 96 | 41 |
| Maya & Will | 2 | 52 | 77 | 77 | 48 | 31 | 95 | 40 | 422 | 137 | 82 |
| Total | 30 | 194 | 162 | 229 | 166 | 129 | 214 | 97 | 1216 | 525 | 246 |

Analysis of codes and themes

The assignment of initial open codes followed inductively from the content provided by the participant. For example, if they were talking about going to see their doctor, it was assigned a code of 'HCP services received' to mean that they received some direct service from a health care provider. Other codes were also assigned based on the value or emotional connection to the description. For example, if they talked about their actions or behaviour in response to some person/situation, or feeling some emotion or reaction, these were assigned a code of 'reactions/ feelings'. A third type of open code pertained to aspects of an evaluative component, for example, views about the services they had received or reflective statements about how their views had changed; these were assigned a code that was either derived from the interpreted significance of the statement ('views about services') or a code derived from the interpreted meaning, often picked from the actual linguistic descriptions, for example the word 'shattered', which was used in numerous instances as a metaphorical descriptor.

In determining the sorting of open codes into axial codes and eventually thematic categories, the codes were grouped by commonalities that aid in answering the research questions. The first criterion for organization was whether and which codes were aspects unique to fetal anomalies as distinguished from other reproductive losses. The second criterion was related to the 'processes', what things happened in the narrative. The third criterion was framed around attempting to sort out how people navigated their way through this experience both physically and emotionally. The

fourth criterion centered on the private lived experiences and views about themselves, their pregnancy, their babies, and their losses. This criterion was distinguished from the third criterion on the basis of whether or not it was related to 'doing' or 'living/feeling/being'. The fifth criterion related to relational dimensions, including intrapersonal experiences and views and interpersonal interactions. The last criterion aimed to answer from a critical view how the content and codes may enrich a broader understanding, hence the interpretations and evaluations of participants was seen to be a valid criterion for this topic and study orientation. Although the thematic areas may overlap with the above list of criteria in their organization, these criteria provide explication of some of the underlying assumptions made during the coding process. In addition, although not consciously viewed as such, the frameworks of locus of control may also be applied here: the internal locus of control relating to what aspects were within the individual's ability to control change or make decisions (based on their reflections) and what aspects were factors outside such ability (as interpreted by the researcher or readers).

Narrative elements - Although, Grounded Theory is usually focused on processes and factors, narratives involving loss, grief, or relationships are often intuitively communicated as relational experiences and told following some narrative structure. In this study, the significant narrative elements were shaped by the first open-ended question: 'Can you please tell me in your own words what happened'. In keeping with convention, the stories began typically at the beginning, or the most

significant beginning which was often the point of transformation from innocence to the initial suspicions or the unexpected confrontation of 'bad news'.

Also noteworthy, were the relational clues. Unequivocally, they all referred to their fetuses with identification of personhood as 'baby'. The linguistic choices were, "our baby"; "our son/daughter"; by pronouns (he/she); or by given names, either formal single or unisex baby names, or in one case the nickname 'Peanut' because the couple had hoped to keep the baby's gender a surprise and formally name the baby at birth which never happened. Quite congruently, they also referred to themselves and each other as parents both in the self-identification and in their emotional responses. For examples,

"you also lost a child"

(Stated by Maya to Will in the interview, she also referred to him as the baby's 'father')

"I said to my husband later that it's weird because as a mother, you have these mother instincts, and now I can have them, so if something happens to my 2-year-old daughter, I can go and get her and I can take all those mother instincts, but with the one who passed away, I can't do anything." (Yvonne)

Theme 1: Prenatal Screening

The theme 'Prenatal Screening' emerged very early in the coding process, as stories began with the initial suspicions that occurred at a prenatal screening event. Initially the theme was organized around what prenatal screening tests were done, but this indicator was later moved under the theme of 'Diagnosis & Prognosis' for better fit with that thematic category. In the final analysis, the theme prenatal screening was focused around the participants' views, knowledge and rationales about participating in screening or testing. The sub-codes were: Prior thoughts on testing; prior knowledge about testing; testing rationales/ or reasons to pursue additional screening/testing. This was in the end, the smallest thematic category representing 30 coded items.

Prior views & prior knowledge:

"We had no idea that there was going to be a problem, we had no idea that there was a problem....I don't know the proper terminology to use, but we were in that pregnancy bliss of that—ignorant bliss—that you assume when you get pregnant, everything's great and you're going to have a healthy pregnancy. So we were in that bliss of just being pregnant, so we had just decided that, I decided let's just go ahead and do it. What's the harm in finding out?" (Fawn)

"I didn't know what all these tests were about ...You know, you think of an IPS test, "Oh, I get to go to an ultrasound and see my baby""(Sophia)

Reasons to pursue or not pursue additional testing:

"We did the 15-week blood work [sic IPS] as well, and once they did all the comparisons of the ultrasound and the two sets of blood work, they had told us that our child, or our baby, had a 66% chance of having Down syndrome, and we had at that point decided to go ahead and proceed at 16 weeks and do an amniocentesis."(Fawn)

This participant elected to follow through with additional testing to get reassurance and confirmation by another method. The amniocentesis came back with a 100% risk probability. The participants in the following quote, determined additional testing to be futile and therefore, did not wish to pursue the options.

“So you’re talking about it’s a spontaneous mutation that could be a gene. Do you have any idea what genes? No. So then there’s no way you’re going to be able to tell. There’s no way you’re going to be able to give me an answer to say, ‘We found it. It’s this gene. ‘So what really would happen in there? He said, you know, all that would really happen is they’d be able to—One, they’d be able to confirm it because she’d come out intact and they could see the legs, and I was like, but you already know that from the ultrasound. The pictures of the bones are right there.” (Maya & Will)

Theme 2: Diagnosis & Prognosis

This thematic area explicates the processes involved in getting to a firm diagnosis. In the narrative ordering, it began with either unexpected shock or initial suspicions based on the behaviour and vague nature of communications from health care providers, particularly ultrasound technicians who are not allowed legally to communicate a medical diagnosis.

The elements of this theme included: initial suspicions; the prenatal screening test done; waiting for results or referrals; uncertainty; hoping; getting tentative diagnoses; seeking reassurances & confirmations; getting a diagnosis and/or risk probabilities.

Particularly noteworthy, waiting was a pervasive feature throughout the process, reflecting 21.6% of the codes in this thematic cluster. In order of frequency, prenatal tests and uncertainty followed as dominant sub-themes

“Her procedure which they said was 10 minutes, but it would be a half hour before I see her. [sic 3 hours later]...And the last hour of that was me literally asking every 10 minutes where she was....You know, there was a point where I was so angry, it was like blind rage inside my head. I didn’t even—you know, at that point it wasn’t even—I didn’t think about what my wife was going through, I didn’t think about the procedure, I didn’t think about what was going on with me; I was just angry, and I couldn’t, I just couldn’t even understand how you lose, how could you lose a patient. Like, you have to know where she is; you can’t not know where she is” (Shawn)

Shawn later reflected that he was terrified that something had happened during the procedure and that he wasn’t being told. In light of the many tragic experiences endured by this couple, the multiple reproductive losses and the loss of both twin babies, the reaction to imagine the worst was understandable.

“She was really good. She didn’t really make me feel like there was anything wrong; I just had heard horror stories from other people, that’s why I had figured it out. At one point she had said to me that she needed to go and get the assistance from another ultrasound tech because she couldn’t quite get a good picture, and she had told me throughout the two hours that she had been doing this for 11 years, so I had a bad feeling at that point as well. So she brought in another tech, and she was wonderful as well, and they were focussing on the head at this time, of my baby girl, and then the new tech had said, “No, you got the right picture because of this.” So I had a bad feeling again. So then I think at that point she was going to go get my husband, so then she brought (husband) in, and ... then she said, “I’m just going to go talk to your doctor”, which I have a 2-year-old daughter, so I know that they don’t usually talk to the doctor before they’re done.” (Yvonne)

Suspicious were distinguished from uncertainty or tentative diagnoses by the intuitive sense of dread. Although, professionals assume and train to keep a neutral expression, patients are highly adept at scrutinizing the facial, body language and

behavioural cues that indicate that some is out of the ordinary. It is also possible that they are emphatically picking up of the emotions of the technicians. Being sent home with these initial suspicions and having to wait until the doctor received the report contributed to the ruminations of uncertainty and anxiety and the simultaneous hopes that everything would turn out all right. In these periods, the seeking of reassurance and confirmations even from tentative diagnoses meant that parents felt that they were included in the information sharing and not left in the dark. Thus, getting to a diagnosis was critically important, even a tentative one that could be followed up.

Theme 3: Decision-making

Once the initial awareness of fetal anomalies surfaced, parents had decisions to make regarding additional testing, treatment options for the obstetrical management of their pregnancies; and most significantly, whether or not to continue or terminate the pregnancy.

The elements in this thematic area are: hypothetical “what-if” decisions; reaffirming the hypothetical decisions; decision factors; the timelines to make decisions; and who actually made the decisions when they were made.

Beyond the factors, two elements are significant: First, the window to make decisions was particularly small, two weeks at the most and others with as little as 6-7

days to go from initial suspicions, gathering all the information to make an informed decision and finally the emotional readiness to follow through. This was overwhelmingly significant. Second, although the articulation of decision to continue or terminate a pregnancy had to be voiced, particularly by the mother as she is the 'patient', to meet the criteria of giving consent, who made the decisions was illuminating. In four of the five cases, the fetal anomaly had been determined to be fatal by the prognostic criteria. For these participants, the lethality of the condition or the 'conclusive' risk probabilities, as it had been communicated to them, was interpreted by some participants, that nature had decided the most critical factor for them. One couple experienced that given the woman's obstetrical risk factors, the lethality of the fetal anomaly, and the growing attachment of two very young children to the twin babies, the physicians made the decision that the pregnancy should not be prolonged and the termination option decided in light of managing obstetrical risks to the mother. In other cases, while the decisions on whether to continue or terminate were made as a couple, male partners deferred to the mother's decision on the choice of procedure as they viewed that it was her body and thus should support the woman's decision. When asked explicitly, what the male partners would have decided they expressed that the primary concern was whatever would be the least risk to their partner.

Decision factors – The decision factors related to two dimensions: whether to continue or terminate the pregnancy; and second, if the decision was not to continue

to full-term whether to do so a surgical procedure or whether to have an induction of labour.

With regards to the outcome of the pregnancy, the decision factors were:

- Quality of life: including suffering, survival, viability, sparing pain, not being 'trapped'
- Lifespan health: including future care and unknown future risks; how the child would live and function in the world, expressed as 'what kind of life?'
- Disability: the concerns for how the world treats people with disabilities; and level of awareness about disabilities, including knowledge of programs for financial and other aid; the personal experiences of people with disabilities or special needs; the assessment of personal and familial resources and limits; and how their child would be treated by others, and the implications of undue hardships for the child
- To fight or let go: the emotional meaning constructions about being parents; doing everything to fight; feelings that they were 'giving up'; distinguishing between their own desires and the best interests of the child; and their emotional limits
- Taking care of everyone in the picture: especially for the couples who had other living children, the assessment of resources and limits to be able to take care of all their obligations to other dependents; balancing the decisions in the current pregnancy with obligations to future children; concern for the well-being of the spouse; considering future feelings of guilt or regrets

- Certainty: the risk probabilities; the confidence in the accuracy of the diagnosis; having a 'firm' diagnosis; reassurances and confirmations of the diagnosis, prognosis and future; level of understanding, including a visual and empathic understanding.

"The suffering. That was really the biggest thing for me, because it would be so hard to watch that day in and day out. Not only that, but there was other factors there, too, like maybe not even being able to go to full-term, the risk that that would put on not just the baby but for (Maya), and then not even knowing the extent of, like, (fetal anomaly condition) and it just seemed to compile and compile and compile, so to me, at that point, it was like, yeah...For me, I wanted the suffering to end as quick as possible. That was one of the biggest things, and to limit as much risk as possible. So it just, that was the only option for me, but at that point, I can really only voice an opinion or sit there and listen, you know, but it's not my decision. I can only sit there and hold your hand or rub your back, or whatever, or give you Kleenex. I can really only bring it up to say that I'd like you to limit the risk and do it quickly, you know, for both of us and for (baby) Peanut". (Will)

With regards to choosing between the surgical or induction of labour, only one couple opted for an induction of labour, although one other couple would have preferred induction but weren't given the option due to pre-existing obstetrical risks. Another couple, decided against it assuming traumatic outcomes and now wonder if they may have chosen differently. Although the conclusions here are limited by a very small sample size, the following criteria may help illuminate the reasons behind procedural decisions. They are:

Desire to choose Induction of Labour:

"When they said "surgery", to be honest, I didn't know a lot about the surgery option, but I just knew I wanted the labour option. So they told me, they said, you know, you can either have a surgery to remove your baby, or you can have the full labour, and I said, okay, and I said I want the labour, 'cause I wanted to be able to hold her, and I wanted to feel—let me think—I wanted—Yeah, I just

wanted her to be brought into the world with love. I wanted her to be brought into the world with her mum and dad. Even though she was already passed by the time she came to the world, I just wanted her to be in my arms right away. That was the decision. I've grown to understand why people pick the surgery now, but I have no regrets at all. I knew I wanted the labour right away. It was just an easy decision for me." (Yvonne)

"So it was not an option for me to deliver, to be able to see the baby, 'cause I would have liked that, but they said that I could have some major health issues from that, and they also were concerned for our kids, you know, continuing to attach to the babies. So we had surgery that Friday" (Ellen)

Choosing the surgical Dilation &Evacuation:

"my picture was absolutely terrifying and absolutely horrible and I thought, you know, who wants to go through labour only to leave the hospital empty-handed, having left your baby in a morgue somewhere in the hospital. It's like, I can't imagine that. That's not at all what I've ever pictured pregnancy to be like, or my first pregnancy, for that matter, or any pregnancy. It's like I can't—and I knew that if I did, I really did think, if I do go through this, it's going to be hard enough to try and pick the pieces up and to pick ourselves up off the ground and move forward. If I do go through with this, let's say I can pick myself up, when I do get pregnant the next time, it's going to be that much worse because every association I'll have with the hospital, or every association I'll have with labour and delivery would be associated with that, and I thought I'd be, I could picture myself coming back in another room for delivery and everything hitting me again, and it was like, I can't do that. (Maya)

"I still know that the surgery was the right thing 'cause I'm a strong person; I am not strong enough to handle that...because I know that I'm not strong enough to bury my own child. I know that that is one thing in this life I cannot handle.being our first pregnancy, I didn't want it to be that traumatic delivering a baby and not being able to have that baby. So we knew that this was the best." (Sophia)

The three couples, for whom the experience occurred in their first pregnancies, the fear and imagery associated with not having a prior embodied awareness of labour, delivery, and birth; coupled with the risk of delivering a stillborn fetus or infant

who may die shortly was traumatic. They did not know, in an embodied way, how much pain to expect, how their bodies would react, whether they would emotionally and physically be able to endure. For the partners, the concerns for the risks to the mother were also noted, and women and their partners interpreted the information given with the understanding that the surgical option was less traumatic, more distanced, a more controlled environment and variables and the structure of knowing when the end would be final. For both the men and the women, but especially the women, the preservation of some semblance of 'normal' in a subsequent pregnancy was paramount in their ability to cope with the current and future reproductive plans and to mitigate the risks of a post-traumatic experience in the post-partum period and in subsequent pregnancies.

Theme 4: Navigating through the system

This theme focuses on the many ways that parents needed to navigate through the system to access specialized services. It specifically looks at the referral processes when suspicions and tentative diagnoses are made; the actual health care services received; parents views about the services they received; the service gaps and recommendations and the value of continuity of care.

Overall, these participants were especially grateful for the specialized services that they had received and recognized that in many communities such access is more difficult to obtain. The importance of continuity of care was highlighted in the recommendations for service following termination as well as for subsequent reproduction plans. Most surprisingly, there was confusion in the communication

about follow-up care. Participants were willing to give the benefit of doubt that perhaps in their emotional distress they either didn't hear or process the information at the time. They reported that they felt that they had access to a wide range of specialist during the diagnostic period, but in the post-loss phase they did not know whom to see for medical follow-up care. Consequently, they stated that in their interpretation about services, they left with the impression that once they were no longer pregnant there was no concern to follow-up. The implications for the therapeutic relationship in the current and subsequent pregnancies is the risk that patients may that a lack of continuity to be interpreted as that they are not deserving of the same level of care when they make a decision to terminate a pregnancy.

"I was handed a pamphlet, literally, as soon as I woke up from being put under. I woke up and they gave me a pamphlet and the nurse kind of went through it, and I remember her giving me a shot, saying something about Rh, and then she said something about, then highlighted "Call this number" and come back in, like, three weeks. Make an appointment with your physician, or your OB, and I didn't even think about it. We went home and I'm like, who do I call? My family doctor? The first OB? The second OB? The third OB? Like, the guy who prepped me? The person who did the surgery? Like, who am I supposed to call for a follow-up? So I was like, this is crazy. ... I understand, but even something as simple as, you know, you're being followed by these people, like, literally the day we went in to say that we'd made the decision that we were going to terminate, that was it. Like, they were like, okay, well our secretary will call you with a date, and that was it. That was the last time I ever heard from them. There was no follow-up, there was nothing. Like, it was just like I know that you, I don't expect you to be the counsellor, I don't expect you to be a social worker, but there should be something. There needs to be something in place. It can't just be like the last time I saw you was in a boardroom with six other people where you broke my heart and ripped the carpet out from underneath me, The End. Like, I was like, how can you be surprised that I don't want to come back and see the same OB when that's my last experience with you. That was my last interaction. I can't come back in and see the same person." (Maya)

In a subsequent pregnancy when the assumptions about a healthy pregnancy and healthy fetus have been shattered by a fetal anomaly diagnosis, the emotional reassurances and confirmations that everything is indeed well take on a heightened significance. For a couple where the communication about future obstetrical care was made clear, the peace of mind was evident.

“This is the other thing I really like is that now we were under a lot of guidance, so when I get pregnant again, I can immediately call—the genetic counsellor who has been sitting in on our group sessions for the therapy, and I can call her right away and she will get me set up with the high-risk Ob/Gyn right away, and then they will have ultrasounds a lot earlier and they will guide me the whole way. So if I go to my family doctor, he said it would simply just be to confirm that a pregnancy is present. He wouldn’t follow me at all. I would go straight to the Ob/Gyn.” (Yvonne)

Parents also reflected that the volume of information and decisions to be made within a short window of time and a legal deadline, imposed limitations on how much information can be emotionally processed and hence the processing of information and decisions related to informed consent are prioritized on the most pressing decisions. In the aftermath, the reflections about wishes and desires surface, especially around the tasks of mourning and creating remembrances. Reproductive losses are especially marked by the absence/ limitations of having tangible mementos, the opportunities to gather and retrieve physical artifacts is limited to the pregnancy and hence may present as missed opportunities later.

“The other thing that I can think of is having them do the handprints and the feet prints. Later when we got introduced to the support group and whatnot, we all sort of brought in different things to show, like, how we commemorate and whatnot, and I guess you’re given the option, but with so much stuff just thrown at you, you’re making decisions like that [snaps fingers quickly], and you don’t really, you might not make the right decision, or it might get overlooked or

whatever, and if it was just done and even if it was kept on file or whatever, then at least you have the option to go back and get it versus if you just said no, or if it wasn't even thought of or whatever at the time. Then, like, you can still get it, you know?" (Will)

Theme 5: Information & Communication

The highlights of this thematic category are the ways in which parents and health care providers worked together to provide information that would become the basis of informed consent. The four sub-codes were: information seeking; information sharing; language and communication; and the responses from health care providers.

Information seeking is a pertinent factor mediating between suspicions, uncertainty and the need for answers. When communication was vague, or delayed by referrals backlog parents ventured on their own to seek information on the internet. They often didn't have sufficient information such as a tentative diagnosis use in a search, or they didn't know where to begin their search. This led to exposure to inaccurate information, forums filled with arm-chair experts, and in one case visually disturbing images that the participant could then not un-know.

Furthermore, in instances where there was confusion about whom to contact for follow-up questions, they called and got generic advice from the physician's secretaries. In one instance, the advice about dealing with lactation that was provided by the secretary, while good advice for a woman who has a living baby, the erroneous advice actually did more harm by encouraging a lactation response and ultimately resulting in an infection.

The participants noted sensitivity to language and delivery of information. Although words like 'abortion' have specific meaning in medical terminology, participants identified that such language was further stigmatizing because of the societal connotations and the metanarratives that did not resonate with the emotional difficulties of their situation. They did however appreciate greatly the open, candid, frank and honest communications and responses of sensitivity and explanation that facilitated their ability to make informed decisions.

In appreciation for the ability to process information when distressed, a male participant explains the emotional limits:

"They told us a lot of stuff, but to be honest with you, I blocked most of it out. You know, I really stopped listening at one point where it became irrelevant"
(Shawn)

Participants also understood that in some cases, the conditions are so rare that the base of knowledge is limited.

"When we asked what it was, what caused it, 'cause there was a genetic counsellor there as part of the group that we saw, and they said they weren't sure because it's so rare, and ... I don't remember who it was, but I remember in the group someone said like, "It's just a spontaneous mutation and it's just, it's rare, and it's like you're outside on a sunny day and you guys got hit by lightning." That's never left me. I always think about that phrase. I always think, "Oh, yeah." So and every time when I hear a stat, I'm always like, what does it matter? I was outside on a sunny day and I got hit by lightning, so why wouldn't this happen to me, too?" (Maya & Will)

The following quote illustrates metaphorically the reduction of the baby to a sum of its parts. This couple explained that while they appreciated the information, this

reductionism became yet another loss in the validation of the baby that was celebrated previously. Hence, the need for sensitivity in communication.

“Like, just talking the way we talked about her before, the way people talk to her about us, and seeing the ultrasounds. Like, going through the ultrasounds, it was no longer like a picture of a baby; it was here’s the bone or here’s the piece of the jaw, whereas before they show you a whole baby” (Maya & Will)

“That’s a term that they explain to you, like, the Genetics Department will explain to you. They don’t call it a termination; they call it an interruption. Even the social worker that you’re set up with—When you’re set up with a genetics counsellor, you’re also set up to meet with a social worker just before, if you choose to quote unquote ‘interrupt the pregnancy’, and I think maybe even if you decide to follow through with the pregnancy, you’re still again set up with a social worker at the hospital...Out of all the terms that you can use, the interruption is probably the nicest, and probably the most accepting form of words to use” (Fawn)

Theme 6: About the pregnancy & the relationship to the baby

This theme was cohesively focused on reproductive history; the pregnancy history and details; factors surrounding the events of the loss and trauma (physical and emotional) associated with the loss; and the relationship to the baby. The relationship to the baby included dimensions of prenatal attachments, wantedness, investment in healthy outcomes, parental behaviours indicative of attachment and inclusion of the baby within the family.

Significance of gender and naming in the grieving process:

“We weren’t able to find out the sex, so when we found out the sex, it’s almost like from the time that it happened to the time that we did find out the sex, we

couldn't have closure because it wasn't done, and so when we found out, at least for me, it was, it was sort of like, you know, she was born that day and died that day all over again. So it was, it was nice 'cause it made it more real, and then I was able to name her and we decided to name the other baby as well, to be fair, and so we were able to name then and then do our memory box and kind of finish the process, if you can ever finish it, but also it made it real and it was like we lost all over again." (Ellen)

Maternal behaviours:

And then I think when I started to wear the maternity clothes and stuff ...And I had started, a few weeks prior, going through the books and I was remembering how big are they and all this stuff, and I was just waiting for them to start moving, and I actually, the week before I just bought my cocoa butter cream to start doing my routine of putting the cocoa butter cream and all this stuff for stretch marks and stuff. (Ellen)

Couple investment behaviours

"So then my husband and I left kind of hopeful after that. So we went out for dinner together and we went shopping for things for her room because at that time, until that day we didn't know that she was a girl. So we went out, we bought a few girl things that I wanted to buy but I didn't know if she was a girl or not. So we bought those for her room." (Yvonne)

Relocating the baby within the family

"You know all your options and everything as soon as you can, yeah. So there's that. And I also think that, for me personally, and you can say if it's the same for you or different, I feel like this pregnancy has actually made me feel closer to Peanut, 'cause I really do feel like she's watching out over me, and over her baby sister or brother. Like, I really do feel that way, and so it's funny 'cause every little time I have an ultrasound that's good and I get positive news, like, I automatically, like, oh, my god, I'm so grateful, I'm so happy for this baby, and then I'll go home I'll say, like, a little prayer and thank Peanut, 'cause I know you're watching out over us." (Maya & Will)

Reproductive losses are not commonly identified as the loss/ death of a child, in the manner that the death of a living child is socially acknowledged. However, in cases where the identity of a child within the family has been acknowledged, the non-death

losses that also manifest are the loss of the unborn child's identity, the ambiguity of the relationship and place within the family unit and the social acceptance by others for recognition of the life and the death. The ritual of naming a baby in reproductive losses, is deeply significant for the existential process of making meaning. The ritual of naming a baby provides a way for parents and families to re-frame the identity and relocate the child within the family structure. It also salvages some of the prenatal attachment that was abruptly interrupted and provides a trajectory of transition. Transition rituals in mourning seek to create some order to the chaos of the liminal space between life and death. In the area of reproductive loss, the assumption that birth precedes death is altered and with it the legal and social status of identity left existentially unresolved. Quite practically, the naming of a baby also gives parents and families a way to talk about, remember and mourn their loss without having to allude to vague pronouns like he/she to refer to their baby. The confusion of vague pronouns to refer to a significant loss may create further disenfranchisement and a sense of hurt that others are not readily responding. Naming a baby re-creates a sense of identity and allows the social community to engage in mourning and remembrance, thus re-enfranchising a disenfranchised loss.

Theme 7: Relational & Post-loss experiences

This theme is distinguished from the theme of Individual experiences, by the focus of interaction – interpersonal relationships. The elements of this theme are:

Taking care of self and other, including the couple's relationship; disclosing news about what happened; the availability and accessing social support networks, the responses from the social networks; stigma and disenfranchisement; and subsequent pregnancy.

*"So since then, you know, because there have been too many, I've decided to no longer talk about it to protect myself because these last few comments I thought, like, if I hear one more thing it's going to possibly harm my relationship with my family. So I'm choosing now that if they bring it up, I'm just going to say "I'm not talking about this anymore." Which is sad, but I just have to do it."
(Ellen)*

*"However, the one thing I wish that they wouldn't say in the surgery, you're lying on the table and before they put they put the anesthetic in, the surgeon calls out your name, and says "and having an elective abortion", and at that point I just started to bawl because to me it wasn't an abortion because to me that is such a—there's a stereotype that comes with that word, and what we wanted was we wanted a baby, we wanted a child, and it's just something we couldn't have ...there's just too much stigmatism around that word ...maybe if they had said at the end of it, you know, "abortion due to genetic anomalies" or "chromosomal abnormalities" or something just to make people—I know everybody in the room knows what's going on, but just so that we feel the comfort of knowing that, okay, they're not passing judgement on us...That word means unwanted, to me. It means it's an unwanted pregnancy."
(Sophia)*

*"So I don't have the co-workers. My friends weren't there, and my family are not good with their emotions, so they provided supported when I guess you asked for, or you showed that you needed it, but if you weren't there and you weren't showing it, you were just left to yourself...Yeah, I guess, but I was walking through my days as a daze, you know? ... Now, with my role, I'm there to support and whatnot, but nobody really asks about you, nobody really checks in to see how you're doing. It's all, "Oh, how is she doing?" ... You're trying to be strong for everybody else and you're trying to pick up some of the slack. ..Girls can usually get, and if you have a friend, usually talk about anything. Guys? You punch each other in the shoulder, and go have a drink or something."
(Will)*

The availability, quality and willingness to access social support is frequently identified as supportive factors in grieving. In cases where the loss is disenfranchised the ability to ascertain the quality of support is emotionally challenging. Quite significantly in this thematic area, the struggle and decisions about whether or not to disclose the circumstances of the loss were poignant. In some cases, couples had a pre-determined which individuals would say hurtful or stigmatizing comments and made a decision to either avoid disclosing the news to such individuals or contain the details to an indication that the baby had died. In some other cases, couples had assumed that certain individuals would have been supportive only to have to encounter openly hurtful or un-informed opinions. While the death of a child, in any stage of development, is highly distressing, having to justify or defend one's medical decisions adds layers of disenfranchisement, stigma, social blaming that adds to perceptions of emotional culpability rather than constructive social support. In addition, the gendered differences or social perceptions about grieving may not actively acknowledge the experiences and emotions of male partners, adding additional layers to disenfranchisement.

The language and linguistic associations of medical terminology that has been absorbed into political meta-narratives, adds additional layers to the stigma. Although the word, 'abortion' has a specific medical meaning, this word has been deeply value-laden in the metanarratives, as implying 'killing' or 'unwanted child'. The implications for professionals, is that for clinically sensitive practice, an open acknowledgment between clinicians and patients, that certain language is not value-neutral. Either, the language when communicating to and in the presence of patients should change to adopting more sensitive language or that patients receive some explanation of the reasoning behind the medical meaning and implications of certain terms, such that they are not left with a perception of stigma from their health care provider. A number of participants spoke about the implications of hearing such terminology –

for women undergoing surgical termination, this is often the last thing they hear and remember before the anaesthetic takes effect and hence last thing on their conscious awareness that resurfaces when they wake up, triggering additional distress. A suggestion put forth by these participants, was that if the term 'abortion' must be used that the following considerations may help: first, that the consent form with this wording be presented and signed prior to the day of surgery, if possible; and second that a suffix be added to contextualize the reason - 'abortion for fetal anomalies'.

Theme 8: Individual Experiences

This theme reflects four aspects: reactions/feelings; grief and mourning; coping and moving forward; and the shattering of the prior assumptive world. The feelings of injustice at devastating outcomes; the ongoing stress of shock and uncertainty; the feeling and associations of being on a rollercoaster of emotions, hope, needing to accept reality; and a profound transformation of self and the world that nothing was safe anymore made this an intensely deep and rich theme. While multiple quotes could be used, the following two are illustrative of shattered assumptions.

In the first quote, the additional familial context also represents disenfranchisement, wherein the participant's father does not recognize that the couple has lost their child. Rather the father views it as a pregnancy loss and 'something to get over'. The participant's identification as a bereaved parent is summarily also disenfranchised and grief dismissed. The quote is in reaction to her sister "taking it for granted", that people get pregnant and have healthy babies.

“We (sister) were pregnant together. We had planned it, to be pregnant at the same time, and then she said that she didn’t want any more kids, that she was done. She has a daughter already. And then she said, “You know what? One’s enough. She’s 3, she’s busy, and it’s expensive.” She didn’t want another child, and this baby happened as an oops! So you have all of the questions like she didn’t even want this baby” (Sophia)

The second quote references the multiple reproductive and concurrent losses.

This quote is included for two reasons: First, the perspectives of fathers are highly limited in the literature and thus this view represents a lesser known perspective of a partner’s perspective after loss. Second, it is illustrative of the layers of infertility, multiple reproductive losses and now ‘being out of reproductive chances’ due to using the last remaining viable conceptions to conceive the pregnancy that ended in fetal death in one twin and a lethal anomaly in the other. The pregnancy was the last hope for another biological child. They were simultaneously grieving the deaths of two babies, their fertility, all the past failed treatment cycles, the hardships imposed on their children and family life and the financial strain that now emerged to the forefront.

“But it doesn’t actually come into play until well after the situation is over, and that’s when you suddenly realize how much money you spent to go through—I think that’s the problem is that if it would have just failed from the beginning, it wouldn’t have been a big deal. You wouldn’t have felt so ripped off, right? But the fact that you basically paid all this money to go through what right now is the worst thing we’ve ever had to go through. That’s why you feel ripped off, right? It’s not so much the money, because I would have paid twice as much for healthy kids, right?... And then on top of that, you have to decide. So you paid for this, you paid for these kids, and now you have to decide whether or not you’re going to terminate the pregnancy. There’s like this layer of—I have no idea, you know, just all these psychological nightmares going on, right?, where once you sit back and reflect on it, you realize that you just paid a crapload of money to have to decide—you know, it’s almost like paying for a really expensive car and then having somebody burn it.” (Shawn)

Conclusion

Limitations – Although the methodology is identified as Grounded Theory, this was a preliminary exploration into the parental experiences and the phenomenon of fetal anomalies. At such an initial stage, a more tentative claim would be that this was a descriptive exploration of the phenomenon leading to the generation of a conceptual model. Future research in the areas of reproductive loss, fetal anomalies, and reproductive technologies would be needed to compile a more comprehensive representation. A comparative analysis of other forms or typologies of reproductive loss in multiple sites and diverse communities would also be needed to refine these preliminary conceptual descriptive models towards the formulation of a ‘theory’.

While the rich descriptions, reflections and interpretations of participants provided an enriched understanding of previously private perspectives, these were the experiences of a small sample. Fetal anomalies, with a prevalence rate of 3% of the general pregnancy population and a locally referred population of limited geographical range posed significant limits to recruitment of larger sample sizes. Furthermore, in recognition of the potential for distress, and the requirements to balance the potential benefits with potential risks, the recruitment was capped at a small conservative sample size for a preliminary exploration.

The perspective of male partners, although clinically significant, is limited to the voice of two participants. Both participants illuminated important considerations for clinical practice and the under-represented view of fathers. Clearly much work still

needs to be done to research and acknowledge the view of partners, both male and same sex partners.

From a pregnancy outcomes perspective, there are potentially three groups – those who continue a pregnancy, those who elect for an early induction of labour and those who opt for a surgical termination of pregnancy. Although, a perspective was shared by those who had either an early induction or surgical termination, the perspective of those who continue a pregnancy after a fetal anomaly diagnosis was a limitation. Although, this group was also included in the eligibility criteria, this group was in the end, not represented. Given the ethics board parameter of a ‘prospective population’, this requirement posed a logistical challenge to recruitment of this group. This group, in the prospective period, would likely be dealing with maternal and/or neonatal concerns, or otherwise, engaged in providing care for an infant at home or in the NICU. Quite reasonably, in a prospective period, this group was not successfully recruited. In future studies, a consideration that recruiting from this group as a retrospective population may provide better success.

Although political metanarratives create a perception of a dichotomous choice, the reality for parents experiencing a diagnosis of fetal anomalies, is anything but simplistic. The simple assumption that all one needs to do is decide is pre-determined by a political stance on the pro-life pro-choice debate, is quite fallacious. The reality is that parents are faced with complex diagnostic and prognostic criteria that are often case-specific risk probabilities. The complexity of decisions feature at the points of

negotiation between rational (information based) decisions, intuitive (emotional and value based) and the relational bases. The process of decision making was logically also complex with multiple points of divergence based on further testing and diagnoses, creating a process map that is non-linear. Decisions are often made tentatively, and reassessed in light of new information, marked by uncertainty and needing to be continually reaffirmed during the process.

The losses are multiple, beginning with the initial suspicions and the first loss as that of the idealized healthy child and healthy pregnancy. These losses are not necessarily limited to death, they may be non-death losses, such as the loss of innocence about a happy pregnancy. The pregnancy and subsequent pregnancies after such losses are marked by uncertainty and professional determinations of what is considered 'low risk' or 'high risk' may not necessarily be congruent with the emotional anxieties for parents, who come to view subsequent experiences through the lens of risks – that if bad things could happen once, might bad things happen again.

Chapter 4: Theoretical Discussion

Nature of Grief and Bereavement in Reproductive Loss

The field of Thanatology reflects several theories of grief and bereavement. Unlike other fields where it is possible to contextualize an issue within one particular theory that is used as a template to model explanations, life and death do not follow neatly structured patterns and hence a template model does not necessarily fit due to the nature or complexity of the issue. Thus, several psychological and thanatological theories help explore the understanding of fetal anomalies as a specific typology of reproductive loss.

Situating reproductive losses within the identified perspective of couples who view themselves as parents in the perinatal period allows for the transition to parenthood to be acknowledged as a spectrum of increasing attachments that may come to be interrupted before birth by a death.

“Birth and death are traditionally viewed as opposite ends in the spectrum of the life cycle which intersect too soon for bereaved parents, especially in pregnancy loss when death comes before birth. The greatest disruptions to our assumptions of life and the universe are when the natural order is changed unpredictably. For parents who face the death of their children, the natural order of life and generational progression is shattered. For parents who lose their child in pregnancy there is an added layer of unpredictability that life can end before birth” (Fernandez, 2008, p. 5).

While common empathy reinforces the notion of the tragedy of parents who outlive their child, the trajectories of losses of reproduction pose unique contexts for the numerous ways non-death losses that also feature concurrently and layer additionally upon the death: such as confidence in one's biological ability, the hopes, dreams, future plans and self-identity as 'parent.' In the context of fetal anomalies, in addition to the trauma of unexpected 'bad news' about the health or viability of the fetus, the moral distress at having to make decisions pertaining to life, death, treatment, and palliative care add additional complexities to the trauma and grief of these parents.

Historical frameworks

Thanatology theorists have, in the past, phrased their models as stage, phase, or task- oriented models. Without belaboring the tremendous contributions of these theorists here, I would highlight a few models that provide different perspectives to the topic.

Stage/ Phase models -Dr. Elisabeth Kubler-Ross is one of the best known pioneers in the field of bereavement. She put some order onto the explanation of the pain of grief following death. Her most famous theory conceptualizes grief as comprised of stages. These stages involve, again theoretically, a progression from: shock, denial, anger, bargaining, depression, testing and acceptance (Kubler-Ross, 1969). However, an assumption that is made based on Kubler-Ross' model, is that grief will follow a linear and logical progression that starts with shock and ends with

acceptance. In reality, this progression may not be so orderly. James Thorson is one bereavement specialist among many who have criticized Kubler-Ross' approach as reflecting "a hierarchy." He holds that people can be adaptive and experience more than one emotion at a time – reflecting an "adaptive repertoire" (Thorson, 1996). Kubler-Ross also proposed that the process of grieving affects four aspects or "quadrants," namely mind, body, heart, and soul (as cited in Panuthos & Romeo, 1984). Although, Kubler-Ross did not conceptualize her theory to apply to reproductive loss, it is often featured in medical and public arenas as a sort of how-to-fix-yourself manual. Without intending harm, when applied as a catch-all to reproductive loss, the contexts mired in deep distress and multiple existential losses may be overlooked, oversimplified, or minimized.

Task models - William Worden's theory conceptualizes the process of grief as reflecting four main "tasks of grief." They are: to accept the reality of the loss; to process the pain of grief; to adjust to an environment in which the deceased is missing; and to find an enduring connection with the deceased in the midst of embarking on a new life.

(Worden, 2002 & 2009; Worden & Winokuer, 2011). In this theoretical conceptualization, the process of grief is viewed as emotional work rather than consisting of passive phases. The concept of "tasks" is akin to acknowledgement and active processing while not presuming a hierarchy or logical progression. It allows for, and gives permission to, people to continue to feel and experience the pain of grief

even though time may have passed as they are working on their adjustment. There is fluidity between the rawness of pain and making meaningful connection and detachment to the deceased loved one. The idea of tasks may particularly appeal to instrumental grievers (Martin & Doka, 2000; Doka & Martin, 2010).

Grief-Restoration models - Simon Shimson Rubin's two-track model (Rubin, 1999; Rubin, Malkinson & Witztum, 2003) and Stroebe & Schut's dual-process model (1999; 2001; 2005) proposed that a person need not have a discrete phase as 'grieving' versus 'living/moving forward.' Rather that model allows for the experiences of being bereaved and moving forward to occur in parallel (two-track model) or to oscillate between periods of intense grief (grief focused) and continuing with daily life (restoration focused). For couples dealing with reproductive losses that are very private and may not have been openly disclosed, they may, in fact, have to function in both capacities as bereaved privately and normal daily functioning in public. Furthermore, a common situation after a reproductive loss is the decision on whether and when to attempt conception again, and hence the restoration focus may in these instances have been emotionally and physically determined.

Mediators of Mourning - There are, on occasion, assumptions that individuals who are challenged with the same type of loss will respond in the same or similar way. While this may be true in acknowledging how some losses are qualitatively unique from other losses, there is danger in presuming that individual reactions to grief can be

categorized in such a standard manner. This assumption can lead to a narrow view of what is an acceptable grief response; what is 'normal' grief; and how long grief should last (Harris, 2009). Quite problematically, when bereavement doesn't go according to a social script, these assumptions present in the professional discourse as psychological pathology (depression, non-functioning) rather than an existential human response; and may unintentionally lead to unfortunate comparisons about whose grief is more tragic or more deserving of lengthier bereavement; for example, pregnancy loss versus death of a live born child; and platitudes such as "you're young, you can still have other children." Aries (2004) reflects that in Western society death has become constructed as a failure of medicine or technology. Harris (2009) critiques that the implicit "should" and "should not" have laid out an unspoken set of social scripts for grieving rules which she calls the "oppression of the bereaved": who has permission to be bereaved; how long grief should last; what is an emotionally appropriate response and even whether the death or loss is socially acceptable or stigmatized.

While grief, as with many aspects of the human condition, has a range and spectrum, clinicians must be able to distinguish between truly pathological or complicated grief and normal grieving in order to provide effective and safe services. Rather than having to rely solely on anecdotal comparisons of case based experiences, Worden indicates that several factors can mediate the grief response and while not everyone responds to an event in the same way these factors provide a deeper assessment and appreciation of the complexity of each case. According to Worden, the

factors mediating the grief response include who the person was; the nature of the attachment; the mode of death; historical antecedents; personality variables (mourner's personality); social variables; and concurrent stressors (Worden, 2002, pp. 38-44; 2009, pp. 57-76).

Fetal anomalies as a distinct type of reproductive loss

Anticipatory Grief

Loss and grief are inextricably bound to each other with the anticipation of death as a unique dimension that invokes pain prior to the loss. When the loss is sudden and unanticipated, the process of grief begins with the shock, as in Kubler-Ross' theory (1969). In my previous research, most of the participants' experiences with pregnancy loss occurred suddenly and hence the grief began from that point. Two participants in previous research (Fernandez, 2008; Fernandez, Harris & Leschied, 2011) who had experiences with genetic anomalies identified that the losses began with the suspicions of problems related to the pregnancy. As they waited for diagnoses and answers, and the seeming inevitability that their babies would die, the threat of imminent death hung over them. These women talked about the trauma of having to wait, knowing that nothing could be done to save their babies from this fate.

Therese Rando (1986; 2000) referred to this process as anticipatory grief, defined as "the phenomenon encompassing the process of mourning, coping, interaction, planning, and the psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present and future" and that "by definition that griever is pulled in opposing directions" (Rando, 1986, p. 24). In 2000, Rando redefined the terminology to *anticipatory mourning* to convey the intended inclusiveness of both the reactions to loss (grief) and the processes (mourning).

In cases of fetal anomalies, frequently there is the struggle between acceptance of the loss of a child and hope for survival. Hope is placed in miracles, faith, in medical advances, in treatment after birth including technological advances in hope for experimental approaches through fetal surgery. Rando also clarifies that anticipatory grief relates not only to the preparation for impending bereavement; it is also the loss and grief of a past, present and future (Rando, 1986, p. 15). In the case of fetal anomalies, the past is the loss of the perfect child, the present reflects losses such as the multiple losses associated through diagnosis and medical decisions, and the future losses encompass the hopes, dreams for the child and ideals of what the family could have been.

In addition, there are “critical situational factors” that influence the process of anticipatory grief, including : “1) at what point the patient and family are in the illness trajectory; 2) the amount of time elapsed since the diagnosis; 3) and the circumstances that have transpired since the diagnosis, including the patient’s attitude and approach to life” (Rando, T., 1986, p. 25). These factors were initially developed with regards to the dying patient who was born. However, these same factors could be transferable when considering fetal anomalies. The woman is both patient and parent and the attitudes of the parents are relevant.

Rando (2000) classifies six dimensions to anticipatory mourning: perspective (dying patient, those in close intimate relationships to the patient, concerned others,

and caregivers); time (past, present, and future); influencing factors (psychological, social, and physiological); adaptation demands (loss, trauma); generic operations (grief and mourning, coping, interactions, psychosocial reorganization, planning, balancing conflicting demands, facilitating an appropriate death); and contextual processes, intrapsychic, interpersonal, systemic (pp. 51-102).

In 1986 when the concept of anticipatory grief was relatively new, Therese Rando noted anticipatory grief as a theoretical construct for naming the liminal space formerly deemed the “living-dying interval” (Pattison, 1977, 1978 as cited in Rando 1986, p. 5). Subsequently, in the following decades the theoretical discussion about what defines and characterises anticipatory grief as a unique phenomenon distinct from other bereavement has been refined to a more comprehensive understanding of the typology than just a name for the liminal space between life and death. Rando (1986) stressed that the experience of anticipatory grief was not just about a “forewarning” awareness of impending death or that such grief was a portioned out quantity of grief as a false assumption of a fixed and finite amount of reaction to loss experienced on an earlier timetable (p. 8-10). While foreknowledge would logically lead to a sense of anticipation or foreboding, the experience of anticipatory grief also encompasses the struggles of relinquishing denial, ambivalence, hope and acceptance of the inevitable. Thus the period of anticipatory grief is experienced as an emotional push-pull.

Rando (1986) distinguishes post-loss grief from anticipatory grief by drawing reference to the temporal structure of anticipatory loss *preceding* and marked by a finite endpoint brought about by the death/loss. She conceptualizes the temporal continuum as mourning the past, present and future, where the future entails not just the impending death/ loss but also all the things that will never be (p. 10-15). The latter point is significant to reproductive loss in particular as the potential person with all the promise, hopes, and dreams that are effectively existentially erased when the life ceases to exist.

Disenfranchised Grief

Reproductive losses are uniquely stigmatizing and silenced in society. Death is a difficult reality to comprehend and to draw meaning from; it is particularly challenging when the death involves an unborn child. In part, society is reluctant to talk about reproduction –the challenges and the losses, miscarriages, infertility, abortions, and fetal anomalies. They are often silenced, almost in a conspiracy –as if, through silence we need not acknowledge that it occurs. The reality however, is that for as long as humans have attempted reproduction such losses have occurred.

Pine (1986) raises the question of “appropriateness of death” and its role in the experience of anticipatory grief. Although it appears at first to be a controversial question, the question when viewed through a constructivist or critical theory lens enables an examination of why some deaths and indeed some losses are regarded by

society as more or less taboo or acceptable. Worden (2002, 2009) itemizes his theory of the 'mediators of mourning' wherein he considers the relationships, the nature, timing and mode of death among other things for a clinical explanation, whereas Pine offers a sociological view about the assumptions that are revealed in the social construction of loss, death, whose life was worth more and perceptions about the quality of the dying person's life (1986, p. 42-43).

In observations within the clinical setting, one of the first questions frequently spoken through tears is 'what did I do wrong?' The concept of genetic and prenatal testing, while useful for diagnosis, can also propel this implicit judgment of parents who ask in the clinic –'is there something wrong with us, did we give this to our baby?' leading to the appreciation that with fetal anomalies, there are multiple layers of stigma or disenfranchisement that come with the type of loss and mode of death: the genetic or heritable aspect as a biological determinism where a chromosomal abnormality is identified ; a prenatal biological health promotion responsibility or genetic citizenship that is placed on parents by implicit or explicit social messages regarding 'health,' illness, and disability; the sense of biological failure to produce a 'healthy' child; and the stigma of decisions to be made, whether stigma over the decision to terminate the pregnancy or the judgements about continuing 'a life of suffering,' or 'not fighting hard enough.'

Kenneth Doka (1989; 1997; 2002) speaks about unrecognized grief and griever. "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). Grief may be disenfranchised in any one of the following ways: the relationship is not recognized; the loss is not recognized; the griever is not recognized; and the death is disenfranchising (Doka, 1997, p. 276-279). Pregnancy loss often may feature all four ways of disenfranchisement, particularly when there was little or no tangible “proof” of the baby’s existence (Fernandez, 2008; Fernandez, Harris & Leschied, 2011).

Attachment and Hope

Certain aspects of the reason for reproductive losses being disenfranchised may reflect that society, family and friends do not know the deceased fetus in the same way as a person who was once born and alive. The unique nature of the relationship that an unborn child has is with their parents, but even within parents, there is a difference between mothers and fathers. Nevertheless, the formation of attachment, desire and investment in an unborn child precedes the birth of the baby.

Prenatal Attachment - Peppers & Knapp (1980) identify nine events that contribute to the formation of attachment between mother and infant. These include: planning the pregnancy; confirming the pregnancy; accepting the pregnancy; feeling fetal movement; accepting the fetus as a person; giving birth; seeing the baby; touching the baby; and giving care to the baby. Indeed fathers often also participate in the development of attachment in these ways. Such losses interrupt the normal progression of parental attachment. Attachment and a sense of who the baby would

have been play a major role in the experience of loss. Abboud & Liamputtong (2003) state that this makes, “the loss of the baby more profound because hopes and expectations were set on the potential person” (p. 56).

Moulder (1994) distinguishes between attachment and investment; “attachment is concerned with the development of feelings for the baby, whereas investment is a more active process of involvement in the pregnancy” (O’Leary 2004, p. 10). Ritsher, & Neugebauer, (2002) speak to the investment and ‘wantedness’ as indicators of attachment. They included in their study four items measuring investment, namely, thinking about a name for the baby, making changes to the home in preparation for the baby’s arrival, purchasing items for the baby, and thinking of what is lost as the loss of a baby or child. Ritsher & Neugebauer (2002) also looked at the effect of quickening (fetal movement) and identified that those women who had experienced quickening, as well as those with greater investment in the pregnancy had higher grief scores following their loss. For women, behavioral indicators of attachment may include: walking like a pregnant woman, touching or patting the belly, feelings of longing, dreaming about the baby, imagining how the baby would look, wondering about the sex of the baby (Ritsher & Neugebauer, 2002). Fetal anomalies are typically identified in the second trimester when prenatal screening methods are sensitive enough to detect such anomalies. The earliest screening is at 11-14 weeks gestation, but more typically such anomalies become revealed at the detailed anatomical ultrasound scan between 16-22 weeks, at which time there has been significant

development of the fetus and quickening has likely occurred as well as bodily changes of the maternal condition.

Effects of Technology on Relationship & Attachment

Access to pregnancy confirmation from home pregnancy tests “combined with first trimester sonograms, leads to an earlier bonding with the fetus in-utero and the development of a mental representation of the child” (Keefe-Cooperman, 2005, p. 282).

The fascination with visualizing the gestating fetus has been prevalent since the 1960’s when Lennart Nilsson first began to photograph in the womb using endoscopes for intrauterine visualization (‘Drama of life before birth’, n.d.). The fetus in the womb as depicted in Nilsson’s images were featured on the front cover of the 1965 issue of LIFE magazine, and his subsequent coffee table photography books (Nilsson, 1965 as cited in Maienschein & Robert, 2010; Haraway, 1992). Ultrasound technology (now a routine prenatal care service in developed countries), has made this means of visual knowledge and visual bonding accessible to the average woman and couple. Haraway (1992) suggested that the “technoscientific” advances into reproductive technologies become a metaphorical “virtual speculum.” It is not limited to the image itself by the act of seeing in the formation of a bonding experience: anticipating ‘baby’s first picture’; imagining what they will ‘look like’; having a doctor or technician point out details like the face, limbs and interpretations about the actions of the fetus like

'hiding,' 'shy,' 'active,' hearing a heartbeat; getting a printed picture to take home and show others.

"The description is performative; i.e., the object described comes into existence, experientially, for all the participants in the drama. ... Life itself becomes an object of experience, which can be shared and memorialized...the mother touches the on-screen fetus, establishing a tactile link between parents –to-be and child-to-be...and turn machines into eloquent witnesses and storytellers" (Haraway, 1992, p. 26).

Visual technologies appear then to bridge the gaps between 'hidden' and 'visible' transforming 'gamete tissues' into 'persons' with what was 'potential life' or 'fetus' redefined as 'baby'. 3D and real time 4D ultrasounds have further transformed grainy black and white images into facial features and visible movements, like a gestational Skype session and some boutique services will happily record the session to take home as 'baby's first home video.'

Technological advances in imaging technology are "providing parents an opportunity to visually bond with their infant, although the effect does not appear to be as significant as quickening" (Robinson, Baker & Nackerud, 1999). West (1995) makes a distinction between mothers who consciously or unconsciously may be withholding emotional attachment as a protective mechanism versus those mothers who allow themselves to engage emotionally because they are anticipating a normal pregnancy, thereby adding another variable to the fetal-maternal attachment process. What should be considered is that with additional ultrasound technology, in order to

screen and diagnosis anomalies there is also the effect of visually stimulated attachment occurring. For parents, the knowledge that they are experiencing a high risk pregnancy with a fetal anomaly is like a double edged sword; on the one hand it is a medical necessity to provide answers while on the other hand it allows the parents to 'know' their child visually. In cases where the anomalies are explicitly visible the ability to see with one's own eyes and have visual reassurances about the accuracy of the diagnosis may be therapeutic to validating decisions as the 'right/ best'. However, where the chromosomal genetic structure is the primary anomaly or where the structural anomalies are not directly obvious to the untrained eye, the added confusion must also be factored for its ambiguity.

When the outcome results in a spontaneous fetal death or termination the result reflects two losses; the loss of the idealized 'healthy baby' and the anticipated loss of relationship to the child with whom the parents have visually bonded. In the absence of other tangible "proof," these images remain powerful memories and provide a way to re-enfranchise a disenfranchised loss.

Torn between Hope and Acceptance

In cases of fetal anomalies, often there is the struggle between acceptance of the loss of a child and hope for survival. Further, reflective of the limitations in medical science, professionals assessing the viability of life and the fetus' prognosis have termed certain anomalies 'lethal' such as Anencephaly and Trisomy 13 and

Trisomy 18. Conditions such as Trisomy 18 or 13, once considered 'lethal,' are now, in rare cases, resulting in a live birth. However, it remains 'lethal' due to the fact that the child will not live for an extended period of time in the neonatal period. However, given the potential of a live birth, Koogler, Wilfond & Ross (2003) propose that the term lethal should no longer be used due to the potential directive influence of language. They argue that, "although many of the congenital syndromes that at one time were considered lethal, no longer remain so, even though they are routinely referred to as 'lethal anomalies.'

Ambiguous losses

Pauline Boss (1999) defined such losses as the "ambiguity of absence and presence" (p. 2). Ambiguous loss is marked by the stress of "waiting and wondering" (p. 5); "indefinitely unclear" and "indeterminate" continuation of doubt and hope that "defies closure" (p. 6); marking an extreme and persistent ambivalence to accept or deny an uncertain reality and "clarify who is *irretrievably lost*" (p. 12). Thereby, freezing lives, relationships, and identities and inadvertently complicating the grieving process by the lack of answers, lack of confirmation about the finality of the loss, and lack of ritual to mark the transitions. Hence, "just as ambiguity complicates loss, it complicates the mourning process" (p. 10).

Typically featuring four characteristics: *Uncertainty* creates confusion because it is unclear whether the loss is final, permanent or what is now distinct in a change for the survivors; *Frozen* because the lack of clear demarcation of loss as discrete prevents

survivors from reorganizing their lives to accommodate to the loss and functions as stuck-ness, unable to go back and undo the circumstances but also unable to move forward towards resolution; *Lack of ritual* - to mark the loss symbolically, receive validation and support from one's support system and hence mark the transitions; and *Absurdity*, an existential shattering of the previously held worldviews about safety and the world as just and rational (Boss, 1999, p. 7-8).

Ambiguous loss is marked by uncertainty as the prevailing criteria, although the range of reasons and the subsequent search for answers to make sense of it may be varied, at the core the very loss itself is not clear. Ambiguous loss is distinct from disenfranchised loss, although the sequelae of an ambiguous loss may well be disenfranchised. Boss (1999) profiles that the two faces of ambiguous loss are: '*Physically absent but psychologically present*' and '*physically present but psychologically absent.*'

The psychological tasks in the absence of certainty, may be to '*revise the family portrait*' by taking stock of who remains, what their relationship used to mean, how/whether the relationships change as a result, redefining the nature of the new family 'portrait' and second, "the ability to let go of needing an absolute and precise definition of family" (Boss, 1999, p. 32).

Each of these factors play a role in fetal anomalies, where the ambiguity of reaching diagnosis, the uncertainty about the accuracy upon which decisions are made, and the multiple losses that are often not tangible (such as self-identity), or non-finite

(loss of a healthy pregnancy) may not be socially recognized even if the fetal death is so recognized as a death-related loss. The existential experience in reproductive loss encompasses more than the physical and emotional manifestations of grief. Gray and Lassance (2003) iterate that it also manifests as: Loss of a part of the self, loss of self-esteem, loss of identity, loss of innocence, affected mothering instinct, impact of attachment and bonding, ambivalence in subsequent pregnancies, uncertainty about the timing or success of subsequent conception, worries about a 'replacement baby,' impact on sexual relationships, challenges in distinguishing between grief and post-partum depression, anxiety about receiving more 'bad news,' and concerns about returning to the same health care providers and institutions for fear of being triggered or experiencing post-traumatic reactions (p. 81 -130).

Considering Perinatal Palliative Care for High Risk Pregnancies involving Fetal

Anomalies

The institution of hospice palliative care has been in existence for many decades whether as a formal institution or a group of caring individuals dedicated to easing suffering and joining in solidarity with the dying person and their family (Canadian Hospice Palliative Care Association, 2002).

The concept of palliative care offered during pregnancy occurred to me rather surprisingly. During observation in the field at a high-risk pregnancy clinic, I noted that the language parents used was relational language. I cannot recall a single time in my observation where the parents referred to their fetus as 'fetus'; they tended to say "my baby" and where they knew the gender, they would use pronouns (he/ she). As I walked home after a particularly heart-wrenching clinic day filled with one session of 'bad news' after the other, I noted with frustration and my own feelings of sadness that there were multiple losses and anticipatory grief; both compounded by a lack of time. However, it was a comment from a parent insisting that all interventions necessary should be implemented despite medical futility. The linguistic usage reflected how family members typically speak about an elderly person in palliative care. At the time, she was still pregnant but her language reflected how one speaks for and advocates for a person who is born and physically accessible for intervention. There was something in her manner that day that jolted me into wondering, why can we not incorporate the

principles of hospice palliative care during pregnancy for parents anticipating the death of their baby?

I was challenged by the unspoken assumptions - that palliative care seems traditionally to be something available when the person is physically available to provide comfort care, ease pain and suffering, etc. However, at a conceptual level, the principles of palliative care may still be possible even though the fetal patient is not physically accessible due to the confines of the womb. I wonder if in an age where technology can, in rare cases, permit invasive fetal surgery, the barrier of being contained within the uterus may be a shifting perinatal threshold of a 'physically accessible' fetus as patient.

Furthermore, as in pediatric palliative care in consideration of developmental stage of the minor, capacity for decision making and advocacy rests with the parents or guardians (Canadian Hospice Palliative Care Association, 2006). During the prenatal period, the pregnant woman is both patient and parent. This section aims to begin a discussion about a broader understanding of the application of palliative care principles in the prenatal period.

Hospice Palliative Care

"Hospice palliative care strives to help patients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; prepare for and manage self-determined

life closure and the dying process; and cope with loss and grief during the illness and bereavement” (Canadian Hospice Palliative Care Association, 2002).

Pediatric hospice palliative care is based on the same principles as adult hospice palliative care but also recognizes the unique needs of families faced with a child’s illness and death. In particular, special consideration is given to: development stage (physical, cognitive, emotional and spiritual); communication and understanding of illness, coping, death, and the associated emotions and reactions; incorporation of family, school and community as integral to the child’s life; differing reactions to interventions and therapies; reliance on family for advocacy and decision making; familial considerations and parental responsibility to the ill child as well as other children and family members; concurrent stressors for parents; grief for all members of the family, and special consideration to the bereavement issues for surviving siblings (Canadian Hospice Palliative Care Association, 2006).

Neonatal Palliative Care, in addition to general principles for adult and pediatric palliative, care also addresses that suffering requires attention to the physical and developmental environment of the NICU as a family-centered philosophy of care. These measures include aiding decision making with parents, psychosocial and spiritual support of the family and the inclusion of siblings (Carter, 2004). With regards to the environment of a NICU, Toce, Leuthner, Dokken, Carter & Catlin (2004) recommend that “high tech and high touch co-exist and complement each other.” In this definition, the practical issues are centrally featured in the delivery of palliative care to a

neonatal/ perinatal population. Aspects such as providing a quiet room with NICU and consideration for whether delivery takes place on a labor and delivery unit or gynecological unit, and whether the grieving family is located within women's care/gynecological units or antenatal/postpartum units are logistical issues.

While there is a large amount of literature on palliative care for adults and the pediatric population there is very little on the concept of addressing palliative care during pregnancy and prenatal consultation. The majority of the information in this area is from perinatal and neonatal populations. Though these are developmental extensions of the same continuum- conception to birth, from my clinical reflections the discrete and distinct difference is the fact that in neonatal palliative care the child is born and therefore physically accessible to provide interventions or palliative care. As well the determination of life or death is clear and unambiguous even if the prognosis is not certain.

During pregnancy issues surrounding gestational age, viability, compatibility/incompatibility with life, and the options for continuation or termination of pregnancy are fundamentally different characteristics of this period. Therefore, these unique aspects have to be contextualized when considering palliative care principles during the prenatal period. Among these is the balance between "beneficence owed to the fetus" and "the principle of maternal autonomy" (Catlin, 2005). During the prenatal period the pregnant woman essentially contains the

identities of two conceptualizations of 'patient' and hence she has to make dual and intertwined decisions and physicians need to address aspects of medical care for both the mother and the child understanding that each affect the other. The complexity of this dual principle is reflected in the delivery of care in maternal-fetal medicine.

Viewing this period of development from an attachment perspective, there is a qualitative difference for parents and family when there is an option to see, hold, touch, provide care, make sensory and tangible memories, and involve others in the acknowledgement of the child's existence than when this is not available as a choice. During the prenatal period, while attachment is possible it is further removed physically. The connection and attachment operates through the physical barrier and parents engage in attachment and connection facilitated by viewing ultrasounds, feeling fetal movement, and experiencing pregnancy embodiment (Fernandez, 2008).

From my consultations with staff working with this population, those couples who opt for an early induction of labor the possibility to see, hold, touch, provide care, make sensory and tangible memories and involve others in the acknowledgement of the child's existence, can be facilitated through perinatal bereavement programs. Thus even after delivery there is a chance to salvage some precious time to have connection and make memories (Burden, J; Conacher, S; Poole, M; Kinlin, K. , Personal Communications, 2008). However, for those who opt for surgical termination of pregnancy (D&E) for genetic conditions, due to the nature of the procedure and sterile

surgical spaces, there is not an option for parents to view their deceased fetus, should that be desired.

Given that there was not a great deal of specific resources addressing palliative care within pregnancy, I broadened my search to include combinations of terms including: perinatal, neonatal, NICU, palliative care for newborns/ neonates, fetal anomalies, pediatric palliative care, and end-of-life care for newborns/ neonates/perinatal. This was conducted over several weeks and multiple searches including resources from published articles, books, palliative care groups website resources etc. The only limitations were language specification being that texts be English. Most of the resources generated from such a search were expected- issues pertaining to grief/bereavement, palliative principles and considerations for translation into practice, and parents and family issues.

Addressing palliative care during pregnancy when determined provides a continuity of care that travels alongside the patient and family for the full duration. This is also the time when parents “must make numerous decisions, arguably the most difficult of which is whether or not to continue the pregnancy” (Sumner & Kavanaugh, 2006).

During pregnancy the medical management is through the Obstetrics department; once the pregnancy ends, the care is taken over by Neonatology in the

NICU, other departmental referrals or referral back to the family physician/ public health nurse. The incorporation of an interdisciplinary palliative care team that extends their care into the developmental phase of pregnancy can ensure that there is a key stable contact even if patients are shuffled throughout the system. Furthermore, when parents determine that continuing the pregnancy is not their decision or not feasible, beginning the discussion of palliative care during pregnancy allows more time with which to make decisions, plan, express wishes, and time to deal with the anticipatory grief.

Staff may be better able to incorporate all of the domains of issues such as medical management, physical, psychological, social, spiritual, practical, loss/ grief, and end of life care and death arrangements (CHPCA, 2002). Following the CHPCA model for 'Norms of Practice' and processes for provision of care can plan to have continuity of care that incorporates ongoing assessment, information sharing, decision making, care planning, care delivery and confirmations (CHPCA, 2002) integrated in such a way that service is consistent and that when the death occurs there is an intact system that has been on standby to support the patient and family.

That said, broaching the words "palliative care" while the woman is still pregnant may seem jarring and insensitive if not framed within a context of service provision that intends to provide holistic care, thus reframing some of the

communication from 'nothing more that can be done' to 'here's what we can offer' as opposed to just the bad news alone.

At times balancing hope and medical futility is just as difficult for family with a fetus or newborn baby as it may be to make such decisions for an adult patient. A newborn who is ill and possibly also premature brings the added challenge of considering how much can be done invasively to a fragile infant within bounds of safety to ensure that the intervention does not cause more harm than good. During pregnancy balance between diagnosis, prognosis, what can reasonably be done after birth, and parents' perceptions about the kind of life they want should all be considered and with that an appreciation that the added challenge of whether to continue or terminate the pregnancy. As advances in technology continue within fetal surgery, the window to accessibility is pushed further and even during pregnancy there may need to be considerations of intervention versus comfort care.

In conclusion, the core principles and values of hospice palliative care seem consistent and transferable to various populations and developmental stages. Just as with pediatric and neonatal populations, there are special considerations for considering the concept of palliative care during pregnancy. Given the possibility of death and multiple losses, a palliative care approach still has a place, albeit the delivery of such care may look modified and different.

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Chapter 5: Philosophical Discussion

Biopolitics: A Foucauldian framework for considering prenatal screening and decision-making

In examining the notion of the healthy embryo/ fetus from the perspective of biopolitics it is imperative to ask what we can know in determining ideas about the construction of 'health'. More importantly, we need to ask why we need to know, and how we will arrive at ascertaining this knowledge. The taken for granted answers seem obvious and simple enough: don't we want healthy fetuses and therefore healthy babies?

Drawing on Foucault's concept of the clinical gaze (Foucault, 1975) I seek to problematize this simple answer about why we should care about healthy embryos, and turn the focus instead to how we 'construct' the notions of health. As such, I propose a philosophical analysis with regards to prenatal testing: that it is revealing not a discrete uninfluenced objective reality, but rather about how we construct 'reality' in the ways that we look, see, talk about and ascribe meaning to the those things before our eyes. Furthermore, drawing on Foucault's work, I contend that within the context of prenatal testing, which tends to ascertain fetal health by the presence or absence of anomalies, it is also important to examine the underlying subliminal, albeit, perhaps well intentioned motivations behind the desire to see, to know, to gaze beneath the tissue and sinew into the private hidden space of the womb. Although the simple obvious answer to the invitation to participate in prenatal screening seems

intuitively like a common sense response, it is not sufficient to end the discourse there without examining the manner in which such a process and its technologies are managed; and considering the implications for the individual and the social structure. In this paper I therefore chose to adopt a critical look at the structural significance of prenatal screening within a relational structure encircling the individual and extended to the didactics of the clinical interaction and the broader social structure.

Two central works of Michael Foucault, the *Birth of the Clinic: An Archaeology of Medical Perception* (1975) and *History of Sexuality: Volume 1* (1990) inform the theoretical basis for this analysis. Specifically, Foucault's notions of the 'clinical gaze' and 'biopolitics' offer a theoretical conceptual framework with which to examine the manner in which prenatal testing may be used as a technology. In particular, as a technology that might be seen as a tool to manage the vitality of the species that through careful scrutiny, selection and social cooperation ensures that the healthiest fetuses are primed for survival. The term prenatal screening in this paper is used broadly to include the various techniques and technologies by which investigations of the fetus or embryo are carried out, and includes pre-implantation genetic diagnosis (PGD); visual technology such as ultrasound; blood or serum based screening such as maternal serum screening (MSS), amniocentesis, chronic villus sampling (CVS), and integrated prenatal screening (IPS).

At its most basic level, the desire to ensure survival of the healthiest fetuses by affording the best available technological advances towards prenatal care has dramatically improved maternal and fetal health outcomes reflected in the decreasing morbidity and mortality rates. “Perinatal mortality appears as a category in local, regional, national and global statistical systems, governed as part of the vital statistics of population.” (Weir, 2006, p. 11). At a social level, the investment in healthy fetuses bears not only medical consequences during pregnancy but also economic consequences for the larger social structure and the duration of lifespan of these fetuses.

The analysis in this paper will begin with an overview of prenatal screening as a way of knowing, followed by a discussion of Foucault’s theories of biopolitics and the clinical gaze and the relation of these theories to prenatal testing. Specifically, drawing on the concept of biopolitics in Foucault’s *History of Sexuality* (1990) this paper positions a lens through which one could view prenatal screening as serving the function of the following four arguments: a *‘confessional narrative’* of genetic secrets embodied within the unborn; the manner in which prenatal testing exercises surveillance and *‘disciplining of the body’* of an individual prior to birth; the motivations as an *‘investment in life’* and finally the broader economic-political motivations that drives the regulation of health prior to birth.

Prenatal screening as a way of seeing & knowing

In examining the claim that prenatal screening is intended to improve fetal health outcomes, I propose two prongs to the examination. First, how do we see and come to know the hidden fetus to reveal its manner of gestation and to know the gestating being intimately enough to ascertain its conditions of health. Second, is the manner of the discourse about the fetus. Both the manner of knowing and the manner of speaking constitute a discourse relevant to biopolitics because as Foucault (1975) asserts, it is “the eye that knows and decides” and “the eye that governs” (p. 89).

At the level of the individual, knowledge about the fetus allows for decisions related directly to the health of the fetus, such as, would maternal exposure to some illness or toxin compromise the development of the fetus? Such knowledge may inform pregnant women’s decisions to abstain from alcohol due to adverse effects on the fetus, or relate to the prescription of folic acid supplements to prevent neural tube defects in the fetus. At the level of the ‘*species body*’, a term that Foucault (1990) uses to refer to the population, these prenatal understandings help anticipate the developmental/ lifespan health of the fetus in relation to the health of the general population. The ability to anticipate the needs of a child born with a fetal anomaly enables not just health care management decisions during pregnancy but also allows one to plan a lifespan needs assessment from personal, familial, educational, social and health resources that will be eventually be required. The ability to exercise surveillance

during the prenatal period may also be seen as an epidemiological awareness of the current and future needs of citizens. When considering the lifespan implication, according to the Barker Hypothesis as cited in Mykitiuk & Nisker (2010), the social determinants of the health of embryos can manifest additional health implications as the embryos progress developmentally towards adulthood.

The translation of the discourse from 'test' to 'clinical practice guidelines' is not just for the benefit of health professionals and policy makers. It is, also for public consumption such as when wait staff can justifiably refuse to serve a pregnant woman alcohol - a knowledge made accessible to the public to facilitate social cooperation in regulating the health of individuals and therefore, by extension, the health of the population.

The subject and object of knowledge in prenatal screening

To see, to examine, to engage in a discourse, requires a constituted subject to be known and a knower to reveal or uncover knowledge. Historically the subject to be known, in this regard the unborn fetus, was separated by its cloistered state. Duden (2002) referred to this state as "*non-dum*" or "*not-yet*" whose "uncertain knowledge" would come to be revealed at the time of birth (as cited in Weir, 2006, p. 12). The period of gestation seems on the verge of something, but is removed from view and

hence removed from knowing and intervening. “The perinatal threshold marked a historical break from birth as the entry into human status, a break based on a conceptual innovation: the constitution of a temporal interval encompassing newborn child and intrauterine fetus in a common bodily substance” (Weir, 2006, p. 6).

According to Weir (2006) the perinatal threshold, a construct to address the “ambiguous interval” between gestation and birth began between the 1920-1950’s as a public health enterprise to address risks of perinatal morbidity and mortality for the fetus and mother. In counting perinatal mortality, stillbirths and neonatal deaths are rendered equivalent for the purposes of an administrative” (Weir, 2006, p. 11). More precisely, fetuses who die at or after 20 weeks gestation, the halfway point of pregnancy, are deemed as stillbirths. The perinatal threshold, therefore, attempts to cross the duality of “inside and outside” and treats the perinatal period as an “in between”. (Weir, 2006, pp. 1-3). This conception is premised on the rationale that “the unborn late in pregnancy and the newborns are thought to die of the same causes” (Weir, 2006, p. 32).

Weir (2006) considers that the ‘invention’ of the perinatal threshold followed from three levels of analysis: at the epistemological level perinatal as a ‘concept’ that attempts to cross dualistic boundaries of born versus unborn; at the technical level it contributes to the calculation of ‘risk based assessment’, and at the governmental level

it reflects the mortality rates of the perinatal period as a target upon which to measure the success and health of the population (p. 32).

In this way the investment in the health of the unborn and the outcome of population health are tied together by the common threats of mortality, and offer a justification for considering the biopolitics of the perinatal threshold and the prenatal risk assessments. The concept of the perinatal threshold as “in between” allows for the possibility of a continuum of life rather than a duality of life versus non-life and thus creates room to circumvent the objections from those who contest when life begins and what should count as human life. Judith Butler (2004) views loss and grief through the lens of the social vulnerability of the body, and points out the precarious nature of life at the intersection of power, vulnerability and politics. She raises the question of “what counts as lives? And finally, what counts as a grievable life?” (p. 20). According to Weir (2006), the perinatal threshold attempts to fill the void between gestation and birth and hence, “this subject can be called living because it was regarded as capable of dying, with its death multiply consequential for health governance: recorded in mortality statistics, subjected to perinatal death reviews and mourned as perinatal loss.” (Weir, 2006, p. 12). The invention of a perinatal threshold then opened up a temporal-spatial arena to the scientific gaze, to the scrutiny of individuals and to the regulation of public health. What was hidden from view, has now expanded into a field of reproductive technologies that enable ways to see and to know and ways to intervene to aid, enhance, prohibit or alter.

Lennon & Whitford (1994) suggest that “all knowers are situated (spatio/temporally, historically/culturally/socially), and these dimensions of the situation all become part of the epistemological context” (p. 3). Prenatal screening with its motivations and intentions is similarly situated. It is thus not a singular pursuit of a singular external reality, but rather reveals both the subject to be known and the knower within a situated context. Lennon & Whitford (1994) contend that “what one sees is a product of positioning, and different accounts of the world involve political struggles over *how* to see and *how* to interpret” (p. 5). The issue of prenatal screening and all that it implies becomes problematized when one considers the simple question of ‘why not’ (participate in prenatal screening). When phrased as an overly simplified question, it fails to take into account the scope of situated knowledge and the complexity of intersections between personal and socio-political such as they become determinants of health.

Foucault’s Biopolitics & the Clinical Gaze

According to the translator’s note, Foucault’s term ‘*la clinique*’ encompasses not a specific clinic as we consider in common day to day English usage, but rather an institution of knowledge. As such the ‘clinic’ may be seen as clinical practice and the acquisition and transmission of knowledge – “both clinical medicine and the teaching hospital” (Foucault, 1975, p. vii). Hence the clinical gaze is used here in a similar way to how Foucault uses it, to reflect that the power, functions and motivations of the gaze

are not limited or specific to individuals or groups of clinicians; rather the gaze is seen to exert its own power in the ways of discourse. Given that Foucault's language, particularly in his work *'The Birth of the Clinic'* (1975), centers around the history of medical science and its positivist traditions, it bears saying that the intention is not a criticism of medical science, technology, or clinical practice of any health professional discipline. Rather, this work is concerned with deconstructing taken for granted assumptions about the construction of our understandings about the health of fetuses, and to acknowledge that considerations about notions of health in the prenatal period in this work are approached from within a constructivist-interpretivist epistemological position rather than a positivist one.

Biopolitics in this paper refers to Foucault's theory postulated in *The History of Sexuality, Volume 1* (1990). Although this theory is primarily an analysis of the power and functions of sex and sexuality, I suggest that one can grant extension of this theory to the discussion of prenatal screening. Given the consideration that this theory in part concerns the drive of reproduction in the significance of power relations and the structural significance of sexuality and its management. "Broadly speaking, at the juncture of the "body" and the "population," sex became the crucial target of a power organized around the management of life rather than the menace of death" (Foucault 1990, p. 147). Hence given that sex is a condition towards the procreative cycle, the discourse of biopower and biopolitics derived from the theory can be extended to a

later point in the reproduction cycle, namely the prenatal period. With respect to biopower,

“the mechanism of power are addressed to the body, to life, to what causes it to proliferate, to what reinforces the species, its stamina, its ability to dominate, or its capacity for being used. Through the themes of health, progeny, race, the future of the species, the vitality of the social body, power spoke of sexuality and to sexuality; the latter was not a mark or a symbol, it was an object and a target.” (Foucault 1990, p. 147).

Biopolitics exercises management at two levels. At the level of the individual, the disciplining of “the body as a machine” through “*anatomo-politics of the human body*” and at the level of the “species body” which Foucault (1990) describes as “*a biopolitics of the population*” (p.139). Prenatal screening is the tool with which biopolitics is managed between conception and birth. It exercises biopolitics at the individual level through the disciplining of the ‘body as machine’ by placing it under surveillance at the physiologic, functional and genetic levels while in utero through various means of employing a clinical gaze to screen, to detect normalcy and anomalies and generate a diagnosis and prognosis of health. At the level of the ‘species body’/population biopolitics is exercised through the discourse and interpretations of what constitutes normalcy, determinants of health more by the act of diagnosis in deeming lethal and non-lethal predictions. Prenatal screening yields information about the constitution of the unborn fetus that has implications not just for the outcome of the gestation period, but also for the developmental lifespan. Hence, the surveillance and scrutiny of prenatal screening during the prenatal period may be likened to a metaphor of a framed window looking out towards a developmental trajectory.

The Techniques of the Clinical Gaze

In the preface of *Birth of the Clinic: An Archaeology of Medical Perception*, a visual graphic of coming to understand the anatomy of the body in the mid eighteenth century is portrayed as a metaphor of layers, “membranous tissues like pieces of damp parchment...peel away with some slight discomfort”(Foucault, 1975, p. ix). In some ways our modern technology of prenatal screening might be seen to achieve the same symbolic means of study as well; to peel away layers of skin, flesh, sinew to peer deeper into the lesser known aspects of the human anatomy. The layers representing the skin, flesh, tissues of the woman, the placenta and amniotic fluid, reveal the shape of the fetus, the manner of its gestation, the organs, bones and the tissues within the fetus. Through the many techniques of screening, 2D, 3D and 4D ultrasound technology, amniocentesis, CVS, MSS and IPS screening, prenatal testing might be seen as the modern version of peeling away layers to reveal, uncover the biologic truth at physiologic and genetic levels and thus reveal aspects of the gestating being prior to birth. As layers are (visually) peeled away to reveal aspects of pregnant women and fetuses, medical technologies may be viewed as ways of seeing and ways of knowing about the bodies of women and fetuses prior to birth. Nonetheless, these ways of seeing and knowing require interpretations to name the things visualized, ascribe meaning to them and define them within a larger context – what does it mean; what is defined as normal; what is able to survive? Hence, Foucault (1975) contends that technologies of the clinical gaze, such as those of modern prenatal screening, are

“about space, about language, and about death; it is about the act of seeing, the gaze”
(p. ix).

Evelyn Fox Keller (1983) suggests that the observing gaze within an objectivist paradigm holds particular value, given “the importance of sight – the most notable of the senses – as the qualifier for western knowledge” (as cited in Braidotti, 1994, p. 27). In examining the genealogy of the “clinical gaze”, Foucault examined ways of seeing and knowing as a genealogy of the way human anatomy is investigated through observation, classification, description, and deciphering (Foucault, 1975). To lend itself to establishing legitimacy as a science, the clinical gaze draws upon 3 aspects described below: (a) the codification of knowledge such as through a botanical model, (b) the attention of the clinician’s perception of signs and symptoms and (c) a mathematical model (Foucault, 1975).

The Botanical Model - Drawing on the botanical model as a way of understanding, the tasks were, first to “observe attentively the clear and natural phenomenon of diseases”, second to differentiate based on the “degree of their resemblance”, to order and organize “relative mappings” of the human anatomy and to classify normal and diseased (Foucault, 1975, pp. 5-9). According to Foucault, in the eighteenth century under the botanical model the clinical gaze was to the effect that:

“the clinic demands as much of the gaze as natural history. As much, and to a certain extent, the same thing: to see, to isolate features, to recognize those that are identical and those that are different, to regroup them, to classify them by species or families” (Foucault, 1975, p. 89).

In the relatively recent development of prenatal screening we still employ this structure with new tools. By direct observation such as through ultrasound we visually observe the shape, structure, growth processes of the gestation phenomenon. We pay close attention to new, unusual or absent signs and track their progress making observations about the nature and resemblance to other similar or dissimilar signs and symptoms. We record and compare with other clinicians in dialogue and scholarly discourse about whether these anomalies are noted elsewhere and what methods of intervention and outcomes others have noted. We order and organize the relative mappings based on structure (head, circulatory, digestive, skeletal and so on), function, or genetics; and whether these are anomalies of presence, absence, growth or deficiency. Foucault points out that this is a botanical model. “The body is open to scrutiny, to observation by the biomedical gaze, is a body that can be manipulated; it is a useful, purposeful body, that can produce knowledge, thus legitimating the power of the bio-medical profession” (Braidotti, 1994, p. 21).

The Perceptual Gaze of the Clinician - According to Foucault, with the need to establish the legitimization of clinical experience as a scientific discourse, the decisions made by clinicians needed to be organized within a common understanding. The ability

to have authority and therefore power required that the clinical experience assert its knowledge and be able to justify a course of action based on some reasonable premise.

“So many powers, from the slow illumination of obscurities, the ever-prudent reading of the essential, the calculation of times and risks, to the mastery of the heart and the majestic confiscation of paternal authority, are just so many forms in which the sovereignty of the gaze gradually establishes itself – the eye that knows and decides, the eye that governs” (Foucault, 1975, pp. 88-89).

For Foucault, the exercise of power however, requires more than just a cataloguing of observations, signs and symptoms; these must be deciphered, interpreted and reorganized to manage chance and risks towards desired outcomes.

Hence,

“the medical gaze was also organized in a new way. First, it was no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention. Moreover, it was a gaze that was not bound by the narrow grid of structure (form, arrangement, number, size), but that could and should grasp colours, variations, tiny anomalies, always receptive to the deviant. Finally, it was a gaze that was not content to observe what was self-evident; it must make it possible to outline chances and risks; it was calculating” (Foucault, 1975, p. 89).

In applying these ideas to the local context, it can be seen that at the clinical level for the reasoning of the clinician to be validated, prenatal risk assessments have become part of a standardized program of screening. In Ontario the Ontario Antenatal Record is a standardized screening tool. Upon completion it broadly categorizes the

finding into risk assessment levels of “healthy pregnancy, no predictable risk”, “pregnancy at risk” and “pregnancy at high risk” based on a matrix that accounts for fetal and maternal health factors. Everything related to pregnancy and fertility from menstrual history, past obstetrical and gynaecological history, to physical health, social, familial health histories, lifestyle, and fetal growth are recorded in detail. The standardization of such risk assessment screening is not just the botanical model of observation and classification, it is also a directive model that instructs health providers about what they must ask, what counsel they must provide, what services should be offered and what referrals are to be made around the exercise of optimizing health. By standardizing the governance of prenatal health and risk, the fetus, mother and health provider are bound together in duty and obligation towards the health of individuals and the health of the population. If the incitement and desire towards health should fail to provide sufficient motivation towards social cooperation for enhancing the health of the population, the governance by duty and obligation requires it, and forces it by threat of malpractice risks for health providers, tort law and perceived negligence of the expectant parents.

Mathematical Model & the Calculation of Risk – In an attempt to calculate risks under some common understanding, the science also needs to address the degree of certainty to the decipherment and interpretation of what signs and symptoms were indicated for health and disease: a calculation of risk. Weir (2006) conceptualizes the

perinatal threshold as four risk techniques: epidemiological, clinical, actuarial and legal (p. 17).

According to Foucault (1975) “medicine discovered that uncertainty may be treated, analytically, as the sum of a certain number of isolatable degrees of certainty that were capable of rigorous calculation” (p. 97). In this mathematical model, the functions of “complexity of combination” concerned the ways in which signs and symptoms were related to other signs and symptoms by some degree or association; the “principle of analogy” concerned the manner of recognizing the parts of the phenomenon and the constellation of factors that could distinguish the disease and its trajectory of illness; the “perception of frequencies” which is an epidemiological awareness; and finally the “calculation of degrees of certainty” which is the probability function that answers queries about the chances and risks (Foucault, 1975, pp. 99-105).

“Through the introduction of probabilistic thought, medicine entirely renewed the *perceptual values* of its domain: the space in which the doctor’s attention had to operate became an unlimited space, made up of isolatable events whose form of solidarity was the order of the series. The simple dialectic of the pathological species and the sick individual, an enclosed space and an uncertain time, was, in principle, dislocated. Medicine no longer tried to see the essential truth beneath the sensible individuality; it was faced by the task of perceiving, and to infinity, the events of an open domain. This was the clinic.” (Foucault, 1975, pp. 97-98).

Within the construct of the clinical gaze the observations made during prenatal screening including attention to ‘complexity of combination’ and ‘principle of analogy’ with careful noting of the phenomenon; the detailed description, deciphering and

classification of the constellation of anomalous signs and symptoms to ascertain the patterns in the manifestation of disease; attention to the severity of the condition as individual parts and the collective impact on the whole; are used to generate an understanding and prediction about the trajectory. To understand the constellation of factors and track its outcome allows not only the calculation of predictions about fatality or survival, it is also the window that opens a possibility to interventions that hold hope to modify or change a negative trajectory. In this reflexive path of observation, trial, and re-observation with meticulous recording of details, we hope not only to know more, calculate better, but also to make more reasonable guesses towards the investment of life. As “enabling prevention, risk governance attempts to arrest future harm before it exists by selecting options for action based on a calculation of probabilities” (Weir, 2006, p. 17).

The ‘perception of frequencies’ serves two functions; one for the lens of the scientist-clinician that seeks to answer: how common is this problem, what might be responsible for it, what are the trends? This serves not just the clinician’s understanding but is of significance for public health policy. The other serves the existential need for the parents to have answers – why did this happen, will it happen again. The ‘calculation of degrees of certainty’ is the mathematical model that lends support to justify the advice of clinicians and to reframe emotional distress into an arms-length cognitive process. To answer the difficult questions of why a negative event occurred or whether it will happen again, the mathematical model allows uncertainty as an answer by citing probability odds. Instead of ‘I don’t know’ an answer

that will likely provoke greater anxiety, we say instead, 'the odds are one in 'x' (number). The answer is no more conclusive, rather it is couched and reframed within a range and the recipient's interpretation of the value of the range then becomes the barometer of hope or distress, in other words, a perception of risk. The mathematical odds are an abstract qualification to an emotional need for answers; perception therein, is the link. A mathematical model presumes that an informed choice is an intelligent decision based on probability – a view supported by a positivist model. What is unknown is the extent to which people actually make life and death decisions based on a detached unemotionally invested mathematical-rational-probability model or to what extent other factors and processes that account for part of the decision making process in terms of how information is processed and weighed against such factors are incorporated. A view more consistent with a constructivist-interpretivist model.

The confessional narrative and anatomo-politics of the body

In order to know, there must be participation in which the subjects open themselves up for observation and therefore bare themselves to the view of the clinical gaze. But it is not just that one is passively present and accessible, rather that the subject to be known and the gaze that seeks knowledge operate in dialogue - to see and to tell what one knows. "The confession became one of the West's most highly valued techniques for producing truth" (Foucault, 1990, p. 59). The manner of drawing out knowledge about the fetus is where the 'confessional narrative' is of relevance. We

ask the expectant parents, the contributors of genetic material, to tell all they know about their individual health. Not just their own health by a genealogical picture of their DNA by asking about the health of their children, the health of family members, what diseases, ages and manner of death relatives succumbed to. We enquire into their occupations, households, the things consumed, activities past and present and anything of relevance that may elicit clues towards perceptions of risk and the ability to provide answers not just for the individual but also clues gathered to form epidemiological hypotheses. The asking is one part of the dialogue, the telling of the confessional is the other. Whether we realize it or not,

“the obligation to confess is now relayed through so many different points, is so deeply ingrained in us, that we no longer perceive it as the effect of a power that constrains us; on the contrary, it seems to us that truth, lodged in our most secret nature, “demands” only to surface; that if it fails to do so, this is because a constraint holds it in place” (Foucault, 1990, p. 60).

In the case of prenatal screening the invitation to participate is a seductive one. It is not seductive just to science but also to the general population by virtue of what the gaze has to offer – to see, to know. For the expectant parents what the gaze has to offer is highly seductive – to see and know your child, to visualize his or her shape and form, to see and hear the heartbeat, to visually bond and form attachments prenatally, and even to know the child at the level of their genetic code before they are even born. Not only is the offer seductive and enticing, it also implies a chiding expectation – don’t you want to do what is best for your child? In exchange for participation you are compensated by the gaze with a grainy black and white memento or a more

sophisticated 3D or 4D visual that shows the shape of the face, the movements, recorded and provided to legitimize parents sentiments and attachments by having something tangible, a proof, with which to share a hidden private truth with the external world.

“The confession is a ritual of discourse in which the speaking subject is also the subject of the statement; it is also a ritual that unfolds within a power relationship, for one does not confess without the presence (or virtual presence) of a partner who is not simply the interlocutor but the authority who requires the confession, prescribes and appreciates it, and intervenes in order to judge, punish, forgive, console, and reconcile; a ritual in which the truth is corroborated by the obstacles and resistances it has had to surmount in order to be formulated; and finally, a ritual in which the expression alone, independently of its external consequences, produces intrinsic modifications in the person who articulates it” (Foucault, 1990, pp.61-62)

Hence we participate willingly for all that the gaze has to offer in return, and the perceived small cost of baring all in the confession.

The method of the confessional narrative outlined as *'scientia sexualis'* (Foucault, 1990, pp. 53-73) is “situated at the point of intersection of a technique of confession and a scientific discursivity” (Foucault, 1990, p.68). The various procedures to draw out a telling of the story so to speak, is accomplished by gathering and coding information in a common format such as taking a patient’s history, measuring signs and symptoms, asking particular and detailed questions and “reinscribing the procedure of confession in a field of scientifically acceptable observations” and through

medicalization and interpretation it needed to be validated as scientific, “a hermeneutic function” (Foucault, 1990, pp. 65-67).

Given that the gestating fetus is hidden from direct access, knowing this subject is through the pregnant woman who must participate in revealing whatever embodied understanding is perceived corporeally. The manner in which the woman can participate is limited to her body, her ability to self-report signs and symptoms and whatever is disclosed about her lived experience. This is a rather removed way of knowing the fetus because at best it is through an intermediary of sorts. The technology of prenatal screening offers to the clinical gaze a way to see and know the fetal subject directly, either visually through ultrasound images, or genetically through testing, or both.

Through use of prenatal screening the fetus then becomes the direct subject and object of investigation – a way to see, to observe, to order the signs and symptoms, to order and classify the ranges of observation within the scope of normal and anomaly, to describe to expectant parents what was visualized or gleaned in lab results, to decipher the meaning of these signs and interpret its meaning with respect to diagnosis and prognosis. The fetus thus potentially not only bares the secrets of its being, it also bares the genetic secrets of its lineage transmitted through reproduction within the limits of technology.

“Offering everything for display or show, representing the unrepresentable (like the origins of life), means producing images that displace the boundaries of space (inside/ outside the mother’s body) and of time (before/ after birth).” ...
“The image acquires a life of its own, distinct from anything else. It is quite clear that echograms of the foetus confer upon it an identity, a visual shape, a visible and intelligible existence that the foetus would not usually have. The act of visualization emancipates the object that it represents; it makes it into an object of consumption, it allows it to circulate, it detaches it from the mother’s body where it is located.” (Braidotti, 1994, p. 25)

Ironically whether intended by anyone or not, this role in the confessional narrative has a dual outcome – for the fetus to be known before birth allows the access to some forms of knowledge about its health and in the same stroke cast into existence not as a blank slate of possibility but one labelled with a report card of health and hardiness, a calculated prediction about its ability to thrive. In this way the ‘anatomopolitics of the human body’ and the disciplining of the ‘body as machine’ may be seen to be exercised. The biopolitics of prenatal screening then is not just about what it offers to the clinical gaze in the production of knowledge, it serves as well as a sort of probability generated quality assurance program at the level of the individual, an accounting that the sum of the parts produces a healthy enough fetus. “And this discourse of truth finally takes effect, not in the one who receives it, but in the one from whom it is wrested” (Foucault, 1990, p. 62)

Prenatal surveillance and the 'Disciplining of the body'

Sawicki as cited in Weir (2006) noted reproductive technologies as “positive power” through the “disciplinary incitement of desire” and suggested that rather than exercising power through traditional oppression or prohibition that positive power directs itself by “optimizing, inciting and making happen” (Weir, 2006, p. 12). Positive power is crucial in eliciting the social cooperation of the population; to be constructed as a beneficial resource it invites participation and intuitively aligns with the general public view of ‘why not’ utilize a resource that is available. Through this incitement the public participates in the security of the population, the discipline of individuals and the governance of health. The desire for the product of a “perfect baby” positions women and parents as “genetic gatekeepers” (Williams, Anderson & Farsides, 2001, as cited in Karpin, 2010, p. 148).

What then is the explanation for those who do not participate in this biopolitics exercise? Reflective dialogue with clinicians indicates that in clinical obstetric practice three types of patients are frequently observed – those who have clear rigid ideas about the notion of a ‘perfect child’; those whose values are accepting of any outcome; and the broad third group who enter into reproduction without overt awareness of risks involved with pregnancy, a blissful ignorance if you will. (R. Natale, personal communication, May 9, 2011)

Those who do not participate in prenatal screening therefore are not part of the confessional narrative in this sense. At a basic level there is an assumption that people will avail themselves of the latest technology, particularly those technologies that promise that participation is directed towards the enhancement of health or at the very least towards conscious attention towards health(ier) outcomes. The problem then is what to make of those who do not participate and avail themselves of these interventions and technologies. The rash quick judgments of the simple answer hinge on the rationale of 'why not?' Although an intuitive response, the argument is stifled if it remains there; one needs to establish if it is a question of reasonable access to these services or whether it is a conscious decision not to participate. If it is the former, then the next line of investigation should lead to an analysis of resources, allocation of those resources and barriers that account for reduced participation. However, if it is about a conscious decision not to participate then that is one of significant difference and hence the rationale of 'why not' does not hold. Those who *cannot* avail themselves due to some systemic barrier but would participate were it possible are qualitatively a different group than those who *will not* avail themselves and consciously decline to participate regardless of the question of access to the resource.

At a deeper level, the question of those who *cannot* and those who *will not* avail themselves of such knowledge bespeaks a second assumption; that knowledge gleaned from this participation in screening will direct a prescribed order of actions to follow. Implicit in this assumption is that there is a certain expectation to follow through on

choices and decisions based on the 'evidence-based' knowledge gleaned from these investigations. Investigations from prenatal screening present certain 'facts', the 'facts' are interpreted and ascribed meanings and value by means of diagnosis and prognosis. The diagnosis and prognosis directs a pathway to certain possibilities, these possibilities narrow the range of options and choices that ultimately result in a definite outcome. It is hence, an implicit understanding that participation will require one to participate in this formula. Perhaps those who *will not* avail themselves of available technology are consciously declining because they do not agree with or do not want to be held to this formula. Although informed consent allows one the option to stop, refuse or decline at any point, when social structural implication strongly suggests its rationale as 'why not' implicitly meaning 'why don't you want the best for your unborn child?' the emotional freedom to withdraw from participation at a later point or to object to the prescribed formula of choices may not be easily done without implicit or explicit judgments. Perhaps those who *will not* avail themselves of available technology are consciously declining because they do not want to find themselves in that type of situation and hence would rather not participate from the get go. Regarding moral choices Foucault views that within the ways that people manage or govern themselves and the choices they make align with 'the ethics of care for the self as a practice of freedom' (1997).

As a second speculation, perhaps this group declines to participate in order to postpone their decision in order to formulate a synthesis of their values in response to the question 'what would I do if...?' In this scenario, those who decline may be

ambivalent about their position on possible choices and hence would rather that they are not in a position to choose anything either way; that nature will progress, or not progress, without interference or any input from technology. A key construct here is the attention one pays to the things one can know and ignore, if desired. Perhaps the resistance in this speculation is about what one cannot *un-know*, the bell cannot be un-rung. The ambivalent position hence leaves open the possibility to change one's mind at a later time, a possibility that may no longer seem as open from the time one consents to screening. Hence it is not just the outcome of the results that constructs a reality of risk, it is the moment of initiation into screening that informs the construction of a worldview that changes 'blissful innocence' about risk such that it becomes about a constant evaluation of risk perceptions. The nature of the pregnancy and the fetus altered into perceptions of risk reframes the experience as a type of loss – a loss of innocence, a loss of an idealized healthy child and of a healthy pregnancy (Fernandez, Harris & Leschied, 2011, p. 158)

In a third speculation, perhaps this group declines to participate because they are quite certain that they will not do anything with the knowledge gleaned from these investigations and hence the result is of no consequence to their conscious decision making process either way. In this scenario, the hassle to participate, utilize limited resources, endure the uncertainty, in the end only to decline to know the results and consciously choose to do nothing different makes for an unnecessary pursuit. A pursuit

that could potentially invite directives and prescription from the formula that they do not wish to entertain and do not wish to be socially pressured to consider.

Although health professionals in various disciplines are socialized by their training to see things a certain way, to appreciate a certain method of knowing as scientific, and to follow through with a prescribed course of action that institutionally legitimizes the advice and decisions of clinicians as valid, as competent and as ethical. The general public and expectant parents are not necessarily socialized to accept this formula. The obligation of clinicians to follow through with 'best-practice guidelines' is motivated often by working within professionally sanctioned frameworks; and thus one retains the learned and trusted privilege conferred by society, and avoids malpractice risks. The motivations for expectant parents and the general public is not governed by these same motivations, the reasons to do or not do something are motivated towards an ends of self and preservation. The gaze appeals and speaks to both, albeit, directing them differently but to the same outcome – to see, to know and thus to cooperate together towards the task of investing in life. Nisker (2010) notes a concern that speaks to the notion of access to reproductive technologies as an implicit call for biologic or genetic responsibility: "In some countries, for example, the professional obligation to offer all pregnant women screening for chromosomal anomalies could suggest that all pregnant women must not only be aware that it is possible to control particular characteristics of the 'health' of their embryo but also that undergoing prenatal screening is a responsible practice" (p. ix). This parallels the notion of relational citizenship that suggests that participation in screening is the 'responsible thing to do'

as a sort of moral obligation to yourself and those you care about (Howson, 1998; Rabinow & Rose, 2006). The call to act autonomously in decision making about risk factors and risk perceptions is a technique of biopolitics that aims at having people be “self-regulating and self-disciplining” by the construction of risk categories such as “age-related risk”, “added risk”, “background risk” and “reassurance” and thus places the responsibility with the individual (Tremain, 2006, p. 47).

Biopower as the ‘Investment in Life’

If prenatal screening is merely the tool for biopolitics, the tool must be directed towards some goal, some ends; a force or motivation that drives the curiosity to know, the development and production in the advancement of technology has to fulfill a concrete purpose and thus, to render itself useful. The cost of research and development alone would demand an economic justification for funding, mere curiosity is not sufficient when other worthy causes vie for the same limited funds. Prenatal screening must thus justify not just its scientific value but also its economic value as it stakes its claim that it functions as an investment in life.

In order to stake a claim as bold as ‘investment in life’ the use of screening must be measured against some common denominator. Life then becomes measured against the most uncontested, most universal common denominator, death. The indisputable,

irreversible nature of death makes it an ideal yardstick; it is both an 'absolute' quantity (Foucault, 1975, p. 140) and is vilified as 'failure' (Aries, 2004). First, by establishing the link between mortality connections before and after birth under the premise that viable fetuses and newborns are susceptible to similar risks of death (Weir, 2006, p. 32). Second, by including fetal deaths (stillbirths) together with neonatal (newborn) deaths in the perinatal mortality statistics as part of the vital statistics of the population, fetuses are counted as legitimate population subjects and therefore preventable deaths with regards to governing health (Weir, 2006, p. 11). The justification of biopolitics and prenatal screening carves out a legitimate rationale as an 'investment in life'. Foucault noted, through the concept of biopower that

"biological existence was reflected in political existence; the fact of living was no longer an inaccessible substrate that only emerged from time to time, amid the randomness of death and its fatality; part of it passed into knowledge's field of control and power's sphere of intervention. Power would no longer be dealing simply with legal subjects over whom the ultimate dominion was death, but with living subjects, and the mastery it would be able to exercise over them would have to be applied at the level of life itself; it was the taking charge of life more than the threat of death, that gave power its access even to the body." (Foucault 1990, p. 142-143).

It is the shift in perspective from the natural order of life to the control over death; the turn which gives power to the motivations behind an investment in life. Investing in life under no threat doesn't supply much support to justify the time, the dedication of the clinical gaze, the funds needed to support the clinical gaze in its quest. To invest in life under the threat of death was seen by Foucault to examine what 'fostered life' and what 'disallowed it' (Foucault 1990, p. 138).

“Life, disease, and death now form a technical and conceptual trinity. The continuity of the age old beliefs that placed the threat of disease in life and of the approaching presence of death in disease is broken; in its place is articulated a triangular figure the summit of which is defined by death. It is from the height of death that one can see and analyze organic dependencies and pathological sequences.” (Foucault, 1975, p. 144).

Prior to birth, life may still face the threat of death for the unborn fetus. “For the disciplinary triad to be invoked, security must be invested with life-death significance” (Weir, 2006, p. 15). In this instance, the mechanisms of power are not just directed at the life of the unborn as it exists, but the future capacity of the individual and its future costs and the possible future contributions of the individual to the species body (population). The significance then becomes directed at attempting to identify flaws that threaten life prior to birth and that ascertain the level of risk against the yardstick of survival – what risks can be tolerated for the fetus to be viable, survivable and thrive-able. In the investment in life, prenatal screening occupies a role as a tool,

“in a position of ‘biological responsibility’ with regard to the species: not only could sex be affected by its own diseases, it could also, if it was not controlled, transmit diseases or create others that would afflict future generations” (Foucault 1990, p. 118).

The investment in life is not just the disciplining of the body as machine for individual fetuses, in the genomic age it is “directed toward the performances of the body, with attention to the processes of life – characterized as a power whose highest function was perhaps no longer to kill, but to invest life through and through.”

(Foucault 1990, p. 139). However, at the level of the individual this function is limited both in what it offers to the clinical gaze as well as to the biopolitics of the population.

In order to understand the predictors of biological survival of the species body,

“Governments perceived that they were not dealing simply with subjects or even a “people”, but with a “population”, with its specific phenomenon and its peculiar variables: birth and death rates, life expectancy, fertility, state of health, frequency of illnesses, patterns of diet and habitation” (Foucault, 1990, p. 25).

Of particular relevance are heritable traits. The motivations and functions of this bio-power are aimed at identifying hardiness, ability to survive and those at risk either because they are afflicted by disease directly or because they carry the possibility of ‘undesirable’ heritable diseases. The choice of prenatal screening is hence “the decision that initiates them and the one that terminates them are in fact increasingly informed by the naked question of survival” (Foucault 1990, p. 137).

For example, in infertility treatments pre-implantation genetic diagnosis (PGD) is a specific method that screens embryos and selects only the ‘healthiest’ embryos for implantation into the woman’s uterus with assisted reproductive methods. Those embryos that do not measure up to the quality of the ‘healthy embryo’ are therefore eliminated from the reproductive process of gestation, thereby attempting to mitigate the chances and risks of a failed pregnancy or an ‘unhealthy’ fetus that has a diminished chance for ‘survival’. The investment includes both medical and economic

costs as well as personal costs, premised on the position that people do not wish to endure reproductive hardships only to then have to contend with a reality of a “defective child” (Maienschein & Robert, 2010, p. 8). Scully, Rehmann-Sutter & Porz (2010) label two types of PGD embryos – the “valid PGD embryo” and the “invalidated PGD embryo”, both created for the purposes of in-vitro fertilization (IVF) and genetically tested; but the “invalidated” embryos are “not transferred because it is not of the desired genetic constitution” (p. 21).

The notion of ‘undesirable’ is not necessarily synonymous with ‘unhealthy’. Individuals may desire a child that looks like the intended parents, have a certain IQ range, possess physiological characteristics that one believes to be related to ‘attractiveness’ and so on. But these are not necessarily the makings of health, viable, survivable or thrive-able. Mykitiuk & Nisker (2010) highlight that constructions of the health of embryos/fetuses are constructed on preconceived perceptions of health. They illustrate by example, that the desire not to have a child with an X-linked recessive condition that would compromise health or survival is a qualitatively different desire than not wanting a girl child as the reason for gender selection in screening (p. 118).

The Economic Motivations of Biopower

Prenatal screening is not the only tool that may be considered as related to the use of biopower in terms of life-death investments. Issues around end-of-life care, the quest in the cure for cancer and other life threatening diseases, for example are spurred forward and find justification with the general population in answer to how public funds and resources are allocated. But it is not all just in the guise of sparing one the psychological impacts of loss, grief and trauma, the motivations of bio-power and biopolitics have broader economic implications, that of managing and allocating finite resources and maintaining distributive justice, particularly in those countries that have socialized medicine and social services as an infrastructure.

At the macro level, the political investment in life in the prenatal period has not only to consider the economic costs of higher risks in pregnancy and neonatal periods, it also views the costs to healthcare, social, educational services, labour industry and broad infrastructure during the lifespan. In countries with rapidly declining birth rates that are forced to supplement the population numbers through immigration to ensure economy viability and future citizens who will contribute labour, taxes and funds to support social service infrastructure, the investment in the health of each viable fetus is paramount to the viability of the species body. But more than mere viability, that the investment of biopower to produce healthy citizens who will in turn hold the future potential to contribute gainfully to the vitality of the population's wellbeing.

The investment in life is thus not just to satisfy the curiosity of science, the pursuit of knowledge, the improvement of clinical practice, or better health outcomes for one or few individuals; rather it demands that the justification for the investment in life, even before birth, must benefit the greater good – the species body. Thus, the technologies of investing in life need to manage and justify their claims at the level of the individual fetus and its disciplining of ‘body as machine’ but also to justify their claims to the biopolitics of the population. Many health professions have in their codes of ethics a default aimed towards this Utilitarian understanding – to maximize good for the greatest number and to minimize harms. “Broadly speaking, at the juncture of the “body” and the “population,” sex became the crucial target of a power organized around the management of life rather than the menace of death” (Foucault 1990, p. 147).

Conclusion: the dilemma

In conclusion, a significant dilemma of a moral and ethical nature rests on how the discourse constructs notions of ‘normal’, ‘at risk’, ‘healthy’, ‘unhealthy’, ‘anomalous’, ‘viable’, ‘incompatible with life’, ‘lethal’, ‘undesirable’ and so on. These constructions are variable depending on the criteria preselected as the benchmark. From the perspective of biopower these notions are influenced by the value laden nature of language, social acceptance, appeals to power and authority and so on that shapes the hermeneutic (interpretive) aspect, rather than on a purely black and white

reality. A major criticism to the application of a strongly positivist position is that it presupposes black and white options to the problems perceived as arising within a clear cut, black and white reality. With regards to reproductive biopolitics, the dark history of eugenics, sterilization of persons and other atrocities levied at the level of individuals and populations is a significant criticism and cautionary note about the dangers of failing to consider multiple constructions and varied interpretations. How healthy is healthy enough and who decides?

Prenatal screening operates within this space – to ascertain those details that promise the ability to thrive and to identify those features that do not bode well. Rather than waiting for the threshold of birth to predict birth and death rates, this frontier is pushed into the prenatal period (Weir, 2006). The ‘complexity of combination’, ‘principle of analogy’, ‘perception of frequencies’ and ‘calculation of degrees of certainty’ put forth as knowledge from the clinical gaze allow for reasoned predictions about morbidity and mortality, life expectancy, state of health and essentially those features related to survival and quality of life. These are however, predictions, albeit calculated predictions, that are ‘constructed’ to form a picture of health based on building blocks furnished by the clinical gaze. These are not absolute truths, these are educated guesses within the limits of existing knowledge and situated within a range of margins of error. It is not that statistical margins of error indicate any failure or incompetency, it is a margin within the finite and situated knowledge of the time, the place, the circumstances, the view offered up to the clinical gaze. We are thus

limited at any time about what we can conclusively know, we are limited within a field of interpretations that may reasonably be made and the lack of omniscience in human knowing. To propose that we can gaze into the existential cusp prior to birth and claim conclusive singular truths is a fallacy that sets up unreasonable expectations and the possibility of relational trust or distrust between those who grant access to this knowing and those who must live with the decisions made as a result of it, precisely because it challenges the ideas of hope, survival and the investment in life.

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Chapter 6: Concluding reflections on the research process

Overview: Reflexivity as rigour and quality in qualitative research

Qualitative research and in particular the constructivist-interpretivist epistemological and ontological orientation of the methodology utilized in this research recognizes the intersection between the worldview of the researchers and the phenomenon under investigation and consequently, the need for criteria to evaluate the worth of knowledge generation (Charmaz, 2006; Finlay, 2006, pp. 20-22; Corbin & Strauss, 2008, pp. 297-307; Crotty, 1998; Ahern, 1999; Guba & Lincoln (1994); Lincoln & Guba, 2003; Ponterotto, 2005; Sergi & Hallin, 2011; Tracy, 2010). As such, the requirements for the rigour and quality criteria also require that researchers attend to the ways in which they negotiated access, observed, participated, recruited participants and the processes involved in assembling knowledge generation.

While positivist and post-positivist paradigms view rigour and quality criteria as validity, reliability, objectivity and generalizability, more constructivist and interpretivist qualitative paradigms recognize the agency, interactions and inter-subjective relationships between the researcher and phenomenon, as well as, between the researcher and participants. Hence, rigour and quality criteria specify that these dimensions should also feature in the write up so that the reader can assess for themselves and appreciate the contexts and the meanings generated in the construction of knowledge claims.

Guba & Lincoln (1994) and Lincoln & Guba (2003) view these quality criteria summed up as “trustworthiness & authenticity” in a constructivist paradigm. They specify ‘*trustworthiness*’ criteria as “credibility (paralleling internal validity), transferability (paralleling external validity), dependability (paralleling reliability, and confirmability (paralleling objectivity)” (Guba, 1981 & Lincoln & Guba, 1985 as cited in Guba & Lincoln, 1994, p. 114) and ‘*authenticity*’ as “fairness, ontological authenticity (enlarges personal constructions), educative authenticity (leads to improved understanding of the constructions of others), catalytic authenticity (stimulates to action), and tactical authenticity (empowers action)” (Guba & Lincoln, 1989 as cited in Guba & Lincoln, 1994, p. 114). A critical paradigm would also consider the “historical situatedness of the inquiry (i.e. that takes account of the social, political, cultural economic, ethnic and gender antecedents of the studied situation)” (Guba & Lincoln, 1994, p. 114). Lincoln & Guba (2003) further elaborate that the voice or stance of the researcher is one that is viewed as “ ‘passionate participant’ as facilitator of multivocal reconstruction” for a constructivist paradigm and in a critical paradigm may also take the position of “ ‘transformative intellectual’ as advocate and activist” (pp. 257-263). There is an inherent recognition within the paradigms used in this study that recognizes that in the reflexivity and representations, the voices of the various participants and informants are mixed and multivocal, representing multiple views and positions as contributing agents rather than controlled factors and variables.

Tracy (2010) pulls together a set of eight overarching criteria for qualitative research in general (i.e. not limited to method specific criteria): worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence. Ballinger (2006) puts forth four 'considerations for evaluation': "coherence", "systematic and careful conduct", "convincing and relevant interpretation", and finally "whether the role of the researcher is accounted for in a way that is consistent with the orientation of the research" (pp. 240-242). Ballinger (2006) also proposes nine general means of demonstrating rigour: prolonged involvement, persistent observation, triangulation, peer debriefing, negative case analysis, member checks, thick description, enquiry audit and audit trail.

Underpinning several of these listed criteria for rigour and quality is the assumption that the researcher will show himself/herself, his/her journey and thinking in the account of the research, with at least, the intention of transparency. It is in this spirit that this chapter features three sections to elucidate the process of the researcher's journey over the last five years.

The first section provides an orientation to the conceptual potential and the practical considerations of doing interdisciplinary doctoral research. The second section explains the theoretical frameworks and distinctions of the reflexive approach. The third section shares the researcher's journey including a situated awareness of the

local contexts and reflections of the personal awareness and transformation of the researcher in the course of engagement with the topic and phenomenon. This section may be viewed by the reader as either phenomenological – an analysis of the ‘lived experiences of the researcher’ or as reflexivity criteria requirements for rigour and quality in qualitative research or both. The final section provides a theoretical reframing of the challenges and calls for a research attitude of an ethic of care as a conceptual extension for the additional considerations and requirements of researchers to provide safety in areas of research that involve controversial or sensitive topics with populations who may be vulnerable or socially marginalized.

Locating the researcher- methodological and practical considerations of interdisciplinary work

In the introduction of this manuscript, the theoretical scope of the study was defined as spanning five disciplinary perspectives – psychology, thanatology, reproductive medicine, bioethics, and biopolitics. It bears some discussion about the possibilities and challenges of an interdisciplinary bricolage. Two terms first need clarification for their meanings: *interdisciplinary* and *bricoleur/bricolage*.

Interdisciplinary - I view the term interdisciplinary as Kincheloe (2001) sets out as a “fuzzy concept at best, interdisciplinarity generally refers to a process where disciplinary boundaries are crossed and the analytical frames of more than one discipline are employed by the researcher” (p. 685).

Bricolage and the researcher as Bricoleur - In 1966, Levi-Strauss referred to the idea of a bricoleur as a “jack of all trades” (Levi-Strauss, 1966, p. 17, as cited in Denzin & Lincoln, 2005, p. 4). I would take certain exception to bricolage being identified in this way, as it connotes some haphazard unreflected manner of characterization. However, the term and the history of qualitative research has changed and undergone numerous refinements since the initial ideas. Kincheloe’s (2001) conceptualization of bricolage as “boundary-work” resonates more accurately with my experiences of the research process, and the methodological and theoretical decisions to pursue an interdisciplinary bricolage. Lincoln, Pinar. & McLaren (2001) respond to the critique of

the bricoleur as a jack of all trades handyman, reiterating support for Kincheloe's (2001) broadened view that the

“bricoleur is far more skilled than merely a handyman. This bricoleur looks for not yet imagined tools, fashioning them with not yet imagined connections. This handyman is searching for the nodes, the nexuses, the linkages, the interconnections, the fragile bonds between disciplines, between bodies of knowledge, between knowing and understanding themselves. This is not your father's bricolage. It is “boundary-work” taken to the extreme...It works the margins and liminal spaces between both formal knowledge, and what has been proposed as boundary knowledge, knitting them together, forming a new consciousness” (pp. 693-694).

Hence, bricolage is best characterized as a melding or knitting of the multiple perspectives and multiple constructions of knowledge and the production of meanings. As a research method, bricolage implies its concern with social change, production of meanings, understanding power and social transformation, and the spirit of the dialectic (Kincheloe & McLaren, 2005, p. 318- 320).

Kincheloe & McLaren (2005) reiterate in response to the critique that such diverse breadth may be haphazard at worst and superficial at best without ascribing to any predefined quality of rigorous criteria, reiterating that “the bricolage is dedicated to a form of rigour that is conversant with numerous modes of meaning-making and

knowledge production” (p. 318). In this particular study, Grounded Theory was used as a methodology for its flexibility in incorporating diverse methods while still having an overarching set of criteria for quality, rigour, and credibility. Denzin & Lincoln (2005) further elaborate that in order to use bricolage,

“The methodological bricoleur is adept at performing a large number of diverse tasks, ranging from interviewing to intensive self-reflection and introspection. The theoretical bricoleur reads widely and is knowledgeable about the many interpretive paradigms...that can be brought to any particular problem” (p. 6) and as such the researcher “works between and within competing and overlapping perspectives and paradigms” (p. 6).

Finally to reiterate the nature of the engagement, it is:

“A deep interdisciplinarity seeks to modify the disciplines and the view of research brought to the negotiating table constructed by the bricolage. ...The point of interaction is not standardized agreement as to some reductionistic notion of the ‘the proper interdisciplinary research method’ but an awareness of the diverse tools in the researcher’s toolbox” (Kincheloe & McLaren, 2005, p. 320).

Grounded Theory requires a bracketed mindset to resist against the formulaic verification or nullification of grand theories to produce a novel contribution (Glaser & Strauss, 1967, pp. 1-12). Grounded Theory also expects then that its users be sufficiently adept and versed in a number of theoretical perspectives in recognizing and

drawing upon a diverse set of explanations in building the model without falling into what is the accepted discourse (Glaser & Strauss, 1967, pp. 46-47). Furthermore, beyond the methodological rigour and theoretical justifications, the context of the phenomenon showed itself to be richly layered between the private subjective experiences, the relational dimensions of interrelationships, the socio-political tensions, and the day to day realities of clinical practice. For any and all of these reasons, an interdisciplinary bricolage fits. Furthermore, my enrollment in an interdisciplinary doctoral program created, encouraged and appreciated this approach.

Rather than viewed as a limitation, I would add a word of caution that this sort of bricolage imposes certain additional demands for the graduate student in order to complete the project successfully. Embarking on this journey requires the sustained vision, commitment, patience, and appreciation for this approach by a number of individuals.

First, one needs an advisory committee that can represent the entire theoretical breadth that is covered. While this seems simple enough, the reality is that the previous decades of academia have traditionally been discipline-specific and thus putting together a committee requires collaborations with people and departments in a new way. The novelty of these collaborations takes time to establish, and can be met with administrative back and forth until the idea, roles, responsibilities, possibilities, and risks are clearly accepted within each of the departments. It can also be stated that

signing off on the paperwork can cause significant delays. In my case, each of the four committee members held an area of expertise, and all were incredibly amenable to the directions and advice of each other even if they themselves were not versed in the topic at hand. In my view, each of them has 'supervised' me in some capacity at a given time. However, for the purposes of a graduate department, the student should have one designated supervisor governing the committee and ultimately being responsible for the student. It bears saying that that this person requires the utmost skill of diplomacy to facilitate the project, allow the breadth and scope even in areas outside their expertise and be able to negotiate and compromise with the committee and the departments on what is sufficient depth, breadth and mastery without the student having to complete five different dissertations.

Second, the 'home department' needs to be defined and flexible. For the student, the home department is his/her graduate program. However, since my training and access to the field occurred within a healthcare setting, for a period of time I also required a 'home department' and a 'supervisor' from within that institution. My particular graduate program did not have a clinical component and thus did not have an existing clinical affiliation within the healthcare institution. My 'home department' and 'supervisor' for that period of time and hospital administration deferred to the home department of the committee member who had an existing membership in the area of my topic. Negotiating access and status in a hospital setting which is rigorously demarcated around discipline-specific boundaries was a herculean

challenge, and required the vision and endorsement of the hospital vice-president of clinical practice and the permissions from the administrative heads of each department with whom I might have had some contact – obstetrics, neonatology, social work, nursing, and pastoral care. My request and presence as an interdisciplinary scholar who also happened to be a clinician was a novel situation for this institution and at the time it did not have an existing protocol to process the requisite paperwork. Quite frequently, I was asked, “So who are you? What’s your home department? and Who’s your supervisor?” In the end, my hospital identification badge just said my name followed with “PHD student, Obstetrics” as that was all that could fit on the badge and that seemed momentarily sufficient for the staff to know that I belonged somewhere.

Third, Lincoln, Pinar, & McLaren (2001) reflect that “We have few models to show us how such interdisciplinary collaboration might work. Such collaboration is neither well understood, nor is it well rewarded in the academy” (p. 694). From my own reflective memos, I noted that at many times I felt that I had set sail without a map nor a course that was charted compared to my peers who had pursued discipline-specific programs. In my reflective discussions with the staff in the hospital, some of the metaphors they used to describe the tensions and ambiguity I was feeling, included: “trying to walk up a gravel slope,” “being on the shoreline,” “bumper cars,” “walking on eggshells,” and as one person cautioned that following the controversial events involving the institution, that I would need to tread gently and carefully because “how many snakes can you handle being kicked up” (Memos: February to March 2010).

My own feelings at various times as I tried to navigate unfamiliar territory and an unorthodox but innovative educational plan could be summed up as feeling that interdisciplinary work left me 'belonging in no place in particular.' More specifically, I was at various times at a shifting threshold between an 'outsider' and 'insider'/'embedded researcher'; 'observer' and 'participant'; 'nomad' and 'marginal member'; and at a later brief period as both 'scholar/researcher' and 'patient.'

Finally, a student embarking on an interdisciplinary project should be prepared to appreciate and embrace the additional coursework, depth, and breadth that are required to demonstrate competence in training across each of the areas. By extension, it also takes a longer duration of study period in order to do so, with practical implications for funding timelines and livelihood. As a particular personal requirement, students will need to forge new collaborations, invite and engage multiple gatekeepers, must be prepared to be their own advocates, to know and ask for what they need openly, and as my supervisor advised, to have a thick skin in the process.

Reflection, Reflexivity & Reflective Practices

A distinction is required regarding what I mean when I use the words reflection, critical reflection, and reflexivity as these concepts then frame the context for subsequent points made about the research as a journey and about how I have moved within these settings, and how my experiences have shaped the understanding shared forthwith and throughout the discussion of this manuscript. Growing academic critique among scholars (Kinsella, 2006, 2007, 2009, 2012; Polkinghorne, 2004; Brookfield, 1998, 2000) have argued that the terminology around the concepts of 'reflection' tend to be used interchangeably, inconsistently, and without much distinction either between the terms and their assumptions or as distinguished from the concept of 'critical thinking.' For the purposes of discussion I will use the following understanding as the theoretical underpinnings for my own reflections:

Reflective thought - is "active, persistent and careful consideration of any belief or supposed form of knowledge in light of the grounds that support it and further conclusion to which it tends" (Dewey, 1933, as cited in Kinsella, 2009, p. 7). Reflective thought as I've used it in the research journey has been very much in this vein, to stop and think about what I've seen, heard, and experienced. In my dialogues with people about new insights, I often collectively referred to my mulling thoughts or reflections as 'putting words to the things before my eyes.'

Reflective Practice -Donald Schon's (1983; 1987) notion that the reflective practitioner is much more than someone who goes about the tasks by rote never considering, tweaking, or questioning his/her methods; rather, the reflective practitioner brings a conscious awareness. He further elaborates that beyond the technical skill or 'technical rationality,' a reflective practitioner also uses improvisational skills which Schon refers to as 'reflection-in-action' and 'reflection-on-action,' which is a post-action conscious awareness that considers the choices made and the impacts for future actions. Kinsella (2009) proposes that rather than a populist term, the term 'reflective practice' has specific meanings and epistemological underpinnings. She identifies these as five themes: a critique of technical rationality; professional practice knowledge as artistry; constructivist assumptions in the theory; significance of tacit knowledge; and overcoming mind-body dualism (p. 6). More specifically, that "reflective practice asks professionals and policy makers to rethink the dominant, taken-for-granted epistemological assumptions of professional knowledge-technical rationality" (p. 6).

Although, Schon conceptualized his theory to apply to clinicians, it could broadly also be applied to researchers or any others engaged in 'doing.' My identification with this theory came naturally from my own identities as both researcher and clinician. In the day to day of the research process, this concept and its sub-parts gave me a framework to rationally critique what I was doing at any given time, why I was doing it a particular way and what implications would this have, not just for my own study but

also as a check on my moral responsibilities of treading carefully into controversial areas.

Critical reflection/ critically reflective practice – Brookfield (2000) states that reflection alone does not imply that it need be necessarily 'critical.' It is more than critical thinking or mere reasoning and rationality. In a multi-disciplinary setting the word 'critical' is taken to mean many different things from critical thinking, critique, and criticism to language that may bear specific clinically laden meanings about critical times, vital signs, or dosages. Academic scholars and 'critical theorists' may have other theoretically specific meanings as to whether the implied term references specific ideological schools of thought, such as the Frankfurt School. Although this research is conceptualized primarily as a constructivist-interpretivist study, "critical theory differs from constructivism in that the emphasis is on concepts and practices that aim to emancipate and enlighten individuals and groups, illuminate power relations and the role of economics, and uncover the ideologies that implicitly shape people's lives" and hence multiple realities are 'tempered' by historical realities (Carpenter & Suto, 2008, p. 24).

Brookfield (2000) identifies the concept of critically reflective practice as attention to uncover "submerged power dynamics." He elaborates that, in part, such critical reflection would consider moral implications, ideology conveyed through

language and linguistics, hegemony, privilege, and voice that keeps persons or issues silenced or disenfranchised. The term 'critical reflection' in this manuscript and research is used to raise a conscious awareness to the dynamics of power, both overt and covert, that play a role in the phenomenon, in shaping issues of access to the phenomenon, in the relational dynamics amongst individuals and indeed also in acknowledgment of the write up of this research as one standpoint amongst various perspectives and disciplines.

Reflexivity – “is self-aware critical reflection of the ways in which the researcher might have influenced the objectives, process, and outcomes of the research. In contrast to reflection, reflexivity involves a more immediate dynamic and continuing self-reflection” (Finlay & Ballinger, 2006, p. 263). Rather than clear or arbitrary boundaries between these terms, Kinsella’s (2012) theory of the continuum of reflection is much more appreciative of the fluid dimensions and the ebb and flow in which one might engage with these types or nuances of reflections. She broadly categorizes the tasks, behaviours, cognitions and so on and locates them as a continuum from: receptive reflection, intentional reflection, embodied reflection, and reflexivity.

Personal Reflections: The researcher's journey, challenges and transformations

As part of critical reflection and reflexivity, it is acknowledged that the shaping of this dissertation requires the period of time and place in which it unfolded to be provided with a situated awareness. A situated awareness is one that addresses the many factors occurring around you that implicitly or explicitly had a role in shaping the research decisions, the ways in which choices related to navigating the tensions and thereby addressing the many limitations outside of the volition of the researchers. From a methodological viewpoint Guba & Lincoln (1994) sum it up as an epistemological question of “what is the nature of the relationship between the knower or would-be knower and what can be known?” (p. 108).

Situated awareness of the local context

In 2009, the local medical community came under the closest of media scrutiny over journalistic accusations claiming that the provision of healthcare services that allowed or even condoned the option to terminate a pregnancy for reasons of fetal and/or genetic anomalies as a healthcare choice was a form of eugenics. It was particularly devastating that the clinic was housed at the time in a Catholic affiliated institution. The resulting response of the media's portrayal invoked scrutiny from the Catholic Church administrators regarding the parameters of morally permissible healthcare services allowed in an affiliated institution in accordance with the teachings of Catholic doctrine.

That same year (2009), Dr. George Tiller, a healthcare provider in the United States, a well-known yet controversial physician who provided abortions (including late-term terminations of pregnancy) was murdered. Although occurring in Wichita Kansas, the impact certainly crossed the minds of many women's healthcare providers who offered or supported women in this option, regardless of whether they performed the procedure themselves.

The following year, in 2010, the local medical community was once more surrounded by controversy in the 'Baby Joseph' case. The case of 'Baby Joseph' involved an infant with a diagnosis of an inherited rare neuro-metabolic disorder called Leigh's disease. Among many clinical factors, the case also reflected the complexity of ethical and legal decision-making related to balancing the risks and benefits of treatment options and the medical determination of clinicians to ethically refuse to perform a procedure for reasons of medical futility; and from a familial perspective, the hopes, challenges, and the legal dilemmas for the parents in an attempt to advocate for the best interests of their child. The case of 'Baby Joseph' involved not just a journalistic expose of the case but also the legal and ethical implications for staff and hospitals on both sides of the US-Canada border, as well as precedents for other rare cases. Local media at the time reported that the staff and hospital administrators received reportedly thousands of death threats from the public in reaction to the decisions made.

All three of these events, although not directly featured in the day-to-day operation of my research, touched the topic in a certain and profound way. The presence of the clinic within a Catholic institution, the murder of Dr. George Tiller that served as a vivid reminder of the risks of controversial work, and the Baby Joseph case that brought the questions of quality of life, lifespan health, and the attachment of parents into sharp focus. Underscoring all of these events was a pervasive undercurrent of a lack of safety.

For two years following the initial controversy, I had also served as community member on one of the hospital's ethics sub-committees. At the end of that term the sub-committee was retired as part of an organizational restructuring. Hence those last two years were marked by transition and a cloud of tension precipitated by the aftermath of these events. The tensions and the pervasive uncertainty of safety were significant enough that several members declined to be photographed for the final editorial in the hospital newsletter for fear of being publically identified by name and face. Furthermore, during this period of transition and organizational restructuring of women's and neonatal care in the local community, the added layers of job insecurity, potential downsizing, and a community deeply affected by the economic recession and funding cuts added another palpable layer of tension. I often wondered how staff viewed my presence within the organization. I was quite aware that I had gained access not solely by my own promise or merit but also because of the tremendous influence of a committee of highly regarded experts and the invitation of the highest echelons in

hospital administration. While this greatly facilitated access, I also wondered about which staff engaged or avoided me because of who my committee represented and whether my association posed a 'perception of risk' to them. There were some who engaged willingly and viewed the research as something of benefit to them- to provide some 'evidence based research' to support what they were already doing in their work; others were slightly more cautious and likely worried about whether this could potentially be used as covert program or performance evaluation that may threaten jobs. My clinician gatekeeper tended to also be vocal about his long-term visions and acknowledged my capacity to be both a clinician and a researcher openly. At times, this became its own source of tension; in a period of job insecurity this posed a potential double threat to staff. Although I attempted to make it explicitly clear that I was not interested in going after anyone's job I continued to wonder about what my presence meant for them in the power dynamics.

As part of my ongoing supervision and reflexivity, I've had numerous discussions over the last five years with my supervisor and advisory committee; academic peers and professors; medical residents, and clinicians who were informants and mentors in the field; and professional colleagues about how to live and work with these tensions, what could be discussed and how. To be completely honest, there were times I felt concerned for wellbeing of clinicians I had come to know; as well as an ethical concern over how my research may be used or misused in socio-political agendas such as those that had transpired. The critical reflection on these things had created a need to

continually ‘take the pulse’ reaction as I navigated my way from the methodological decisions, ethical decisions, and even the day to day dance in the field about the times to engage and times to withdraw. This process became a daily assessment of tone and moods within the organization and its members.

Retrospective and emergent personal reflections on the journey

Naïveté- While the initial decision to pursue fetal anomalies as a dissertation topic was an extension of my previous research on perinatal loss which had largely focused on miscarriage, there was a sense at the conclusion of the previous research that integrating all the antecedents of perinatal loss together lost the nuance and complexity of the various trajectories and divergences among the types of reproductive loss. However, in the early years when I embarked on this path I had not foreseen the extent of the controversy embroiled in the area of reproductive health and thus how controversial this topic could become in light of the events of 2009 and 2010 as elucidated above. Perhaps I went into the research with a great deal of naïveté thinking that academia could be a pursuit of knowledge without the overlay of political divide in such a contentious area.

Stigma - Several people said directly in accusatory tones “why are you doing abortion research” and even when the topic and scope was clarified, these persons still held fast to the view that any discussion about birth choices or options was an implicit

action in the termination of life. There were those who went on to exhort and admonish me, attempting to dissuade me from the topic. One individual went so far as to say “these people should not be called parents.” Others had openly confronted me, demanding to know where I stake my dichotomous political flag in the pro-life, pro-choice debate. Some invited me in (cautiously after first vetting); others eyed me with suspicion and avoided me all together.

Unsafe research - I and the many people who have helped support me in this venture have at some point also been ‘vulnerable’ to these tensions, controversies, and an unknown shaky sense of trust in the aftermath of the controversy. I had written reflexivity memos at 3 AM when I could not sleep, questioning how to feasibly continue this work that had seemingly become or found itself in controversial territory. Ultimately, it required a critical awareness to the following issues: to stay true to the results and not be swayed by either my overwhelming feelings of vulnerability as a researcher and the pervasive theme of “unsafe research”; to not be swayed by the strongly vocal groups and individuals to whom I owed access and gate-keeping; and finally to not be swayed by my feelings towards protectiveness, shielding or censoring the impact for the insiders whom I had come to know and respect; and on the flip side not wanting the frankness of the research to be mistakenly interpreted as an ‘invited guest who left and betrayed them.’

Expanded inclusion of vulnerability and risk – Over the duration of the research, my views on who was ‘vulnerable’ began to transform and I began to see that vulnerability was not limited to the patient/couple. In research studies involving humans, the research ethics boards are thorough and conservative in granting permissions. For the purposes of a research ethics board’s evaluation of risks, my dissertation involved the risks of: ‘patient and medical setting,’ ‘pregnant woman,’ ‘fetus,’ ‘fetal anomaly,’ and ‘grief/distress.’ Any one of these criteria would warrant a full ethics board approval process rather than an expedited approval. As the primary/sole research university in the city that is also affiliated with the various teaching hospitals, the research ethics board no doubt also had to consider the collective consciousness of the university as well as the teaching hospitals and the town, particularly in light of the immediate aftermath of the controversial events. However, in my day to day experience of partaking in the research process, the vulnerability that was so pervasive was not limited to the five risk criteria above. The pregnant woman’s partner, the families of the parents, their medical specialists, the large collective group of healthcare providers and indeed even the hospital administrators (whom patients almost never meet) could also be constituted as ‘vulnerable,’ albeit each group in their own way. As a researcher, it was not just I who was vulnerable for being the student researching this topic, my advisors were also similarly vulnerable for their vicarious exposure to hearing my account and questions during supervision and debriefing and helping me navigate through the policies and barriers of these tension- filled times.

Raised consciousness of pregnancy risks – Following from the theme *naiveté*, in 2008 at the beginning of this research, I had a very limited understanding of the risks involved in pregnancy. My understanding then was fairly representative of ‘the average woman.’ I knew whatever public health messages had made common knowledge such as abstaining from alcohol, smoking, and any other substance use and the importance of preconception folic acid among other things. Prior to this study, while I certainly was aware about congenital birth defects, I hadn’t been really consciously mindful of the myriad risks from levels of toxicological contaminants in our everyday lives, the complexities of fetal anomaly diagnoses and prognoses, the complexity and ambiguity at reaching consensus amongst clinicians and broadly, just how many things could go wrong in the 40 weeks of pregnancy.

At one point I found myself confessing to a fellow colleague that as a woman of childbearing age I had lost my innocence and with it any bliss of having an experience of pregnancy as a regular woman as a result of vicarious exposure to the many risks of pregnancy. Implicit in the confession was recognition that the awareness had fundamentally transformed not just a past view but also a future experience. It was also an acknowledgment of the vicarious toll of witnessing distress week after week and in part my confession was to acknowledge this with transparency and also to seek some insight on how others managed this personal toll in their lives.

During the period of this research, two very close friends became pregnant with their first babies. I found myself worrying silently and overtly celebrating with them. I sent one friend an email celebrating the milestone of gestational viability as I had come to appreciate that this was no small achievement. My friends have been wonderfully supportive in sharing their pregnancies openly, in allowing me to be involved in preparing the nursery, shopping for baby things and making personalized baby clothes and playing with their little ones after birth. I found the rituals of normal joyful anticipation to be very therapeutic to buffer against the vicarious sadness of this research, all the while being explicitly aware of my own transformation.

Unforeseen circumstances and practical considerations – In 2012, nearing the end of my research I happened to become pregnant. The timing of my research conflicted with the timing of my happy news of pregnancy and I became very concerned about re-negotiating the timelines of various stages of the research so that I would not be doing interviews with participants while I was visibly pregnant. I did not wish to impose a bodily confrontation of a big round belly to parents who were faced with or grieving the many losses that come with a diagnosis of fetal anomaly. Although, no text and theory could have previously prepared me for this challenge, the simple reality was that I needed to find a compromise that would be relationally sensitive as well as ethically sensitive. My advisors and I had agreed to do as much as possible before I started ‘showing’ and then postpone the final stage of the work until after delivery. However, in the fourth month at a routine appointment we learned

unexpectedly of the silent death of our baby/fetus. At that point, I had to withdraw from the research both physically and emotionally to grieve and recover. The experience of being pregnant and experiencing the loss undoubtedly gave me a bodily awareness and embodied reflection that an empathic imagination and sensitivity can approximate but not make 'real' in quite the same way.

Evolving identity as a researcher - During this process of pregnancy and loss, I found myself now with a new identity in the research process. In a relatively small town, I needed to negotiate not just access to the field for research, but also, access to who would be involved in my personal obstetrical care and who would have access to my body. I felt in some ways torn between wanting to exercise privacy regarding my body while at the same time feeling hypocritical that I had benefitted so greatly from being allowed to observe and participate in the medical setting. I felt a reciprocal obligation to in turn, allow access to my medical history and body as a patient. The difficulty was that I had come to be known by various healthcare providers as an academic colleague; the discomfort of them seeing me physically and intimately exposed was incredibly awkward. Conversely, I had come to know of their expertise, their manner and care directly and I trusted them explicitly. Between the emotional negotiation of my discomfort and my need to entrust my care to a colleague, I also had to ethically consider and avoid as much as possible any dual relationships that might compromise or raise suspicions about the integrity of the study. I had been in the same spaces as a researcher and as a patient, the irony struck me and I made a comment to

the staff and to my advisors about the familiarity and strangeness of 'being on both sides of the hospital curtain.'

Concluding thought: Balancing the requirements of qualitative research with personal privacy

Despite my personal desires to be very private, the question about self-disclosure as an authentic and openly reflexive audit, especially in a qualitative constructivist-interpretivist methodology, became a consideration for the rigour and quality criteria. More to the point was the deliberation about how much of one's personal life to make public domain. Albeit, this was never imposed or asked of me by anyone on my advisory committee, but rather, it was I who debated the balance between my desire for privacy and the integrity of the research process. However, in negotiating boundaries, some aspects of my personal experiences (being a patient) are a shared story with my husband and therefore his consent, willingness and privacy was also paramount, as in those aspects, the question of privacy was not solely my decision.

Implications for 'sensitive research' with 'vulnerable people'

For many reasons such as vulnerability, risks, safety, distress, death and so on, this research study could well be conceptualized as 'sensitive research;' research with 'vulnerable people' and 'emotionally or ethically sensitive.' What precisely is definitive of 'sensitive or vulnerable' research is a gray area, in part because of the context that surrounds these issues or populations is socially constructed and laden with hegemonic meanings (Liamputtong, 2007). In my deliberation with the research ethics boards, the implicit questions around risk seemed to hinge on the 'vulnerability' of the parents. No doubt, the ethics boards had to consider whether participating in a research study may trigger or exacerbate emotional distress and indeed this was a significant concern for us as a research team as well in determining when, who and how people should be approached while balancing the aims of answering the research questions. At the same time, the question of pursuing the topic for its clinical benefit to other future parents and families also needed to be considered. To fail to pursue the topic altogether would not serve future knowledge generation and perpetuate the view that 'sensitive' topics and 'vulnerable' people are not risk-worthy of research, arguably a paternalistic approach. Rather, in the end the goal was to find some way to negotiate balance and approach candidates who were sufficiently emotionally and psychologically able to participate in a way that may be meaningful to them and the research. However, to do so may also require a purposeful or convenience consenting sample rather than a random or other sampling method.

For a framework to conceptualize what constitutes 'sensitive research' and 'vulnerable,' the broad general criteria that I used are: research that is "intimate, discreditable or incriminating" (Renzetti & Lee, 1993, p. ix); where "there are potential consequences or implications either directly for the participants in the research or for the class of individuals represented by the research" (Seiber & Stanley, 1988, p. 49); topics that are "private, stressful or sacred" or taboo (Lee, 1993, p. 4; Dickson-Swift, James & Liamputtong, 2008; Bishop, 2005; Chiappetta-Swanson, 2001 & 2005); that have potential for any kind of threat or lack of safety or exposure to psychological, emotional, or moral distress (Lee, 1993; Dickson-Swift et al., 2008; McCosker, Barnard & Gerber, 2001); involving persons who may be stigmatized, marginalized or disenfranchised or because these represent "hidden" or "hard to reach populations" (Melrose, 2002 & Benoit et al., 2005 as cited in Liamputtong, 2007, p.3; Doka, 1989, 1997 & 2002)); with an appreciation that 'vulnerable' can include anyone exposed to a sensitive topic or situation such as they may be exposed to direct or secondary traumatization, burnout, compassion fatigue, or moral distress/residue (McCosker, et al., 2001; Bishop 2005; Chiappetta-Swanson, 2001 & 2005; Gold, Kuznia & Hayward, 2008; Hendron, Irving & Taylor, 2012; Leinweber & Rowe, 2008; Rice & Warland, 2013; Sharp, 2008); and finally an inclusive awareness whether or not these are overt or "perceived sensitivities" (Dickson-Swift et al., 2008. p.4).

As a concluding thought to this section, I would propose an alternative or augmented consideration for understanding the nuances of research with humans-

that researchers should adopt a broad appreciation of the sensitivities and vulnerabilities that go beyond the requirements of Ethics Boards. Institutional ethics boards need to maintain a threshold based balance of risks and benefits to the research. This rule-based ethics has application for providing a more uniform and transparent code of conduct for researchers and public accountability. However, this format cannot feasibly cover all contingencies that may arise nor can it anticipate unforeseen public and private events that may intersect with the research. As such, I propose that beyond the rule and duty based obligations of ethical approval, researchers involved in areas or topics that intersect with vulnerable and other sensitive issues also strive to adopt a research attitude of an ethic of care to guide the nuances of relational ethical management. For example, with a critical awareness to the emotional resurgences of grief and trauma that people may encounter when they return to an environment associated with traumatic experiences and a pragmatic appreciation of high costs of hospital parking, we elected to do the interviews with participants in non-clinical settings – a university office or telephone interviews that would provide the requirements of privacy and confidentiality without triggers of traumatic sensory stimuli or additional financial or personal hardships. In another example, at the conclusion of the interview two individuals reached out to hug me and I reciprocated mutually given the emotional sharing of the previous two and half hours. While a positivist framework that espouses that researchers must be ‘detached’ may have viewed this human interaction as ‘biased’ and ‘contaminated,’ a constructivist, interpretivist, or feminist researcher would view this as ‘normal,’ ‘makes sense,’

'demonstration of trust and rapport,' 'relationally sensitive,' and from a critical viewpoint that the reciprocation is an act of acknowledgement for the generosity and altruism of the participant in ways that may be validating, especially to those who are silenced and disenfranchised. In this particular research, where parents facing such diagnoses are openly faced with meta-narratives of stigma, to not reciprocate would risk being inconsistent and inauthentic to the rapport, trust, and expression of gratitude established and thereby the perceived rejection would run the risk of being incredibly damning to their psychological integrity as bereaved parents and invalidate the tremendous emotional courage of sharing a very private lived experience.

Implications for future clinical practice

While this study was set up to explore the parental experiences for dealing with a diagnosis of fetal anomalies, I have come to an appreciation of the many players in this scenario. The professional experiences for dealing with moral dilemmas, the risk of secondary traumatization, compassion fatigue, and moral distress and residue are also important considerations for the therapeutic relationship between clinicians and patients.

Although the medical field is one in which, inevitably, the professional will encounter death, it would appear that there is a perception that certain specialty areas such as oncology, geriatrics and cardiology/ cardiothoracic surgery should anticipate death more than other fields such as obstetrics and pediatrics (Gold, Kuznia &

Hayward, 2008; Aase, Nordrehaug, Malterud, 2007). In a paper on bioethics and medical teaching, Sharp (2008) acknowledges that “coping with these professional experiences of death are a part of medicine that my ethics lectures had always assumed but never examined.” Aase, Nordrehaug & Malterud (2007), echo a prevailing stereotype that clinician in health care should be tough enough to be unaffected by death, as an occupational hazard of the job, they pose a concern that consequently “Western medical education may not be properly aimed at dealing with existential issues”. While the response of adding bereavement training has surged, medical students still report that the amount and quality of the training on personal and relational dimensions is ‘low’ with an average of 12 hours of training and only two thirds of that training addresses cultural aspects, beliefs and practices of death and dying which is the focus for palliative care and terminal illness (Gold, Kuznia & Hayward, 2008).

For Chiappetta-Swanson (2001) in her doctoral dissertation on the professional experiences of nurses providing care to women undergoing terminations for fetal anomalies, the overarching theme was “Dirty Work”, a view that providing care was a moral dilemma between the obligations to do the job and personal conscientious objections. Among several things were the social isolation which was adapted into professional and moral autonomy to practice the core values of the profession; the tensions between providing care versus routine procedure; the personal tensions of caring for patients and their own emotional well-being in emotional intense and

ethically contentious work; subtle workplace coercion and the responsibility of caring for two patients –the woman and the stillborn baby.

Bishop (2007) in a study on nurses working with women undergoing induction of labour for fetal anomalies, similarly found a prevailing theme of ‘Taboo work’ which involved: making choices, being pulled in two directions, given token bones, and riding the emotional rollercoaster. The stigma of working with death and the death of a child being considered ‘a bad death’, hence making choices about whether to do the work, whether to be emotionally engaged or just get through it and about testing one’s moral limits. In being pulled in two directions it is about being open versus concealing the nature of the work to provide optimal care as well as having to attend to different patients with different needs on a shift. In the absence of formal support to care providers the rewards are like token value without recognition of the value of the work or the impact on the nurses doing it. The emotional rollercoaster is the peaks and lows of viewing this as doing rewarding work but also overwhelmed by the sadness, grief and trauma.

In midwifery, the discourse focus on the overarching theme is ‘being with the woman’. In a study that looked at how 83 midwives provided perinatal loss care the aspects of satisfaction were: being able to provide skilled midwifery care, provide continuity of care throughout labour, birth and in the postnatal period by providing supportive individualized care, facilitating understanding, grieving and memories. What they found was reported as least satisfying were the emotional challenges of being “emotionally drained”, “to ‘witness’ the ‘trauma’ ‘shock’ and ‘disbelief’ experienced by

a woman whose baby had died". Some felt that their own shock and confusion was hard to accept and uncomfortable when providing perinatal loss care which could be 'all consuming and exhausting' and left one feeling that they had 'lived with it'. They also felt unsure, hesitant, not knowing what to do or say, worried about saying the wrong thing, feelings of helplessness and frustration. Limited emotional support from colleagues and the hospital system was depicted as another factor that it was 'struggling' and 'lonely journey' as well as frustration with paperwork related tasks. (Fenwick, Jennings, Downie, Butt, & Okanaga, 2007). Leinwebe & Rowe (2008) conceptualized this secondary traumatic stress in midwifery and the 'cost of caring', a concept which was described in three ways: compassion fatigue, post-traumatic stress disorder (DSM criterion) and secondary traumatic stress. As well vicarious traumatization within this article was differentiated from the other three by "emphasis on the transformation in the professional, affecting his or her private and professional life" (Thomas & Wilson, 2004 as cited in Leinweber & Rowe, 2008). The article drew aspects of how childbirth, particularly when escalating into emergency situations can become traumatic due to "excruciating and uncontrollable pain, disgust at the sight of blood and other bodily fluids, the horror of cut or torn flesh, and fear of her own or her baby's death" and other psychological birth traumas. The authors conclusions of the review indicate that the key factors in midwives 'costs of being with the woman' centers around the reciprocal relationship and empathic identification with the woman which "can have a transformative effect on the midwife herself" which can be implicated in experiencing "personal bereavement". The authors recognize that little

attention has been given to the issue of impact on those who ‘witness’ the traumatic experience of the childbearing woman, including the experience of the woman’s partner in witness such trauma. Leinweber, J., Rowe, H, 2008).

Conclusion

In a genomic era, the implications of prenatal screening and diagnosis of fetal anomalies is layered with multiple layers of loss, both death and non-death losses. As reproductive technologies advance, a serious ethical discussion about the moral and ethical standards for genetic privacy, the critique about screening as a form of microeugenics or selectivity for genetic enhancement will need to be addressed at the forefront.

In the meanwhile, I am deeply indebted to the many people who have helped shape and transform this research – the clinicians who invited me into their clinics to let me observe and train within their program, the parents for the willingness to bear the sorrow in retelling the story and their little babies who have left a lasting legacy in their short lives. Finally, to my supervisor and advisory committee for their tremendous visionary foresight and perseverance to see this to completion and the many others who have been my teachers.

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Appendix 1: Medical terminology

Amniocentesis - a prenatal test where amniotic fluid is withdrawn using a needle inserted into the uterus. (The fluid removed contains cells that contain a baby's genetic makeup thus can be used to test for the presence of certain genetic conditions. This may include Down Syndrome, Trisomy 13 or Trisomy 18

Amniotic fluid - clear fluid that surrounds, cushions and protects the fetus during pregnancy.

Anomaly - a change or deviation from what is considered normal such as a malformation of a body part. The term "Congenital Anomaly" is a medical term to describe a birth defect.

Chorionic Villus Sampling - a prenatal test usually done in the 1st trimester to detect fetal abnormalities. A small piece of the developing placenta is withdrawn; because this has the same genetic make-up as the developing fetus, it can be used for genetic or chromosome tests.

Chromosome - Structures found in the cell which contain a package of the cell's DNA. Chromosomes come in pairs and a normal human cell has 46 chromosomes: 22 pairs of autosomes and two sex chromosomes.

Chromosome abnormality - packages containing the genes, located in every cell of the body. Normally, humans have 46 chromosomes-half come from the mother and half from the father. Extra or missing chromosomes-or even parts of chromosomes-may result in birth defects or cognitive difficulties. Trisomy-47 chromosomes instead of the usual 46-is the most common type.

Congenital abnormality - a problem present at birth.

Fetal echocardiography - A test that uses high-frequency sound waves (i.e. an ultrasound) to show the structure of an unborn baby's heart.

Fetus - from approximately three months after conception the offspring take on a recognizable form. In human development, the period after the seventh or eighth week of pregnancy is the fetal period.

Genetic - involving DNA, the genes or the chromosomes. Related to a condition that is inherited or caused by an alteration in genetic material (chromosomes or genes).

Gestation - Length of pregnancy. For example, "20 weeks gestation" refers to the 20th week of pregnancy. The normal human gestation is 37-42 weeks.

Miscarriage - pregnancy loss occurring before 20 weeks gestation (the first half of pregnancy). Also called spontaneous abortion.

Perinatal - Pertaining to or occurring in the period shortly before and after birth, variously defined as beginning with completion of the twentieth to twenty eighth week of gestation and ending 7 to 28 days after birth.

Structural abnormalities/defects - problems in prenatal development affecting the body structure, either externally (for example, cleft lip or missing limbs) or internally (such as heart defects, kidney defects). Also called malformations.

Trimester - the amount of time that pregnancy is broken down into. There are three trimesters in a pregnancy, each being approximately three months in length.

Trisomy - 3 copies of a chromosome instead of the usual pair, generally resulting in

structural birth defects and mental retardation. Humans normally have 23 pairs of chromosomes, numbered 1-22 plus the sex-determining pair. The most common trisomy is an extra 21 chromosome (trisomy 21 or Down syndrome); trisomy 13 and 18 are also seen.

Ultrasound - prenatal test using sound waves to create a picture of the developing fetus. Ultrasound can measure growth and examine body structures such as the heart and spine.

References

(Twining, P., McHugo, J., & Pilling, D., 2007; Congenital Anomalies in Canada, 2002; Fetal Alert Network; Jones, K.L., 2006)

Appendix 2: Examples of Anomalies

Head: Anencephaly, Holoprosencephaly, Dandy-Walker Malformation etc. Facial anomalies include cleft lip and cleft palate, which can be traumatic for parents

Neural tube: anomalies involve the head, neck and central nervous system. One such condition that is well known to the public is Spina Bifida.

Cardiovascular: anomalies involve the heart and circulatory systems and such conditions like Atrial Septal Defect (ASD) and Ventricular Septal Defect (VSD) involved 'holes in the heart'. These conditions vary greatly in severity, some being minor and survivable with great vigilance, other reparable in several surgeries throughout childhood, while others may be severe enough to implicate all four of the heart chambers with extremely poor prognosis of survival.

Gastrointestinal: A wide range of anomalies such as obstructions in the digestive system, abdominal organs hernias (into chest, protruding outside the body) or conditions in which the bowels and other organs are exposed outside the body because the abdominal wall does not close completely (Gastroschisis and Omphalocele). These conditions complicate the labour and delivery and always require that the newborn remains in the Neonatal Intensive Care Unit (NICU) for long durations. In addition the physical appearance can be traumatic to parents.

Renal: anomalies involve the kidney and bladder systems. Often kidney tissue damage can be detected in prenatal ultrasound but the function of the kidney is unknown.

Respiratory: Cystic Fibrosis is an example of respiratory anomaly

Musculoskeletal: anomalies can range from growth of the fetus to any bone structure.

In some cases such as those of the thalidomide era, there is a reduction in limbs, either absence of entire limbs or shortening of limbs and appendages. In some cases there are extra bones and digits. More rare cases are those such as the different forms of dwarfism.

Trisomy: these anomalies involve an extra copy (three copies) of the same chromosome. There are three conditions each affecting a different chromosome number. Trisomy 21 is Down's syndrome, and the other two Trisomy 13 and Trisomy 18 are severe conditions that are considered "lethal".

References

(Twining, P., McHugo, J., & Pilling, D., 2007; Congenital Anomalies in Canada, 2002; Fetal Alert Network; Jones, K.L., 2006)

Appendix 3: Letter of Information



Information Letter & Invitation to Participate in Research

Title: Exploring the lived experience of parents who are dealing with fetal anomalies.

Principal Investigator: Dr. Alan Leschied (PhD., C. Psych)
Researchers: Ramona Fernandez (M.Ed. Counselling Psych, CCC, CT, PhD Candidate);
Dr Darcy Harris (M.Ed., RSW, PhD, FT)
Dr. Renato Natale (MD, FRCS(c), SJHC) City-wide Chief of Obstetrics
Dr. Jeff Nisker (MD, PhD, FRCSC, FCAHS)

Purpose of the Study:

You are invited to participate in a study that seeks to understand the lived experience of parents who are faced with a diagnosis of fetal anomalies in pregnancy. Currently, there is very little research that illuminates the struggles of parents in this situation. We recognize that this critical period requires that parents and families, such as yourselves, require sensitive support. We believe it is important to understand this from your experience and perspective to inform the future delivery of service without making preconceived notions.

We recognize that this is an extremely difficult time. It is our aim to be mindful and aware of your distress and learn from you your thoughts on how we can support you and others who are also faced with a similar experience. We are asking you to tell us what helps, what does not help and to share what this experience looks like to you on a daily basis.

Participation Details:

We are hoping to invite between 15-20 people for this study including mothers and partners. Your doctor, medical staff or the researcher will provide you with this letter of information and a contact information consent form. If you are uncertain about whether or not you would like to participate and are interested in learning more about the study, please complete the contact information consent form so that the researcher can contact you at a more convenient time. This does not obligate you to consent to participate in the study. Both mothers and partners are invited to participate. Each person would consent to study and participate independently to ensure confidentiality.

If you agree to participate in this study and sign the consent form, you will be asked to complete a set of questionnaires on demographics, pregnancy related items (mothers), and an evaluation of the services you have received, as well as an interview to share your story. The questionnaires will take no more than 5 - 10 minutes. The interview will take approximately 1 hour and will be loosely structured so you may share only what you wish. The location and times for the interview will be arranged directly with you to accommodate convenience, privacy and confidentiality.

Confidentiality:

The information collected will be used for research purposes only. Your name and any identifying information will not be used in any publication or presentation of the study results. The interview will be audio-taped and transcribed to allow for research analysis and will be accessible only to the researcher for data collection. Identifying information will be deleted from the interview transcripts to ensure your confidentiality.

Please initial here

Pg 1 of 2; version March, 28 2012

The University of Western Ontario
Faculty of Health Sciences • Health & Rehabilitation Science
Elborn College • London, Ontario • CANADA - N6G 1H1
Telephone: 519-661-2111 • www.uwo.ca



All information collected for the study will be kept confidential. All data will be kept in a secure location with access only to the researcher. Paper materials with any identifying information will be destroyed upon completion of the study. Transcripts and analysis will be retained for 7 years after the end of the study to allow for publication of results.

If some of your responses indicate that you are in acute distress, we will want to discuss this with you to be sure that you are receiving support during this time and provide assistance in getting you access to the service that you need. Please note that confidentiality will be maintained unless disclosure is required by law, and hence this would be the only aspect of confidentiality that would be limited.

Voluntary participation:

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your current or future healthcare.

Risks: There are no known risks to participating in this study although actively recalling the events and sharing your story may be emotional or distressing.

Benefits: There may be no direct benefit to you associated with your participation in this study. The researcher will provide support to you during this process and can also facilitate helping you access further supports and resources in the community to help you and your family cope if you desire.

Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

If you have any questions about the conduct of this study or your rights as a research subject you may contact the Dr. David Hill, Scientific Director, Lawson Health Research Institute

If you have any questions about this study, please contact:

Ramona Fernandez, Researcher

Dr. Alan Leschied, Principal Investigator (PI)

This Letter is yours to keep for your information. Thank you for your time.

Please initial here

Pg 2 of 2; version March, 28 2012

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Appendix 4: Research Ethics Board Approval



Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Alan Leschied
 Review Number: 18913
 Review Level: Full Board
 Approved Local Adult Participants: 20
 Approved Local Minor Participants: 0
 Protocol Title: Exploring the lived experience of parents who are dealing with fetal anomalies.
 Department & Institution: Education/Faculty of Education, University of Western Ontario
 Sponsor:
 Ethics Approval Date: April 03, 2012
 Ethics Expiry Date: April 30, 2013

Documents Reviewed & Approved & Documents Received for Information:

| Document Name | Comments | Version Date |
|---------------------------------|---|--------------|
| Western University Protocol | Including all instruments listed in section B.1 | |
| Letter of Information & Consent | | 2012/03/28 |

This is to notify you that the University of Western Ontario Health Sciences Research Ethics Board (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/CH Good Clinical Practice Practices, Consolidated Guidelines, and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this HSREB also complies with the membership requirements for HSREBs 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 University of Western Ontario Updated Approval Request form.

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

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Signature

Ethics Officer to Contact for Further Information

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This is an official document. Please make use 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

Exploring the lived experience of parents who are faced with a diagnosis of fetal anomalies in pregnancy

1.) Thematic Question: “Would you tell me in your own words what happened?”

Prompt Questions: a) “Could you share your thoughts about yourself and your baby while pregnant?”

b) “Could you elaborate on what this experience has been like for you on a daily basis?”

2.) Thematic Question: “When did the pregnancy and baby seem real to you?”

Prompt Questions: a) “Were there times that you may have felt a connection?”

3.) Thematic Question: “Is there anything you wished someone would do or say that might have helped?”

Prompt Questions: a) “Was there anything that was unhelpful or upsetting?”

4.) Thematic Question: “What are your needs at this time?”

Prompt Questions: a) “What emotional, physical or other needs do you need at this point?”

b) “Are there any supports or services that would be useful to you?”

Vita

| | |
|--------------------------|--|
| Name | Ramona L. Fernandez |
| Degrees | PhD. Health Professional Education (2008- 2013) Western University M.Ed. Counselling Psychology (2006 -2008) Western University Certificate in Grief & Bereavement (2009) Kings University College Bachelor of Arts (2000-2005) Western University |
| Professional Credentials | Certified Canadian Counsellor (CCC), CCPA (2008- current) Certified Thanatologist, ADEC (2010- current) Fellow in Thanatology, ADEC (2013 –current) |
| Awards | Student Initiative Scholarship, ADEC, 2013 Graduate Thesis Research Award, University of Western Ontario, 2013 Ontario Graduate Scholarship (OGS), 2011 Student Initiative Scholarship, ADEC 2011 FHS Graduate Student Travel Award, University of Western Ontario, 2011 Dean’s Entrance Scholarship, University of Western Ontario, 2008 Student Initiative Scholarship, ADEC 2009 FHS Graduate Student Travel Award, University of Western Ontario, 2008 Graduate Thesis Research Award, University of Western Ontario, 2007 Internal Research & Development Grant, University of Western Ontario, 2007 Graduate Thesis Research Award, University of Western Ontario, 2006 Lieutenant-Governor General’s Medal, 2000 Entrance Scholarship, Carleton University, Ottawa, ON (declined, 2000) |
| Publications | Fernandez, R. , Harris, D., & Leschied, A. (2011) Understanding Grief Following Pregnancy Loss: A Retrospective Analysis Regarding Women’s Coping Responses. <i>Illness, Crisis and Loss</i> 19(2) Fernandez, R. (2009) Open Adoption II: The Perceptions and Ethical Implications. Practice and Research Together, http://www.partontario.org) Fernandez, R. (2009) The Debate in-favour and against open adoption. Practice and Research Together, http://www.partontario.org) Fernandez R. (2008) <i>Grief Related to Pregnancy Loss: Understanding the Experience of Losing a Child Before Birth</i> . Unpublished master’s thesis, The University of Western Ontario, London, Ontario, Canada. Crooks, C., Fernandez, R. , Topham, A., Acton, W., Brotzel, D., Toni Swart, G., & VanMeyel, R. (2005). Children under 12 years with sexual behaviour problems in London and Middlesex County: Trends and professionals' perceptions. London, Ontario: Centre for Research on Violence against Women and Children. |