PRENATAL SCREENING AND THE DIAGNOSES OF FETAL ANOMALIES: A DECONSTRUCTION OF POWER/KNOWLEDGE, DISCOURSE AND AGENCY IN ANTENATAL CARE

by

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ABSTRACT

Background: Improved prenatal screening has resulted in significantly more parents facing a diagnosis of a fetal anomaly (FA). This experience can profoundly affect parents' wellbeing and contribute to challenges in antenatal communication and decision-making. Research Purpose: To more fully understand: (1) the communication and decisionmaking dynamics associated with antenatal screening and the diagnosis of an FA: (2) the underlying frameworks and power relations shaping health care provider (HCP)-parent interactions; and (3) potential strategies for HCPs to support parental decision-making. Methods: Guided by a blend of critical and Foucauldian theoretical perspectives and a critical ethnographic approach, data collection occurred at two specialized women's centres and involved over 275 hours of observational fieldwork and 119 hours of participant interviews. A diverse sample of 114 parent participants was recruited for 67 participant observation sessions. Informal interviews were conducted with all parents and in-depth formal interviews with 18 parent participants. Ten antenatal HCPs from a broad range of disciplines/subspecialties were also interviewed. Findings: (1) HCP-parent communication and decision-making is significantly shaped by dominant biomedical, efficiency, individualism, responsibilization and disability discourses in combination with underlying power relations. (2) A biomedical lens combined with organizational imperatives promoting brevity in HCP-parent interactions can result in parents' needs not being addressed and thereby lead to increased parental distress, inadequately informed decisions and health inequities. (3) Despite HCPs' nondirectional intentions, diagnostic and prognostic information is often presented in biased ways, which can lead to guarded HCP-parent interactions and increased parental distress. (4) Parents' emotional responses to an FA are conceptualized as a complex matrix of prominent emotions

vacillating between four intersecting continua: (i) dread/despair-hope; (ii) powerlessnesscontrol; (iii) self-stigma-self-respect (and associated social isolation-social integration); and (iv) low parent-fetal attachment (PFA)-high PFA. Supportive interactions are those that facilitate parents to move their emotional stance toward hope, control, self-respect, social integration, and high PFA. **Implications:** Based on study results, I propose multilevel recommendations for antenatal communication and care practices, education programs and future research, with the ultimate goal of promoting excellence and equity in antenatal care delivery and HCP-parent communication and decision-making support.

LAY SUMMARY

Improved prenatal screening has resulted in more parents facing a diagnosis of a fetal health concern. This experience can have significant effects on parents' wellbeing and is often associated with difficulties in health care provider (HCP)-parent communication and parental decision-making. This research aimed to understand the communication and decision-making dynamics associated with antenatal screening and diagnosis, the underlying frameworks and power relations shaping antenatal interactions, and how HCPs can better support parents. The research approach involved observational fieldwork and interviews with parents and HCPs. Findings provide new insights into parents' mental health. Findings also help to understand how dominant healthcare frameworks and power relations contribute to uninformed and/or biased decisions and differences in parents' health experiences. Recommendations include strategies to improve antenatal communication, decision-making support and healthcare education as well as considerations for future research.

PREFACE

This dissertation is an original intellectual product of the author, Loryle Cender. The fieldwork reported in Chapter 3 was covered by The University of British Columbia and C&W Research Ethics Board Certificate number H14-02404 and The University of Alberta/Alberta Health Services Health Research Ethics Board Certificate number Pro00055383.

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DEDICATION

This research is dedicated to Emilia and Wilhelm Kruger, my grandparents, for their endless love and for teaching me the life lessons that I continue to treasure: be kind; love unconditionally; work hard for the joy and satisfaction gained from the process, not necessarily the outcome; smile from your heart; laugh often and deeply; be brave— remember one cannot be successful unless they are courageous enough to risk failure; and view each day as a gift—an opportunity to learn and grow and try new and wonderful things. My life would not be the same without you in it. I love you both and you continue to inspire me every day.

CHAPTER ONE: INTRODUCTION TO THE STUDY

Improved prenatal screening has resulted in an increasing number of parents facing a fetal diagnosis of a structural and/or chromosomal anomaly as early as 14 to 20 weeks gestation, and sometimes even earlier. This experience can have profound effects on parents' well-being, including acute grief reactions and heightened anxieties, and these can contribute to complex communication challenges between parents and health care providers (HCPs) (Askelsdottir, Conroy, & Rempel, 2008). Information communicated badly can increase parents' psychological and emotional distress and undermine the future health of both parent and child (Araki, 2010; Hedrick, 2005; Korenromp et al., 2005); conversely, information provided with sensitivity can provide inestimable support to parents' ability to manage, integrate new understandings, and make informed decisions (Lalor, Begley, & Galavan, 2008).

Previous research points to inequities in HCP-parent decision-making support and indicates HCPs may unintentionally (and sometimes intentionally) influence parents' decisions to align with what the healthcare team views as in the parents' best interests without a clear understanding of the parents' preferences and beliefs (Anderson, 1999). Contextual factors such as an emphasis on efficiency and biomedical concerns and/or a dominant biomedical perspective in HCP-parent interactions may undermine HCP-parent communication and contribute to inadequate parental decision-making support (Aarthun & Akerjordet, 2014; Jackson, Cheater, & Reid, 2008). In addition, HCP-parent interactions that focus on pregnancy or complex treatment options, such as complex neonatal medical or surgical procedures, may obscure the wide range of experiences and decisions parents face.

Socioeconomic, gender and other differences between HCPs and parents may also shape HCP-parent interactions and parental decisions and create inequities among groups of parents (Cooper-Patrick et al., 1999; Pletcher, Basco, Hotaling, Sigrest, & Simon, 2013; Thornton, Powe, Roter, & Cooper, 2011). Moreover, power imbalances are magnified when parents are from disadvantaged groups or when their voices are suppressed due to gender, language, socio-economic, educational or other differences. Inadequate support may result in parents being poorly prepared for the complexity of their child's medical treatments and the impact on personal and family life (Rempel, Rogers, Ravindran, & Magill-Evans, 2012). This has the potential to create situations where individuals who could most benefit from therapeutic relationships that address psychosocial, emotional and contextual needs related to health and illness receive inadequate attention and face the greatest care burden. Further research is required that illuminates the nuances, complexities and contradictions associated with health communication and parental decision-making support, specifically as it relates to the diagnosis of a fetal anomaly.

In my previous clinical practice as a pediatric Clinical Nurse Specialist (CNS) working with parents who received an antenatal diagnosis of congenital heart disease (CHD), it was not uncommon to witness variations in the way diagnostic and treatment information was presented to families of different socioeconomic status, ethnicity, or other visible differences. For example, one day I provided support to two separate families who both received a fetal diagnosis of the same complex CHD. The first discussion was with a set of parents who were both HCPs themselves. The information provided by the specialist was clearly biased toward treatment of the condition through his positive tone, in-depth discussion of improved outcomes, and depiction of an excellent quality of life for

infants and children with this form of CHD. This discussion was in sharp contrast to the following session with a single 15-year-old First Nations woman who received information regarding the fetal CHD in sombre tones, emphasizing "the long and hard journey ahead" and the mother's right to terminate the pregnancy. This clinical example illustrates the importance of understanding the multiple intersecting factors shaping HCP-parent interactions, the potential for inequities among particular groups of parents, and the possible influence HCPs have in how diagnostic and prognostic information is provided to parents. It is of paramount importance that HCP communication standards safeguard *all* families from professional practices that deny parents the information and decision-making support they require to make informed and reasoned decisions related to the diagnosis of a fetal anomaly. Improving communication and parental decision-making support related to pregnancy and treatment options is one of the most important actions HCPs can take to ensure quality and equitable care during this time-pressured and emotionally taxing time.

A search of relevant literature, which will be reviewed in Chapter Two, indicates that the complex communication and decision-making dynamics associated with prenatal screening and the diagnosis of a fetal anomaly are not well understood. There is limited research examining the experiences of parents who receive a diagnosis of a fetal anomaly, particularly for those parents who pursue termination of pregnancy (TOP). Much of the research that has been done in this area emphasizes the considerable psychological and emotional impact on parents following the diagnosis of a fetal anomaly (for example, see Araki, 2010; Cole et al., 2016; Horsch, Brooks, & Fletcher, 2013; Rempel et al., 2012; Titapant & Chuenwattana, 2015) and the nature of parental decisionmaking (for example, see Benute et al., 2012; Lotto, Smith, & Armstrong, 2017; Rempel, Cender, Lynam, Sandor, & Farquharson, 2004). However, my clinical experience and recommendations from the existing literature emphasize the need for a better understanding of how HCPs can improve HCP-parent communication and decision-making support related to the diagnosis of a fetal anomaly, including the content and delivery of information related to diagnostic testing, prognostic information, and pregnancy and treatment options. Previous research also underscores the need to more clearly understand the experiences and perspectives of parents, including those who pursue TOP following diagnosis of a fetal anomaly, as well as the experiences of HCPs involved in providing antenatal care and support. Finally, previous research findings highlight the need for HCPs to have a greater awareness and understanding of the multiple intersecting personal and contextual factors influencing parents' overall antenatal experiences.

In the following section I will provide an overview of the theoretical lens that guided the research process in order to set the stage for a summary of the research purpose, questions, definition of terms, and assumptions.

Theoretical Perspectives Guiding the Research

A qualitative descriptive perspective as well as a blend of critical and Foucauldian theoretical perspectives provided a theoretical lens to guide the research. In setting out to do this research, I had initially set out to employ a blend of critical and Foucauldian perspectives to provide a theoretical lens focused on scrutinizing the prevailing dominant discourses in healthcare and society and the inherent power dynamics underpinning how antenatal health care interactions and decision-making are conceptualized and enacted in clinical practice. However, as I delved into the fieldwork and the iterative process of data collection and analysis, I realized that understanding the nature of parents' experiences and emotional responses was foundational to fully understanding the broader discourses and power relations influencing and shaping antenatal care. Therefore, I was compelled to also examine, analyze and describe the overall nature of parent's antenatal experiences and, in particular, the complexities of parents' emotional reactions to the diagnosis of a fetal anomaly. Although this additional angle of view was influenced by the intersectional lens implicit within a critical theoretical perspective in that I considered the complex interrelationships influencing and shaping parents' emotional responses, it was primarily descriptive in nature and distinct from the blended critical and Foucauldian governmentality perspective that I employed to explore the overall culture and intricacies of power/knowledge, discourse and agency underlying and constituting antenatal HCPparent interactions and decision-making. Importantly, the use of this descriptive lens allowed for an in-depth exploration of parents' emotional responses following the diagnosis of a fetal anomaly and, ultimately, a preliminary framework to guide HCPs' provision of individualized and comprehensive parental support, which was pivotal to my overall research purpose.

Overview of a Critical Theoretical Perspective

A theoretical perspective is a philosophical stance informing the strategy of inquiry, providing a context for the inquiry process and grounding its logic and criteria (Crotty, 1998). A critical theoretical perspective is motivated by concern with social inequities, focuses on the intricacies of power relations, and desires positive social change (Carspecken, 1996; Lincoln, 2011). Ontologically, a critical theoretical perspective is based on the view that reality is shaped by social, political, cultural, economic, ethnic and gender values that crystallize over time (Lincoln, 2011). Altheide and Johnson (2011) assert that from this ontological position, what we experience reflects an external reality;

objects in the world exist and shape human experience, theories are grounded in values and perspectives, and all knowledge is contextual and partial. An essential ontological premise of critical perspectives is that human nature functions in a world based on struggles for power, and this leads to interactions of privilege and oppression best understood by intersectional analyses considering the complex interrelationships among factors such as race, socioeconomic class, gender, mental or physical abilities, ethnicity, and/or sexual preferences (Giroux, 1982; Lincoln, 2011).

A critical perspective embodies a transactional intersubjectivist epistemology and fits with a social constructionist perspective in which individuals construct meaning as they engage with the world they are interpreting (Crotty, 1998; Denzin, 2005; Guba, 2005). The combination of a constructionist epistemology with a critical perspective directs the researcher to be critically reflexive and to critique constructed meanings of the world in order to understand how particular sets of meanings support power structures, resist movement toward more equitable situations, and encourage marginalization, manipulation and other forms of injustice (Crotty, 1998). A critical perspective supports a dialogic and dialectical methodology, with an emphasis on supporting social transformation and justice (Lincoln, 2011). Consistent with this theoretical lens, values are formative and the inquirer's stance is as a "transformative intellectual," advocate and activist (Guba, 2005). Specific methodological underpinnings of a critical perspective are highlighted in Chapter Three (Research Design and Implementation).

A Foucauldian Perspective: Power/Knowledge and Discourse

In order to understand Foucault's concept of governmentality, it is imperative to consider Foucault's perspectives on power, knowledge and discourse. In contrast to definitions of power put forth by Marx, Nietzsche, Weber and others presenting it in terms

of repression and prohibition, Foucault's view of power is as a positive and productive force. Rather than viewing power as only an act of domination by an individual or group over others, Foucault's (Foucault, 1979, 1980, 1983) explanation of power emphasizes the complex relational aspects of power playing out in everyday life. Foucault (Foucault, 1990) views power as coming from everywhere; one can simultaneously exert power, resist power and be the subject of power. By understanding the complex and subtle ways in which power is exercised in society, we can better understand the fluidity and net-like organization of power and the way power contributes to construction of subjectivities through established forms of knowledge and institutionalized practices (Foucault, 1990; Holmes & Gastaldo, 2002).

Power is inherently linked to how dominant discourses shape health and health interactions. Foucault viewed power and knowledge as inextricably intertwined ("power/knowledge") and focused on how power/knowledge is employed through discursive practices in specific institutional settings to govern or regulate the conduct of individuals (Dzurec, 2003; Hall, 2010). In addition, discourses are historically and culturally situated, are action rather than representation, as well as being plural, contradictory and inextricably enmeshed with power and inequality (Allen & Hardin, 2001; Hall, 2010). Any dominant discourse is challenged by other discourses, and the governance of society involves a constant struggle of conflicting interests (Holmes & Gastaldo, 2002). Understanding Foucault's conceptualization of power/knowledge/discourse can lead to optimism, in that exposing the discursive nature of healthcare can allow for consideration of alternative possibilities and perspectives, thereby offering the potential to resist and change unchallenged assumptions about health (Cheek & Porter, 1997).

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How HCPs enact health communication in practice and research is inextricably shaped and sustained by the prevailing dominant discourses in healthcare and society. By deconstructing dominant frameworks shaping health communication and decisionmaking it is possible to expose creative spaces for alternative solutions that challenge the dominant structures, moving to the forefront questions of social justice, equity, participation, and structural transformation (Dutta, 2010). Dominant discourses shape health communication both at the interpersonal and broader organizational and population levels of healthcare. As Anderson, Blue and Lau (1991) assert, "the vocabularies of the larger social organization are reproduced in micro level interactions between [patients/families] and health professionals through a set of ideologies that structure health delivery" (p. 102). Nurses in particular have been criticized for perpetuating apolitical perspectives in relation to health discourses (Holmes & Gastaldo, 2002). By maintaining this view, nurses fail to acknowledge and challenge how dominant discourses and associated power relations create and sustain current health communication practices and how HCPs' unchallenged perspectives and practices contribute to health care inequities, inadequately informed or biased parent/family decisions, and professional practices that serve to meet the goals of healthcare institutions and HCPs rather than the needs of patients and families.

Studying dominant discourses moves the focus of this research beyond exploring communication and language use in individual interactions to explore how meaning is produced and to analyze the foundations on which knowledge is built, subjectivities are constructed, and societies are managed (Taylor, 2003). Postmodernism and poststructuralism, predominant intellectual movements in recent years, have been central to discourse study and the associated questioning and skepticism of the grand narratives

of the Enlightenment and modernist ideas of truth, progress, scientific certainty and rational control of self and society (Taylor, 2003). Examining health discourses encourages reflexivity regarding how knowledge is constituted and the role of dominant structures in shaping health. By unmasking what has been taken for granted, it is possible to examine how dominant discourses and associated power dynamics shape health interactions and the resulting consequences for health care practice and, ultimately, health outcomes for patients and families. In turn, this creates opportunities and space for alternative strategies that challenge the status quo in health and healthcare delivery and provides new insights into the systemic structures and policies constraining HCPs' decisions (Hartrick Doane & Varcoe, 2005b). Foucault's concept of discourse is inextricably connected to his concept of governmentality. In the following section I provide an overview of this key concept including an exploration of Foucault's notion of disciplinary and pastoral power.

Governmentality. Stemming from his early work on disciplinary power, Foucault outlined the concept of governmentality, which does not refer to "government" in the usual sense, but rather is concerned with "the conduct of conduct" (Dean, 1999, p. 340) and includes the "calculations and tactics" involved in how power is exercised to shape human behaviour by influencing the manner in which individuals conduct themselves (Foucault, 2003). The concept of governmentality deals with "those practices that try and shape, sculpt, mobilize and work through the choices, desires, aspirations, needs, wants, and lifestyles of individuals and groups" (Dean, 1999, p. 12). This concept of governmentality is underpinned by productive, facilitative and creative perspectives of power (Foucault, 2003). Given Foucault's view that power is present in all human relations, the political task is not to create a society without relations of power but to create rules of law, techniques

of management, and the practice of self that allow these power dynamics to be enacted with a minimum of domination (Foucault, 1991).

Over the course of his work, Foucault's concept of governmentality evolved and developed. In the following section I will focus primarily on his notions of disciplinary and pastoral power, realizing the boundaries distinguishing them are somewhat blurred and individuals often use and/or are exposed to these two types of power at the same time and in combination (Holmes & Gastaldo, 2002; Holmes, Perron, & Savoie, 2006).

Disciplinary power. Foucault conceptualized disciplinary power as a subtle nonviolent form of power exercised over individuals or groups with the intent of changing their conduct, habits and attitudes in certain ways and helping them achieve new skills and ways of thinking (Holmes & Gastaldo, 2002). Holmes and Gastaldo, using a Foucauldian perspective, assert nurses and other HCPs enact disciplinary power through an impressive set of techniques (often unwittingly) including hierarchical observation, normalizing judgment, and examination. Each of these will be briefly described and explored within the context of antenatal HCP-parent interactions.

In healthcare settings, hierarchical observation is characterized by the idea that patients and their families are under constant surveillance. This notion is similar to Bentham's vision of the panopticon, an architectural structure consisting of a tower surrounded by prison cells with each cell under constant surveillance by a watchman situated in the tower (Holmes & Gastaldo, 2002). In the context of antenatal screening and diagnoses of fetal anomalies, HCPs have the ability to constantly observe parents during diagnostic tests, medical procedures and detailed and lengthy discussions about pregnancy and treatment options. This "gaze" dictates specific methods of observation and procedures for investigation, thereby participating in the construction of a sophisticated apparatus of surveillance (Gastaldo & Holmes, 1999). The biomedical gaze is apparent in HCPs' actions related to collecting objective health-related data such as maternal age, obstetrical history, and alcohol and drug intake. These data facilitate HCPs categorizing women to determine the risk of a fetal anomaly, often ignoring other important contextual and individual factors such as social determinants of health and parents' psychosocial concerns.

Hierarchical observation works in tandem with normalizing judgment through the use of rewards and micro-penalties in which ranking serves to reward or punish (Perron, Fluet, & Holmes, 2005). Normalizing judgment is often used in combination with pastoral power to determine if patients are "normal" or "deviant" in comparison to HCP-constructed health behaviour norms (Foucault, 1980). The third element of disciplinary power, examination, involves a combination of hierarchical surveillance and corrective normalization, and is enacted through evaluating individuals' abilities and knowledge, analyzing behaviours, validating if performances meet expectations and enforcing sanctions when performances do not meet set norms (Perron et al., 2005). Examination works in combination with pastoral power through the use of confession, often in the form of therapeutic listening, because in order to be effective HCPs must understand individuals "better than they know themselves" (Perron et al., 2005, p. 539).

Emerging research examining women's decision-making related to amniocentesis points to the power dynamics at work related to antenatal screening. For example, in a study by Hunt and colleagues (2005), HCPs viewed women who consented to amniocentesis as making "reasoned and deliberate" decisions based on an examination of the risks and benefits of the procedure. In contrast, Hunt and colleagues found that women who declined amniocentesis were perceived by HCPs to have based their decisions on "unreasoned emotion" (p. 307–308). This example illustrates how HCPs enact hierarchical observation, normalizing judgment and examination in combination with pastoral power techniques to idealize certain opinions and behaviours and thereby potentially influence parents in their seemingly autonomous decisions to consent to antenatal screening. Parents who adhered to pre-established HCP-constructed norms by consenting to amniocentesis were viewed as acting in their unborn child's best interests and constructed as moral and conscientious by serving both the individual and collective good. In contrast, those who declined were viewed as noncompliant, less medically sophisticated, and irresponsible (Hunt et al, 2005).

Pastoral power. Foucault identified that guiding people involves exerting a form of power over them that functions to informally regulate behaviour (O'Byrne & Holmes, 2009). Pastoral power is a strategy where individuals are evaluated through a process of verbal disclosure (confession) to identify areas of themselves that may be deviant (O'Byrne & Holmes, 2009). HCPs enact pastoral power by coming to understand patients in detail, often through therapeutic "confessions" in combination with professional scrutiny to determine if individuals are "normal" or "deviant" in comparison to HCP-constructed health behaviour norms, with the goal of reforming deviant behaviours through normalizing sanctions (Foucault, 1980). Moreover, confession, introspection and self-examination, the three strategies used to enact pastoral power, are common techniques used by HCPs in health education and counselling to encourage patients to gain a conscious awareness of their own health knowledge and behaviours and thus exercise "surveillance" over and against themselves (Foucault, 1980; Holmes & Gastaldo, 2002). HCPs' source of influence for this approach is embedded in the therapeutic HCP-

patient/parent relationship in which feelings, fears and suffering are shared, and wherein HCPs appear "on the same side" as patients/parents (O'Byrne & Holmes, 2009, p. 156).

Understanding HCPs' interactions through the lens of governmentality facilitates the ability to unmask how disciplinary and pastoral power are enacted in everyday HCPparent interactions, and encourages questioning whether the dominant discourses shaping HCP knowledge and actions act to serve the best interests of patients and families (Holmes & Gastaldo, 2002; Perron et al., 2005). On the basis of the documented benefits of antenatal screening, including the potential to improve neonatal outcomes (Khairy et al., 2010; Levey et al., 2010), HCPs encourage "at risk" women to participate in prenatal screening, with an underlying assumption that the diagnosis of a fetal anomaly will facilitate parental decision-making related to continuing or terminating the pregnancy and choices about complex neonatal medical treatments. This assumption is underpinned by biomedical and individualism discourses that foster techno-rational approaches emphasizing scientific problem-solving in addressing diagnostic and treatment options (Kinsella, 2007), and foregrounding individual autonomy, personal rights and selfdetermination over the broader contextual determinants of health (Browne, 2001; Browne, 2004; Raphael, Curry-Stevens, & Bryant, 2008). In addition, this assumption reflects a responsibilization discourse, where an emphasis on individual responsibility for health and a focus on reducing the risk of being afflicted with specific diseases shift the responsibility of health from the state to the individual citizen (Orsini, 2007). Moreover, as Petersen (2003) asserts, there is an increasing emphasis in health care on individuals' right to know about risks related to health, the possibilities for prevention and treatment, and the right to choose among predetermined options; however there is minimal discussion in either the literature or in practice about one's right not to know and not to choose, since this would

challenge the legitimacy of the compulsory structures that compel individuals to behave in particular ways.

A governmentality lens exposes the power HCPs have in determining how parents participate in decision-making, what decisions they make, and the outcomes of these decisions. The manner in which benefits and risks of various diagnostic and treatment options are presented to parents often suggests the desirability of one option over another, especially when an option is deemed by HCPs to be less costly or more ethically acceptable (Petersen, 2003). This option may not be aligned with or take into consideration parents' desires, lifestyles, values or specific individual or contextual factors such as socioeconomic issues or existing stressors impacting parents' abilities to manage the outcomes of their decisions. Furthermore, parents who receive a diagnosis of a fetal anomaly often describe intense emotional reactions including shock, grief, anger and guilt (Araki, 2010; Hedrick, 2005), which may make parents more susceptible to agree with HCPs' "suggestions" without clearly thinking through whether they are the best decisions for their family (Vandvik & Forde, 2000). Although resistance is always possible, many parents may sense they should consider the option "suggested" by the healthcare team over other options in order to reconcile their preferences with those of the healthcare team, and in this sense "the boundary between one's desires and another entity's directives is blurred to the point that the latter becomes the former" (Holmes et al., 2006, p. 5).

Agency and resistance. Wherever power is at work there is also resistance; dominant discourses and opposing discourses operate simultaneously. Therefore, HCPs must convince parents their goals (such as quality of life and minimal suffering) related to a child's health are in fact desirable and achievable. As described in the preceding section, by idealizing specific health-related behaviours, consistent with dominant discourses, HCPs facilitate individuals to manage themselves (Rose, 1999). However, a governmentality lens offers new possibilities by exposing contradictory discourses shaping health and healthcare, and illuminating how power operates through knowledge embedded within certain discursive frames, thereby placing us in a better position to resist unchallenged authority of such knowledge (Cheek & Porter, 1997). In addition, by understanding that power can be productive and power relations are "changeable, reversible and unstable" (Foucault, 1991), we can better appreciate how Foucault's conceptualization of power enables the possibility for resistance to domination.

An analysis of governmentality underscores that neither parents nor professionals are powerless in HCP-parent interactions; rather, Foucault believed in the possibility of individual agency to effect change in power relations and underscored that where there is power there is necessarily the possibility of resistance (Foucault, 1980, 1990). In fact, our ability to resist power is enacted through the very techniques by which we are governed (Petersen, 2003); both those who govern and those who are governed hold power, either directly or through resistance to power (Cheek & Porter, 1997). In the context of antenatal diagnosis (AD), parents are not viewed as what Allen and Hardin (2001) refer to as "discursive marionettes," devoid of agency or free will, but as individuals who can resist the disciplinary and pastoral power enacted by HCPs and others. As will be described in more detail in the review of the literature, findings of several studies on parents' experiences of a diagnosis of a fetal anomaly (for example, see Rempel et al (2004) and Vandvik & Forde (2000)) indicate parents do not always acquiesce to HCP-constructed norms for desirable parental behaviours. Many resist by challenging HCPs' perspectives

or making diagnostic or treatment decisions based on alternative perspectives and values, irrespective of what they might perceive HCPs to prefer.

Having provided an overview of the theoretical lens guiding this research, the focus now shifts to an outline of the research purpose and the specific research questions that guided the study.

Research Purpose

The overarching purpose of this study was to more fully understand: (1) the complex communication and decision-making dynamics associated with antenatal screening and the diagnosis of a fetal anomaly; (2) the underlying frameworks and power relations that influenced and shaped HCP-parent interactions; and (3) potential strategies for how HCPs can better support parental decision-making, ease parents' distress, promote parents' resilience and foster equity in HCP-parent interactions and decision-making support. Moreover, this study was undertaken with the specific intention of generating recommendations for HCPs and leaders in clinical practice, education, research and policy development to promote equity and optimize opportunities for health in the provision of antenatal care and parental decision-making support.

Research Questions

The specific research questions explored were:

 What challenges do parents encounter in HCP-parent antenatal interactions and antenatal decision-making? What HCP strategies/approaches are viewed as supportive?
How are parents' antenatal interactions influenced and shaped by relations of power and contextual factors including dominant discourses and ideologies?

3. What shapes variations in HCP-parent interactions? What are the effects of these variations?

Definition of Terms

To enhance clarity, I provide an overview of my understanding of key terms used in the design, implementation and analysis of this research project.

1. Antenatal Diagnosis (AD) refers to the medical diagnosis of a fetal anomaly (structural, chromosomal, or other) during pregnancy.

2. Decision-making is the action or process of making important judgments, conclusions or decisions. For the purpose of this research, decision-making will be in reference to the health care provided to the mother and fetus/infant following the diagnosis of a fetal anomaly including, but not limited to, decisions related to prenatal screening, pregnancy options, antenatal diagnostic testing and neonatal treatment and management options.

3. Fetal anomaly refers to a structural, chromosomal or functional anomaly that occurs during intrauterine life that is identified antenatally.

4. HCP-parent interactions: Interaction is defined as communication or direct involvement with someone or something (Oxford Online Dictionary, n.d.). For the purposes of this research, I understand HCP-parent interaction to refer to communication or direct involvement between health care providers (either individually or as part of a team) and parent(s). It is assumed that each individual involved in an interaction influences and is influenced by the other. These interactions can be shaped by multiple factors including, but not limited to, the purpose/goal of the interaction and verbal and nonverbal communication practices.

5. Discourse: In contrast to linguistic definitions of discourse, I understand discourse in the Foucauldian sense as "practices that systematically form the objects of which they speak" (Foucault, 1972, p. 49). From this perspective, discourses construct the topic, define and create the objects of our knowledge, govern the way a topic can be

meaningfully discussed and reasoned about, and shape the way ideas and concepts are put into practice and utilized to regulate the conduct of individuals (Hall, 2010). As noted, Foucault viewed power and knowledge as inextricably intertwined ("power/knowledge") and focused on how power/knowledge is employed through discursive practices in institutional settings to govern or regulate the conduct of individuals (Hall, 2010). Hall underscores from Foucault's perspective the origins of meaning and the organization of knowledge and power are historically and culturally specific; they cannot meaningfully exist outside of the way they are represented in specific discourses of a particular context and time period.

6. Ideology: Ideology is often used interchangeably with discourse, although there are distinct differences. Stoddart (2007) emphasizes that ideology and discourse are not mutually contradictory options for understanding social power; rather, they are intertwined with each other, with ideology viewed as an effect of discourse. "In essence, where discourse is mobilized to reinforce systems of social power it functions as ideology...discourse is not necessarily ideological; however, ideology is discursive" (Stoddart, 2007, p. 193).

8. Health equity: I understand health equity to exist when all individuals can reach their full health potential and are not disadvantaged from attaining it because of their race, ethnicity, religion, age, gender, social class, sexual orientation, socioeconomic status or other socially-determined circumstances (Dahlgren and Whitehead, 2006). Moreover, I view health equity as a goal that " is never fully attained, varies with contexts and situations, but is possible to promote in every moment, situation and context" (Varcoe, Browne and Cender, 2015, p. 272), and involves "striving for the highest possible

standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on social conditions" (Braveman, 2014, p.6).

9. **Health inequities:** I understand health inequities to be differences in health status among population groups that are unfair, unjust, and preventable, as well as socially produced and systematic in their distribution across a population (Commission for Social Determinants of Health, 2007).

Assumptions

There were several assumptions underlying the research project that were important to clearly articulate prior to initiating the study. These assumptions are consistent with the theoretical lens guiding the study and the review of relevant literature. **1.** There is a pervasive assumption related to HCP-parent interactions that parents should make informed decisions regarding the health and healthcare of their young children (including fetuses), and that this decision-making process optimally involves a rational and deliberate approach which includes careful consideration of the risks and benefits and short- and long-term outcomes for all possible treatment and diagnostic options. However, contrary to this popularly perceived notion of the "ideal" decision-making process, for the purposes of this research it was assumed health care decisions were shaped and influenced by multiple unconscious and conscious factors including, but not limited to, the personal and professional perspectives of HCPs; the manner in which pregnancy and treatment options were presented; factors such as previous exposure to a concept, word or event (Kahneman, 2013a); and the parents' familiarity with different treatment and diagnostic options.

2. Individuals are often unaware of the multiplicity of factors influencing and shaping their decision-making process such as the manner in which a decision is framed, and the way treatment options are presented (Kahneman, 2013b).

3. Despite a predominant emphasis in healthcare and society on a parent's right to make free and independent decisions related to pregnancy and fetal/child health issues, parents do not always feel these decisions are free or independent. Parents may feel only one option exists or feel that HCPs, family members or significant others could strongly influence and shape the process and outcome of important decisions (Anderson, 1999; Koponen, Laaksonen, Vehkakoski, & Vehmas, 2013; Korenromp et al., 2005; Rempel et al., 2004).

4. Dominant discourses and ideologies are significant factors shaping health, the provision of healthcare, and health-related decision-making. Therefore, in relation to this research, it was important to examine the dominant underlying discourses and ideologies shaping HCP-parent interactions and decision-making related to the diagnosis of a fetal anomaly.

5. Health and healthcare inequities exist. Not all individuals receive equitable care.

6. Encouraging reflexivity and awareness regarding the role of dominant discourses, power dynamics and other factors shaping and influencing HCP-patient/parent interactions and relationships leads nurses and other HCPs to challenge existing structures; propose alternative strategies for how health communication is enacted in clinical practice, research and health policy initiatives; and work toward a more equitable society.

Organization of the Thesis

This research project focused on the complex HCP-parent interactions and decision-making processes associated with prenatal screening and an antenatal diagnosis of a fetal anomaly. The preceding introduction of the foundational elements of the research and overview of the research problem, study purpose and specific research guestions guiding the research process sets the stage for Chapter Two, which focuses on a detailed review of selected literature, with the intention of positioning the study within the current body of relevant theoretical literature and clinical research and the subsequent third chapter, which provides an explicit overview of the methodology guiding the inquiry and the specifics of the research design and method. This is followed by Chapter Four, which provides an overview of the nature of antenatal care including an exploration of the dominant frameworks underpinning HCP-parent interactions. This sets the stage for Chapter Five, which provides an analysis of how dominant discourses in health care and society and underlying power relations work together to create and sustain current health perspectives and practices shaping HCP-parent interactions and parental decisionmaking. This includes an examination of how discourses and associated power relations create and sustain current health perspectives and practices, and how HCPs' unchallenged perspectives and practices contribute to health inequities and lead to unaddressed parental feelings of emotional distress, inadequately informed or biased parental decisions, and unnecessary pressure on parents to succumb to system-centred imperatives. The analysis of the nature of antenatal care and the deconstruction of underlying power relations in HCP-parent communication and decision-making provided in Chapters Four and Five provides the foundation for Chapter Six, which presents an indepth analysis of parents' emotional responses to the diagnosis of a fetal anomaly.

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Specifically, a framework is introduced that describes the nature of parents' emotional responses to the loss of the anticipated and hoped-for baby, which were distinctive in that they occurred within the context of an evolving pregnancy and were intertwined with what I found was a complex matrix of emotional responses. This matrix was comprised of parental emotions vacillating between four intersecting continua of prominent emotions. These continua were constructed as: (1) dread/despair-hope; (2) powerlessness-control; (3) self-stigma-self-respect (and associated social isolation-social integration); and (4) low parent-fetal attachment-high parent-fetal attachment. In addition, findings suggest that as parents wrestled with the fetal diagnosis and enacted their first parenting decisions, they moved through four phases of parental response to the diagnosis of a fetal anomaly: (1) Overwhelmed: a whirlwind of conflicting emotions; (2) Treading water: looking inward and considering options; (3) Taking control: looking forward and enacting parenting decisions; and (4) After the pregnancy ends: now it's real. These findings are incorporated into the discussion of results in Chapter Seven, highlighting how they can inform future HCP initiatives focused on improving HCP-parent communication and the provision of antenatal parent and family support. Finally, the chapter concludes by highlighting the recommendations for clinical practice, education, policy initiatives and future research stemming from the findings of this study.

CHAPTER TWO: REVIEW OF SELECTED LITERATURE

A research focus on the complex communication and decision-making dynamics associated with antenatal screening and the diagnosis of a fetal anomaly can be positioned within several empirical and theoretical domains ranging from trends in the medical care of children with congenital anomalies to various perspectives on health care provider (HCP)-parent communication and emerging perspectives on health decisionmaking. Having established the theoretical lens guiding the research and given an overview of the research purpose and questions in Chapter One, in this chapter I provide a review of selected literature with the intent of summarizing previous research and insights into the current understanding of this topic from the perspective of both HCPs and parents. This literature review begins by examining the trends in the healthcare and support of children with congenital anomalies, followed by an exploration of the experiences of parents who receive a diagnosis of a fetal anomaly-capturing both the experiences of those who continue the pregnancy and seek medical intervention in the neonatal period as well as those who pursue termination of pregnancy (TOP). The literature review concludes by providing a snapshot of multiple perspectives on HCPparent communication and decision-making, including consideration of personal, relational and organizational factors influencing HCP-parent interactions, with a specific focus on parental decision-making related to the diagnosis of a fetal anomaly.

Trends in The Medical Care of Children with Congenital and Chromosomal Anomalies

Prior to delving into the current understanding of HCP-parent communication and decision-making related to prenatal screening and the diagnosis of a fetal anomaly, it is necessary to review the broader trends and shifts in the healthcare of infants and children

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with complex congenital and chromosomal anomalies. Two to three percent of all fetuses have a congenital anomaly (Viaris de Lesegno & Duncan, 2017). Over the past decade significant technological advances in molecular genetics, fetal imaging and minimally invasive surgical treatment of specific fetal anomalies have resulted in substantial improvements in HCPs' abilities to diagnose and treat certain fetal anomalies antenatally (Viaris de Lesegno & Duncan, 2017). To highlight the trends in medical management and care of children with congenital and chromosomal anomalies, I will draw particular attention to the literature on the subpopulation of infants and children with congenital heart disease (CHD). As CHD is the most common birth defect, includes a range of severity from mild to severe, and is commonly associated with chromosomal and/or other structural abnormalities, this subpopulation serves as an excellent example to showcase many of the general trends and changes in health and medical care for children with a diverse range of congenital anomalies.

Forty years ago most parents were not aware of the presence of a fetal anomaly until their baby was born and the congenital condition was diagnosed in the neonatal period. However, with significant improvements in diagnostic and technological capabilities and public health changes encouraging prenatal screening, a growing number of parents receive a diagnosis of a fetal anomaly during pregnancy rather than waiting until after the baby's birth to learn this information. Moreover, technological and medical advances continue to evolve, allowing fetal anomalies to be diagnosed earlier than ever before. An example is specialized fetal echocardiography, which facilitates the diagnosis of fetal heart defects as early as 11 to 13 weeks gestation (Jicinska et al., 2017; Quarello, Lafouge, Fries, Salomon, & Cfef, 2017). In addition, the prenatal detection rate of CHD has considerably improved over the last several decades with the pooled detection rate of CHD in unselected populations at 45.1 percent and the rate of more complex cardiac anomalies, specifically univentricular defects and heterotaxy at above 85 percent (van Velzen, Ket, van de Ven, Blom, & Haak, 2018).

Over the last 20 to 30 years, there has also been a considerable shift from a predominant emphasis on developing innovative surgical and medical interventions to address high mortality rates associated with surgical repair of complex congenital anomalies to the current emphasis by many pediatric HCPs on antenatal diagnosis and improvement of long-term outcomes, functional status and guality of life (QOL). For example, prior to the 1980s most babies born with hypoplastic left heart syndrome (HLHS), a complex form of CHD, died within the first week of life and were provided with palliative or comfort care in the newborn period (Feinstein, Benson, Dubin, & Cohen, 2012). With significant medical, surgical and technological advances, a series of staged surgical procedures were developed for HLHS leading to initial mortality rates for neonatal surgery at 40 to 60 percent in the 1990s (Moons, Bovijn, Budts, Belmans, & Gewillig, 2010). Additional advances in surgical techniques and home-monitoring amongst others have further decreased mortality rates by approximately 15 to 20 percent in the modern era (Abernathy, 2018; Castellanos et al., 2016) and have led HCPs to shift their focus from improving short-term surgical mortality and morbidity to exploring how to facilitate improved long-term outcomes and overall QOL. The following review of the literature draws attention to how these shifts in focus in medical care for infants and children with CHD is paralleled in HCPs' priorities in their interactions with parents related to the provision of diagnostic, treatment and prognostic information. For example, given that only a small percentage of children with complex CHD survived to adulthood 40 to 50 years ago and those that did received significantly different surgical repairs and/or

medical treatments than are currently available, combined with the relatively recent shifts in improved morbidity and mortality for children and adults with complex CHD (Moons et al., 2010) and the increased medical focus on long-term outcomes, associated genetic anomalies and neurodevelopmental concerns, it is not surprising that parents who receive a diagnosis of a complex fetal CHD often describe receiving conflicting and unclear prognostic information related to long-term outcomes, potential complications and anticipated QOL. These trends and research findings have a significant impact on HCPparent interactions and decision-making, particularly in the content of information provided to parents who receive a diagnosis of a fetal anomaly and how parents view various pregnancy and treatment options.

Changing Population Trends

Heart defects are the most common form of congenital structural anomalies, with an estimated prevalence of 11.9 per 1,000 children (Khairy et al., 2010). Over the last twenty to thirty years there have been significant changes in the population trends for children and adults living with CHD, most notably a sharp increase in the number of children with severe forms of CHD surviving and living into adulthood (Khairy et al., 2010; Moons et al., 2010). Khairy and colleagues published the results of one of the few population-based retrospective cohort studies of patients with CHD living in Canada, exposing the changing morbidity and mortality outcomes (Khairy et al., 2010). Specifically, their study involved children with CHD living in Quebec from July 1987 to June 2005. Overall, their results indicated a significant reduction over time in infant mortality, an increase in age at death, and substantial decreases in mortality rates for children and adolescents with CHD. Results also indicated an overall decrease in mortality of 31 percent in the last period of observation (2002–2005) compared to the first (1987–1990). In addition, the proportion of infant and childhood deaths markedly decreased from 1987 to 2005, with a 59 percent decrease in mortality in children less than 18 years of age and a 16 percent decrease in mortality in adults 18 to 64 years of age. The largest decrease in mortality was for children with severe forms of CHD with a 67 percent reduction, which was consistent across most subgroups of complex CHD (Khairy et al., 2010).

As is true for a wide range of congenital anomalies, gains in survival for individuals with CHD are likely multifactorial and reflective of major advances in patient care and overall improvements in survival in the general population due to such factors as improved quality and access to medical care and enhancements in socioeconomic conditions and public health practices (Khairy et al., 2010). Antenatal diagnosis of CHD has also been credited with improved morbidity and mortality for multiple forms of complex CHD compared to a postnatal diagnosis (Fuchs et al., 2007; Holland, Myers, & Woods, 2015; van Velzen et al., 2015; Yates, 2004). Moreover, an antenatal diagnosis of CHD allows for: additional antenatal monitoring including antenatal testing for associated structural and genetic anomalies; optimization of delivery and neonatal care; and individualized counselling about pregnancy and neonatal management options (van Velzen et al., 2018). Other factors contributing to improved survival for infants, children and adults with CHD include: innovative neonatal and staged surgical procedures for complex CHD; interventional cardiac catheterization procedures that preclude the need for neonatal surgery for certain CHDs such as critical aortic or pulmonary stenosis; improved coordination and organization of care in intensive care units; and miniaturization of medical tools and techniques (Khairy et al., 2010). Furthermore, an often unacknowledged yet equally important factor in the changing mortality trends is that a relatively high proportion of fetuses with the most severe forms of CHD do not survive to

require neonatal treatment as a result of TOP following antenatal diagnosis of CHD (Khairy et al., 2010; van Velzen et al., 2015; van Velzen et al., 2018; Yates, 2004).

Increased Complexity of Parental Decisions

In tandem with significant advances in diagnostic technologies and medical/surgical treatments for CHD over the past three to four decades, parents who receive a diagnosis of a fetal anomaly face increasingly complex health decisions concerning prenatal screening and associated pregnancy and neonatal treatment options. This is largely due to the wealth of information available to them concerning available antenatal diagnostic tests (such as amniocentesis and fetal MRI), which can potentially provide greater clarity on associated structural and genetic anomalies as well as a growing mass of prognostic information on short- and long-term outcomes associated with the fetal anomaly and associated treatment options. However, despite significant advances in prenatal screening, the results of several studies indicate women and their partners often enter into prenatal screening inadequately informed about the scope and limits of prenatal screening and the numerous decisions related to additional testing and/or pregnancy and neonatal management they may face as a result (Constantine, Allyse, Wall, Vries, & Rockwood, 2014; Jaques, Sheffield, & Halliday, 2005; Schoonen et al., 2012; Skirton & Barr, 2010). Furthermore, several authors have found that women make uninformed choices related to prenatal screening in that either their decisions are not based on relevant or accurate information and/or their decisions are not aligned with their (the parent's) values and beliefs (Dixon & Burton, 2014; Fransen et al., 2010; Jaques et al.; Shea, 2017). In addition, several researchers have underscored that differences in informed antenatal decision-making exist among patient groups with statistically significant predictors of uninformed choice associated with lower educational level

(Constantine et al., 2014; Fransen et al., 2010; Jaques et al., 2005; Schoonen et al., 2012).

Significantly adding to the gravity and complexity of antenatal decision-making is the fact that in Canada a fetal diagnosis within approximately the first 24 weeks of pregnancy (the exact gestational age varies from province to province) provides parents with the decision of *choosing* to have a baby with a known fetal anomaly. However, as will be discussed in greater detail in a subsequent section of this chapter, despite the growing evidence that a significant number of women/parents choose TOP following the diagnosis of a fetal anomaly (Maguire et al., 2015), combined with a growing number of articles illuminating the significant psychological and emotional distress associated with this decision and its aftermath (Kersting et al., 2009; Koponen et al., 2013; Maguire et al., 2015), there is a startling lack of research examining how women and their partners come to this decision and the forms of support parents would find most helpful in easing their distress, supporting their decision-making and addressing potential or existing inequities.

Parents who choose to continue the pregnancy often face decisions concerning complex neonatal (and sometimes fetal) treatments for life-threatening fetal anomalies. For some parents this may involve deciding to pursue neonatal open-heart surgery to repair or treat complex forms of CHD. In addition, parents may be faced with considering the possible need for higher risk procedures and/or postoperative supports such as the use of extracorporeal life support (ECLS) to support a critically ill infant or child for days to weeks, cardiac transplantation, short or long-term use of ventricular assist devices, and multiple staged cardiac surgeries in the first three to five years of life. However, there is a paucity of research examining *how* parents make these decisions and *what* they find

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supportive in HCP-parent interactions and decision-making related to the health of their child.

In combination with the need for parents to weigh the pros and cons of specific short-term medical treatments such as the short-term morbidity and mortality rates associated with neonatal treatments, those who receive an antenatal diagnosis of a fetal anomaly are also asked to consider prognostic information about long-term health outcomes for infants and children with the same or similar health concerns in their decision-making about pregnancy and/or neonatal treatment options. With technological and medical advances over the past 30 to 40 years resulting in substantial overall improvements in survival rates for medical and surgical treatment of CHD (Moons et al., 2010), the focus of discussions on future improvements in patient care increasingly emphasizes the need to address concerns about the overall QOL for children and adults living with CHD and the effects of short and long-term complications associated with medical treatments (Mahle, Clancy, Moss, Jobes, & Wernovsky, 2000). For example, as will be described in the following section, neuro-cognitive impairment, ranging from subtle to overt, is well recognized in infants and children living with severe forms of CHD, and the impact this will have on the aging and increasingly complex patient population living with CHD is likely to be considerable (Mahle et al., 2000; Nattel et al., 2017; Ringle & Wernovsky, 2016).

Neurodevelopmental Outcomes and Quality of Life Considerations

Improved survival for children with complex forms of CHD has led to a shift in focus from improving survival rates to an increased emphasis on neurodevelopmental and QOL outcomes when evaluating healthcare outcomes for infants and children with complex CHD. This has significant ramifications for antenatal decision-making, as parents are

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often presented with and asked to consider prognostic information about not only the short and long-term results of cardiac treatment but also potential concerns with long-term neurodevelopment and QOL. Results of several studies indicated children with complex CHD can have normal neurodevelopmental outcomes but are at significant risk for learning disorders, lowered academic achievement and behavioural abnormalities (Goldberg, Mussatto, Licht, & Wernovsky, 2011; Nattel et al., 2017; Ryberg, Sunnegardh, Thorson, & Broberg, 2016). For example, several studies revealed developmental delay in older infants and toddlers and consistently lower scores on tests of intelligence in preschool and school-age children with complex or severe forms of CHD (Goldberg et al., 2011; Ryberg et al., 2016). Specifically, Mahle and colleagues conducted one of the first studies examining neurological outcomes in a historical cohort involving some of the first survivors of a three-staged surgical reconstruction for HLHS and found approximately one third of children were receiving special education services and 69.5 percent had evidence of attention deficit disorder, compared to three to five percent in the general school age population (Mahle et al., 2000). More recently, Ringle and Wernovsky (2016) reported that although survival for children with complex forms of congenital heart disease is improving, there remains significant morbidity following surgical repair with many infants and children demonstrating neurological sequelae including delayed developmental milestones and speech and learning challenges. In addition, the researchers found adolescents with complex congenital heart conditions were more likely to suffer from concerns with processing speed and executive function as well as exercise intolerance, obesity and mental health comorbidities (Ringle & Wernovsky, 2016).

Parents making antenatal decisions about pregnancy and neonatal options for a fetal diagnosis of complex CHD often receive prognostic information about both

modifiable and non-modifiable factors influencing neurodevelopmental outcomes in this population, which can have considerable influence on their decisions. Moreover, with current medical and technological advances, the understanding of the link between CHD and neurodevelopmental outcomes is increasing rapidly. For example, recently Nattel and colleagues (2017) reported children with congenital heart disease are at increased risk of neurodevelopmental disorders and psychiatric conditions including cognitive, adaptive, motor, speech, behavioural and executive functioning impairments as well as autism spectrum disorder and psychiatric disorders. They emphasized that structural and functional neuroimaging have revealed brain anomalies in young children with CHD prior to their surgical repair, likely resulting from in utero developmental insults (Nattel et al., 2017). Furthermore, they highlighted that recent genetic advances have allowed genetic specialists to identify an increasing number of genetic mutations that may explain some of the neurodevelopmental disorders associated with congenital heart disease (Nattel et al., 2017). Many of the intrinsic risk factors for developmental delay, learning disorders and behavioural abnormalities are not modifiable (e.g. presence of a genetic syndrome, chromosomal anomaly or congenital neurological malformations); however in recent years both researchers and clinical experts have also placed increased emphasis on modifiable risk factors in the peri-operative period, such as fine-tuning of cardiopulmonary bypass techniques, surgical strategies, postoperative mechanical ventilation and nutrition as well as family- and patient-centred strategies such as physical, occupational and speech and language therapies to improve outcomes (Goldberg et al., 2011; Robertson et al., 2004). In addition, findings from multiple studies have highlighted an association between family and patient education and support and improved maternal and child outcomes for children and youth living with complex forms of CHD (Goldberg et al., 2011; Mackie et al., 2018).

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In addition to neurodevelopmental outcomes and co-morbidities associated with specific CHDs, functional outcomes are important considerations affecting QOL for children and adolescents with complex forms of CHD such as HLHS (Goldberg et al., 2011). QOL is a subjective measure shaped by the presence of disease, personal viewpoints, health expectations and satisfaction, and functional status (Goldberg et al., 2011). Potentially adding to expectant parents' confusion concerning prognostic outcomes for a fetal diagnosis of a cardiac anomaly, are the conflicting research findings related to QOL for children with CHD. For example, Lambert and colleagues (2009) emphasized, at least among certain groups of children with specific cardiac diagnoses, health-related QOL does not appear to correlate with severity of CHD, whereas a study by Uzark and colleagues (2008) indicated children with more complex CHD are more likely to rate their QOL lower than those with less severe CHD. In addition, a large multi-centre cross-sectional study involving children with complex CHD revealed parents rate their child's functional status as lower than the patients themselves (Lambert et al., 2009). Moreover, research by Mellander and colleagues indicated children with HLHS have lower self-esteem, greater psychosomatic symptoms and lower acceptance by peers (Mellander, Berntsson, & Nilsson, 2006). Given the complex and dynamic nature of prognostic information available on behavioural and developmental outcomes for children and young adults with complex CHD, for parents who receive a diagnosis of a cardiac fetal anomaly there are often no clear and simple answers about their child's future QOL and future opportunities to maintain jobs, participate in healthy relationships, and contribute positively to their communities and society, which can significantly contribute to parents' uncertainty regarding pregnancy and treatment options. In addition, the manner and content of prognostic information presented by HCPs at the time of an antenatal

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diagnosis can potentially have a significant influence on parents' decisions. For example, HCPs who emphasize historical outcome data may paint quite a different picture for survivor QOL than those who focus on more recent research demonstrating evidence that innovative perioperative technical advances combined with an increased focus on early psychosocial interventions and comprehensive in-home support for infants and children with CHD has shown promising outcomes, with the majority of children surviving with fulfilling lives and intelligence and social skills in the normal range (Ringle & Wernovsky, 2016).

Given the increased complexity of treatment options and the enormity of the impact of relevant research findings on potential short- and long-term complications, comorbidities and QOL measurements amongst others, how do parents wade through this information within the time-pressured context of an evolving pregnancy? Is it necessary and/or helpful to understand this prognostic information in order for women and their partners to make decisions regarding pregnancy and treatment options? What diagnostic and prognostic information is prioritized in HCP-parent antenatal discussions? These questions have not been adequately addressed. As will be discussed in subsequent sections of this literature review, much of the health information typically provided to parents by HCPs is information HCPs themselves prioritize as important—the physiological and functional nature of the fetal anomaly, the medical prognosis, and detailed information about diagnostic and treatment options. What additional information and/or supports do parents require to make decisions they think are reasonably informed and in the best interests of their unborn child?

Although survival and overall morbidity rates have improved considerably for infants, children and adults living with CHD and other forms of congenital and/or

chromosomal anomalies, additional research is required that seeks to understand the experiences of parents and their families as they navigate the healthcare system and the nature of HCP-parent interactions and decision-making in this rapidly changing system. Changes in the diagnosis and treatment of fetal anomalies have considerable influence on HCP-parent interactions and communication, particularly in how HCPs share health-related information with parents who receive a diagnosis of a fetal anomaly and in how this information shapes parents' perceptions of antenatal decisions and, for those who continue the pregnancy, their child's future health decisions. A more comprehensive and detailed understanding is required from both HCPs' and parents' perspectives on how to better support parental decision-making related to the diagnosis of a fetal anomaly.

Experiences of Parents Who Continue Their Pregnancy Following the Diagnosis of a Fetal Anomaly

Although limited in number and scope, several researchers have explored the experiences of women who received a diagnosis of a fetal anomaly following routine prenatal screening procedures. In the following section, I review the findings of a number of research articles that provide insight into the experiences of parents who continue their pregnancy following the diagnosis of a fetal anomaly with a specific focus on the underlying power relations and unspoken rules in HCP-parent interactions. In addition, I provide an overview of previous research that highlights the grief, dilemma, uncertainty and isolation that contribute to a psychological framework reflective of women's experiences following diagnosis of a fetal anomaly (Araki, 2010). In addition, relevant literature is reviewed on the impact of a diagnosis of a fetal anomaly on the parent-child attachment process. Finally, highlights from selected studies that examined the facets of parenting a child with complex congenital anomalies are described. Focusing on the

postnatal experiences of these parents provides insight and clarity into the potential outcomes of parental antenatal decisions and the nature of their evolving experiences after the birth of their children.

Antenatal Screening: Underlying Power Imbalances and Unspoken Rules

The benefits of antenatal screening for congenital anomalies such as CHD are well documented in terms of decreasing neonatal morbidity, particularly for those with complex anomalies requiring neonatal intervention (Holland et al., 2015; Khairy et al., 2010; Levey et al., 2010; Mahle et al., 2000; van Velzen et al., 2015). HCPs involved in performing and reading antenatal ultrasounds are often the first members of the healthcare team with whom parents interact when learning of a fetal anomaly, and as such they have a powerful influence on subsequent parental decision-making related to the pregnancy and potential neonatal treatments (Van der Zalm & Byrne, 2006). Routine antenatal screening for congenital anomalies is standard practice in Canada with most women receiving a detailed screening ultrasound between 18 and 22 weeks of pregnancy. Additional prenatal screening for common chromosomal or other disorders (many of which are associated with CHD) includes a nuchal translucency measurement between 11 and 13 weeks gestation and one to two blood tests (usually between 10 and 13 weeks gestation and 15 and 20 weeks gestation). When a detailed screening ultrasound raises suspicion of a fetal anomaly, a referral is made to a pediatric/fetal specialist or team of specialists for more focused and specialized ultrasounds and assessments of the suspected anomaly. In the case of a suspected fetal heart anomaly, a referral is made to a pediatric/fetal cardiologist for a fetal echocardiogram (FE), a specialized fetal ultrasound of the heart, to confirm the presence of a CHD. Given that a detailed screening ultrasound is standard practice, parents enter into this initial experience expecting to discover more

about their fetus including size, sex and well-being; however most parents do not expect to receive a diagnosis of fetal anomaly associated with the need for complex medical interventions and the possibility of early death (Menahem & Gillam, 2007; Shea, 2017). As will be reported in greater detail in subsequent sections, the diagnosis of a fetal anomaly is commonly associated with parental grief reactions, shock and sadness, and it is in this setting that complex medical information needs to be imparted to expectant parents (Cole et al., 2016; Menahem & Gillam, 2007; Rempel et al., 2004).

In recent years there has been an increasing amount of research exploring parents' experiences with prenatal screening resulting in the diagnosis of a fetal anomaly. A Canadian study of particular note (Van der Zalm & Byrne, 2006) involved a non-structured interview with eight participants who received a diagnosis of a fetal anomaly (including two with a diagnosis of a cardiac anomaly) on a routine ultrasound completed between 11 and 38 weeks gestation. Thematic analysis of participant interviews indicated women's antenatal ultrasound examination experience is shaped by physical and environmental factors and by behaviours of the ultrasound examiner (usually a specialized sonographer or physician specialist). A finding particularly relevant to the current study is that all participants described being acutely sensitive to the surrounding environment and demonstrated acute recall of their sensations during the ultrasound procedure. In particular, participants were very attentive to verbal and nonverbal communication cues including the length of time to complete the scan and the personnel present. In addition, findings were consistent with previous research in that participants identified being objectified by the examination, with the majority of participants describing feeling like passive objects, "lying on the table and having the procedure done to them" (Van der Zalm & Byrne, 2006, p. 404). Women who perceived that the ultrasound examiner did not

adequately address their physical comfort and/or did not attempt to interact with them during the scan claimed that this contributed to their feelings of being objectified, as well as their feelings of anger and frustration with the interaction (Van der Zalm & Byrne, 2006). Moreover, all participants expressed a strong desire for their significant other to be present during the scan; however, these individuals tended to be excluded until after the examination was completed. Furthermore, women's descriptions of an immediate emotional tie and a perception of "the reality" of the baby when viewing the fetal images during the scan suggest the ultrasound experience has a "powerful influence" on a woman's subsequent decision-making about the pregnancy (Van der Zalm & Byrne, 2006). Finally, women detected unspoken communication "rules" during their interactions with HCPs concerning what information could be provided and by whom. For example, even when women picked up on nonverbal cues that the examiner noted a suspected fetal concern, the majority did not raise questions. In addition, women expressed dissatisfaction, frustration, and distress when they had to wait as long as seven days before ultrasound results were reviewed with them by their family doctor or obstetrician, especially when they perceived this delay decreased the time available to make decisions related to continuing or terminating the pregnancy (Van der Zalm & Byrne, 2006).

Results of the preceding study indicated women can clearly describe what ultrasound examiners need to do in order for an ultrasound examination to be considered "good," including speaking directly to and having eye contact with the woman being examined, ensuring the woman's physical comfort during the exam, responding to questions openly and honestly, providing face-to-face interpretation of the ultrasound process and results, demonstrating sensitivity to the woman's unspoken needs, and ensuring a personal support person is present if requested (Van der Zalm & Byrne, 2006). Similarly, a more recent study by Hodgson and colleagues (2016) found that the diagnosis of a fetal anomaly is shocking for parents even when they are aware of the possibility of abnormal results, and that parents greatly valued HCPs' sensitivity, provision of comprehensive information about the results, and empathic acknowledgement of the enormity of the impact of a fetal diagnosis on parents' emotional well-being. It is interesting to note that the communication skills valued by parents are usually considered basic communication skills among HCPs, yet many women noted significant concerns with HCPs' abilities to communicate and relate to parents during prenatal assessments. Further research is required to address the multiple unanswered questions related to the nature of parents' experiences when a more collaborative HCP-parent relationship is encouraged during prenatal screening. For example, do more collaborative or relational HCP approaches encourage parents to ask more questions, seek clarification, or be more active in their decision-making? Moreover, does a collaborative approach contribute to parents feeling more supported and/or informed in relation to the antenatal decisions they face?

Noting that none of the participants questioned the ultrasound diagnosis, Van der Zalm and Byrne (2006) raised the question as to "whether women who have unexpected prenatal ultrasound images interpreted to them are emotionally and psychologically able to question the interpretations at that time" (Van der Zalm & Byrne, 2006, p. 406). Based on my professional experience providing information to parents who receive a fetal diagnosis of CHD, many women and their partners *do* question information provided by HCPs including the diagnosis, prognostic information, and pregnancy and treatment options. Further research is required that aims to understand what factors shape parents' experiences and their abilities to question and clarify health information. In addition, given

previous findings that many women feel objectified during ultrasound procedures, a closer examination of the power dynamics at play during these health interactions may shed light on what factors encourage parents to take on a role consistent with the level of participation they feel is appropriate for them.

Psychological Impact

The diagnosis of a fetal anomaly is strongly associated with parental psychological and emotional distress (Araki, 2010; Cole et al., 2016; Hedrick, 2005; Horsch et al., 2013; Rempel et al., 2004; Rempel et al., 2012; Titapant & Chuenwattana, 2015). Specifically, findings from several studies underscore parental feelings of grief, worry, uncertainty and anxiety associated with the diagnosis of a fetal anomaly (Araki, 2010; Hedrick; Lou et al., 2017; Rempel et al., 2004; Rempel et al., 2012). Furthermore, Cole and colleagues found that 19.3 percent of expectant mothers and 13.1 percent of expectant fathers experienced post-traumatic stress symptoms, with 23 percent of women and 14 percent of men scoring positive for a major depressive disorder following an antenatal diagnosis of a fetal anomaly. These findings build on the earlier work of Horsch and colleagues who found that 35 percent of expectant mothers met the full diagnostic criteria for post-traumatic stress disorder following the diagnosis of a fetal anomaly.

Araki (2010) conducted a review of the current international literature concerning the experiences of women who receive a diagnosis of a fetal anomaly. Araki identified five themes (grief, attachment, dilemma, uncertainty and isolation) that form a psychological framework reflecting the mothers' experiences. This review selected 12 articles from a total of 165 available; the 12 included a variety of qualitative approaches and a range of sample sizes from one to 38 women. The majority of studies in this review focused on mothers' perspectives; only two of the studies included the perspectives of fathers. Findings from this review as well as additional research indicate women who receive a diagnosis of a fetal anomaly experience feelings of grief comparable to the experiences of women whose child died, in that it is characterized by shock, anger, guilt, gaining meaning and rebuilding (Araki; Hedrick, 2005; Titapant & Chuenwattana, 2015). However, in contrast to these initial feelings, many women also described coming to find hope as they struggled to accept the reality of their new situation with a concurrent increase in mother-child attachment as the pregnancy evolved (Araki, 2010). That is, women described feeling sorrow and sadness as well as the positive feelings associated with being pregnant. Araki emphasized that each parent's experience is unique, and strongly recommended future researchers consider the social, contextual, and organizational factors shaping parents' experiences and the delivery of antenatal care.

Several authors have emphasized that uncertainty is a pervasive feeling associated with parents' experience of a diagnosis of a fetal anomaly (Araki, 2010; Hedrick, 2005; Lotto et al., 2017; Rempel et al., 2004; Titapant & Chuenwattana, 2015). Women question multiple aspects of what the future holds—what life will be like following the birth of their child, if medical treatment will be possible and/or successful, and ultimately whether their fetus/child will survive. Some women describe their perception of time as a paradox. Time is positive in that it allows opportunities to confirm the diagnosis and learn about the causes, prognosis, and possible complications associated with the fetal malformation through discussions with HCPs, further tests and procedures and other sources such as internet websites (Hedrick, 2005; Rempel et al., 2004); however, mothers also view time as "the enemy" because the remainder of the pregnancy is filled with worry, uncertainty and anxious waiting for the baby's birth (Askelsdottir et al., 2008; Hedrick, 2005; Rempel et al., 2004). Interestingly, despite receiving information about a complex fetal anomaly, parents often feel hopeful their baby will be born as normal as possible (Araki, 2010; Benute et al., 2012; Rempel, 1993). Moreover, for some women, the experience of hearing the fetal heartbeat during an ultrasound reinforces to them the baby is strong and doing well, despite evidence on the scan clearly indicating a severe anomaly (Araki, 2010; Rempel, 1993). Araki's review underscored that these feelings are often present even when the fetal anomaly is considered complex and the accuracy of the fetal diagnosis is not in question. In addition, women in multiple studies described enacting hope in the face of their fetus' uncertain future by holding on to an underlying belief that their antenatal experience will result in personal strength or growth (Araki, 2010; Hedrick, 2005; Rempel et al., 2004).

Another component of the psychological impact of a diagnosis of a fetal anomaly is the worry, anxiety and distress evoked as parents face antenatal decisions, which they describe as "dilemmas" (Araki, 2010). These dilemmas arise from differences between expectant mothers' own values and social norms (Araki, 2010). Specifically, given the available option of TOP, many women describe a need to consider their own values and beliefs on disability and abortion, which in turn prompts conflicting feelings of both wanting to protect and reject the fetus (Araki, 2010). In addition, ambivalent reactions such as maintaining hope while experiencing periods of despair and hopelessness are common (Araki, 2010; Hedrick, 2005; Rempel et al., 2004). Interestingly, dilemmas and the women's related ambivalent reactions are associated with changes to existing attitudes. Furthermore, as Araki highlighted, pregnancy is a time during which women start to view society from the position of a parent, which can lead to significant changes in perspective, especially when faced with a diagnosis of a fetal anomaly. As a result, women are likely to

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challenge values, social norms, ideologies and ethics with which they previously agreed and establish new ones based on their antenatal experience (Araki, 2010).

Results of multiple studies also underscored issues of stigmatization in relation to how parents assumed they would be perceived by family members, friends, HCPs, and society in general for the decisions they made in relation to the diagnosis of a fetal anomaly (Araki, 2010; Lou et al., 2017). Feelings of being rejected by someone they felt close to because of conflicting ideas about choosing to continue the pregnancy or raising a child with a disability were associated with feelings of isolation (Araki, 2010). Interestingly, research indicated that the more a woman feels pressured to be a "good mother," the more she restricts herself from discussing her thoughts of abortion and rejection of her disabled child and, in turn, these complex and conflicting feelings are often associated with greater isolation from the woman's social support system (Araki, 2010). Whereas some women seek out support from HCPs because they expect them to understand the nature of their dilemmas, others describe avoiding professional assistance due to feelings of guilt associated with negative thoughts about their fetus (Araki, 2010).

Findings from a review of the literature on the psychological impact of a diagnosis of a fetal anomaly reinforce the complexity of decisions and dilemmas faced by parents. Recommended nursing actions stemming from this review include "active listening," "therapeutic communication," and "encouraging a positive attitude while remaining truthful" (Hedrick, 2005, p. 739), which are general recommendations for any HCP-patient/parent interactions and lack specific insights based on a detailed analysis of HCP-parent antenatal interactions or the overall nature of parents' experiences. In addition, recommendations from multiple studies emphasize the clear need for further research to untangle the various interpersonal, contextual and social factors at play (Shea, 2017).

Specifically, further research is required that addresses both mothers' *and* fathers' experiences with the diagnosis of a fetal anomaly; the nature of HCP-parent interactions; the effects of inherent power imbalances between HCPs and parents; and the socioeconomic, educational, cultural, and other factors shaping parents' experiences. Further research is also required that examines how the psychological framework of parents' experience following the diagnosis of a fetal anomaly intersects with how individuals make important decisions. For example, given the extreme distress and grief reactions associated with an antenatal diagnosis, the decision-making dilemmas faced by parents, and an understanding of the decision-making process, we need to understand how HCPs can present parents with information in ways that acknowledge the shock and acute grief reaction associated with the diagnosis of a fetal anomaly and the complexity of information to be presented. Moreover, we need knowledge of what support strategies parents would find helpful to ease their distress and/or aid their decision-making.

The literature on the psychological impact of the diagnosis of a fetal anomaly also underscores the psychological distress and uncertainty associated with it and thereby the need to consider organizational and contextual factors shaping antenatal care delivery. Despite a review of the literature highlighting the need for HCPs to acknowledge and address the psychological impact of a fetal anomaly on parents and family members, my clinical experience suggests that HCPs often face significant time pressures in providing antenatal care, particularly in addressing parents' needs for emotional support. Therefore, questions arising from the preceding review of selected literature included: (1) How do prevailing efficiency discourses in healthcare settings shape the quality and amount of time HCPs spend with parents following the diagnosis of a fetal anomaly? (2) Do parents find they can take in the information provided by HCPs immediately following the diagnosis? (3) Do parents perceive that the time they spend with HCPs is adequate for them to understand the decisions they face? (4) Do HCP-parent interactions feel rushed or hurried? and (5) Are HCPs accessible when parents have questions or concerns? Further research is required that examines these questions and informs providers on the complexities and subtle nuances in HCP-parent interactions in order to better understand the support parents and families require, and to ease the psychological and emotional distress commonly associated with the diagnosis of a fetal anomaly.

Impact on Parental Attachment

Several studies indicate that for those who continue the pregnancy following the diagnosis of a fetal anomaly, mother-child attachment grows as the pregnancy evolves (Araki, 2010; Asplin, Wessel, Marions, & Georgsson Ohman, 2015; Ruschel et al., 2014). In addition, a growing sense of closeness to the anticipated baby and the idea of living together seems to lead expectant mothers to determine how to reconstruct their lives in order to face the medical treatments and challenges that lay ahead (Araki, 2010). Hedrick (2005), in reporting the findings of a qualitative study involving mothers who received a fetal diagnosis of a "nonlethal" congenital anomaly, emphasized that prenatal attachment occurred "despite the realization that the baby had an anomaly" (p. 734). The researcher described this finding as a paradox, noting even though the mothers recognized the "lifelong commitment to their baby with an anomaly," they accepted and loved the baby nonetheless (Hedrick, 2005, p. 737). It is important to note that much of the previous research demonstrating increasing maternal-fetal attachment following the diagnosis of a fetal anomaly is limited to those parents who continued the pregnancy and excludes fetal anomalies not compatible with life, as well as those with known genetic syndromes and/or neurological impairment. Additionally, the majority of studies in this area have focused

exclusively on maternal-fetal attachment, excluding the nature of the partner's experience. Further research is required which examines parent-fetal attachment (for both parents), including a comparison of the experiences of groups of parents with different fetal diagnoses.

Hedrick (2005) found that parents who receive a diagnosis of a fetal anomaly described feeling prepared for the intensity of complex diagnostic tests and neonatal treatments, and the antenatal anticipatory guidance they received was perceived as valuable in supporting them to care for and bond with their infant during this emotionally taxing time. In fact, parents indicated they were "glad to learn of the anomaly before delivery" (rather than postnatally), and the benefits of information provided to them concerning the fetal condition and anticipated neonatal treatments outweighed the negative consequences resulting from a diagnosis of a fetal anomaly detected complex congenital anomalies describe feeling overwhelmed and distressed with not only their newborn's diagnosis, but also the complex diagnostic tests and neonatal treatments required (Rempel et al., 2012).

Medical and technological advances have made it possible to accurately diagnose many complex forms of CHD in the first trimester of pregnancy (i.e. as early as 11 to 13 weeks gestation) (Jicinska et al., 2017; Quarello et al., 2017). Early fetal diagnosis of complex forms of CHD, particularly those associated with additional chromosomal and structural anomalies, is associated with increased pregnancy termination rates (Allen, 2000; Jicinska et al., 2017). Moreover, findings of a systematic review indicated TOP for a fetal anomaly earlier in pregnancy is associated with less parental psychological distress as compared to those who undergo TOP at a later gestation (Daugirdaite, van den Akker, & Purewal, 2015), raising questions as to whether this is related to lower parental attachment to the fetus earlier in pregnancy, different methods used for TOP depending on gestational age of the fetus, or other factors (Korenromp, 2006). Further research is necessary to sensitize HCPs to the nuances of parents' experiences and the multiple factors affecting parent-fetal attachment and how this shapes parental decisionmaking related to pregnancy management and neonatal treatment options.

In summary, there is a paucity of research addressing how evolving parent-fetal attachment (for both mothers and fathers) shapes decision-making related to the diagnosis of a fetal anomaly. Moreover, the limited research that does exist primarily focuses on the perspectives of mothers who continue their pregnancy, with a negligible amount of research addressing the perspectives of fathers/partners and/or those parents who choose TOP. Several important questions remain unanswered, including: (1) How does parental-child attachment shape parental decision-making? (2) How does decisionmaking shape/affect parental-child attachment? (3) Do parents postpone or interrupt the parent-child attachment process when making decisions related to a diagnosis of a fetal anomaly? (4) For those who do not continue the pregnancy, how do parents frame attachment? (5) Are parents who consider themselves less attached more likely to make different decisions or engage in decision-making differently? (6) How do gestational age, obstetrical history and other factors influence and shape parent-fetal attachment? and (7) Is parent-fetal attachment addressed in HCP-parent interactions antenatally? Further research is required to examine these questions in order for HCPs to understand parents' experiences, provide supportive interventions and offer effective decision-making support.

Parenting a Child with a Congenital Anomaly: The Journey Following Diagnosis of a Fetal Anomaly

Understanding parents' subsequent postnatal experiences provides important insights into the outcomes of antenatal decisions and the evolving psychological, physical and social impact on parents and families. Findings from several studies describe the considerable stress, uncertainty and emotional turmoil experienced by parents and other family members following the diagnosis of a fetal/congenital anomaly, whether during pregnancy or in the newborn period (Lawoko & Soares, 2002; Rempel & Harrison, 2007; Rempel et al., 2012). In one of the few studies specific to the experiences of families who receive an antenatal or neonatal diagnosis of CHD, Rempel and colleagues (2012) employed an interpretive description approach to explore the process of parenting when an infant is diagnosed with a complex CHD (HLHS specifically). Of the family members interviewed, ten of the fifteen children had CHD diagnosed antenatally. It is important to note HLHS is a severe form of CHD in which the left-sided chambers, valves and aorta are undeveloped or non-functional, and therefore the experiences of this subset of parents may not reflect those of parents whose children are born with less complex cardiac anomalies. At the time of Rempel's study, potential neonatal options included a series of three or more staged cardiac surgeries in the first three to five years of life, neonatal cardiac transplantation (depending on donor availability, which was limited), and palliative care, which usually resulted in the infant's death in the first week to month of life.

Results of Rempel and colleagues' (2012) analysis of interviews underscored several factors that contributed to the persistent stress and uncertainty experienced by parents and grandparents following a fetal diagnosis of CHD. These included the need to make "life-altering urgent decisions" (p. 3) that parents perceived would set the course for

their infant's and family's life, parents' feelings of powerlessness to help their hospitalized child, and the frustration and concern parents experienced when restrictions were placed on their parenting role by HCPs in critical care settings, such as being instructed not to touch their child (Rempel et al., 2012). Parents and grandparents also described their evolving expertise as they became more knowledgeable and proficient in the care of their child/grandchild. For these families, expert parenting involved a steep learning curve and an extraordinary caregiving burden. For example, parents described giving up to 27 syringes of medications per day, learning how to provide naso-gastric tube and enteral tube feeds, monitoring fluid intake and output, weighing the baby daily, and performing regular cardiac auscultation and oximetry monitoring (Rempel et al., 2012). In fact, without the emotional and practical support of others, such as grandparents and other extended family members, parents were considered at risk for not coping with the inherent complexities involved in parenting their child, which included becoming an expert caregiver, living with constant uncertainty and relinquishing the parenting role as necessary (Rempel et al., 2012).

Uncertainty, which starts in the antenatal period, continues to be a pervasive theme for parents postnatally as they face a lack of clarity about their child's condition and development, upcoming medical treatments, and future outcomes. Parents described an awareness of the medically fragile and life-threatening nature of their child's complex congenital anomaly through their descriptions of knowing another child who died or their child's own near death experience (Rempel et al., 2012). In addition, parents described how HCPs reinforced the possible risks of morbidity and mortality with each upcoming surgical/medical procedure, which increased parents' anxiety and feelings of uncertainty. At these times, parents described attempting to balance their feelings of increased distress and vulnerability while demonstrating resilience and hope. Interestingly, Rempel's findings indicated many parents and grandparents were able to frame their experiences in a positive light, often providing descriptions of feeling lucky or grateful in comparison to the experiences of other families and emphasizing the personal growth they achieved through parenting a child with a complex congenital anomaly.

Several qualitative studies published over the last four decades focused on the parents' initial responses to their child's diagnosis of complex CHD and associated medical treatments, illuminating the increased parental stress (Hearps et al., 2014; Kaugars, Shields, & Brosig, 2018; Majnemer et al., 2006; K. Uzark & Jones, 2003; Wei, Roscigno, Hanson, & Swanson, 2015), as well as the depression and hopelessness (Lawoko & Soares, 2002; Wei et al., 2015) parents often described. Although helpful in providing insight into parents' experiences and the nature of their psychological responses, findings from these studies did not provide clear direction for specific educational, psychosocial or other interventions aimed at mitigating the psychological concerns experienced by many parents. In contrast, rather than focusing on parental stress and the potential negative consequences to parental mental health, Rempel and colleagues (2012) provided a refreshing alternative perspective, emphasizing parental resilience and underscoring specific HCP interventions aimed at supporting parents and families caring for a child with complex CHD. These interventions include validating emotional parental responses, facilitating decision-making by providing information on treatment options, advocating for increased parental involvement, determining the appropriate timing for educational interventions, and encouraging respite supports (Rempel et al., 2012).

Rempel and colleagues' (2012) framework depicts parents as seeking additional support to accommodate to the parental pressures and demands encountered including the atmosphere of constant uncertainty and medical care requiring them to relinguish their parenting role to HCPs (hands-off parenting). However, the authors do not question if these restrictions on the parenting role are necessary or if there is any impetus for HCPs to consider changes in how they interact and work with parents of children with medically fragile conditions. It is important to emphasize how parents manage and accommodate to the environment of the hospital setting; nonetheless, what remain to be explored are the unspoken rules, the established HCP and parental roles, and the inherent power dynamics at play. Moreover, in addition to HCP-parent collaboration to jointly identify potential sources of further support, further consideration must be given to how differences related to social determinants of health such as gender, educational level, language fluency and income level influence parents' experiences of caring for a child with a congenital/chromosomal anomaly, HCP-parent interactions, and health decisionmaking processes. In addition, further exploration is required of the intricacies of HCPparent interactions, including power relations and the personal, contextual and organizational factors and frameworks shaping HCP-parent communication and decisionmaking.

Experiences of Women Who Terminate a Pregnancy Following Diagnosis of a Fetal Anomaly

Although there is a growing number of clinical and research articles related to the experiences of parents who continue their pregnancy following diagnosis of a fetal anomaly, there is limited research exploring the experiences of those parents who choose TOP. In this section findings from the literature on parents' perspectives of this experience

will be reviewed, highlighting parents' psychological well-being following TOP in the context of a diagnosis of a fetal anomaly and the parents' decision-making process. In particular, findings from multiple studies indicating the significant psychological morbidity associated with this experience and the factors such as gestational age, perceived partner support and educational level that influence parents' psychological response will be highlighted. In addition, selected literature on the nature of HCP-parent interactions and the process of decision-making for those parents who choose TOP following the diagnosis of a fetal anomaly will be explored, emphasizing current gaps in understanding and particular areas of concern in need of further exploration.

Psychological Impact of TOP in the Context of a Fetal Anomaly

Over the last five to ten years there has been an increased emphasis in the research and clinical literature on the psychological outcomes and predictors for adverse outcomes after TOP in the context of a known fetal anomaly. Results of multiple studies indicate this experience is an emotionally traumatic major life event associated with intense grief reactions, depression, anxiety, guilt, and stigma (Asplin, Wessel, Marions, & Georgsson Ohman, 2014; Lafarge, Mitchell, & Fox, 2014; Lotto, Armstrong, & Smith, 2016). Furthermore, multiple studies have found TOP following the diagnosis of a fetal anomaly to be associated with severe psychological sequelae including post-traumatic stress disorders in a substantial number of women (Anette Kersting, Kroker, & Steinhard, 2010; A. Kersting et al., 2009; Korenromp, 2006). For example, in one of the first studies of its kind, Korenromp examined women's long-term psychological well-being following TOP in the context of a known fetal anomaly in order to identify risk factors for psychological morbidity. The researchers collected data two to seven years after TOP and utilized a cross-sectional design that incorporated data on the experiences of 196 of the

254 women who terminated a pregnancy prior to 24 weeks gestation following the diagnosis of a fetal anomaly. Among the sample of participants, there was a wide range of fetal anomalies including 115 women who received a fetal diagnosis of a chromosomal anomaly such as Trisomy 21, 13 or 18, all of which are commonly associated with multiple structural anomalies (Korenromp, 2006). Results of Korenromp's study indicated significant psychological and emotional outcomes for women following TOP in the context of a fetal anomaly. Pathological scores for grief were uncommon (2.6 percent); however, this percentage still represents five women who had pathological scores for grief two to seven years following TOP, which is clinically significant (Korenromp, 2006). In addition, 33 participants (17.3 percent) had pathological scores for grief or post-traumatic stress. Moreover, the number of women with pathological scores for grief or post-traumatic stress symptoms were equally distributed regardless of the time elapsed after the event (two to seven years), suggesting symptoms may remain long-term following TOP (Korenromp, 2006).

Multiple predictors for adverse psychological outcomes following TOP in the context of a known fetal anomaly have been demonstrated. Specifically, a low level of education and low level of perceived partner support have been found to be the most significant risk factors for an unfavourable psychological outcome (Korenromp, 2006). Although not emphasized by the authors, women who had high post-traumatic stress scores were more likely to feel their decision was made under pressure from a family member or significant other, and were less likely to have a paid job (Korenromp, 2006). Interestingly, Korenromp noted significant differences among women's experiences in relation to gestational age at the time of TOP, with advanced gestational age consistently associated with higher levels of grief. In contrast, post-traumatic stress symptoms and long-term psychological morbidity were rarely reported by those who pursued TOP prior

to 14 weeks gestation (Korenromp, 2006). Although not clearly delineated by the authors, they did note gestational age and methods of termination are strongly correlated and their effects are difficult to distinguish. TOP prior to 14 weeks was usually performed by dilatation and evacuation in contrast to TOP performed at a later gestational stage, which involved induction of labour or, in the one case of a selective termination of twins where only one twin had a fetal anomaly, foeticide (Korenromp, 2006). Of particular interest to the current study was the finding that higher levels of maternal grief and doubt were present when the fetal anomaly was assumed to be compatible with life (Korenromp, 2006). Further research that examines the multiple factors contributing to differing levels of psychological morbidity following TOP is required. For example, are higher levels of parental grief associated with increased gestational age because of increased parental attachment, or are other factors at play?

As described, results of numerous studies indicate TOP in the context of a diagnosis of a fetal anomaly is associated with long-lasting and significant psychological morbidity for a substantial number of women. Analysis of risk factors for unfavourable psychological outcomes provides clinically relevant information and insights that can ultimately help improve care delivery and parental outcomes. For example, it underscores the need to develop risk-assessment tools, provide follow-up assessments for a longer duration, and be increasingly sensitive to the possibility parents may require additional support. However, further research is required from a Canadian perspective including the perspectives of fathers/partners. There may be differences in cultural values and beliefs and/or healthcare differences that make the Canadian experience different from that reported by researchers from other countries. Likewise, since most of the research to date has focused on the experience of women, it is imperative HCPs understand the

experience of fathers/partners because they may have significantly different experiences from their partners and undoubtedly influence the well-being of all involved, yet there is very limited research examining their experiences and/or perspectives. Questions for future research include: (1) What is the psychological impact for mothers and fathers/partners following TOP? (2) Are parents' questions and concerns addressed in relation to decisions about continuing or terminating the pregnancy following the diagnosis of a fetal anomaly? and (3) What HCP-initiated approaches and supports do parents find helpful in their decision-making related to diagnostic testing and pregnancy options? Research exploring these elements of parents' experiences will open up new insights into our understanding of antenatal communication and decision-making, thereby sensitizing HCPs to the nature of parents' antenatal experiences and informing clinical practice of potential strategies to optimize HCP-parent interactions and the provision of antenatal support.

TOP in The Context of a Fetal Anomaly: HCP-Parent Interactions and Parental Decision-Making

In recent years, a growing number of research articles have examined the nature of HCP-parent interactions and the process of decision-making for those parents who decide to terminate the pregnancy following diagnosis of a fetal anomaly. Findings from multiple studies underscore the emotional angst associated with decisions to terminate a pregnancy (Andersson, Christensson, & Gemzell-Danielsson, 2014; Hodgson et al., 2016; Hunt, France, Ziebland, Field, & Wyke, 2009; Wool, 2011), with participants' often using strong emotional terms such as "one of the worst things of my life" and "so painful that the thought of killing yourself as well crosses your mind" (Koponen et al., 2013, p. 38). For many prospective parents, the decision to terminate the pregnancy comes after intense deliberation and consideration of their perceptions of multiple factors associated with the fetal anomaly and postnatal treatments including long-term QOL, anticipated pain and suffering (Benute et al., 2012; Hodgson et al., 2016), impact on family life, parenting burden/reward, as well as reflection on personal perspectives on TOP and childhood disabilities (Choi, Van Riper, & Thoyre, 2012; Hodgson et al., 2016). These findings are helpful in sensitizing HCPs to the perspectives of parents who consider TOP; however further research is required to provide greater clarity concerning how HCPs provide information to parents about the diagnosis of a fetal anomaly and associated prognostic outcomes and if parents' perceptions of postnatal treatments, anticipated short- and long-term QOL and the option of TOP are accurate and realistic. In addition, greater insight into the nature of parents' experiences is required to develop parent- and family-informed strategies and resources that will assist parents in this difficult decision-making process.

Multiple studies examining the decision-making process of women who choose TOP in the context of a fetal anomaly emphasize that parents view the decision of continuing or terminating the pregnancy as a dilemma (Carlsson, Bergman, Karlsson, Wadensten, & Mattsson, 2016; Hodgson et al., 2016; J. L. McCoyd, 2007): "a choice between two bad or, as some of them wrote, two wrong options" (Koponen et al., 2013, p. 42). Specifically, many parents described facing a difficult decision between two poor alternatives: either to continue a wanted pregnancy that they perceived would cause suffering, or to terminate the pregnancy with the subsequent experience of guilt and emotional pain (Carlsson et al., 2016). In addition, a significant and common concern described by participants was that either decision conflicted with their personal values and involved wrestling with how to maintain their moral self-worth and manage the attitudes of others (Koponen et al., 2013). In particular, multiple authors reported on the stigma associated with choosing TOP and parental fears of being negatively judged by others for this decision (Hodgson et al., 2016; J. L. McCoyd, 2007; Wool, 2011).

In relation to efficacy of HCP-parent communication for those parents who pursue TOP following the diagnosis of a fetal anomaly, findings from multiple studies highlight the challenges parents face in seeking out comprehensive, accurate and balanced information related to the fetal anomaly and/or the option of TOP (Benute et al., 2012; Carlsson et al., 2016; Hodgson et al., 2016; Koponen et al., 2013). In addition, research findings highlight that women/parents often turn to the Internet, including websites and online forums, as one of their main sources of information related to the decision to terminate the pregnancy, thereby relying on largely unmoderated and non-evidencebased information for their antenatal decisions (Carlsson et al., 2016; Hodgson et al., 2016). In addition, there is a discrepancy between parents' expectations and experiences related to follow-up support after TOP, with participants expecting HCPs to provide emotional support and develop an ongoing plan of care, but finding that HCPs often provided insufficient emotional support, lacked a clear agenda in providing care and support, and/or did not individualize the care to the participants' unique needs (Hodgson et al., 2016; Koponen et al., 2013). Moreover, participants stated that sensitive communication was essential, noting that the nature and content of HCPs' communications could provide great comfort or cause further distress, with statements acknowledging the emotional impact of the parents' experience being perceived by parents as the most helpful (Hodgson et al., 2016). Interestingly, Koponen and colleagues (2013) noted the polarity of roles HCPs are expected to fill: on the one hand they are expected to provide objective nondirective information, which parents perceived to require
a certain emotional distance between HCPs and patients; on the other hand, they are expected to act empathetically and provide emotional support.

Of particular relevance to the current study, findings from a study by Koponen and colleagues (2013) underscored that considerable tension existed between the way some mothers attributed a decision of TOP in the context of a known fetal anomaly to their own control, such as "my husband and I discussed, we came to the conclusion" (p. 38), which conflicted with their description of the fetal anomaly in terms that implied the decision was not really within their control, such as, "the only option would be, the case was so definite—there was no hope" (p. 38). The authors concluded that, although the mothers communicated the intentionality of their decision, they also presented themselves to be partially unaccountable and forced to settle for termination for medical reasons. Furthermore, the mothers in this study referred to their decision-making related to TOP as "artificial" in their descriptions of not perceiving a choice other than TOP to avoid their

unborn child's unnecessary suffering. Koponen and colleagues' (2013) research findings hold up for questioning the assumption of parental autonomy and informed choice that is commonly valued in public and professional discussions concerning antenatal diagnosis of a fetal anomaly. In this study women did not view themselves as having a real choice in TOP. Moreover, the descriptions of their experiences suggest that, at least for some women, the actions of HCPs were largely ineffective and unsupportive. Clearly, clinical practice would be enhanced by further research illuminating parents' perspectives on how to support antenatal decision-making and care delivery for those who choose TOP. In addition, there is a need for research that seeks to understand HCPs' perceptions of their role in providing informational, emotional and decision-making support to parents as well as the contextual and organizational challenges they face. A review of the literature on TOP in the context of a diagnosis of a fetal anomaly provides insight into this experience and underscores the need for further research in this area, particularly from a Canadian perspective. Building on a review of the literature related to both the experiences of parents who choose to continue their pregnancy following a diagnosis of a fetal anomaly and those parents who choose TOP, the focus will now shift to a review of selected research and clinical literature specific to health communication and decision-making.

HCP-Parent Interactions and Decision-making: HCPs' Perspectives

Despite the substantial increase in the number of antenatal diagnoses of fetal anomalies over the past 30 to 40 years, there is a paucity of research examining what HCPs working in maternal-fetal care view as best practices in antenatal HCP-parent communication and decision-making support. In the following sections I will review two prominent approaches to HCP-parent interactions and decision-making support: (1) the traditional nondirective approach emphasizing parental informed consent; and (2) a shared decision-making model that has emerged in the literature and practice settings more recently. Particular attention will be devoted to the potential for decision-making conflicts between HCP and parents, as well as the legal and ethical considerations potentially influencing practitioners' actions. In addition, concerns with both approaches will be examined, including the potential for HCPs to influence parents' decision-making despite their best intentions to provide nonbiased information.

Traditional Nondirectional Approaches

Relatively unchallenged until the past 15 to 20 years, when shared-decisionmaking models began to surface in the literature, a nondirectional approach has been a "universal norm" and the "guiding principle" in counselling used and advocated by physicians, nurses, and allied health professionals involved in antenatal diagnosis of congenital and genetic anomalies for over thirty years (Weil, 2003; Williams, 2002). It is important to note from the outset that there is general agreement that HCPs can never be completely nondirective; even with HCPs' best efforts to remain neutral, their values and beliefs may be apparent. Therefore, in practice nondirectiveness is considered not an achievable absolute, but rather a goal toward which to strive (Weil, 2003). Nonetheless, nondirectiveness refers to HCPs' attempts to provide value-neutral diagnostic and prognostic information while not intentionally revealing their own emotions or beliefs, giving advice or making therapeutic recommendations (Allan & Huggon, 2004; Weil, 2003). In the setting of medical paternalism and technological advances in healthcare, including the diagnosis of fetal abnormalities, nondirectiveness is seen to support individuals to make independent decisions, free from influence from HCPs (Weil, 2003).

Acknowledging nondirectional counselling is the accepted norm, several authors have provided an overview of their perspective of clinician obligations in HCP-parent interactions following the diagnosis of a fetal anomaly in terms of "what parents need to know". For many clinicians this includes a structured presentation of the medical "facts" including information about the significance of the fetal anomaly and any associated medical ramifications impacting the remainder of the pregnancy; implications for the newborn including anticipated medical and surgical interventions and associated risks; possible long- and short-term outcomes with an emphasis on anticipated QOL; and, depending on the stage of gestation and the nature of the fetal anomaly, information about parental options to terminate or continue the pregnancy (Birkeland, Dahlgren, Hagglof, & Rydberg, 2011; Menahem & Gillam, 2007). Other HCPs advocate for a flexible communication approach, which adapts the information provided depending on

parents' initial reactions and HCPs' estimates of "what kind of information they [the parents] can handle" (Birkeland et al., 2011, p. 288).

Consistent with a nondirective approach, many HCPs have indicated their intention of providing diagnostic and prognostic information related to the diagnosis of a fetal anomaly in a comprehensive and forthright manner without expressing their personal viewpoints as to which option to choose (Menahem & Gillam, 2007). Others emphasized the importance of presenting information with conviction and employing strategies to create confidence in the HCP including being honest, clear, frank and reliable and not trying to conceal something (Birkeland et al., 2011). However, these authors did not address how clinicians should approach diagnostic and prognostic information provision when there is significant uncertainty associated with the diagnosis or treatment management decisions, as is often the case in medical management of infants with complex congenital or chromosomal anomalies.

The science of how HCPs make decisions is traditionally based on a rational decision-making framework that is enmeshed with neoliberal ideology, a biomedical perspective and an evidence-based practice approach. This decision-making approach minimizes the influence of emotions and biases and suggests that HCPs make decisions using a stepwise, logical process that involves assessing important aspects of each situation and selecting the best option (Kahneman, 2013b; MacFadden & Schoech, 2010). Evidence based practice (EBP) goes hand in hand with a rational decision-making model, in which existing research evidence is integrated with clinical experience and patient values and preferences to facilitate clinical decision-making (Orta et al., 2016). EBP is also consistent with a nondirectional approach that emphasizes providing parents with the requisite information to make independent and informed decisions, and privileges

"objectivity," "universality" and "value-free" evidence in HCP-parent interactions (Goldenberg, 2006), while minimizing the role of intuitions and emotions.

Advocates of a nondirective approach often encourage providing as much information as possible to facilitate parents' informed decisions. In fact, Menahem and Gillam, an Australian pediatric cardiologist and clinical ethicist respectively, encouraged clinicians to provide more information about "bad" outcomes in the antenatal context than they would in a comparable postnatal context because of the parental option of TOP (Menahem & Gillam, 2007). They noted once a baby is born with CHD there is a priority on maintaining life and health of the newborn, which leads HCPs to emphasize the best outcomes in HCP-parent discussions in order to facilitate parental hope for their child. Additionally, they emphasized that in postnatal contexts, parents' decisions that are perceived as contrary to the child's best interests can be legally overridden. On the other hand, the authors noted a diagnosis of a fetal cardiac anomaly provides parents with the option of TOP, which may involve parental consideration of not only the future welfare of an unborn child, but also the potential impact on the health and well-being of any siblings as well as the parents themselves (Menahem & Gillam, 2007). Moreover, the authors emphasized that parents who consider TOP often deliberate over whether their child's life would be fulfilling, express concerns about the need for lifelong medical interventions and follow-up, and note worries about the potential psychological impact associated with the death of a child following medical intervention. Interestingly, Menahem and Gillam (2007) emphasized these parental concerns when parents have the option of considering TOP; however, for parents who receive a postnatal diagnosis of CHD, (i.e. when termination is not an option and/or the option of medical treatment is not in question), HCPs emphasize optimal medical and treatment interventions and encouraging parental hope. They assert:

It can be argued that in the prenatal situation, it is reasonable to look at the outcome of the anomaly diagnosed, when termination of pregnancy is an available option. This would involve more explicitly noting and describing possible poor outcomes, even those that are unlikely but potentially severe, than would be the case after the birth of an infant. (Menahem & Gillam, 2007, p. 236)

This perspective highlights important differences between antenatal and postnatal communication of prognostic and treatment information related to the diagnosis of a fetal/congenital anomaly, and underscores how HCPs can influence and shape parental decisions even when they perceive the manner and content of their communications are nondirective.

Aligned with a perspective of evidence-based practice, rational decision-making and a nondirectional approach, there is often an underlying assumption when making important health-related decisions that parents should carefully consider the pros and cons of each option and ideally make a logical and deliberate decision related to the health of their child. In contrast, parents who do not approach decision-making within these guidelines are often disparaged for making decisions based on emotion or intuition or are questioned by HCPs about whether they have adequately considered all of their options. This was evident in the findings of Hunt and colleagues (2005), who noted that when HCPs were asked for their perceptions of what motivated people to accept or decline amniocentesis, HCPs articulated a clear distinction in the parental decisionmaking process they perceived to be taking place. Ninety-six percent of the HCPs interviewed described decisions to have an amniocentesis as based on a reasoned and deliberate intention to "have knowledge about the health of the fetus in order to be able to respond in the event of an undesired outcome" (Hunt et al., 2005, p. 308). In contrast, parental decisions to decline amniocentesis were perceived by HCPs to be based on unreasoned emotion and rooted in fear, cultural beliefs and misunderstanding (Hunt et al., 2005). Interestingly, 79 percent of women "accepted" an amniocentesis and 21 percent declined (Hunt et al., 2005). These results suggest HCPs privileged decisions that were made using a rational and deliberate framework and disparaged those in which they perceived emotionality had come into play.

In tandem with a nondirective approach, there is considerable emphasis in the literature on antenatal HCP-parent communication and decision-making concerning the ethical and legal elements of informed consent, which involves providing parents with information relevant to the decisions being made. Given that in Canada women have the right to terminate a pregnancy for any reason during a predefined stage of pregnancy, there is an underlying assumption that antenatal diagnosis will facilitate parental decision-making related to choosing TOP or continuing the pregnancy as well as choices regarding neonatal treatment options. This assumption is underpinned by biomedical and individualism discourses which foster techno-rational approaches emphasizing scientific problem-solving in addressing diagnostic and treatment options (Kinsella, 2007), and foreground individual autonomy, personal rights and self-determination over the broader contextual determinants of health (Raphael et al., 2008). This assumption and the associated underlying discourses contribute to placing an emphasis on individuals' right to know about risks related to health, the possibilities related to prevention and treatment, and the right to choose among predetermined options (Petersen, 1999). These are important considerations in understanding how and what information HCPs provide to parents, and how parental decisions are viewed by HCPs. Much of the information currently provided to parents focuses on relaying information that HCPs perceive parents need to know, often emphasizing medical treatment options that occur in hospital and not the long-term lived experiences of child and family, or socio-cultural and other factors

which may significantly impact health decisions. However, this assumes HCPs understand what should be given priority in HCP-parent discussions in order for parents to make informed decisions aligned with the interests of their child and family. There is no clear evidence that this is the case. Further research is required to understand what information parents find essential and supportive, how best to present this information, and what additional decision-making supports are required.

Menahem and Gillam (2007) have also provided an interesting perspective into the experience of clinicians involved in providing antenatal information and decision-making support to expectant parents. Specifically, they described the distress clinicians experience when parental decisions are different from the clinician's perspective, especially in the scenario where TOP is considered for an anomaly that the clinician does not perceive as serious (Menahem & Gillam, 2007). Moreover, the authors note that although most HCPs tend to keep their personal perspectives to themselves, some disagree with this perspective. They recommend that in HCP-parent discussions clinicians should focus on frankly and comprehensively reviewing the medical issues pertinent to the child's future QOL rather than the moral decisions to be made (Menahem & Gillam, 2007). However, further research is required to understand how the content of diagnostic and prognostic information, and the manner in which it is conveyed, influence and shape parents' understanding of the fetal condition and their subsequent decision-making. Menahem and Gillam (2007) also claim that clinicians have "a valid claim to autonomy and personal integrity" and "the right to conscientious objection [allowing them] to opt out of a process leading to termination" (p. 236) by referring parents to another specialist for ongoing management. This perspective provides further insight into the power dynamics underpinning antenatal HCP-parent interactions and raises serious guestions concerning

the implications for parents when an HCP disagrees with their decisions. Further research is required to investigate these relational dynamics in greater depth.

In one of the first published articles examining the experiences of parents' decision-making related to antenatal genetic testing from a critical perspective, Anderson (1999) noted that, despite HCPs' intentions to employ nondirective approaches to purposefully avoid parents being influenced by the HCPs' personal and professional standpoints, the predominant finding from her study was HCPs "cannot help but weave in professional and personal biases, their own values and personal moral judgments with the science and medical knowledge they present to patients and use to make clinical decisions" (p. 129). Anderson's work was one of the first of its kind to openly critique the appropriateness of a nondirective approach in antenatal counselling with parents and to encourage HCPs involved in the provision of genetic information, such as midwives, women's health practitioners and clinical nurse specialists, to question and hold open for critique "the assumption that nondirectiveness protects parents' abilities to make truly autonomous decisions" (p. 127). Anderson emphasized the increased moral tension that develops between HCPs and parents and/or between women and their partners because differences in values, beliefs and moral convictions are not addressed. She contends this tension is further potentiated when HCPs do not acknowledge or fail to understand that their assumptions prevent them from understanding parents' unique perspectives by undermining HCPs' abilities to foster open communication and preventing exploration of parents' personal beliefs and values. Anderson asserted that nurses must critique, rather than merely adopt, knowledge and practices borrowed from other disciplines, and emphasized the need for nurses to listen to patients' stories, acknowledge parental decisions are influenced by a variety of factors including HCPs' personal values and

beliefs, and be skeptical and critical about whether nondirectiveness is possible or desirable.

Shared Decision-Making Approaches

A review of the decision-making literature revealed a shift in Western health systems from a paternalistic model of professional responsibility toward a shared decision-making (SDM) or "consumerist" model (Aarthun & Akerjordet, 2014; Fiks & Jimenez, 2010; Jackson et al., 2008). An SDM approach is situated between medical paternalism, in which clinicians formulate treatment plans and communicate these to patients/parents, and informed choice, which is characterized by patients/parents making independent health decisions after gathering information from health providers and others. The Institute of Medicine as well as the World Health Organization have supported an SDM approach, underscoring its potential to improve HCP-patient/parent communication and thereby improve patient satisfaction, treatment adherence and health outcomes (Fiks & Jimenez, 2010). Moreover, there has been increasing support for SDM in several European countries as well as North America, evident in a 2010 U.S. health reform law supporting the establishment of a national program to promote the implementation of an SDM model characterized by transparency, consumer protection and evidence-based medicine in HCP-patient interactions, which promoted the creation and distribution of patient decision aids as a means of supporting patients and families to learn about the risks and benefits of different medical interventions (Fiks & Jimenez, 2010).

In general, an SDM approach emphasizes exploration of multiple evidence-based options in clinical decision-making and supports families in learning about the risks and benefits of medical treatments (Fiks & Jimenez, 2010). In addition, it emphasizes role negotiation, open communication, and "user involvement" in decision-making (Aarthun & Akerjordet, 2014), while explicitly recognizing the information and values both clinicians and patients/parents bring to discussions related to healthcare decisions (Hunt et al., 2005). However, there is not a clear consensus on how SDM ought to be defined or implemented in practice. Consistent with a "consumerist" perspective, some authors provide an interpretation of SDM that emphasizes promotion of informed choice, encourages patients to be active participants in their health and healthcare, and in which informed decisions are based on relevant information as well as evaluation of the decision-maker's values (Jackson et al., 2008). From this perspective the patients/parents are the ultimate decision-makers and there is no expectation of HCPs and patients/parents coming to a mutual agreement on child health decisions. Moreover, decision support is characterized as "anything that helps individuals to gain relevant information and clarify their values about the decision they are trying to make" (Jackson et al., 2008, p. 233). In contrast, other authors define SDM as involving a clinician explaining the medical evidence of different treatment options to the family, jointly discussing these options in the context of the family's personal and moral values, and ultimately the clinician and family jointly agreeing on the treatment plan (Fiks & Jimenez, 2010). This perspective of SDM ideally involves both clinicians and patients/parents feeling they have agreed on the 'best' decision for a particular situation (Hunt et al., 2005). Recommendations to support parents in understanding the medical evidence in order to

be "effective partners" in decision-making include increased use of decision aids, altered reimbursement structures to allow clinicians to provide adequate time for explanation of complex information, and increased use of health information technology to enhance HCP-parent communication (Fiks & Jimenez, 2010). Additional recommendations to offset parents' potential feelings of unease or unfamiliarity with participation in health-related decision-making includes HCPs providing extra emotional support or referring parents to parent support groups or counsellors in order to address unmet emotional needs and facilitate parent participation in healthcare decisions (Fiks & Jimenez, 2010).

A perspective of SDM that emphasizes the expertise that both clinician and parents/patients bring to HCP-parent discussions and draws attention to the need for HCPs to understand the patients/parents lived experiences, values and beliefs as well as the contextual factors that are being considered in making the decision has inherent strengths. However, to assume an SDM approach will ideally result in HCP-parent agreement on final treatment decisions seems far-fetched. Perhaps HCPs might understand the underlying rationale for parents' decisions but to expect mutual agreement, especially when HCP and parent/patient worldviews differ significantly, seems unrealistic. In addition, this perspective raises significant ethical concerns in that if agreement between parents and HCPs is the goal, there is a possibility parents will succumb to the HCPs' perspectives rather than HCPs agreeing with the viewpoints of the parents. Likewise, given the complexity of healthcare teams where numerous HCPs are involved in the care of a patient and family, how would a lack of consensus among various HCPs as to what constitutes the "best" decision be resolved when a mutual decision is the ultimate goal?

Whereas much of the literature on SDM underscores its emphasis on understanding the parents' perspective and building a trusting HCP-patient/parent relationship, other perspectives are strongly aligned with the evidence-based practice movement, which privileges scientific evidence over other forms of knowledge as the basis for parental decision-making. SDM has the potential to foster HCP-parent relationships in which parents' perceptions are valued, subtle individual differences are acknowledged, and contextual factors influencing the family's experience of health are considered. However, the perspective put forth by Fiks and Jimenez (2010) and others appears insufficient in that it draws attention to the benefits of making complex decisions based on weighing the risks and benefits of multiple evidence-based options and oversimplifies the multiple complexities and contextual elements considered in parents' health decisions. Furthermore, privileging scientific evidence from quantitative studies and clinical trials reinforces the idea of straightforward cause and effect when assessing health concerns and simplifies complex decisions to choosing what scientific evidence demonstrates as the best option rather than considering the "messiness" of the multiple intersecting factors at play when individualizing care and treatment choices for patients and families. By not seeking to understand the complexities involved in parental decision-making, the possibility exists that HCPs will prioritize evidence-based assessments and treatments over the perceptions and experiences of parents in HCP-parent interactions.

A review of the literature on nondirectional approaches and shared decisionmaking models in HCP-parent interactions has been summarized. Gaps and controversies in the literature highlight the need for further research to carefully compare and contrast these approaches and the associated outcomes in order to provide direction to clinical practice. Viewing antenatal parental decision-making through a governmentality lens will help to expose the power HCPs and parents have in determining who participates in decision-making, what decisions are made, and the outcomes of these decisions. Moreover, this theoretical lens will support questioning of assumptions aligned with informed decision-making and SDM models, which both emphasize supporting parents to weigh the risks and benefits of multiple evidence-based options. Despite the decision-making model employed, either orientation has the potential to allow HCPs to influence parents' decisions to be aligned with what HCPs perceive to be in the parents' best interests, whether QOL, longevity, or prevention of suffering, making it important to expose and understand the underlying power relations. For example, additional research is required that addresses whether the manner in which benefits and risks of various diagnostic and treatment options are presented to parents idealizes or suggests the desirability of one option over another, thereby serving as a guide for receptive parents while actually endorsing the goals desired by HCPs and the broader organization. In addition, clinical practice would benefit from research examining and comparing different orientations to HCP-parent interactions and decision-making to determine how best to ensure that decisions take parents' perspectives, beliefs and values into consideration as well as attending to specific individual and contextual factors impacting parents' decisions and their outcomes.

Parents' Perspectives on Health Decision-Making: Challenges and Supports

Building on the preceding review of common approaches to HCP-parent interactions and the associated challenges, in the following section selected literature on parents' perspectives on HCP-parent interactions and decision-making is reviewed. The findings from two systematic reviews will be highlighted in order to draw attention to parents' perspectives of the challenges and supports they experience in HCP-parent interactions and health decision-making.

Jackson and colleagues (2008) conducted a systematic review to identify decision supports parents required in their attempts to make informed child health decisions. The authors provided a detailed description of a systematic and rigorous search of nonintervention studies containing data on decision support needs of parents making child health decisions. The initial search of 12,123 articles was subsequently narrowed to 149 research-based articles representing a variety of parental health decisions, including management of acute and long-term conditions, immunizations, end of life and palliative care, and prenatal screening, and also including 18 articles on decisions related to the diagnosis of a fetal anomaly (Jackson et al., 2008). Analysis of decision support needs resulted in three main themes: information provision (including insights about content, delivery, source and timing); talking to others (including concerns about pressure from others); and feeling a sense of control over the process (influencing factors included emotionally charged decisions, the consultation process, and structural/service barriers) (Jackson et al., 2008). Highlights of the results pertinent to the current research will be summarized and augmented with additional findings from selected literature.

Information Provision

Parent reports indicate information received from HCPs is often perceived as promoting a specific course of action rather than a balanced review of all available options (Jackson et al., 2008). Parents emphasized their preference for factual, consistent, comprehensive, value-free information on all available options tailored to their needs and reading level, and described difficulty understanding risk information presented as statistical probabilities or vague descriptors such as "rare" (Jackson et al., 2008). Additionally, several researchers identified that parents' trust in the information provided is dependent on the perceived credibility of the source, with physicians and other HCPs usually viewed as important sources of credible health information (Aarthun & Akerjordet, 2014; Jackson et al., 2008). In terms of information delivery, parents generally preferred to have an opportunity to review written information prior to a face-to-face discussion with an HCP; however, when health information is potentially anxiety provoking, such as antenatal test results, parents preferred to receive and discuss information simultaneously with HCPs (Jackson et al., 2008).

Supportive and Non-Supportive Interactions

The literature emphasizes that parents value the opportunity to share experiences and knowledge and seek reassurance from other parents in similar situations through informal or formal social networks including support groups (Jackson et al., 2008). In contrast, there is clear evidence that parents feel pressure from a range of sources including friends, family, HCPs, healthcare systems and society to make particular decisions, and that these preferences are expressed intentionally and unintentionally (Jackson et al., 2008; Rempel et al., 2004). This is consistent with the findings of Vandvik and Førde (2000), who explored mothers' experiences making "life and death" neonatal decisions related to their infant's diagnosis of HLHS. Analysis of qualitative data indicated that although physicians attempted to provide objective and nondirective information, parents "picked up on" physicians' preferences, and for some families this influenced their decisions to choose palliative care or neonatal surgery for their infants (Vandvik & Forde, 2000). Interestingly, in addition to perceived pressure from individuals, parents also described feeling pressured by healthcare systems when there were assumptions made by healthcare teams about compliance to a particular course of action such as immunization protocols (Jackson et al., 2008).

Control Over Decisions

An over-arching theme related to parental decision-making is that parents want control over their health decisions concerning their child (Jackson et al., 2008). Parents underscored their own emotional reactions that threatened their control over the decisionmaking process; however, they preferred to have HCPs acknowledge these emotions and discuss them within the HCP-parent consultation even if the decisions were considered "routine" from the HCP's perspective (Jackson et al., 2008). Moreover, parents expected HCPs to demonstrate empathy for their experience, recognize their expertise as parents and acknowledge health decisions are not made solely on the basis of information provided by HCPs (Jackson et al., 2008; Rempel et al., 2004). In addition, parents emphasized that compliance with HCPs' recommendations does not necessarily indicate parents are satisfied with a decision, particularly if it is in conflict with their personal values (Jackson et al., 2008).

Jackson's research team (2008) concluded that the three main themes identified in their systematic review are often poorly addressed by HCPs, and underscored that increasing health policy emphasis on patient-centred care and shared and informed decision-making are rarely translated into practice and/or are not reflected in the research conducted with parents on decision support needs. Further research is required to examine why these policies and supportive HCP approaches and interventions are not reflected in parents' perspectives of HCP-parent interactions and decision-making, specifically as it relates to the experience of parents who receive a diagnosis of a fetal anomaly. In addition, findings of this systematic review underscore how clinical practice could benefit from insights and direction gleaned from an examination of broader system and organizational influences shaping health and healthcare delivery.

Parental Participation in Decision-Making

Complementing Jackson and colleagues' systematic review of parental decision supports, Aarthun and Akerjordet (2014) conducted a systematic review of parents' perceptions of participation in health decision-making for their child. This review was prompted by a desire to understand why SDM has not been widely implemented in practice, despite growing emphasis in the literature advocating for inclusion of parents as partners in child healthcare services (Aarthun & Akerjordet, 2014). The researchers' systematic and rigorous search of the literature yielded a list of 1,503 articles that was narrowed down to 18 articles written in English using a qualitative or quantitative research design. Results emphasized three overriding themes related to parental participation in decision-making: relational factors and interdependence, personal factors and attitudes, and organizational factors (Aarthun & Akerjordet, 2014).

Relational Factors and Interdependence

Parents varied in the level of participation in decision-making related to their child's health; however, in general they indicated a preference for greater participation in decisions (Aarthun & Akerjordet, 2014). The competence of HCPs was an important factor in assessing the quality of HCP-parent relationships, with parents emphasizing the importance of HCPs' communicative, educational and relational capabilities in addition to technical knowledge and experience (Aarthun & Akerjordet, 2014; Rempel et al., 2004). Parents noted a power imbalance within HCP-parent relationships, which they perceived as posing a major challenge to their participation in decision-making (Aarthun & Akerjordet, 2014). Specifically, Aarthun and Akerjordet (2014) drew attention to HCPs' greater power and authority in HCP-parent interactions in that they manage health services, hold the medical expertise, and use their discretion as to which decisions to include parents in and when to facilitate parent participation in decision-making. These results highlight the importance of scrutinizing the inherent power relations in HCP-parent relationships when seeking to understand HCP-parent communication and decisionmaking.

Personal Factors and Attitudes

Aarthun and Akerjordet's (2014) integrative review clearly indicates parents' preference for HCP-parent relationships characterized by mutual trust and respect. reciprocal listening, sharing of information and opportunities to have questions answered; however, an interesting distinction made by the research team is that parents and HCPs perceive parental participation differently. On the one hand, parents emphasize the need to "draw together" and work collaboratively with HCPs to make decisions related to their child's health, whereas HCPs' attitudes reflect "distancing" and a greater concern with legal provisions than truly shared decision-making (Aarthun & Akerjordet, 2014). Equally relevant to the current study is that personal factors such as level of education, age, income and marital status were found to influence parents' participation in decisionmaking (Aarthun & Akerjordet, 2014; Penticuff & Arheart, 2005). For example, in a study aimed at improving HCP-parent collaboration in neonatal intensive care, Penticuff and Arheart (2005) found mothers who were married, had higher levels of education, and/or had higher incomes tended to be less satisfied with the decision-making process. In contrast, mothers who were classified as young, less educated, low-income, and of an ethnic minority tended to have a greater number of decision-making conflicts (Penticuff & Arheart, 2005). These findings point to the importance of considering how social determinants of health such as education, socioeconomic factors, and language fluency intersect to shape and influence parents' experiences and health decision-making.

Organizational Factors

Parents perceived that organizational factors influence HCPs' opportunities to facilitate parents' participation in health decision-making (Aarthun & Akerjordet, 2014). Specifically, parents perceived HCPs' availability of resources and time to provide

information, discuss options, and negotiate treatment plans considerably shaped parents' participation in decision-making (Aarthun & Akerjordet, 2014). In addition, short hospital stays and lack of standardized routines for providing health information and including parents ultimately impeded parents' participation in decision-making (Aarthun & Akerjordet, 2014). This was consistent with literature indicating that a dominant efficiency discourse, one of the driving forces underpinning healthcare delivery, promotes the notion there is insufficient time for detailed conversations that would facilitate HCPs' comprehensive understanding of families' unique experiences and better equip them to provide psychosocial and emotional support (Crawford & Brown, 2011). This creates a situation where the families that could most benefit from supportive HCP relationships that address psychosocial, emotional and contextual needs related to health and illness often receive inadequate attention and face the greatest care burden. From this perspective, HCPs assume significant power, often unwittingly, by defining expectations for care and emphasizing certain aspects of care and care delivery while minimizing others. These contextual factors have received little attention in previous literature related to parental decision-making yet are important considerations in understanding the nature of the experience.

Overall, a review of selected literature from a variety of contexts within child health services provides important insights into relational, personal and organizational factors influencing and shaping parental participation in decision-making. However, further research is required that specifically examines these factors in relation to the experience of a diagnosis of a fetal anomaly, which may have unique features for multiple reasons including the time-pressured nature of an evolving pregnancy, the uncertainty and complexity associated with many fetal anomalies, and the antenatal option of TOP. In contrast to the previous sections highlighting parents' perspectives on HCPparent communication and decision-making in general, the following section will focus on research specifically examining the process of parental decision-making related to the diagnosis of a fetal anomaly.

Parental Decision-Making Related to the Diagnosis of a Fetal Anomaly

Although limited in breadth and scope, recent research on parental decisionmaking related to the diagnosis of a fetal anomaly provides rich descriptions of the timepressured nature of a progressing pregnancy, the influence of the shock and distress associated with the initial diagnosis, the evolving relationship between parents and their developing fetus, the uncertainty permeating the experience, and the struggle to come to terms with the fetal diagnosis while seeking additional information and making decisions about further diagnostic tests, continuing the pregnancy, and complex postnatal treatment options (Hodgson et al., 2016; Lotto, Smith, & Armstrong, 2018; Rempel et al., 2004). Interestingly, parents perceive their antenatal decisions concerning additional antenatal diagnostic tests and continuation of pregnancy as their first parenting decisions (Rempel et al., 2004). For many parents these decisions are enormously difficult and emotionallyladen, particularly those concerning whether to continue or terminate the pregnancy, and often involve a process of reflection on moral and cultural values related to the decision (Benute et al., 2012) as well as the perception that a decision needs to be made between "two horrible options" (Hodgson et al., 2016, p. 609).

In one of the first studies on antenatal parental decision-making, Rempel and colleagues (2004) identified that parents' decision-making is characterized by varying levels of ease and deliberation. As has been substantiated in more recent research, antenatal parental decision-making is typically characterized by gathering information,

considering the future consequences and risks and benefits of each option, and reflecting on the individual and family implications of decisions (Gawron, Cameron, Phisuthikul, & Simon, 2013; Lotto et al., 2018; Rempel et al., 2004). A common theme among parents who deliberate more about pregnancy and treatment decisions is that they more readily seek out the expert advice of HCPs, which they clearly articulate is not with the intent of being told what to do but rather as a means of facilitating the making of "smart decisions" (Rempel et al., 2004). Conversely, parents who come to their decisions with apparent ease and less deliberation often have clear ideas about what they would do given a certain scenario such as an amniocentesis result indicating a diagnosis of Down syndrome (Rempel et al., 2004) or fundamental beliefs that preclude certain decisions such as TOP (Lotto et al., 2018; Rempel et al., 2004). Interestingly, parents who deliberate over decisions less do not readily seek the opinions of others and describe feeling offended when they perceive HCPs are presenting information about pregnancy or treatment options in a biased manner (Rempel et al., 2004). One participant who received a fetal diagnosis of a heart defect in tandem with a suspected diagnosis of Trisomy 18 provided a particularly poignant example of how the information about her child's diagnosis and the possible option of TOP was presented to her while she "lay half naked on a table" (Rempel et al., 2004, p. 68) during the ultrasound. In this example, the HCPs involved did not attempt to seek the woman's perspective, which was to be able to proceed to a natural delivery and a chance to hold her baby before he died. The woman described the HCP's "offer of a single option that ensured her baby would be stillborn as making her 'furious' and sad for the professionals" (Rempel et al., 2004, p. 68). After reflecting on her experience for several weeks the mother had the following advice for

HCPs: "[Don't] assume any one emotion or way of dealing with it, but ask a whole lot of questions before you make statements" (Rempel et al., 2004, p. 68).

As previously described, the psychological stress and uncertainty associated with a diagnosis of a fetal anomaly is well established, yet few studies have considered what HCP actions or supports would facilitate parents' decision-making in terms of the timing, format, content and delivery of information related to a suspected or confirmed fetal anomaly. Marokakis and colleagues (Marokakis, Kasparian, & Kennedy, 2016), in a systematic review of prenatal counselling for congenital anomalies, reported that most parents prefer comprehensive information on all aspects of the fetal anomaly as soon as possible after antenatal diagnosis in order to decrease the stress associated with waiting and to facilitate timely decision-making about TOP when this option exists. The authors noted that parents indicated the most needed improvements to prenatal counselling were ensuring consistent and clear information, extending the length of HCP-parent consultations, and using understandable language. Moreover, several researchers have reported that parents find it beneficial and supportive to receive written, visual and webbased informational resources related to antenatal and neonatal decisions as well as relevant support group contacts (Lou et al., 2017; Marokakis et al., 2016). In addition, Carlsson and colleagues (Carlsson et al., 2016) reported that women who choose TOP following the diagnosis of a fetal anomaly often feel unprepared for the procedure and the subsequent psychosocial and reproductive consequences, highlighting the need for comprehensive information and support for all parents, regardless of the decisions made. Finally, recommendations from several other studies also emphasized the need for individualized, respectful, empathetic, and coordinated parental support that

demonstrates an acknowledgement of different decision-making approaches and parenting beliefs (Hodgson et al., 2016; Lou et al., 2017; Rempel et al., 2004).

Findings and recommendations from the existing literature on antenatal parental decision-making related to the diagnosis of a fetal anomaly underscore the need for a greater understanding of how HCPs can improve HCP-parent communication and support related to the diagnosis of a fetal anomaly, including the content and delivery of information related to diagnostic testing, prognostic information, and pregnancy and treatment options. Results draw attention to potential HCP-parent power imbalances, parental concerns with paternalistic HCP actions, and a need for increased understanding of parental beliefs, values and priorities in HCP-parent interactions. In addition, study findings highlight and support the need for further research to elucidate the experiences and perspectives of parents who choose TOP following the diagnosis of a fetal anomaly, as well as those of HCPs involved in antenatal education and parental decision-making support about the obstacles and challenges they face in providing antenatal care. Finally, these results underscore the need for HCPs to have a greater awareness and understanding of the complexities of the intersecting personal, organizational and contextual factors influencing parents' overall experience, healthcare interactions and decision-making.

Summary

The complex communication and decision-making dynamics associated with antenatal screening and the diagnosis of a fetal anomaly are poorly understood. Much of the existing literature focuses on the shift in the medical and surgical care of infants and children born with complex congenital abnormalities from an earlier emphasis on addressing high mortality rates to the current spotlight on improving morbidity and QOL

issues, in that more and more children with complex congenital and chromosomal abnormalities are now surviving into adulthood. The preceding review of selected literature underscores the paucity of research examining the experiences of parents who receive a diagnosis of a fetal anomaly, particularly for those parents who consider TOP. Much of the research focuses on the significant psychological and emotional impact of a diagnosis of a fetal anomaly on parents, providing glimpses into the challenges, difficulties and long-term effects many parents may face. In addition, previous research highlights potential inequities in HCP-parent decision-making support and the clear need to more closely examine parents' and HCPs' perceptions of HCP-parent interactions, the nature of decision-making processes and the operant power dynamics. Finally, so that we can better inform clinical practice and the development of supportive programs for patients and families, we must begin to study the issue of antenatal decision-making support to capture the nuances, complexities and contradictions of how socioeconomic, gender, language, educational and other differences between HCPs and parents might shape HCP-parent interactions, decision-making processes, and parent and child outcomes.

CHAPTER THREE: RESEARCH DESIGN AND IMPLEMENTATION

In Chapter Two I provided a review of selected literature in order to situate the research problem and questions within the broader context of relevant theoretical and clinical research. In this chapter, my aim is to describe the methodology guiding the inquiry and the specifics of the research design and method. I begin by providing an overview of the guiding principles and core elements of a critical ethnographic (CE) approach. Next, I set the stage for later sections by providing a description of sampling and recruitment techniques and a summary of parent and health care provider (HCP) participants. This is followed by an overview of the strategies employed to maximize a thick and rich data set through the gathering of textual data in the form of field notes and interview transcripts from non-participant and participant observation sessions, formal and informal interviews, and review of relevant supplementary data. Next, I describe the process of data analysis, including particular coding techniques, the use of specific analytical lenses congruent with the theoretical perspective and research approach, and the examination of multiple and competing discourses within the data. The final sections of the chapter focus on strategies and techniques employed to ensure scientific rigour and ethically sound research practices throughout all stages of the research process.

Methodology: A Critical Ethnographic Approach

Ethnographers are committed to the art and craft of fieldwork and aim to study social action and explain this action by examining places and social systems that intertwine with the site of interest (Carspecken, 1996). A CE approach is guided by specific theoretical perspectives, which share a critical orientation and ideally have compatible ontological, epistemological and methodological underpinnings. These theoretical perspectives inform the strategy of inquiry and ground its logic and criteria

(Crotty, 1998). Immersion in the research setting, through multiple participant observation (PO) sessions and detailed recordings of field notes, is the cornerstone of ethnographic research (Atkinson, 2010). Additional potential methods of data collection include in-depth interviews, focus groups and review of collateral data. Data are collected in the form of texts including transcribed interviews and field notes. Consistent with a critical perspective, a central element of "giving voice" to those silenced or marginalized is that the researcher-participant relationship is characterized by relationality, respect and collaboration. This fosters trust, supports open sharing of experiences, and encourages participants to question the researcher's understanding of data analysis, thereby guarding against theoretical imposition (Reimer-Kirkham & Anderson, 2010). Another central assumption consistent with a critical perspective is that analysis is largely inductive (Khan, 2007). Reimer Kirkham and Anderson (2002) emphasize the need to start with the everyday world of participants as the entry point and link particular contexts and experiences to the general context, including an analysis of the complex interrelationships among individual, organizational, social, economic, political and historical forces. This maintains the agency of individuals and avoids objectifying the nature of their experience (Reimer Kirkham & Anderson, 2002). A thematic analytical approach is employed, characterized by an iterative process of moving back and forth between the data as they are collected and coded. As data collection and analysis proceed, categories are collapsed, expanded, modified and refined, recognizing that the particular selections and the act of grouping itself create a perspective or statement (Madison, 2012). Given its aim of studying social action within social systems, concern with social inequities, and focus on power dynamics and desire for positive social change (Carspecken, 1996), a CE approach lends itself to examination of dominant discourses and ideologies as a means of

encouraging reflexivity regarding how knowledge is constituted and the role of dominant structures in shaping health.

Building on the preceding overview of a CE approach, in the following sections I set out to summarize the research design and how the research process unfolded, including a summary of both parent and HCP participants and specific data collection and analysis techniques employed. I draw attention to methodological considerations throughout the research process, including deviations from the original plan as well as lessons learned along the way, recognizing there are no definitive "rules" dictating how to proceed and that any approach needs to be scrutinized for its compatibility with the theoretical underpinnings guiding the strategy of inquiry (Taylor, 2003).

Research Process: Negotiating Access and Recruitment

Consistent with an ethnographic approach centred on generating insights, seeking understanding and working toward change, multiple ethnographic research methods were employed to guide my work. Prolonged time in the field and attention to inconsistencies between data gathered through informal and formal participant interviews, as well as relevant supplementary materials and actions observed in non-participant and participant observation sessions, supported construction of a rich data set, thereby facilitating analysis of the data reflected in the transcribed interviews and field notes (Browne, 2005; Emerson, Fretz, & Shaw, 2010). Gaining insights into the antenatal HCP-parent communication and decision-making experiences of a wide range of parent and HCP participants added richness to the data. In the following sections I will provide a summary of the various components of the research process including negotiating entry and access to the field, sampling and recruitment approaches, and specific data collection and analysis strategies employed.

Negotiating Entry and Access

To optimize diversity and confidentiality, data collection occurred at two Canadian health centres with well-established fetal cardiology programs. Both health centres acted as provincial referral centres for obstetric and women's health services and were the primary referral centres for women with a suspected or confirmed fetal anomaly. It should be underscored that requesting multi-site institutional approval to study how HCPs provide health information and support to parents taking part in prenatal screening for a fetal anomaly was not taken lightly. Not only was I interested in interviewing parents on a wide range of potentially emotionally-laden and distressing topics, I was also requesting to observe and participate in the emotionally-charged and sensitive communications and interactions between multiple HCPs and expectant parents, including often extremely emotional conversations on ethically and morally challenging topics such as continuing or terminating a pregnancy following the diagnosis of a fetal anomaly. Moreover, given that the primary goals of my research were improving HCPs' provision of health information and parental decision-making support and promoting equity in antenatal HCP-parent interactions, I realized there was a strong possibility the healthcare teams at the selected research sites may be resistant to my research proposal, particularly if it was viewed as critiquing or judging their interactions with parents and families.

I am not confident that institutional approval for my research would have been granted had it not been for my familiarity with the healthcare team and established credibility as both a clinician and researcher in the area of antenatal care. Specifically, my professional background and over fifteen years of experience as an advanced practice nurse working with and supporting parents who received an antenatal diagnosis of congenital heart disease (CHD), as well as my past experience on a multidisciplinary research team that examined parents' decision-making following a diagnosis of a fetal cardiac condition, provided credibility. These professional experiences also contributed to the development of strong working relationships with many members of the healthcare team employed at one of the research sites (Site A). I believe this familiarity and established credibility with the healthcare team at Site A was central in gaining their receptivity to my research project and the subsequent institutional approval required to proceed. Similarly, although I did not have as close a professional relationship with the healthcare team at Site B, I had worked on professional committees and task forces as well as collaborated on patient care with several members of the pediatric cardiology team in my previous clinical role. Once my research was well underway at Site A, I contacted the head of the fetal cardiology program at Site B, who was enthusiastic and supportive of my research project and offered to collaborate with me as a co-investigator. As an established leader, expert clinician and researcher in fetal cardiology, their strong support of this research project was invaluable in facilitating approval by the institutional review committee and, ultimately, access to the second site.

In addition to gaining approval by the respective university ethics boards and institutional and program review committees, negotiating entry to the field and access to potential participants required clear communication with multiple healthcare teams at both sites. This included multiple individual meetings and group presentations with a wide range of HCPs/health teams involved in antenatal care (e.g. perinatologists, pediatric cardiologists, geneticists, genetic counsellors, nurses, social workers and others), which provided opportunities to discuss the proposed research, address any questions or concerns and review participant recruitment and data collection strategies. In general, the members of the various healthcare teams were supportive of the research project, with

several HCPs commenting on the importance of the proposed research in guiding practice. However, receptivity was not equal across all teams—HCPs I had worked with the least were the most guarded in terms of the planned observations of their interactions with parent participants, with one team requesting an additional meeting to discuss their specific concerns and questions prior to providing program approval.

Sampling Approach

Sampling was theoretical and purposeful, designed to elucidate the nature of the parental experience and generate a rich data set with maximum variation. In order to meet this goal, I initially set out to recruit 10 to 12 sets of parents (or individual parents as necessary) from each site. A diverse sample was sought, including parents from diverse cultural and socioeconomic backgrounds and with a variety of antenatal experiences, for initial participant observation sessions of FEs including subsequent HCP-parent interactions for those receiving a suspected or confirmed diagnosis of a fetal anomaly. From this sample, select parents representing a wide range of antenatal experiences related to antenatal care delivery, including both those who continued and those who terminated the pregnancy, were recruited for in-depth interviews. For the purposes of this study, parents were considered women undergoing fetal diagnostic testing and their partner and/or significant other(s). In addition, I sought to recruit HCP participants from each site representing a range of disciplines involved in fetal diagnostic testing and antenatal parental education and support. This included but was not limited to sonographers, pediatric/fetal cardiologists, perinatologists, pediatric and maternal-fetal advanced practice nurses, genetic counsellors and genetic medical specialists, perinatologists, obstetricians, and social workers.

Selection criteria. Women and their partners who were taking part in prenatal screening (including fetal echocardiography) for a fetal heart anomaly were recruited. Inclusion criteria for potential parent participants included: (1) Language: parents were recruited who had a comfortable fluency with oral English. Due to financial restrictions, parental dyads where neither parent spoke English were not recruited; however, parental dyads where one parent had a comfortable fluency with oral English were included. Although I set out to obtain interpreter services to interview any non-English speaking parents to ensure both parental perspectives were captured effectively, this was not required. (2) Participating in screening for a fetal cardiac anomaly: all parents participating in an initial fetal echocardiogram (FE) as part of antenatal screening for a fetal cardiac anomaly during the recruitment period were considered eligible to participate in the initial participant observation component of this study. This included a wide range of women (see Figure 1, Parent Participants: Reasons for Referral for a Fetal Echocardiogram, on the following page) and their significant others, including those with: (a) increased suspicion of a CHD raised on a detailed screening ultrasound or another ultrasound at any time during the pregnancy; (b) an antenatal diagnosis (AD) of a fetal chromosomal anomaly associated with congenital heart disease (suspected on detailed ultrasound or confirmed by amniocentesis or chorionic villus sampling); (c) an antenatal diagnosis or suspicion of an extracardiac structural fetal anomaly (FA) associated with CHD (including but not limited to fetal kidney, brain, facial, limb, gastro-intestinal, and lung anomalies); and (d) parental/family history or maternal health concerns associated with an increased risk of CHD in a fetus. (3) Timing: all women scheduled for an initial FE at any gestational age were considered eligible for participation in the study, recognizing routine screening

for cardiac anomalies is recommended between 18 and 22 weeks gestation but can occur at any time between approximately 14 and 39 weeks of pregnancy.



Figure 1. Parent Participants: Reasons for Referral for a Fetal Echocardiogram.

Entering the Field

Fieldwork was initiated at Site A in February 2015 and continued for 6 months until the end of August 2015. Although initially I hoped to start data collection at Site B in the fall of 2015, ethics and institutional approval took longer than anticipated, resulting in data collection commencing at Site B in April 2016, with data collection completed by the end of September 2016.

My initial entry to the field involved non-participant observations of the physical and organizational attributes of the antenatal clinic, HCP-parent interactions and contextual circumstances influencing and shaping antenatal care provision. Early in my research planning I developed an observation guide informed by Emerson, Fretz and Shaw (2010), Carspecken (1996), and Thorne (2008) that guided both my non-participant and participant observations over the course of the study (please refer to Appendix A: Observation Guide for a detailed overview of the elements I considered during my observation sessions and in writing up the associated field notes). Non-participant observations, also called direct observations, were those with minimal or no verbal interactions between myself and others, and involved close inspection of the field work settings (Roper & Shapira, 2000). These made up my initial observations at the start of fieldwork at each site, during which I focused on the physical spaces and interactions within the antenatal clinics specifically as well as the general environs of the two health centres where antenatal HCP-parent interactions took place. Since I had worked in the first research setting (Site A) for many years, I consciously challenged myself to view these physical structures and interactions with fresh eyes, often simply sitting quietly in the waiting areas of the health centre, taking in the mood and ambience of the interactions, closely examining the signs and posters on the walls, observing the patients, family members and staff going about their day-to-day work as well as critically examining the lay out and physical structures of the health centre itself and the nearby community in which it was situated. This process was helpful in developing a greater understanding of both research settings, including common HCP-parent interactions prior to initiating participant observation sessions and formal and informal interviews.

The use of non-participant observation was particularly useful in providing a rich description of the health centre and the nature and pattern of activities observed. I spent approximately 20 hours on non-participant observation in the early stages of my project at Site A, often walking around the centre or sitting in the waiting room or other public areas before or after meetings with multiple healthcare teams about the project. In addition, as I

started participant recruitment and participant observation sessions I continued to have several opportunities while waiting for participants to arrive or when there was a gap in participation observation opportunities to quietly observe the clinic area and HCP and parent interactions from the study carrel assigned to me, which was situated between the reception area of the antenatal clinic and the patient waiting area. All of these observations were detailed in my field notes as general observations. In comparison, I spent approximately 15 hours in initial non-participant observation at Site B prior to initiating participant recruitment, taking the time to acquaint myself with the health centre and its environs. Concurrently with participant recruitment and participation in observation sessions, I continued to spend several hours each week involved in non-participant observations of interactions within the health centre and particularly the reception, waiting and assessment areas of the fetal echocardiography clinic. At Site B I was again fortunate to have a workspace assigned to me that allowed me to easily listen and observe the daily clinic activities and compare and contrast differences and similarities between the two research sites.

Participant Recruitment

Recruitment plans for parent and HCP participants were finalized once the requisite university, institutional and program approvals were in place. A member of the Maternal Fetal Medicine (MFM) team identified potential parent participants based on the inclusion criteria and sent them an information letter informing them of the possibility of participating in the research at the time the FE was scheduled (usually one to four weeks prior to the appointment for non-urgent referrals) (Please refer to Appendix B to review the parent information letter for each site). This letter was sent by regular mail because institutional policy did not allow for it to be sent by e-mail. When requested, I reimbursed

the hospital departments involved for the support received by hospital staff identifying potential participants and sending out information letters. The information letters encouraged parents to contact the researcher if they were interested in participating in the study. In addition, at the time they checked in for their FE appointment, a previously identified member of the healthcare team asked potential participants if they were interested in participating in the study. This strategy was effective for recruiting several participants; however, it did not allow for recruitment of those parents for whom a suspicion of fetal anomaly had been raised on a community screening ultrasound as there was inadequate time for the information letter to be received prior to their appointment. To resolve this issue, approximately one month after initial recruitment was initiated, an amendment was submitted and approved to allow recruitment of potential participants booked for FEs on short notice, provided there was adequate time at check in for parents to review the information letter prior to their appointment.

An organized plan and clear communication with the multiple staff involved in participant recruitment were essential to initiating participant recruitment in an orderly fashion. Within the constraints of overlapping FE appointments and the inability to predict which appointments might result in the diagnosis of a fetal anomaly, I initially attempted to recruit every consecutive eligible parent for observation of all HCP-parent interactions and discussions related to prenatal screening and/or the diagnosis of a fetal anomaly (including discussions with any and all subspecialist teams) until a diverse group of participants was recruited. Following participant observation sessions, selected parents were approached to set up individual follow-up interviews at a mutually convenient time and place, usually at least four to six weeks following the initial observation session. A separate consent form was completed with each parent prior to initiating the in-depth
interviews, often at the end of the initial observation sessions (Refer to Appendix B – Participant Consent Forms).

Prior to the recruitment amendment being approved, it was frustrating to not be able to recruit potential parents who had a high likelihood of receiving a diagnosis of a fetal anomaly, as it felt like a missed opportunity. However, I grew to appreciate that observation of "normal" screening ultrasounds and FEs provided new insights and understandings that I had not appreciated in my previous clinical role. Moreover, recruiting parent participants with a broad range of prenatal screening experiences was valuable in having the ability to compare and contrast the experiences of parents who: (1) had increased suspicion of a fetal anomaly raised at a local community centre but were informed of normal results upon further assessment at the specialized centre; (2) participated in specialized FE screening with normal results; and (3) participated in routine prenatal screening (detailed ultrasound) and were informed of a diagnosis of a suspected fetal anomaly that was confirmed and/or modified at the specialized centre.

As recruitment progressed, sampling became more purposeful in that I was more intentional in recruiting parents with a known or suspected diagnosis of a fetal anomaly. Given that past research indicated the severity of a fetal anomaly significantly impacts both the antenatal and postnatal experiences of parents and families (Rempel et al., 2004; Rempel & Harrison, 2007), I continued to recruit participants until I had a group with a range of mild to severe fetal anomalies. My past clinical experience also suggested antenatal diagnoses of fetal cardiac anomalies were associated with parents receiving greater organizational resources and support, including specialized nursing and social work services, in comparison to parents with antenatal diagnoses of chromosomal and/or less common structural fetal anomalies. For this reason, I purposefully sought to recruit a

group of parent participants who received a range of antenatal support services as well as those from diverse socioeconomic and education backgrounds, and from a range of urban, rural and remote geographic areas, because I felt it was important to consider how these multiple factors impacted and shaped the parents' experiences.

HCP participants were also recruited at both sites. Selected HCPs at both centres who met the inclusion criteria were provided with a preliminary letter outlining the purpose and specifics of the study and requesting their participation in individual interviews. In addition, during preliminary meetings with the maternal-fetal and pediatric cardiology teams, HCPs who met the selection criteria were encouraged to contact the researcher to set up an interview. In general HCPs were very receptive to being interviewed, with every HCP who was approached consenting to an interview.

Participants

Parent Participants

A diverse group of parent participants were recruited for participant observation sessions including 61 mothers, 39 fathers, and 13 significant others (including nine grandmothers, two aunts, one uncle, and one close friend). In addition, one mother who had a diagnosis of a fetal anomaly within the previous two years contacted the researcher requesting to be involved in the study, indicating her keen desire to share her story in the hopes of "helping other parents in the future." In total, the group of 114 parent participants included 13 unaccompanied mothers, 36 parental dyads (mothers and fathers), 10 mothers accompanied by a significant other(s), and three parental dyads accompanied by a grandmother. The majority of mothers identified as being in heterosexual common-law or married relationships (there was no known opportunity to recruit women in other forms of relationships), with two women who described themselves as living on their own. The maternal age at the time of initial recruitment ranged from 16 to 39 years (maternal age was not captured for two participants), with a mean age of 31 years (mode—29 years, median—31 years). Gestational age at the time of initial recruitment ranged from 17 weeks to 36 weeks, with an average gestational age of 23.7 weeks (mode—20 weeks, median—22 weeks). The most common reasons for referral for FE were: (1) diagnosis of an extracardiac anomaly on a previous screening ultrasound (n=19); (2) suspected cardiac anomaly (including fetal cardiac arrhythmia) on a previous screening ultrasound (n=18); and (3) parental (mother or father) history of CHD and/or a chromosomal anomaly associated with an increased risk of fetal CHD (n=10). Additional reasons for referral for FE included: (1) maternal insulin-dependent diabetes (n=7); (2) family history of CHD (most commonly previous child with CHD) (n=5); (3) a pregnancy resulting from IVF techniques, known to increase the risk of a fetal cardiac anomaly (n=1); and (4) inability to obtain the requisite fetal cardiac images on a community prenatal screening ultrasound (n=1). Of the 62 parents/sets of parents recruited, 29 received a diagnosis of a fetal anomaly, either prior to or as a result of the ultrasound assessment observed. This included a wide range of fetal anomalies ranging from mild to severe in complexity including, but not limited to¹, cardiac anomalies (n=12), lung anomalies (n=4), oomphalocele, gastroschisis, kidney anomalies, brain anomalies, and chromosomal anomalies (isolated or combined with structural anomalies). The FEs of the remaining 33 parents/sets of parents were reported as normal, although a number of parents were advised to seek out additional genetic testing to rule out a chromosomal anomaly. Finally, 17 parents self-identified as having significant health concerns, including: (1) seven parents having a history of CHD ranging from mild to severe; (2) seven mothers indicating

¹ Some fetal anomalies are not listed because they are so rare or complex that reporting them may have compromised participant anonymity.

they had insulin-dependent diabetes; and (3) three parents having a known chromosomal anomaly, two of which were associated with significant learning challenges.

Parent participants were from a wide range of socio-cultural backgrounds and geographic areas. Specifically, 10 identified as Indigenous (seven mothers and three fathers; 23 were visible minorities (11 mothers and 10 fathers, including those of Chinese, South Asian, Filipino, Middle Eastern, and Latin American descent); 15 identified as born in Canada with English not being their first language (eight mothers and seven fathers including those with a wide range of first languages including French, German, Spanish, Arabic, and multiple Chinese and South Asian dialects); and 19 parents identified as being born outside of Canada (nine mothers and 10 fathers who identified as moving to Canada from a range of geographical areas including China, Great Britain, Central America, Africa, India, Australasia, the Philippines, Europe, and the Middle East). The remaining parent participants were Caucasian, born in Canada, and identified English as their first language (n=55). Demographic information such as employment, education and financial income were not specifically collected from each participant; rather, this was noted as parents and significant others shared aspects of their lives. Specifically, parents described a wide range of educational and employment backgrounds, ranging from a small number who had not completed or were in the process of completing a high school diploma to those with graduate degrees. Moreover, a diverse range of careers and professions were represented within the participant group including homemakers, training and employment in a trade, and a wide range of professionals. In addition, the sample included parents living in rural, urban and remote areas of two provinces and one Canadian territory.

HCP Participants

A range of members of the healthcare teams involved in providing fetal diagnostic testing and/or parental education and support related to the diagnosis of a fetal anomaly (including physicians, nurses and sonographers) were recruited for this study. In many cases, HCPs who were involved in the observed HCP-parent consultations for prenatal screening and/or the diagnosis or follow-up of a fetal anomaly were recruited for interviews. In total, 10 HCPs consented to participate in the study, with six participating in in-depth interviews, which were audiotaped and transcribed. The remaining four HCPs participated in informal interviews and also agreed to participate in formal audio-taped interviews as well; however as data collection and analysis proceeded, these interviews were not considered necessary.

Data Collection: Methods and Considerations

As anticipated, fieldwork was iterative with data collection focused on understanding the nature of participants' experiences at multiple points in time from the initial diagnostic screening until three to six months following the baby's birth or termination of pregnancy (TOP). This was not a linear process. As the research project unfolded, it was common to be involved in PO sessions and/or complete interviews with parents who were at different places in their antenatal trajectory (e.g. a PO session with parents just learning of a fetal anomaly occurred on the same day as the delivery of a baby I followed with a known fetal anomaly and a follow-up interview with a parent participant). Moreover, there was generally a great deal of uncertainty when I arrived at the research site. Would I recruit any parent participants? What would the nature of their experience be? Would they agree to a follow-up interview? Would they receive a diagnosis of a fetal anomaly or would the scan results be normal? Would I spend 45

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minutes with them or four hours? Given these uncertainties, throughout the data collection process I sought to optimize opportunities for detailed interactions with HCP and parent participants aimed at capturing the nature of evolving HCP-parent interactions and highlighting the existing supports and challenges, barriers and gaps in antenatal communication and decision-making support.

My initial plans involved three phases of data collection, including an initial followup interview with parent participants during the antenatal period (for those who continued their pregnancy) or within three months following TOP, as well as an additional smaller series of parent interviews within six months of the baby's birth or three to six months following TOP. However, as the research unfolded I decided to limit the number of second interviews to two, given that the parents I did interview or contacted to interview no longer appeared focused on their antenatal experience or antenatal decision-making; rather they (understandably) spoke at length of their recent postnatal experiences involving prolonged stays in hospital and negotiation of parent roles in neonatal and critical care areas. To be clear, their stories and descriptions were compelling and described their evolving journey following the birth of their baby; however, these experiences were not aligned with the goals of the research project. As a result, additional second interviews were not pursued; they will, however, be considered as the focus of a potential future research project.

Participant Observations

Consistent with an ethnographic approach, participant observations were integral to data collection. As the project progressed my observations shifted from the initial nonparticipant observations I engaged in as I entered the field to a predominant focus on participant observation sessions characterized by direct interactions between myself and the research participants as we engaged in shared activities (Roper & Shapira, 2000). PO sessions allowed for observation of HCP-parent interactions during: (1) detailed ultrasounds and/or FEs; (2) discussions of normal antenatal screening results; and (3) HCP provision of information and support related to a diagnosis of a structural or chromosomal fetal anomaly. These observation sessions made up the primary method of data generation for the remainder of my research project. I completed observation sessions at Site A over a course of seven months, attending the antenatal clinic initially on the three days each week that women were booked for FEs. As the study progressed and I began to balance HCP and parent interviews with observational sessions, I often decreased the number of clinics I attended to one or two days per week, depending on whether there were potential participants I was interested in recruiting to add diversity to my participant sample and/or if I had made arrangements to attend planned follow-up appointments. In total, I completed 197 hours of non-participant and participant observation at Site A over this seven month period, with considerably more sessions over the initial four months, tapering down to fewer sessions over the final two months. In comparison, at Site B FEs were scheduled five days per week, which allowed me to recruit the remaining participants over a shorter period of time. I completed participant observation sessions at Site B over a two-month period, participating in a total of 15 days of participant observations and completing 78 hours of observation. In total, I completed 275 hours of observation at the two research sites, not including the time engaged in formal and informal interviews, which I accounted for separately.

Consistent with a CE approach, participant-observation did not involve being a researcher who was a neutral, passive observer akin to a fly on the wall. Rather, I was an active participant to varying degrees as I engaged with others at the research site. My

participant observations almost always started with observing the woman's detailed scan and/or FE (for the majority of participants this was a combined procedure; for the remainder it was limited to a FE). Having met with the parents to review and obtain consent prior to the scan, I usually had an opportunity to begin to build rapport with the parent(s) and any significant others who accompanied them. Given that it was not uncommon for FE appointments to start 15 minutes to an hour or more after the scheduled appointment time, for many parents this time was filled by sharing their personal stories with me, which most did with little to no encouragement. In this way, I was able to develop an initial rapport with the parents, allowing for considerable insight into the parents' experiences prior to the start of the scan. This was extremely valuable in helping me to understand the parents' unique antenatal journeys as well as the context in which they learned the results of the FE and any additional antenatal assessments on the day of their FE appointment.

Once the sonographer or medical fellow performing the scan was ready to start, I usually accompanied the parents to the ultrasound room, listening to the sonographer's greeting and initial assessment questions. During the scans I preferred to sit behind the sonographer, which allowed me to view the images on the sonographer's screen while facing the parents who were simultaneously observing the scan results on a large screen mounted on the wall opposite to them. Having reviewed the nature of my research interests with the parents in detail prior to the scan, parents were aware I would be writing brief notes in my field journal during the scan to aid me in remembering my observations accurately. While none of the parents voiced or otherwise indicated any concerns with this approach, I was also aware that observing HCP-parent interactions while taking copious notes might make some parents and HCPs feel uncomfortable or like they were being

judged or critiqued. Therefore, I focused on balancing my intent of developing respectful research relationships with jotting down brief notes and making mental notes during the observation sessions, later expanding on these with detailed and comprehensive field note entries as soon as the observation sessions were completed.

During the scan, generally the only light illuminating the room emanated from the ultrasound machine and the video wall displays projecting the fetal images, which for the most part held the parents' attention during ultrasound assessments. I listened and observed as the scan proceeded, making eye contact with parents and HCPs when they looked my way and jotting down brief notes to trigger my memory of the timing, flow of assessments, nature of interactions and specific dialogue I wanted to capture. In addition, it was common, particularly during periods when the sonographer left the room to review results with the perinatologist or fetal cardiologist, for parents and me to discuss a variety of topics including their personal journeys to this point in their antenatal experience, their past pregnancies, ongoing treatment of medical concerns, their families and life in general. These discussions ranged from a few minutes to 15 to 20 minutes or longer, particularly if the ultrasound results revealed a fetal anomaly and/or the team was consulting with additional subspecialists. These discussions usually ended once the sonographer or medical trainee returned with a subspecialist or team of subspecialists (such as a perinatologist, fetal cardiologist, fetal radiologist and/or subspecialty medical trainees) and the scan resumed with the subspecialist(s) performing the remainder of the scan.

The duration of the scans ranged considerably depending on several factors, including whether it was a singleton or twin pregnancy, an isolated FE or a combined detailed scan/FE, and whether a fetal anomaly or multiple anomalies was/were suspected or detected. The average scan with normal results took approximately 45 minutes to an hour. In comparison, when a fetal diagnosis was made, the scan took considerably longer. For example, a combined detailed ultrasound and FE of a twin pregnancy that involved the diagnosis of a fetal anomaly usually took over two hours to complete.

Once the scan was over, the lights were turned back on and the HCP(s) usually started to discuss the findings with the parents. During these times I rarely took field notes, as it seemed inappropriate to be writing down notes as the care providers were reviewing results with parents. When a FE indicated a diagnosis of a suspected or confirmed fetal anomaly, parents were usually ushered into a private meeting room where they met with individual or teams of HCPs and reviewed detailed diagnostic, prognostic and treatment information. Moreover, in most cases a diagnosis of a fetal anomaly involved multiple subsequent meetings with different HCPs or specialized teams arranged on the same day as the FE. For example, if the parents learned of a fetal cardiac condition at their 10 a.m. combined detailed scan/FE, they would usually see the pediatric cardiologist and nurse clinician (together or separately) following the exam for a total of 45 minutes to an hour and a half. Following this, parents were generally encouraged to go for a quick lunch, after which they were scheduled for multiple additional appointments such as a genetic counsellor at 1:30 p.m., a perinatologist at 2 p.m., and a geneticist at 2:30 p.m. If I was not with other participants, I accompanied the parents to these appointments, observing every HCP-parent interaction, always obtaining their verbal consent to continue to allow me to observe each HCP-parent interaction. Parent participants never declined my requests to observe their additional HCP interactions; rather, they were generally supportive of the research, with several noting the research was "needed," "very important," and "necessary to improve care in the future." In addition, parents' support for

the research was evident in six parents contacting me to arrange for me to observe their follow-up meetings with HCPs in the weeks following their initial assessment.

Given the emotional and intense nature of HCP-parent discussions related to the initial diagnosis of a fetal anomaly, I generally did not take any notes during these interactions. Rather I sat beside the parents, leaning forward and engaging as they listened and communicated with the HCPs. I sometimes offered to get a box of Kleenex or a drink of water for the parents if it seemed this would be helpful. Parents who I had spent time talking to prior to and/or during the scan often engaged me in their conversations with the HCPs in ways such as, "I was telling Laurie earlier about..." or "Yes, I was talking to Laurie about the history of CHD in my family..." The majority of HCPs were also very open to my presence, often offering to find me a chair or going out of their way to ensure I knew the meeting was about to start. For the most part I observed and listened to these discussions with an engaged body language (leaning forward, making eye contact, nodding my head, passing the parents tissues to wipe their tears) without contributing to the discussion. However, there were a number of times when either HCPs drew me into conversations because of their awareness of my background as an advanced practice nurse or I initiated a comment on my own. For example, in a meeting with members of the MFM team, a set of parents who had received a diagnosis of a fetal heart defect earlier in the day asked questions specific to neonatal postoperative care. Although this information had been briefly reviewed earlier by the pediatric cardiology team, the parents noted they were "too emotional" at the time to take in the information. The perinatologist referred their guestion to me, indicating I would be much more familiar with this information given my experience in the area. During times such as this, I answered the parents' questions and also indicated available resources to contact should they have additional questions. At

other times, I initiated comments on my own because I felt doing so was in the best interest of the parents. For instance, on one occasion I provided clarification about anticipated cardiac postoperative care as the perinatal specialist initially provided outdated information that could have led the parents to believe their child would experience greater pain and discomfort and a longer postoperative course than would generally be anticipated. I provided this information as respectfully as possible, and although I was initially worried about how this might be taken with my "researcher hat" in place, I was relieved when both the parents and HCP expressed appreciation both during and after the meeting for my clarification of this information. In this way, although the majority of the time I was a hands-off observer during HCP-parent interactions, there were times where I weighed the pros and cons of engaging in the conversation and when I felt it was in the parents' best interests to do so, I initiated comments or questions in as respectful a way as possible.

Field Notes

I generated field notes of all observation sessions and HCP and parent interviews. This was essential in developing a detailed account of parents' experiences with prenatal screening and/or the diagnosis of a fetal anomaly, as well as the contextual factors influencing and shaping these experiences. Initially I wrote notes on all aspects of my observations; however, as the research progressed I tended to focus on noting unusual, atypical or differences in HCP-parent interactions or homing in on specific elements of the experience rather than repetitively recording detailed data that I had already observed and recorded multiple times. Keeping in mind Emerson and colleagues' (2010) assertion that field notes inevitably frame events and objects in particular ways, I employed a systematic and consistent format to organize my field notes in a way that supported my evolving analysis and construction of my understanding of the events and interactions I observed. I was also consistent in the manner I recorded my reflections of PO sessions and challenged myself to consider what I centred and decentred in my field notes, as these formed the basis of my evolving analysis. I kept separate paper files containing participant field notes and interview transcripts and maintained a database of PO sessions, formal and informal interviews, and participant phone calls. In addition, I included analytical comments as part of my observational data, often writing down hunches or ideas in the columns of my rough notes, which I later extracted and summarized in separate field journals to record my evolving analysis, including my considerations of contextual elements and broader discourses influencing and shaping HCP-parent interactions, common HCP or parent reactions, and similarities and differences in parents' experiences.

During observations, phone calls and/or interviews I jotted down short notes and key phrases, which I used as starting points for detailed written narratives of each event or interaction. In addition, I often augmented written notes with audiotaped recordings, which I completed while driving home from the research site, capturing reflections and descriptions of events while they were fresh in my mind and transcribing these into textual data at a later point in the week. Field notes were both descriptive and reflective, often including a critical examination of my position and role within the research process, ethical considerations and conundrums I faced in navigating through the data collection and analysis process, and linkages between observational and interview data, past clinical experiences and the theoretical and research literature.

Formal and Informal Participant Interviews

Interviewing is a common technique utilized in ethnographic research that contributes to validating observations made in the field, provides direction for future observations, and contributes insights about aspects of the participants themselves (including their thoughts and opinions) that cannot be observed (Roper & Shapira, 2000). Both informal and formal approaches to interviewing were employed in this research project. Although my original research plan did not lay out a specific plan to include informal interviews, as the research process unfolded it became apparent that there were many instances before, during and after participant observation activities in which discussions with parents about their antenatal experience occurred naturally and spontaneously. As previously described, often these conversations were initiated when I met with parents to review the consent forms and obtain consent and continued until parents were escorted into the FE exam room, as well as during breaks in the ultrasound when the sonographer routinely left the room to consult with a subspecialist. As a result, it was common for me to spend 30 to 45 minutes in conversation with parents prior to and during their ultrasound assessment. In addition, for those parents who received a diagnosis of a fetal anomaly and attended multiple HCP appointments on the day of their FE, I often had many opportunities to discuss parents' evolving thoughts and feelings during the times in between HCP appointments.

Informal interviews were open-ended and conversational in style, focusing on what the participants chose to share about their antenatal journey, factors they viewed as important to their experience, and descriptions of interventions and resources (both HCPprovided and other) they perceived as supportive or non-supportive. Although the majority of parents who participated in informal interviews also agreed to be contacted for a

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possible formal interview at a later date, many times I felt this was unnecessary because these informal discussions were often more than sufficient to glean the insights and understandings I would have sought from a formal interview. These interactions with parent participants were detailed in initial field notes and then expanded after the meeting. Informal interviews comprised a significant portion of field note data. In total (including Site A and Site B) I completed 70 informal interviews (including interviews with 12 unaccompanied mothers, seven mothers accompanied by a maternal or paternal grandmother, one mother accompanied by a maternal aunt, and 42 parental dyads comprised of a mother and father including seven parental dyads who were informally interviewed twice (once during their appointment for their initial FE and once for a followup appointment). The total time spent in informal interviews was 71 hours, with interviews ranging from 15 minutes to two hours and an average interview time of approximately one hour. Informal interviews with parents who knew of or received a diagnosis of a known or suspected fetal anomaly were considerably longer in duration than those with normal FE results (an average of 1.2 hours compared to 0.82 hours).

Formal interviews differed in many ways from informal interviews in that they were pre-scheduled and the majority were audio-taped and transcribed. Consistent with an ethnographic approach (Heyl, 2010), the first scheduled formal interview was conducted two months after the start of participant observations, following completion of over 20 participant observation sessions with parents, which allowed for a nuanced appreciation of the participants' antenatal experiences. Formal interviews were completed with 18 parents/grandparents including 11 mothers, one grandmother and six fathers. I also conducted six formal interviews with a range of HCPs involved in antenatal care. I initially anticipated interviews would be completed within 45 minutes to one hour; however, parent interviews ranged in length from one hour to three and one half hours with most parent interviews ranging from one and one half to two hours (total formal interview time of 40 hours) and most HCP interviews completed within one to one and one half hours (total formal interview time of 8 hours). As a means of acknowledging and respecting the parents' time, efforts and valued contribution to the research project, each parent was provided with an honorarium of twenty dollars for their participation in formal interviews.

The majority of formal interviews were audiotaped and transcribed verbatim. Interview transcripts were supplemented with detailed field notes to capture any additional observations and reflections that occurred during the participant interviews including nonverbal cues and the participants' emotional state, mood and tone of voice (Roper & Shapira, 2000). When it was not possible to audiotape the interview, detailed notes were taken during the interview, which were expanded and reformatted into interview form as soon as possible after the interview. For example, one father requested to complete the interview at the time that I phoned to arrange the interview, indicating he was leaving shortly on a work trip for several weeks. I did not have my audio-recorder available at the time of the call; however, rather than miss the opportunity to conduct the interview, I took detailed notes during the phone interview, which I later entered into a Word document. Similarly, three other parents preferred to complete their formal interviews (one conjoint parental dyad and one separate interview) in combination with their follow-up FE appointments rather than meet at a separate time. Again, I took detailed notes during the interview and reviewed my written notes with the parents at a later date to confirm I had captured their thoughts and ideas accurately. In addition, one HCP requested not to be audiotaped during our pre-scheduled formal interview, preferring I take detailed notes instead. They requested that given the nature of our discussion, which included sharing

their personal viewpoints and experiences on sensitive topics such as childhood disabilities and TOP, they preferred the interview to not be recorded.

Separate interview guides were developed for parent and HCP participants (see Appendix C). Field notes from participant observation sessions involving the particular parent and/or HCP were reviewed in depth prior to formal interviews to facilitate discussion of their unique experiences and/or to gain insights into specific events that occurred during observation sessions. In addition, I wrote field notes about my interview plans and reflections prior to each interview, which facilitated reflexivity on the overall goals of the research and the unique experiences of the individuals being interviewed. Potential parent participants for formal interviews were selected from those recruited for participant observation sessions. I purposefully requested interviews from a diverse group of participants, including those from various socioeconomic and educational levels and geographic locations as well as those with varied antenatal diagnoses and antenatal/postnatal experiences. Timing of follow-up interviews with parent participants depended on the gestational age at the time of diagnosis, the nature of parents' antenatal and postnatal experiences, and the availability of the researcher. Ten initial formal parent interviews were completed in the antenatal period and four were completed in the postnatal period. In addition, as previously noted, a second parent interview was completed with two participants, both at five to six months following the birth of their baby. A noted limitation of the study that will be further addressed in Chapter Seven was that I was able to recruit only one parent who terminated the pregnancy for a follow-up interview. On reflection I think this was due to multiple factors, including that those parents who were considering TOP were less likely to agree to participate in PO sessions, which meant I did not have an opportunity to meet with the family, describe the study or build

rapport. In addition, although I was able to recruit a limited number of individuals who indicated they were considering or planned to pursue TOP following the diagnosis of a fetal anomaly, I was subsequently unable to arrange a formal interview with these parents.

The majority of formal interviews were conducted either face-to-face or by phone with each parent separately. The majority of parents were interviewed individually, although one parental dyad preferred to be interviewed together and one 17-year-old mother preferred to be interviewed with her mother (the baby's grandmother) present. Although face-to-face interviews were preferred, phone interviews were often more convenient as the majority of parents lived several hours away from the research sites. In addition, phone interviews allowed more flexibility in interview start times given the parents' busy schedules, especially for those with a newborn requiring additional care. I was constantly surprised by how keen parents were to be interviewed. Several mothers rescheduled appointments or rearranged previously scheduled phone interviews for later in the day until their baby settled down for a nap or finished feeding. For example, one mother had requested a phone interview at 8 p.m. but then rescheduled at 9 p.m. and again at 10 p.m. when the baby was more settled. Given the late hour, I repeatedly assured the mother that we could reschedule the interview for another day and time; however, she was insistent and indicated, "I am so looking forward to telling you my story and talking to you about what happened after [baby's name] was born." We ended up starting the interview after 10 p.m. and continuing for over two hours as she held and fed the baby and he eventually settled to sleep in her arms. Similarly, another father who shared a home with his large extended family requested a phone interview at 10:30 at night when he "could focus on our discussion." Maintaining flexibility of the location of interviews was also important in scheduling and completing parent interviews. Several

interviews occurred in a pre-booked office in the research wing of one of the health centres, which was convenient for parents who were travelling from out of town for antenatal appointments, temporarily relocated to accommodations nearby the hospital while they awaited the birth of their baby or visiting the baby in hospital after birth. Additionally, at the request of the parents, one interview took place in a quiet café near the parents' home.

I initiated both HCP and parent interviews with a general preamble that provided an overview of what I was interested in understanding and then allowed the participant(s) to freely share their experiences and insights related to the area of interest. Specific trigger questions and probes were used to seek clarification or elaboration of a particular aspect of the participant's experience and/or to maintain the focus of the discussion on the research topic. For the most part, parents shared their stories related to prenatal screening and/or the diagnosis of a fetal anomaly openly and in great detail with very little need for me to use trigger questions or probes during the interview process. Many parents commented that they were keen to participate in the interview because they wanted to share their story with the hope that the research findings would lead to positive changes for other families in the future. Moreover, several mothers and fathers described that it was "cathartic," "freeing," and "therapeutic" to share their story honestly and openly with someone, with several parents noting I was the only person with whom they had shared some of their thoughts and reflections. For example, one mother shared that she might have chosen to terminate the pregnancy if the decision was solely up to her, but given that she perceived her partner would have been against this for religious reasons she had decided to continue, indicating she had not shared this personal struggle with anyone else. Another mother noted she found it helpful to share her story with someone

who "listened and cared, but didn't judge," indicating she often felt like she could not discuss her experience with family or friends because "they didn't understand" or "judged" her for the antenatal decisions she made related to her child's fetal diagnosis.

The most difficult challenges I experienced in conducting participant interviews were related to: (1) resisting my desire to unnecessarily speak and/or add my own insights to a participants' description of their experience; and (2) mentally multi-tasking on my outward demonstration of empathy and support as participants described emotionally distressing experiences and decisions while I simultaneously attempted to conceptually analyze what they were saying and identify and track points to clarify and/or ask them to expand upon. Although at the end of the interview I appreciated parents who described the interview process as helpful for them to sort through their feelings and described being thankful for "having someone who listened," "someone who cared" or "someone interested in hearing my story," for me, conducting the interviews was emotionally and cerebrally exhausting. Understandably, parents were often emotional during the telling of their stories. Many parents, both mothers and fathers, cried as they recounted the emotional trauma of the initial diagnosis of a fetal anomaly or the moral and ethical dilemmas they experienced in making the decision to continue or terminate the pregnancy. Others openly expressed their anger and frustration with the healthcare team and/or families or friends who they perceived had added to their emotional distress. Particularly distressing for me was the lack of support that many of the parents had experienced in their antenatal journey and continued to experience postnatally. Moreover, several of the HCP interviews were also emotionally-laden, with several care providers describing the stress and strain associated with providing antenatal care, the moral dilemmas faced, and the feelings of inadequacy in knowing how best to communicate difficult news or

otherwise support parents and their families. As an advanced practice nurse with over 15 years of experience supporting parents and families who received a diagnosis of a cardiac and/or chromosomal anomaly, I had anticipated these emotional reactions; however, I had not anticipated the helplessness I experienced or my personal dismay and frustration with a healthcare system that was seemingly ineffective in meeting the parents' needs. In sorting through these thoughts and feelings, I found it helpful to journal and reflect on the feelings evoked by the interviews and discuss these in my regular meetings with my doctoral supervisor. I also wrote extensive field notes describing my reflections on topics discussed, emerging themes, nonverbal expressions, the general mood and feeling of the interviews, and "lessons learned"—areas for improvement and refinement in subsequent interviews.

Review of Relevant Supplementary Material

Concurrently with the participant observation sessions and initial parent and HCP interviews, I also initiated a review of collateral data sources such as organizational policies, relevant meeting minutes, and public media to provide valuable insight into the organizational culture, professional values and institutional expectations (Thorne, 2008) as well as general societal views on antenatal testing, fetal interventions, and associated health interventions and outcomes. Specifically, a review of documents outlining the institutions' orientations toward and policies related to patient care, informed consent and care delivery provided valuable starting points to consider the dominant discourses circulating within each organization and the power/knowledge dynamics that contributed to certain discourses being more prominently reflected in HCP-parent interactions than others. In addition, I regularly read and searched out public opinion and general societal views on topics related to my research question including antenatal screening, childhood

disabilities, genetic testing, fetal interventions, HCP-patient/parent relationships, and healthcare communication and decision-making in multiple forms of public media including local and national newspapers, television documentaries and news stories, and relevant internet and social media sites. When possible, I downloaded or created digital copies of websites or articles and/or added reflections and thoughts on these perspectives in my field notes. In reviewing these documents and sources of data I reflected on the extent to which institutional policies and expectations and perspectives put forth in the public media were consistent with HCP-parent interactions observed during PO sessions and the insights and viewpoints shared by individual parents and HCPs. The multiple forms of supplementary data collected throughout the research process were also helpful in gaining insight into and tracking public opinion and general societal views on health communication and decision-making related to prenatal screening, antenatal diagnoses of fetal anomalies, and the broader contextual issues and discourses shaping parents' experiences. Finally, these data supported my evolving construction of the intersecting factors shaping parents' and HCPs' experiences of health communication and decision-making related to prenatal screening and/or the diagnosis of a fetal anomaly.

Data Analysis and Interpretation

Data collection and analysis proceeded in an iterative manner of moving back and forth between the data as they were collected and coded. Guided by both an intersectional and governmentality lens, data analysis was facilitated by employing a system of coding and thematic analysis, comparing and contrasting texts from multiple methods, and using specific strategies to examine multiple and competing discourses as well as individual agency and resistance in the data collected.

Coding and Thematic Analysis

Consistent with a CE approach, field notes provided an important first opportunity to write down and develop emerging sensitivities, theoretical insights, initial interpretations and analyses (Emerson et al., 2010). An advantage of examining data within a CE approach, compared to approaches relying on interview data alone, was that detailed field notes from PO sessions and review of collateral data provided additional detail and insight into the multiple and opposing elements shaping HCP-parent communication and antenatal decision-making. Moreover, as described in previous literature (Browne, 2005; Dyck, Lynam, & Anderson, 1995), field notes from PO sessions often provided additional insights into competing discourses influencing and shaping HCP-parent interactions, not necessarily articulated in participant interviews or consistent with organizational values or mission statements, such as descriptions of sonographers' frustrations when a clinic was running behind, HCPs apologizing for not having more time to spend with parents as they backed out the door to move on to the next patient interaction, and conflicting demands on HCPs' time and attention, all of which were reflective of how dominant efficiency discourses shaped HCP-patient interactions.

The early phases of field work were foundational to initial and subsequent coding in that they were filled with the practice of detailing my observations and reading and rereading field notes and subsequent interview transcripts as I engaged with and reflected on the evolving data. During this process I referred repeatedly to my research questions and theoretical lens to keep the focus of my analysis on track, identifying recurring patterns and similarities in the data as well as the contextual patterns and individual factors accounting for differences in parents' and HCPs' experiences. As the data were collected and reviewed, I created codes based on the themes identified, consistent with

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approaches described by Carabine, Carspecken, and Emerson and colleagues (Carabine, 2003; Carspecken, 1996; Emerson et al., 2010). Early codes were more concrete, often using participant descriptors as initial codes such as "slap in the face" or "like being hit by a truck" to code parents' initial reaction to the diagnosis of a fetal anomaly. Initial coding prompted repeated reviews of the data, searching for additional descriptions or field note reflections on a particular aspect of the participants' experience until I was able to identify broader conceptual categories. At this point, I started to enter and code the textual data in NVivo[©], a software program that facilitates organizing and grouping data for easier comparison and retrieval. Although this process was helpful in many ways in organizing the data, ultimately I found the process did not facilitate, and indeed often seemed contradictory to, my ability to consider the multiple intersecting factors and interrelationships that simultaneously shaped and influenced participants' experiences. In the end, after weeks of inputting my textual data into the NVivo[©] system, I returned to a basic system of creating separate documents to capture data within broad conceptual categories such as "parental emotional reaction to the initial diagnosis." "efficiency discourse." "biomedical approach" and "power relations." entering in relevant field notes. reflections and entire sections of interview transcripts that fit within these broad categories so that I could continue to analyze them in their original context rather than decontextualized from the original meaning.

As analysis progressed, my insights into the nuances and subtleties of the participants' experiences increased through ongoing observation of a wide range of HCP-parent interactions, formal and informal participant interviews and repeated reading and reflection of field notes and transcripts. Consistent with analytic approaches described by Emerson and colleagues (2010), early and ongoing analysis of textual data that occurred

concurrently with data collection facilitated analysis of my interpretations and resulted in a greater ability and confidence to consider different alternatives to my evolving construction of participants' experiences by confirming, amending or rejecting in-process interpretations. As new data were recorded and analyzed I continued to fine-tune the organization and relational attributes identified between and among categories and subcategories, gradually developing an initial overall conceptual framework. This process resulted in further refinement and specificity of coding, reflecting a more theoretical approach to the analysis that included developing theoretical arguments for and against relationships between concepts in the data. Specifically, I wrote arguments, theoretical constructs and propositions concerning relationships I hypothesized between and among various conceptual categories. For example, one of the first theoretical arguments I tentatively put forth proposed the nature of parents' dynamic emotional response to the diagnosis of a fetal anomaly, describing my interpretation of how the multiple parental expressions of hope, despair, powerlessness and control amongst others were relationally connected and the individual and contextual factors that shaped and influenced this experience. This process involved generating arguments on multiple levels—both within and between categories—and returning multiple times to the data to support or rework my theoretical claims. After the data collection period drew to an end, analysis continued until I achieved an overall conceptualization and synthesized account summarizing my critical examination of the nature of HCP-parent communication and decision-making related to prenatal screening and the diagnosis of a fetal anomaly.

Throughout the final stages of analysis and writing up of findings I struggled with the enormity of the task and how to determine which findings to highlight in the final written report. I was guided by the research questions and a reflexive stance that emphasized foregrounding the nature of parents' experiences related to HCP-parent communication and decision-making. As a result, although I had interviewed several HCPs over the course of the study and the insights gained from these interactions and discussions were invaluable in gaining an overall understanding of the nature of the experience being studied, I found that only a small portion of the interviews were applicable to the research questions being asked. Moreover, an emphasis on HCPs' perspectives and insights in the discussion of findings seemed to inappropriately detract from the nature of the parents' experiences. As a result, I included limited data from these interviews in the presentation of findings, with the intent of writing a separate publication that more fully incorporates these findings at a future date.

Analytic Lens: Intersectionality

Consistent with a critical perspective and a reflexive orientation, data analysis was guided by an intersectional lens through which findings were viewed as a set of complex interrelationships rather than a set of discrete factors (Reimer-Kirkham & Anderson, 2010). Hankivsky and colleagues (2010) underscore the idea that intersectional analysis allows for several levels of difference and recognizes "the multidimensional and relational nature of social locations and places lived experiences, social forces, and overlapping systems of discrimination and subordination at the centre of analysis" (p. 3). An intersectionality lens guided data analysis in several ways. From the outset, it facilitated a complex analysis of the multiple factors, including dominant discourses and ideologies, shaping antenatal communication and decision-making, and guided identification of potential reasons for differences between parents' and HCPs' experiences. Specifically, it facilitated a contextual analysis that considered the intricate interrelationships among multiple individual factors (e.g. gender, ethnicity, faith, age, physical ability, mental health

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status, socioeconomic status, language fluency) as they related to power/knowledge, dominant discourses and participants' experiences of HCP-parent communication and decision-making. In addition, adopting an intersectional lens aided in scrutinizing the complexities of individual and broader contextual factors (e.g. access to health resources, geographic location) shaping antenatal communication and decision-making and how these contributed to health inequities.

Analytic Lens: Governmentality

Consistent with a critical and governmentality lens, analysis involved scrutiny of the multiple and competing discourses influencing and shaping antenatal HCP-parent communication and decision-making as well as a comprehensive examination of how participants enacted agency and resistance in healthcare interactions. As Allen and Hardin (2001) underscore, examination of discourses requires reading between the language of personal stories and the multiple and sometimes opposing social, cultural and historical discourses within which these narratives are constructed. Examination of how these opposing narratives are constructed within contemporary and historical medical and socio-cultural discourses allows researchers to move away from critiquing the actions of individuals to demonstrate how dominant discourses shape, influence and position individuals in particular ways.

Examination of multiple and competing discourses. Examination of dominant discourses that influenced and shaped HCP-parent communication and parental decision-making was conducted in a reflexive manner, using multiple approaches including those recommended by Carabine (2003) who, guided by a Foucauldian perspective, encouraged researchers to ask specific questions of the textual data to facilitate examination of dominant discourses. These questions were adapted and applied to the

topic of antenatal HCP-parent communication and decision-making, with the following guestions generated as one means of examining the dominant discourses and ideologies within the data: (1) What frames the way HCPs/parents talk about HCP-parent communication and decision-making? (2) In what ways have ideas and understandings about HCP-parent communication and decision-making constituted policies, procedures, roles, and practices (and vice versa), and to what effect? and (3) How do participants describe their interactions and how does this relate to their perceptions of factors such as socioeconomic status, gender, education level and broader contextual elements? Likewise, consistent with Carabine's (2003) suggestions, questions were posed with respect to aspects one might have anticipated within the parents' experiences that were not present in the actual data set. For example, one question asked of the data was why HCPs tended to focus on presenting parents with the option of pursuing additional diagnostic testing such as amniocentesis to determine the presence or absence of a chromosomal anomaly, but did not emphasize parents' right not to pursue these additional tests. Questioning the data in this way was effective in gaining insight into the influence of dominant discourses such as of biomedicine and individualism in antenatal care and decision-making.

Analysis also involved interrogating the data for resistances, counter discourses, and effects of dominant and counter discourses (Carabine, 2003). This involved systematically asking questions of the data and critically examining parents' and HCPs' responses to specific discourses and counter discourses. For example, one question that was posed for each dominant discourse or counter discourse was: How do HCPs/parents promote, sustain or resist popularized biomedical (and/or efficiency, individualism, relational, and so on) discourses about antenatal communication and decision-making, and what is the effect? Interrogating the data through questions such as these contributed considerably to elucidating the multiple opposing discourses shaping health communication and decision-making and the importance of considering not just which discourses were at work but also responses to and effects of these discourses.

Examination of agency and resistance. Inextricably tied to the examination of multiple and competing discourses in the analysis of textual data was the examination of individual agency and resistance. Allen and Hardin (2001) assert that "the relationship of individual agency to institutions, power relations, and discourse is a key concern in justice-orientated inquiry" (p. 169). They underscore that, over time, discourses become internalized and act as guides, thereby creating and shaping our identities and experiences. Consistent with this perspective, the experiences and stories shared by individuals were conceptualized as the product of discursive systems. However, individuals were not viewed as devoid of agency or free will. Rather than conceptualizing individuals as either having complete agency and free will or conversely as "discursive marionettes," a governmentality lens facilitated scrutiny of the data by prompting an understanding of how participants could both act as agents and simultaneously be positioned as subjects within discursive systems (Allen & Hardin, 2001, p. 169). In addition, this perspective of "subject positions" allowed for the pivotal understanding that subject positions were dynamic-parents and HCPs had the ability to reposition themselves and reshape their worlds by "maneuvering within and among discursive possibilities" (Allen & Hardin, 2001, p. 169).

Similarly, Holloway (2010) argued against a perspective that views discourses as mechanically reproducing themselves and does not account for change or human agency. As was also argued by Holmes (2002), Holloway contended that meanings are multiple, individuals are constituted from multiple and contradictory discourses, and that this alone provides and facilitates considerable flexibility, reflexivity, dialogue and range to question and challenge different perspectives. Guided by Holloway's insights and an intersectionality lens, this perspective encouraged me to consider parents' and HCPs' investment in certain positions within discourses and to ask questions such as: (1) Why do parents/HCPs take up positions in one discourse on health communication and/or decision-making rather than another? and (2) Why do parents take up a subject position in a biomedical discourse shaping decision-making? What is in it for them, and under what conditions does this change? Ultimately, this perspective of human agency and associated emphasis on the fragile and temporary nature of discourses influenced the analysis process by encouraging scrutiny of dominant and opposing discourses with the intent of understanding how participants took up these discourses and the associated effect on their experiences.

Ensuring Quality and Rigour of the Research Process and Outcomes

Consistent with a CE approach, I employed several strategies to ensure quality and rigour of the research process, including those to enhance the quality of the construction of participants' experiences and the broader power relations and discursive practices shaping and influencing these experiences. Many of these strategies were embedded in the manner in which data collection and analysis were enacted, including the aforementioned use of multiple data collection techniques and the inductive analytical approach. In the following sections I will highlight additional strategies I utilized to enhance the scientific quality of the research process and outcomes, including a reflexive approach, an awareness of my positionality in the field, and specific strategies to enhance participant representation and voice.

Researcher as Instrument: Reflexivity and Positionality

A CE approach views researchers as research instruments, thereby enacting pivotal roles in determining how fieldwork unfolds and the nature of data collected (Heyl, 2010). As the primary data research instrument in this study, initial and ongoing selfreflexivity on my personal biases, assumptions and past experiences were foundational to the scientific integrity of the research process. To help offset these inherent concerns, from the outset of the project I maintained journal entries and field notes on my thoughts, feelings and biases in relation to the research focus, and challenged myself to consider my research motives and be self-aware of my positionality in relation to both HCP and parent participants.

Recognizing that the integrity of the findings relied on my self-awareness of my role as a researcher also motivated me to reflexively attend to the power dynamics at play while conducting this research—both in the field and in my analysis of the data. It demanded that I actively consider my position of influence as a Euro-Canadian middle class researcher and critically and reflexively examine how power relations played out and shaped the process of knowledge creation, particularly in my relationships and interactions with participants (Reimer Kirkham & Anderson, 2002). In particular I considered my positionality in terms of my past professional experience as an advanced practice nurse working in the area of antenatal care. This required considerable reflexivity regarding how my past experiences and established understandings may limit my sensitivity to the nuances of HCP-parent interactions and parental decision-making or prevent me from adequately exploring salient aspects of the participants' experiences (Roper & Shapira, 2000). To help offset these potential risks, I focused on maintaining an open mind and consciously set out to enter the field with a stance of "researcher as learner" rather than "researcher as expert knower," in a collaborative process of knowledge generation (Hartrick Doane & Varcoe, 2015). This approach was augmented by completing field work at a second research site with which I was not familiar, thereby providing the opportunity to enter the field with a fresh and unsullied lens that heightened my awareness of elements in HCP-parent interactions and decision-making that I had previously taken for granted. In addition, I consulted with colleagues and members of my dissertation committee, seeking to consider new and alternative ways of thinking about antenatal experiences and HCP-parent interactions.

Representation and Voice

In critical ethnography, data collected as texts through interviews and field notes are conceptualized as a basis from which to scrutinize how individuals are shaped by (and reciprocally shape) the social, cultural, historical and political contexts that created them; however, it is essential that the words of the individuals continue to be central (Allen & Hardin, 2001). Throughout this research process I employed reflexive methods to consider how data collection and analysis procedures influenced which voices were constrained and which voices were heard, with the intention of foregrounding the voices of a wide range of participants. However, it is impossible for ethnographers to describe everything from every perspective; inevitably, conscious decisions must be made about where and whom to observe and when and how to record this data (Emerson et al., 2010; Goodwin, Pope, Mort, & Smith, 2003). As I proceeded through data collection, analysis and the writing up of findings, Allen and Hardin's (2001) assertion that making decisions about what to de-centre or re-centre is one of the most political acts researchers and scholars make was a constant reminder to me of the importance of incorporating reflexivity throughout the research process. This realization prompted a reflexive stance

facilitating a conscious consideration of why certain texts (and the discourses they reflected) were emphasized over others, as well as detailed documentation of observations and reflections throughout the research engagement, which were central to informing an inductive analysis process (Emerson et al., 2010; Thorne, 2008).

Throughout the research process I consciously strived to incorporate the voices of a wide range of participants in a variety of ways. First, I reviewed and re-reviewed the vignettes, quotes and participant examples I chose to represent the data to ensure they represented a range of participants rather than focusing on the most compelling or controversial examples. In addition, I provided examples of a range of participants' experiences, focusing on the group as a whole rather than highlighting the experiences of a select few. Finally, I integrated the use of contextualized and verbatim quotes and descriptions of participants' reactions and responses in a conscious attempt to ground the analysis and documentation of findings in the data generated from observations and interactions with the participants, rather than from my position of power as the author of written reports.

Ethical Considerations

Attending to the multiple ethical considerations underpinning and integral to this research went in tandem with ensuring quality and rigour in the research process. Guillemin and Gillam (2004) distinguished between (1) procedural ethics, involving the ethical rules and procedural guidelines monitored and approved by institutional review boards, and (2) ethics in practice, which centres on the day to day ethical issues and concerns arising when conducting research. There were numerous procedural and ethics in practice considerations involved in the design, implementation and reporting of findings of this research project. First, in accordance with the Tri-Council Policy Statement for the

Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, December 2014), the research protocols were reviewed by the UBC Behavioural Research Ethics Board, the University of Alberta Health Research Ethics Board, and the research review committees of the health centres where PO sessions and recruitment of participants took place with the requisite certificates of approval in place prior to conducting research at either research site. Research protocols and procedures, informed by a CE approach and the Tri-Council Policy guidelines, included procedures and strategies to ensure the protection of the rights of study participants. In the following sections I will highlight various considerations related to informed consent, confidentiality and the nature of researcher-participant relationships, which were particularly important in conducting this research from an ethical stance.

Confidentiality

Ensuring participant confidentiality was an important ethical consideration. The use of two research sites was integral to minimizing the potential for both parent and HCP participants to be identified in the data. Other strategies employed to protect participants' identities in data collection and analysis included: (1) creating and assigning code names to represent each participant and the corresponding data collected in order to ensure no identifying information was linked to a particular participant; (2) removing all identifying information from the data and referring to participants by code names in written reports and presentations; (3) editing identifying information as necessary to ensure participant anonymity; (4) editing rare fetal diagnoses and/or other participants (e.g. very rare fetal diagnoses were not specified in the reporting of findings, rather they were limited to a general category); (5) avoiding the use of specific HCP positions or roles in participants' descriptions of vignettes if there was a potential this could result in identification of the HCP, instead using rather broad categories (e.g. HCP rather than a specific pediatric/MFM specialist role).

Participant confidentiality was also an essential component of the trusting and respectful relationship formed between the participants and myself, and of paramount concern in data management strategies (Canadian Institutes of Health Research et al., December 2014). Methods for ensuring confidentiality were reviewed in detail during formal presentations to the multiple healthcare teams prior to the start of participant recruitment, as well as clearly outlined in participant information letters and consent forms. In addition, the following strategies were consistently enforced throughout the research process: (1) any hard copies of confidential study materials (including interview audiotapes, contact information and consent forms) were stored in a locked filing cabinet to which only I had access; (2) backups of computer files and hard copies of coded or anonymized data were stored in a locked cabinet when not in use; (3) all research-related computer files were password protected; and (4) the list linking participants' assigned code names with identifying information was password protected and stored separately from the data set.

Informed Consent

Consistent with a CE approach, I employed a relational approach to informed consent. For parent participants, signed written consent was obtained prior to initiating any observation sessions or interviews. Participant information letters and consent forms clearly outlined the research purpose, what participation in the study involved, approximate time commitments, and that participation was completely voluntary. This information was reviewed verbally with parent participants, and I also encouraged them to ask questions and seek additional information if they had any concerns prior to signing the consent forms. In addition, I emphasized in all of my verbal and written communications that participants had the right to stop taking part in the study at any time without giving a reason and without any negative consequences. Moreover, the participant information letters acknowledged participation in the study might trigger additional sensitive emotions and encouraged parents to request additional support as needed. In preparation for conducting the participant interviews, I familiarized myself with and made a list of available resources in the event participants requested additional support. Over the course of the study I was able to facilitate referral to additional resources and support services to assist parents in addressing some of their concerns and questions that arose during our conversations. On subsequent follow-up conversations or interviews with these parents, they often expressed their gratitude and appreciation for these informal referrals for additional sources of support.

Additional considerations needed to be made for obtaining informed consent from HCP participants. Employing a similar process as for parent participants, written consent was obtained from each HCP prior to initiating any in-depth interviews. However, given the number of HCPs potentially involved in interacting with parents during an appointment for a FE, logistically it would have been extremely difficult and potentially interruptive to the flow of patient care to take the time to obtain a written consent from every sonographer, fetal/pediatric cardiologist and/or medical trainee, social worker, nurse, genetic counsellor, geneticist, perinatologist and any other HCPs potentially involved in the care of a patient for any given appointment. Rather, several strategies were put in place to ensure informed verbal consent of HCP participants for participant observation
sessions. First, prior to entering the field I provided detailed presentations to each healthcare team summarizing the proposed research and specifically addressing the research purpose, what participation in the study involved, strategies to ensure participant confidentiality, and emphasizing that participation was completely voluntary. Information sheets about the study were also made available to all HCPs potentially involved in participant observation sessions. In addition, on days I planned to observe HCP-parent interactions I arrived at the site early and spoke with all HCPs, medical trainees and students I anticipated would potentially be involved in PO sessions to review the study and seek oral consent prior to observing any scheduled FEs and/or other formal HCPparent interactions. In addition, when accompanying parent participants to additional HCP appointments following the diagnosis of a fetal anomaly, every attempt was made to request verbal consent for observation of the HCP-parent interaction prior to the initiation of the meeting. Field notes were used to document that verbal consent was obtained from the HCPs involved in observation sessions. All HCPs approached for observation of the FE or combined detailed ultrasound/FE and subsequent consultations with parent participants provided verbal consent to my observation of HCP-parent interactions. Moreover, they were usually very accommodating to my presence, often going out of their way to ensure I was sitting in a position that allowed me to observe the scan and parent interactions. Although uncommon, there were four times where subspecialist HCPs at one site declined my request to observe their interactions with parents, indicating the large number of medical trainees and the small size of the meeting rooms did not allow adequate room for me to observe these interactions.

Relevance of the Research

Conducting nursing research has an inherent and pragmatic obligation that the research is relevant for the practice of nursing in the areas of research, education, clinical practice or health policy (Thorne, Kirkham, & O'Flynn-Magee, 2004). Consistent with the aims of critical research, this research project aimed to challenge the dominant frameworks and inherent power dynamics shaping and sustaining healthcare interactions and health decision-making in order to encourage guestioning of taken-for-granted assumptions and open the door for alternative practice, research and policy initiatives that foreground social justice, equity, participation, and structural change. Dissemination of the information generated from this study has the potential to provide nurses and other HCPs with direction for planning, developing and implementing services that are responsive to families' perceived needs and concerns. Research findings also have the potential to unmask potential inequities that exist among groups of parents, which is the required first step in promoting equity in decision-making support. Ultimately, it is my intention that study findings will contribute to developing explicit decision support and communication tools and resources for practice; guiding clinical training programs; and informing health system policies and best practices. The final chapter of this work highlights key recommendations for practice, education, research and policy development stemming from the findings of this research.

Summary

Building on the preceding two chapters, in which the research problem and questions were situated within the broader context of current theoretical and clinical research, in this chapter I described the core principles and elements of a CE approach and highlighted the specifics of the research design and methods. Specific considerations that facilitated a thick and rich data set have been highlighted. In addition, methodological considerations were explored including an overview of the intersectionality and governmentality lenses that facilitated a rigorous analysis of the power relations and discursive practices underpinning HCP-parent antenatal interactions and decision-making. Finally, I discussed the methods employed to ensure scientific rigour and ethically sound research practices throughout all stages of the research process. Having completed an introduction to the research problem and questions, situated these within the context of existing theoretical and empirical research, and reviewed the research design and methods, in the following three chapters I will provide a summary and exploration of study findings.

CHAPTER FOUR: THE NATURE OF ANTENATAL CARE

In this first of three chapters exploring the study findings, I start with a broad overview of the nature of antenatal care, employing a Foucauldian governmentality lens to provide an exploration of the dominant frameworks underpinning health care provider (HCP)-parent interactions, thereby setting the stage for Chapter Five, which provides a detailed analysis of how dominant discourses and associated power dynamics work together in shaping HCP-parent interactions and decision-making and the resulting consequences for parents and families. With a description of the context of antenatal HCP-parent interactions in place, Chapter Six proceeds to explore the unique characteristics of parents' emotional responses to a diagnosis of a fetal anomaly.

This chapter begins by outlining the underlying uncertainty and time-pressured context of an evolving pregnancy that served as a backdrop to antenatal care interactions. This is followed by an overview of the specialized healthcare teams involved in prenatal screening (PNS) and antenatal care delivery, as well as insights into the organizing framework within which antenatal care is provided. Building on this introduction to the setting and HCPs involved in antenatal care delivery, the subsequent section provides an analysis of population-based assessment of fetal health including an exploration of the driving forces behind parents' decisions to conform with organizational and societal imperatives related to PNS. The chapter concludes with an analysis of the dominant frameworks that shape, sustain and reinforce antenatal communication and decision-making practices.

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The Context of Antenatal Care: Systems, Structures and Care Delivery Uncertainty and the Time-Pressured Context of an Evolving Pregnancy

A unique characteristic of PNS and/or the diagnosis of a fetal anomaly was that parents' experiences and decisions were influenced and shaped by uncertainty and the context of a time-pressured evolving pregnancy. The uncertainty inherent in antenatal decision-making was evident in parents' descriptions of acting on "best guesses" and "hunches" while making complex and significant life decisions. In addition, all parents described "planning out" and "working through" multiple antenatal decisions in processes analogous to employing complex decision trees or algorithms involving conditional statements such as "if this, then that" to plot out and prepare for "most likely" and "less likely" outcomes and scenarios. These parental decisions included determining whether to pursue additional genetic testing, deliberating over potential neonatal treatment options, and making practical decisions related to work and family life such as organizing childcare for other children and determining temporary accommodation near the pediatric treatment centre. Many parents also described intensely deliberating over whether to continue or terminate the pregnancy, a weighty decision that generally needed to be made by 24 weeks gestation, in keeping with current Canadian guidelines. Increased uncertainty associated with the fetal diagnosis, prognosis and/or treatment options intensified the pressures parents faced in making these time-sensitive decisions. For example, parents who received a fetal diagnosis of a diaphragmatic hernia or complex cardiac anomaly described the difficulties they faced in making the decision to continue or terminate the pregnancy, given the dynamic nature of the fetal condition and given that initial prognostic information could change considerably as the anomaly evolved over the remainder of the pregnancy. Moreover, although a considerable degree of diagnostic specificity was

attainable antenatally for most fetal anomalies, certain aspects of the diagnosis were difficult to determine until after delivery when fetal and maternal systems were separated and direct assessments of the nature of the condition were possible. In this way, a level of uncertainty inherently existed related to the specific details of the fetal anomaly, the prognosis and associated pregnancy and treatment options. These inherent uncertainties in tandem with the time-pressured nature of parental decision-making were defining characteristics of parents' antenatal experiences.

Coordination and Collaboration Between Parents and Multiple Care Providers

Prenatal screening and the provision of antenatal care for those parents who were assessed for or received a diagnosis of a fetal anomaly involved coordination and collaboration between parents and numerous healthcare teams (see *Figure 2*, Collaborative Nature of Antenatal Care Delivery below). As described in Chapter Three,



Figure 2. Collaborative Nature of Antenatal Care Delivery.

HCPs' recommendations for PNS were dependent on multiple factors including maternal age and maternal health, family history of fetal or genetic anomalies, and whether the pregnancy involved in vitro fertilization techniques. Options for PNS involved: (1) maternal blood work to screen for specific chromosomal anomalies and open neural tube defects; (2) a nuchal translucency test to screen for Down syndrome; (3) detailed ultrasounds to screen for structural anomalies; and (4) chorionic villus sampling (prior to 14 weeks gestation) or amniocentesis for definitive chromosomal analysis. Detailed screening ultrasounds were generally recommended between 18 and 22 weeks' gestation, when fetal structures could be well visualized, and prior to 24 weeks, before which termination of pregnancy for non-life-threatening fetal anomalies was unquestioned. Participation in PNS varied from parent to parent, however for parents in this study almost all mothers participated in standard PNS blood work and all underwent detailed ultrasounds and fetal echocardiograms (FEs). Local community professionals, in coordination with family doctors or obstetrical specialists, typically performed PNS blood work and detailed ultrasound assessments. When PNS indicated an increased risk of a chromosomal anomaly or suspicion of a structural or chromosomal fetal anomaly, women were referred to a tertiary centre for additional assessment, definitive diagnosis and/or and discussion of additional diagnostic testing and management options. At the tertiary centre, parents met with members of multiple health teams including experts in maternal fetal medicine (MFM), genetics, and pediatric subspecialties, depending on the nature of the fetal concern.

HCPs who made up the MFM team played a prominent role in diagnosing fetal anomalies and collaborated with other subspecialists to provide ongoing antenatal care to women following the diagnosis of a fetal anomaly. The MFM team included perinatologists, specialized nurses and social workers who coordinated the care of women with complex and high-risk pregnancies including those involving a fetal anomaly. MFM team members collaborated with obstetricians and/or midwives in coordinating obstetrical care for women who received a diagnosis of a fetal anomaly. MFM members also worked closely with geneticists and genetic counsellors in providing amniocentesis and chorionic villus sampling for those parents who pursued additional diagnostic testing to determine the presence of a fetal chromosomal anomaly. In addition, the MFM team often collaborated with pediatric team members when specialized knowledge was required related to the diagnosis, prognosis and/or treatment of fetal anomalies. For example, as experts in complicated high-risk pregnancies, but not in all of the nuances of pediatric care, MFM team members were disadvantaged in terms of being able to provide detailed information to parents on the care and management of infants and children with complex fetal conditions after birth, thereby necessitating additional referrals to pediatric team members when additional diagnostic, prognostic or treatment details were required. Similarly, in much the same way that MFM team members were not fluent in the language or care specifics of postnatal pediatric care, pediatric care providers were not fluent in the language or care specifics related to high-risk maternal-fetal care or the detailed intricacies of genetic testing for chromosomal anomalies. In this way, delivery of coordinated antenatal care relied on collaboration and communication amongst multiple healthcare teams. As will be demonstrated in Chapter Five, when collaboration and communication amongst and between these different HCPs was suboptimal or when HCPs provided information to parents outside of their area of specialty, increased tensions in HCP-parent interactions occurred that had the potential to significantly impact parents' antenatal experience.

Pediatric Specialists: Prognosticating Futures in a Foreign Land

A unique aspect of antenatal diagnosis of fetal anomalies was that it relied in part on the expertise of pediatric healthcare specialists who were consulted to provide diagnostic and prognostic expertise outside of their usual and familiar sphere of pediatric practice. These specialized healthcare providers, as experts in the diagnosis and treatment of congenital anomalies and concerns specific to their subspecialty (e.g. cardiology, neurology, neonatology), were consulted to diagnose and/or provide prognostic and treatment information in the foreign context of a maternal-fetal healthcare environment. In this way, pediatric subspecialty care providers, including medical specialists, surgical specialists, and specialized pediatric nurses found themselves interacting with and providing consultant services to pregnant women and their partners. Pediatric HCP-parent interactions were inherently shaped by their experiences of primarily working with and caring for children and families with health concerns that were the focus of their pediatric subspecialty practice. Likewise, the perspectives of maternalfetal specialists in HCP-parent interactions were shaped and influenced by their professional orientation and experience predominantly caring for pregnant women. These different perspectives and experiences amongst the various specialist team members contributed to tensions in antenatal interactions. For example, pediatric care providers working in antenatal care were faced with termination of pregnancy as an alternative parental option to the medical or surgical treatments that would have been standard practice if the diagnosis of the anomaly had been made postnatally. Not surprisingly, pediatric subspecialists predominantly focused on the nature of the fetal anomaly and treatment options in their interactions with parents, often not addressing the option of termination of pregnancy or indicating members of the MFM team would review this

option. In addition, as pediatric care providers in the foreign world of antenatal care, pediatric HCPs generally conformed with organizational structures and systems in prioritizing fetal physiology, pathology and neonatal treatment options in antenatal HCP-parent interactions, at times overlooking the full range of parents' physical, emotional and practical health needs, often assuming these would be addressed by the "other" teams involved. Similarly, when pediatric teams were involved in the care of families who received an antenatal diagnosis of a fetal anomaly, MFM team members often did not addressed by the pediatric team. As a result, parents were often caught between these two orientations with unaddressed needs and concerns, and left unsure of where to turn for support.

Structural Inequities Existed in the Design and Delivery of Antenatal Care

Structural inequities existed in the design and delivery of antenatal care services in that availability and accessibility of specialized services and resources varied considerably depending on the nature of the fetal anomaly and the organizational resources and supports in place. Despite the vision and mission statements of the health centres involved in this study emphasizing "patient-focused," "patient-centred," "accessible," "compassionate," and "collaborative" care, multiple structural inequities existed in the provision of antenatal care that impeded these organizational goals and mandates to varying extents.

The system dictated what supports were available and when, and why parents met with a specific specialist or team member, thereby creating opportunities for influence and bias toward certain treatment options and inequities in terms of access to and provision of care and support. For example, given that congenital heart disease (CHD) is the most common form of a structural congenital anomaly, there were formalized processes and designated multidisciplinary pediatric cardiology teams in place involved in collaborating with MFM and genetic subspecialists, amongst others, in diagnosing and providing prognostic information and support to parents at the time of initial diagnosis (usually between 18 and 22 weeks gestation) and continuing at regular intervals until the end of the pregnancy. Moreover, although the makeup of fetal care teams varied between institutions, many parents in this subset also had the opportunity to meet with a nurse and/or a social worker with expertise in the care of infants and children with cardiac conditions who provided additional antenatal education, support and coordination of antenatal and neonatal care.

The rare and complex nature of certain fetal conditions associated with formalized pediatric or MFM health services and supports combined, with the need for frequent monitoring of the fetal condition, was often a source of bonding between parents and subspecialized care providers who were considered experts in these conditions, which ultimately provided this subset of parents with greater antenatal support and resources in comparison to others with equally complex fetal anomalies but for which there were fewer specialized resources available. As will be described in Chapter Six, when parents first learned of the diagnosis of a fetal anomaly, they vividly described feelings of emotional distress associated with social isolation in that their experience became "a different [pregnancy] experience than anyone could even imagine" and that it was "like entering a whole new world of unknowns" (multiple parents, field notes). Contributing to these feelings of isolation, parents described never having even heard of their fetus' condition prior to the antenatal diagnosis and not knowing anyone else who could relate to having a child with the same rare condition as their fetus. In contrast, parents' initial meetings with

subspecialists in their child's rare or complex condition were described as "reassuring" and "comforting" in that these specialized care providers shared their experience of working with many infants and children with the same or similar condition, which parents described as "a source of relief," "feeling like we had joined a new team that shared a common interest," and "we did not feel so alone -- they understood us." For example, Kath commented on her baby's rare cardiac condition and how the knowledge and expertise she received from the pediatric cardiology subspecialty team was very reassuring:

I think in the beginning it was kind of more like, scary, because of how rare [the fetal condition was], because I remember asking the question of, like, how many cases they see in a year ... and Dr. Y said they sometimes get zero, one or two cases a year with [fetal diagnosis] ... So let's say they've been doing this for like 15 to 20 years, they could have only had like, maybe, 20 to 40 cases in their whole career. You know, like, that's not very comforting, right, but of course, you know, they are the experts on rare, so even if they don't see this very often, I don't know, it's just like rare to them is not rare because they are, because they specialize in rare... (Kath, L 1716–1730)

Several other parents also described the "relief," "sense of not being in this alone," and "encouragement" they received from interacting with healthcare professionals or teams who were "familiar with," "invested in," and "had a special interest in" caring for a child with the same or similar condition as their fetus. Moreover, this bond between specialized HCPs and parents continued to evolve and strengthen as the parents developed greater knowledge and expertise in the fetal condition, and as they developed relationships with these experts in their child's condition over the course of the pregnancy.

In contrast to the established and formalized supports available to parents who received a diagnosis of a common fetal anomaly such as CHD, parents who faced the diagnosis of equally complex fetal anomalies such as oomphalocele, gastroschisis, diaphragmatic hernia, lung anomalies, or a range of chromosomal anomalies such as Trisomy 21 or Trisomy 18, had access to less specialized services and fewer resources and supports. For this group of parents, rather than receiving diagnostic, prognostic and treatment information from a pediatric subspecialist, members of the MFM and/or genetics teams usually initially reviewed this information. Although these HCPs had a general knowledge of this area and consulted with pediatric subspecialists as needed, parents often described receiving a "broad overview" or "general sense" of prognostic and treatment information, compared to the "detailed," "precise" and "specific" information others received from pediatric subspecialists. In addition, for this group of parents, meetings with members of the relevant pediatric subspecialty team such as pediatric medical subspecialists, pediatric surgeons, and pediatric nurse clinicians (if available) were usually delayed until the last trimester of pregnancy. The reason for this delay varied, with some pediatric specialists choosing not to meet with parents until the parents had made a definite decision to continue the pregnancy and/or the fetus had reached a gestational age associated with a reasonable chance of survival outside the womb. Other pediatric specialists preferred to meet with parents around 34 to 36 weeks, when parents had temporarily relocated close to the specialized maternity/pediatric centre for delivery and neonatal care and when the specialists could provide individualized treatment and prognostic information based on the most recent fetal imaging of the evolving structural anomalies. As a result, for those parents where pediatric subspecialists were not involved in the initial diagnosis of the fetal anomaly, parents' antenatal decisions, including whether to continue or terminate the pregnancy, were sometimes made based on information provided by the maternal-fetal or genetic team and the parents' own research, without exposure to complete and up-to-date prognostic and treatment information from HCPs with specialized knowledge and experience in the postnatal care of infants and children

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with the antenatally diagnosed condition. Moreover, this subset of parents did not benefit from the additional support, coordination and individualized antenatal care that those who worked with a formalized pediatric subspecialty team received. These structural inequities were rooted in the design and delivery of antenatal health services and will be further explored in Chapter Five.

Having outlined how antenatal care is characterized by uncertainty, time-pressured decisions, and coordination and collaboration amongst multiple healthcare teams, the focus in the following section will shift to an analysis of population-based assessment of fetal health and the driving forces behind parents' decisions to participate in PNS.

Population-Based Assessment of Fetal Health: Seeking Out "Abnormal"

Prenatal screening involved a complex form of population-based assessment that included a wide-ranging and systematic set of processes centred on detecting deviance from normal fetal parameters. Power/knowledge, culture and discourse shaped and structured HCP-parent antenatal interactions and decision-making both at the broader organizational and population-based levels of care, as well as at the interpersonal level of care between parents and health providers. To show this, I have incorporated a series of parent vignettes constructed from my field notes and excerpts from parent and HCP interviews that depict the discourses, frameworks and power relations underpinning a wide range of antenatal experiences and interactions. The first two vignettes depict women's experiences undergoing an initial FE. In the following sections these vignettes serve as reference points for the subsequent analysis of population-based assessment of fetal health and how and why parents ultimately conformed to organizational and societal imperatives related to PNS.

Vignette #1: Anna and Abigail ²³

Anna arrives for her FE appointment accompanied by her sister, Abigail. Anna is currently at 22.5 weeks gestation with her second child. She is married with a two-year-old son. A previous ultrasound at 18 weeks indicated a possible fetal cardiac concern that prompted a referral for an FE. She is aware from previous genetic testing that the fetus is female. Her partner was unable to attend the appointment due to work commitments.

Anna enters the FE exam room and lies on the exam table facing the large screen on the wall where the fetal images will be displayed. Her sister, Abigail, takes a seat in the chair beside her. The sonographer, Daisy, wearing a short white lab coat, sits on the other side of the exam table, facing the ultrasound machine, which is equipped with its own screen. The lights are dimmed. A thin curtain, not completely closed, separates the exam room from the adjacent hallway. A dull hum of other conversations in the hallway and adjacent rooms is audible, but not overly distracting. The room has bulletin boards covered with obstetrical information including normal fetal measurements, illustrations differentiating between various breech positions, and a bright green poster about a study on a common complication of pregnancy. Trans-vaginal probes hang looped on holders on the wall and a laundry basket filled with towels soaked with ultrasound gel is within a throw's distance from the technician. It is a small room designated specifically for ultrasound examinations.

Daisy starts by asking Anna why she is having a "fetal echo" while she squirts warmed gel on Anna's round abdomen. Daisy listens as Anna describes a suspicion of a cardiac concern noted on a previous scan—some "mild left/right imbalance, … they wanted it followed up … Just want to make sure everything is okay." Daisy nods, acknowledging Anna's explanation. Daisy notes Abigail's presence and asks about the baby's father—Anna indicates he is not able to attend the ultrasound because of work commitments.

The scan starts with recording the fetal heart rate— "One hundred fiftyeight—that's good." All heads turn toward the beating heart images. Daisy continues her scan with a systematic progression of fetal assessments and measurements. As images come into view she indicates what she is imaging in short phrases—cardiac outflow tracts, arm bone size, elbow to shoulder—"[I'm]

² The vignettes incorporated in this and subsequent chapters were reconstructed from observations, field notes and interviews with parent participants. Given the rare and unusual nature of some fetal anomalies and the limited number of HCPs involved in some subspecialty fields or disciplines, changes have been made where necessary to HCP gender, fetal diagnosis, and other identifying attributes of both parents and HCP participants. In addition, where necessary to protect participants' identities, some vignettes involve a composite of multiple people and events observed in fieldwork but do not represent a single individual.

³ In the following vignettes, parents, family members and non-physician HCPs (e.g. nurses and sonographers) are referred to by their first names (such as "Anna" and "Daisy"), and physicians are referred to as "Doctor" followed by their surname (e.g. Dr. Jones). This is consistent with my observations in that parents and family members were addressed by their first names in HCP-parent interactions, while physicians were addressed by the honorific "Doctor" in combination with their surname.

measuring everything." When an image is captured and recorded, Daisy checks it off on a computerized checklist of required images.

Daisy inquires if mom had screening blood tests—Anna indicates she did, "They were negative."

Daisy nods. "She's pretty"—smiling.

The scan continues with imaging of the brain. Daisy asks if a nuchal translucency screen was performed. Anna indicates, "Yes, it was normal."

Daisy completes a head circumference measurement. Both mom and aunt have their eyes focused on the screen. Daisy notes that the fetal legs are crossed. Anna smiles and says, "Such a lady." Daisy notes the female genitalia.

Daisy images the umbilical cord with colour flow Doppler and then moves on to discuss that the black circles and shapes on the screen indicate fluid-filled organs such as the stomach and kidneys. Daisy indicates the fetus needs to change position for her to get the necessary images—"I'm hoping she'll roll over."

Daisy moves on to obtain the abdominal circumference and says, "I'm getting her belt size." Daisy's focus then shifts to specific cardiac images including Doppler/wave form measurements. Daisy systematically progresses through a four-chamber view, aortic arch flow, and assessment of the intra-cardiac septum.

Anna is calm, relaxed and chatting with her sister. She talks to her sister about driving her home after the scan. Daisy is less talkative as she focuses on the cardiac images.

The scan finishes with measurements of the spine and feet. Daisy leaves to review the images with the specialist.

While waiting for Daisy to return, Anna, Abigail and I discuss Anna's pregnancy experience to this point. Anna admits to being a little nervous about the FE despite her calm exterior. "They wanted us to follow up with a repeat scan, they weren't that worried, just didn't want to miss anything."

The pediatric cardiologist, Dr. Chang enters the room. He starts with asking a series of questions to gather a brief maternal history—career/profession of mom and dad, general health. The questions are asked in terms of assumptions—"You are healthy?" Both parents are health professionals and Dr. Chang has a brief discussion with Anna about her and her husband's careers. When the specialist asks about a family history of heart disease, Anna shares that her grandmother has a murmur, which prompts Dr. Chang to ask a series of questions related to any other family history of CHD.

Dr. Chang then sits down and starts to scan, rescanning each of the cardiac structures again, getting more detailed information. He points out the different structures that he is imaging using more medical terms than the sonographer— "outflow tract", "A-V valve", "ductus" and "aortic arch". He comments, "Beautiful, beautiful baby." As he is finishing the scan, he explains that everything looks "perfect," but because of the history of a murmur in the grandma, he wants to be "cautious" and see Anna again at 32 weeks gestation to re-review the fetal cardiac anatomy for any indication of a fetal coarctation (narrowing of the aorta). Anna nods her head and inquires how to book the next follow-up scan. She thanks Dr. Chang for his time and he leaves the room "to see the next patient that is waiting."

Vignette #2: Kara and Karina

9:45 appointment; ultrasound started at 10:05.

Mom, Kara, is a healthcare worker. Her mother, Karina, has accompanied her to the appointment. She notes that her boyfriend, the father of the fetus, was unable to attend the appointment because of work, stating, "He was quite upset he couldn't make it."

Kara is at 17 weeks gestation with her first pregnancy. She is aware the fetus is female from the results of previous genetic testing. Kara shares that this was not a planned pregnancy—"We are not married yet, but it was a happy surprise … We've been together a while and I'm 29—not young."

Prior to the scan, Kara explains she was referred for an FE because of a "very abnormal" nuchal translucency screening result. Kara describes her previous meeting with the genetic specialist after the nuchal translucency screening—"We were told the findings were very concerning. In our meeting with the genetic counsellor they showed us the results and they said, 'If it's in this column, it's very bad, and if it's in this column, it's also very bad.' Then they described all of the syndromes that were associated with this finding including Down syndrome and Turner's syndrome … We went through a lot of additional testing. We had genetic testing, which was normal [sigh of relief]. My boyfriend and I also had genetic testing of our own blood, which was also normal. We are here today to see if there is a cardiac reason for the increased nuchal thickening."

The room is very warm—there is a stand-alone air conditioning unit blowing cool air toward the exam table. The room is very small—just enough room for the exam table, ultrasound machine, air conditioning unit and the chairs where Karina, the fellow and me are sitting. The lights are off; the only light in the room is coming from the ultrasound screen. The curtains are closed.

Karina is sitting beside the exam table, to Kara's right. Kara is lying on the examination stretcher, her head twisted to the side to look at the small screen on the ultrasound machine (there is no separate viewing screen on the wall in this room for parents to observe the fetal images).

Dr. North, a cardiac fellow (a physician completing specialist training in pediatric cardiology), is performing the FE. The ultrasound starts. Kara's head is turned to look at the screen. Karina is leaning forward in the chair, straining to get a glimpse at the screen as well, although it is very difficult from the angle where she is sitting.

10:05—Dr. North sets up the monitor and preps Kara for the ultrasound. He appears quite rushed, having noted to me prior to entering the room that they are running behind (I felt like I was being reprimanded because it took time to get the consent prior to the ultrasound). His actions are quick and precise. When he addresses Kara, he speaks fast. He starts the scan with capturing the fetal heart rate. "The heart rate is 145—normal," he notes.

He then moves on to capture specific cardiac images, following a similar pattern to previous patients. Early in the scan, Kara asks him what he is looking at and adds, "Is that normal?" Dr. North replies, "I have to go through everything first, we will talk at the end."

The scan continues. The room is silent except for the clicking of Dr. North's fingers on the ultrasound machine. Images of each of the cardiac chambers,

vessels and structures are captured and labelled in specific order until the checklist is complete. Kara and Karina continue to try to look at the screen and catch glimpses of the fetal images and movements.

10:20—Dr. North notes, "As you can see, baby is quite active. She moves a lot."

Both Kara and Karina lean forward and comment, "Oh yeah, she's moving..."

Dr. North continues, "that's her spine, her head is down." He notes a couple of other structures on the screen and then silence resumes.

10:30—Dr. North notes that he has completed the scan and will review the results with the pediatric cardiologist. He leaves the room while I stay and talk with Kara and Karina.

While waiting for Dr. North to return, Kara describes her antenatal experience to date—she appears very keen to share her story. She describes how when they first met with the genetic team after the nuchal translucency test that they were told "there was a one percent chance that the baby would not have a genetic anomaly ... They [the genetic specialist] said it would basically be a miracle that the baby would survive, knowing that a miracle is a miracle." Kara noted that "it has been a huge waiting game," and that the more than two week wait for the results of the genetic testing (chorionic villus sampling) "seemed to take forever." She notes her emotional distress, worry and anxiety while waiting for the results of the genetic testing. Kara also remarks that her emotional investment in the results of the genetic testing seemed "out of balance" with the way she was told the results were normal, via a short phone call from a member of the genetics team. She goes on to explain that even though the genetic results were normal, she remained in a state of worry and anxiety as to why the nuchal translucency results were "so abnormal," and is concerned that "some other problem will turn up" with additional testing. She explains that part of why she was frustrated her boyfriend could not attend today's appointment is because she is concerned that there will be more "bad news" from the scan.

Kara notes that she and her partner are struggling with whether "to commit or not commit" to the developing fetus. She describes multiple specific interactions that promoted "commitment and bonding" to the fetus such as seeing the fetal image on the ultrasound screen, but at the same time she is finding it difficult to be happy or excited because of the abnormal screening results. Kara notes that it is "so nice" when they see images of the fetus' face or of the fetus doing somersaults on the ultrasound screen because it gives them hope, but at the same time they are scared and worried about getting "too attached" because they are awaiting the results of today's and possibly future prenatal tests before they decide to continue or terminate the pregnancy.

10:55—Dr. North returns to the room and explains that he has reviewed the ultrasound findings with the pediatric cardiologist. He indicates that "everything with the heart is normal," and that no major concerns were detected. He notes, "There is only one thing—there is a small amount of fluid around the heart (a pericardial effusion) that we want to look at again in four to six weeks." Kara immediately questions if this can be normal and if not, what it could be. Dr. North is non-committal concerning possible reasons for the pericardial effusion and repeats that the FE results "could be normal." He explains that the pregnancy is at an earlier gestation than FEs are typically performed at, and it is possible that this finding is

related to gestational age and therefore normal rather than anything more worrying. Kara's body language indicates that she is skeptical of this reassurance. Dr. North reviews how the follow-up FE will be booked and then leaves the room. Kara states she is somewhat relieved but still skeptical. She indicates that she has a detailed scan booked with the MFM team the following week and is anxious to see what they find.

On leaving the ultrasound room, Karina states, "It sounds like this is good news," and smiles reassuringly at Kara. Kara responds, "Yes, but I'm going to be focusing on *that* [pericardial] *fluid* [emphasis in original]."

As illustrated in the preceding vignettes, the system's priorities and perspectives related to PNS were enacted as a complex form of assessment characterized by the comprehensive, systematic and purposeful actions focused on detecting deviance from normal fetal parameters. Prenatal assessment occurred at a broad population level, dictated by the provincial and institutional policies recommending every woman undergo PNS including screening blood work and ultrasounds to search for possible fetal anomalies. Biomedical, individualism, efficiency, responsibilization, and disability discourses, amongst others, influenced, shaped and reinforced the functioning of this prenatal assessment machine.

The sophisticated system that constituted the mechanism of prenatal assessment relied on and was influenced by biomedical and efficiency discourses, which foregrounded quantitative measures, a reductionist lens, a techno-rational approach, and emphasis on scarcity of time and resources in HCP-parent interactions. As illustrated in the preceding vignettes of Anna and Kara's experiences, women entering into PNS were subjected to a standardized biomedical gaze that involved separating the fetus into parts, examining each part individually, and then comparing the findings to a standardized norm. Using a techno-rational approach consistent with a biomedical perspective, any suspected abnormalities were subjected to further scrutiny until a fetal anomaly was either ruled out or confirmed. As was the case for both Anna and Kara, a suspicion of a cardiac anomaly on a routine screening ultrasound set in play an almost automatic series of referrals to maternal-fetal medicine, fetal cardiology and genetics with specific appointments set up for a repeat detailed scan and FE as well as a detailed genetic consultation that centred on discussing the option of prenatal genetic testing to rule out any associated chromosomal abnormalities. Testing continued until expert opinion either confirmed or negated the presence of a fetal anomaly or multiple anomalies beyond a reasonable doubt. Referrals for additional consultation and testing were generally put in play with the unquestioned assumption that parents wanted and needed to pursue this additional understanding of the fetal condition. It was rare for any parents to question or challenge the need for additional prenatal testing aimed at detailing the presence, nature or severity of a fetal anomaly.

Within the healthcare system, PNS was constructed as consistent with "responsible" parents who were making "informed" parenting decisions. In general, HCPs assumed parents understood a major impetus and rationale for participating in PNS was to systematically and comprehensively search for fetal anomalies, thereby providing parents with opportunities for additional diagnostic testing to determine the nature and extent of the anomaly as well as options related to continuing or terminating the pregnancy. In this way, PNS was consistent with dominant individualism discourses foregrounding individual autonomy, personal rights and freedoms, and self-determination in health decisions. Prenatal screening was also underpinned by responsibilization and disability discourses, which emphasized optimizing health and reducing the risk of being afflicted with a specific disease or condition, while maintaining the focus of responsibility for health status on the individual parents. Consistent with these discourses, there was a common undertone in PNS interactions that resulted in many parents feeling pressured to "prevent" childhood disease through termination of pregnancy.

Parents Conformed to Organizational and Societal Imperatives in PNS

Institutional and societal rationales for providing PNS differed significantly from parents' perspectives and motivations to participate; however, ultimately, parents usually complied with screening recommendations. On the one hand, PNS was constructed by the healthcare system as consistent with informed and responsible parenting, with HCPs making implicit assumptions that parents were fully aware that the driving force behind PNS was the detection of fetal anomalies and the parental option of termination of pregnancy (TOP) if a fetal anomaly was detected. On the other hand, the majority of parents entered into PNS as a normative behaviour, acting in compliance with the search for fetal anomalies by unquestioningly following the guidelines put in place by existing provincial and organizational policies and recommendations. Many parents entered into these screening procedures naïvely, unaware that a woman's right to choose to terminate the pregnancy was one of the main reasons behind standardized PNS. Moreover, whereas health providers promoted PNS as a means of identifying fetal anomalies, many parents constructed PNS as a routine part of prenatal care that served as a means for discovering unknown details about their fetus such as size, sex and appearance. In this way, in exchange for "more information" about their fetus, parents conformed with the system's mechanisms of surveillance and scrutiny of suspected fetal anomalies, thereby setting themselves up for potential decisions related to pregnancy and treatment options that were at times in opposition to their stated values and beliefs.

In contrast to the majority of parents, a small subset of parents shared perspectives aligned with HCPs' perspectives on PNS as a mechanism to screen for fetal anomalies. This set of parents shared several characteristics - they were either healthcare professionals or had been exposed to fetal anomalies in the past either by living with a congenital health condition themselves, having a son or daughter with a known health concern, or having a relative or close friend with a child with a fetal/congenital anomaly. In contrast to the parents who entered into PNS primarily as a means of discovering more detailed information about their fetus such as size and sex, these parents often described coming to the ultrasound appointment with a focus on "making sure everything is okay" and "ruling out any problems." They described "researching," "seeking out" and "searching" for more information to ascertain the health status of their fetus. For example, one set of parents, both of whom were scientists, one of whom had a chromosomal anomaly, described themselves as "data seekers" and indicated, "We want to learn as much as possible about this baby to make sure everything is okay—if there is any test available [i.e. fetal testing], we will be signing up" (Fleur, field notes). This couple described how their scientist backgrounds facilitated their appreciation of how technology could be employed to identify fetal anomalies, thereby providing them with information to support them in making informed decisions about additional diagnostic testing and the decision of whether to continue or terminate the pregnancy. Both parents had a detailed understanding of anatomy and physiology, which they described as contributing to their perspective of finding the fetal images fascinating and appreciating the detail with which each fetal system was assessed. Similarly, other parents who entered PNS and/or a FE with a heightened awareness of the possibility of a fetal health concern described feeling "guarded" and "anxious" until the fetal scan was completed and they were informed no abnormalities had been detected. This was particularly evident in discussions with parents who had received an antenatal or postnatal diagnosis of a

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fetal/newborn health concern in a previous pregnancy. This group of parents described "sitting on pins and needles," "being a wreck/ball of anxiety," and "once bitten, twice shy" until the screening ultrasound was completed, and they were assured by the healthcare team of normal results. Many of these parents described significant differences in their current prenatal experience that they attributed to their past experience. One father noted, "With our first pregnancy we didn't even worry about something being wrong with the baby. We were both healthy. We thought our baby would be healthy too. But with this one, it's all different. We *know* [emphasis in original] something can go wrong. We won't be able to relax until all of the [screening] tests are done" (Eli, field notes).

In contrast to the small group of parents who went into PNS with a guarded approach, fully aware of the possibility of uncovering a fetal anomaly, the majority of parents had low expectations they would face a diagnosis of a fetal anomaly. This perspective varied from parent to parent and was shaped and influenced by several factors. For example, parents who were healthy themselves, had no known family history of fetal anomalies or childhood disabilities, and/or already had healthy children often described entering into their pregnancy assuming a negligible risk of a fetal anomaly. In addition, the majority of parents were uninformed of the statistical incidence of fetal anomalies, often expressing surprise at how common some fetal anomalies were (for example, most parents indicated they had not realized approximately one in a hundred babies are born with a form of CHD). Even parents who were referred because of a significantly increased risk of a fetal anomaly, such as parents who had a congenital or genetic anomaly themselves, did not necessarily focus on PNS confirming or negating a fetal concern. For these parents, the differences between HCPs and parents' perspectives on PNS were striking. When a woman was referred for a FE because of an

increased risk of a fetal cardiac anomaly (based on maternal health, family history, or other factors) and/or if a fetal anomaly was suspected on a PNS ultrasound completed in the parents' local community, the healthcare team at the specialized women's centre scrutinized the referral form to determine the likelihood of discovering or confirming a fetal anomaly. In contrast, the majority of parents arriving for their FE appointment were often not aware that a fetal anomaly had been suspected on the community scan and/or assumed that there was a very low possibility their unborn baby had a fetal anomaly. For these parents, they were primarily interested in learning more about their unborn baby's physical characteristics as well as viewing images of their developing fetus; parents rarely commented on or raised concerns about the potential presence of a fetal anomaly. Rather, consistent with the priority given to garnering and communicating immediate results in today's technology-driven world, parents described "wanting to get a glimpse," "have a look," and "take a peek" at their unborn baby on the ultrasound screen, as well as upload printed pictures from the ultrasound to their cell phones or take a printed copy home to share with family and friends. Parents also ascribed personality traits to the fetus based on the images they viewed on the ultrasound screen. For example, one set of parents described their fetus as "feisty" in response to his multiple kicks and turns, whereas another set of parents used terms such as "calm" and "cooperative" when referring to their fetus during the scan. In this way, for the majority of parents, their decision to participate in PNS appeared to be largely motivated by the opportunity to learn more about the physical and personality details of their unborn baby rather than a deliberate decision to determine the presence or absence of a fetal anomaly. In contrast to their expectations entering into PNS, this group of parents described feeling "blown out of the water," "shocked," and "dumbfounded" when the routine PNS uncovered a fetal anomaly.

Parents' priorities related to PNS were evident in their first interactions with the sonographer. For those parents who entered into PNS with no significant concerns regarding the presence of a fetal anomaly, the focus of the initial interactions during the first few minutes of the scan was on the parents' excitement in response to viewing the first fetal images. Parents often commented on the change in fetal appearance from the "blob" or "egg yolk" image they viewed on the initial dating scan to the recognizable body parts of a developing fetus they were able to discern from the ultrasound images. Parents' priorities related to PNS were also evident in their discussions with sonographers about their hopes to learn about the fetal sex, appearance and/or activity level. Often the mother's first unsolicited comment made to the sonographer as the scan was getting started related to the parents' desire to know or not know the sex of the baby, such as, "We are hoping to learn whether it's a boy or a girl," or "We want the sex to be a surprise—please don't tell us."

Parents' compliance with the system's prenatal surveillance mechanisms in exchange for details about their unborn baby and their naivety concerning the purpose of PNS contributed to increased emotional distress of both parents and HCPs, as well as increased tension in HCP-parent interactions when HCPs initially shared the diagnosis of a fetal anomaly with the parents. Parents described multiple feeling such as, the fetal diagnosis "came out of left field," "was a slap in the face," and/or they were "completely blown away that there was anything wrong." Moreover, parents' naivety concerning the purpose of PNS and their unquestioning compliance with screening recommendations often resulted in unexpected exposure to increasingly sophisticated forms of fetal assessments and scrutiny, which subsequently led to additional pregnancy and/or neonatal decisions that parents had not previously considered and which they often found overwhelming.

The detection of a fetal anomaly was also emotionally intense and difficult for the HCPs involved, with parents' naivety concerning the possibility of a fetal anomaly appearing to add to the overall emotional intensity of the experience. In particular, the sonographers and medical professionals performing the ultrasound frequently expressed angst and uncertainty over the best outward response when working with parents who were excited to see the first fetal images but were still unaware that the evolving scan had revealed a fetal anomaly. In particular, sonographers and medical trainees, who usually performed the initial component of the scans but were not in a position to share the findings of a fetal anomaly with parents as the scan unfolded, often described feeling "caught in the middle" between the emotions of the parents who were excited about seeing recognizable images of their fetus and the knowledge that the parents would soon be facing the difficult news of learning about a fetal anomaly. In this context, HCPs were often cautious and guarded in their responses and comments about the fetal images, and although they often acknowledged the parents' comments and excitement, they were less likely to engage in the parents' happiness with a nod or smile and also less likely to make comments such as "beautiful baby." Instead, they tended to focus on the scan itself and made fewer attempts to engage parents in discussion or ask questions. Moreover, several sonographers and medical trainees indicated one of the most difficult aspects of their roles was finding a fetal anomaly during a scan and knowing how difficult it would be for parents to hear this news, particularly those parents who were focused on learning positive details about their baby and not on ruling out a fetal anomaly. For example, Brit, a sonographer, described the thoughts and feelings that went through her head when she

assumed she was doing a "normal" scan and suddenly realized she was imaging a fetus

with a severe cardiac anomaly:

Brit: Yeah, if you are expecting it to be normal and then it's not, yeah. Well usually it's like, oh, [makes guttural sound], oh fuck, alright, well, moving along. I'll just keep scanning all the normal things. Take a cine [a sequence of individual ultrasound images]. Go tell the doctor. Let the doctor come in and scan and talk to them because if it's a hypoplastic left heart [a complex cardiac anomaly], that's heart, so that is usually one I just leave for the doctor because they are pretty complicated...

Researcher (R): So do you try to mask that you've seen something wrong? Brit: Yes, unless they start saying, oh what's that? That looks weird. Then, I'm like, yeah, it looks a little funny to me too. I'm just going to check with the doctor... (Brit, L 412–432)

Brit also noted the emotional intensity of performing an ultrasound to confirm the

presence of a complex fetal anomaly previously detected on a community scan:

Brit: Yeah, there's been a lot of times where I've like, I was trying to hold, hold back tears because it's just so sad what's happening, right?

R: I know. Even when that mom was looking at the ceiling and she was crying, ... it must be hard.

Brit: Yeah, there is nothing I can do. I have to do my scan, right, and I can't really do anything for them, just trying to make them as comfortable as possible, like, yeah. And just get what I need and then be done with it kind of thing. Usually when you're like, I don't know, for me when I'm choking back tears I don't usually like to talk that much so I think silence is kind of okay in that situation. It kind of depends on the person. Like if they want something to distract them, I'll go ahead and chat with them, but [laughing] usually that's not the case (Brit, L 1101–1115).

Population based assessment for fetal anomalies operated in a machine-like

fashion, in that it used systematic mechanisms and complex algorithms to automatically

set in place increasing levels of scrutiny when a woman was considered to be at higher

risk for a fetal anomaly or when a fetal anomaly was suspected on a routine screening

exam. Ultimately, most women conformed to organizational and societal pressures to

participate in PNS, albeit often with different priorities than those set out by the healthcare

system. The dominant discourses and frameworks underpinning HCP-parent interactions

in antenatal care were inherent to and enmeshed within how the process of surveillance

unfolded. Moreover, HCPs often communicated diagnostic, prognostic, pregnancy and treatment options to parents, seemingly without realizing the impact, in ways that appeared to significantly influence and shape parents' perspectives and decisions to be consistent with and conform to dominant discourses and established institutional practices and perspectives. In the following section, the analysis will shift to a deeper exploration of the dominant frameworks shaping, sustaining and reinforcing antenatal communication and decision-making practices.

Dominant Frameworks Underpinning, Shaping and Sustaining Antenatal Interactions and Decision-Making Practices

The vocabularies and perspectives of the broader population-based PNS assessment machine were reflected in the interpersonal interactions between HCPs and parents. Specifically, HCPs involved in providing PNS worked within a complex system in which biomedical, efficiency, individualism, immediacy, and other dominant discourses were entrenched in the organizational culture and, as a result, often went unchallenged. Moreover, HCPs took up these dominant frameworks and perspectives to varying degrees, seemingly unaware of the impact dominant discourses and organizational policies had on their overall experience of providing care as well as parental satisfaction with that care. For example, when health providers placed their full attention on detecting a potential fetal anomaly, they might not have realized they were failing to acknowledge parents as integral participants in PNS and/or address specific parental concerns, including parents' mental and physical health and other health priorities related to their pregnancy.

In the following sections, an analysis of the dominant frameworks underpinning, shaping and sustaining antenatal communication and decision-making practices will be

presented. Although each of these discourses will be examined and analyzed separately in order to highlight the specific impact and influence each exerted on how HCP-parent interactions unfolded and developed, these multiple underlying discourses and frameworks were in reality very complex and messy, sometimes working together toward certain ends and sometimes working in opposition. This examination of dominant discourses sets the stage for Chapter Five, which will expand on this foundational analysis of dominant discourses by exploring how dominant and opposing discourses were inescapably interwoven with the enactment of disciplinary and pastoral power, and how parental agency and resistance were demonstrated within these discursive systems.

Biomedical Discourses

A dominant biomedical discourse was evident in the approach modelled by HCPs in their interactions with parents during patient assessments, as well as in how information related to a suspected or confirmed fetal anomaly was presented to and discussed with parents. Specifically, an underlying biomedical framework was evident in: (1) the priority HCPs placed on collecting objective and scientific data related to the physical properties of the fetus and/or suspected fetal anomaly; and (2) the technorational approach to information provision and decision-making. A dominant biomedical gaze in tandem with a techno-rational approach contributed to foregrounding the physiology and pathology of the fetal condition and associated parental decisions over the holistic care of the family unit and the broader determinants of health. Moreover, an almost exclusive emphasis on fetal physiology and pathology often served to reduce mothers to silenced carriers of objective fetal data.

HCPs prioritized objective data on fetal physiology and pathology. A biomedical gaze was apparent in HCPs' actions that prioritized collecting objective data

on maternal risk factors and fetal physiology and pathology. The gathering of objective data constituted a sophisticated apparatus of prenatal assessment and facilitated categorizing the fetus in relation to the risk of genetic and/or structural anomalies and, if present, the level of complexity or severity. In multiple observations of women undergoing detailed screening ultrasounds and/or FEs, HCPs including sonographers, nurses, medical trainees, and medical specialists generally utilized formalized assessment forms and checklists to initiate a series of questions related to the maternal obstetric history, including number of pregnancies, live births, miscarriages, stillbirths and terminations of pregnancies; presence of any maternal health conditions such as diabetes that could potentially negatively impact the fetus; specific PNS tests performed; family or maternal history of congenital or genetic anomalies; and factors known to increase the risk of a fetal anomaly (e.g. maternal drug or alcohol intake or use of specific prescription drugs known to have teratogenic effects). These questions were either asked at the beginning of the interaction, prior to the start of a discussion or assessment, or during the assessment itself (such as during an ultrasound procedure), usually taking two to three minutes and no more than five minutes to complete. In addition, it was not uncommon for parents to go through a similar round of guestioning each time they met with an HCP or team for the first time; parents often reiterated answers to these assessment questions three to four times on the same day. In addition, it was typical for health providers to stick to a standard script when asking these questions, starting with the reason for referral and then quickly moving through the list of questions, which were usually asked in the same order and in the same manner for each patient. It was rare for HCPs to ask specific questions related to the parents' psychosocial, emotional or practical health needs, or for parents to be

asked if they had any questions, except at the end of HCP-parent interactions in relation to diagnostic, prognostic or treatment information provided.

As evident in the preceding vignettes, a dominant biomedical reductionist gaze in tandem with underlying efficiency imperatives shaped and influenced parents' interactions with sonographers and medical staff during ultrasound exams. In addition to the data gathered through verbal interactions with parents, HCPs employed a checklist of required fetal images to ensure completeness of the objective anatomical and functional data captured in the form of recorded ultrasound images, sequences and video clips. Acronyms or abbreviations for specific body parts were often included as part of the captured ultrasound images. It was common for MFM or pediatric specialists to view the ultrasound images in real time on a satellite screen in a nearby or adjacent room, thereby being available to take over the scan or provide additional consultation should a suspected anomaly be detected. Multiple parents used words such as "focused," "methodical," "on a mission," "streamlined" and robotic" to describe the HCPs' interactions during ultrasound exams. These descriptions highlighted HCPs' emphasis on efficient processing of patients and their intense focus on capturing the necessary fetal information required to ascertain the presence or severity of a fetal anomaly, while drawing attention to the lack of a relational approach that would have supported HCP-parent communication and collaboration based on comprehensive assessments, compassion, trust and mutual understanding. For example, Jesse, whose son was diagnosed with a complex fetal anomaly requiring frequent ultrasound assessments, noted the "robotic" nature of their interactions with sonographers "doing their job" to capture the necessary fetal images:

The ultrasound technicians are kind of like robots [laughter]. Really well oiled, good robots [laughing]. They were very pleasant. I don't use the term robot like they are just zombies. I'm trying to describe their focus and professionalism.

R: The sense I'm getting is that you felt the ultrasound techs were very methodical in terms of what they were getting in terms of the ultrasound images, but I'm just curious if on some level you felt, or I guess what I'm wondering is if you felt sort of a connection, a rapport with the technicians or if that was less so? Do you know what I mean?

Jesse: No, no rapport. The only rapport you maybe get is when they come out and call your name and they're walking you to the [ultrasound] room. And then the rapport will come in a way as a smile or that sort of face-to-face contact before you actually arrive in the room. So you walk, you know, they kind of look at you, there is a rapport there, but it kind of ends once they sit down and start doing their job. Oh and then, and then it picks up when they are done and they say goodbye to you. So because we've been there so many times we recognize a few of them, that's really where the only rapport comes in. Once again, like, the scripts come on. They are like a doctor and they are happy to see you and pleasant and then they get to doing their thing. They switch to the professional mode (Jesse, L 403–409, 410–448).

Jesse also highlighted the streamlined, methodical and systematic manner in which the

sonographers captured the necessary images, often interacting with the parents only

when asked a specific question:

"The ultrasound people [i.e. sonographers] were very professional, you know, of course they are, but they are also very, like they are on a mission. I always find they answer your questions if you ask them, but for the most part it's them quietly doing their thing and we are sort of staring at the screen and sort of seeing what is going on and seeing these acronyms that they [the sonographers] type in to describe the shots that they are taking. Yeah, they are almost kind of robotic, but they are there to take the photos that they need to ... I use the word robotic because they really are in that sense. They are really just streamlined in what they do (Jesse, L 266–276).

In addition to detailed ultrasounds and FEs, some mothers underwent

sophisticated imaging exams and genetic testing to capture more specific details about

the nature of the fetal anomaly. In those instances where ultrasound did not provide

adequate detail as to the specific anomaly, fetal MRIs and/or specialized three-

dimensional ultrasounds were employed to go to the next level of scrutiny to determine

the nature or severity of the fetal condition. In addition, it was standard practice for

parents to be automatically referred to genetic specialists when suspicion was raised of a structural or genetic fetal anomaly, either on the basis of prenatal blood work results or when increased suspicion of a chromosomal anomaly was raised due to structural differences noted on a detailed ultrasound. Genetic specialists gathered assessment data on the family unit by constructing detailed family histories of congenital or other anomalies that could indicate an increased risk of a fetal concern. Stemming from these discussions and analyses of the family's health history as well as the results of prenatal blood work and ultrasound findings, parents were given the choice to undergo additional genetic testing, usually in the form of an amniocentesis to definitively identify if a chromosomal anomaly was present. This information was added to the file of objective data captured on the fetal anomaly, which was the basis for HCP-parent discussions on the nature of the anomaly and decision-making related to pregnancy and neonatal treatments. In contrast, specific information related to parents' priorities, personal or family health concerns, or contextual factors influencing their antenatal experience (e.g. financial concerns, coexisting stressors etc.) were generally not collected as part of the standardized assessment process.

Placing a priority on providing diagnostic and treatment information from a dominant biomedical framework foregrounded the physiology and pathology of the fetal anomaly in HCP-parent interactions. This underlying framework, in tandem with a technorational approach emphasizing scientific problem-solving based on objective and scientific data, served to medicalize parents' perspectives and decision-making and implicitly exclude parents from the discussion due to the specialized knowledge and skill required, often reducing them to silenced sources of data. Moreover, the prioritizing in HCP-parent interactions of diagnostic testing and the treatment of disease often resulted in HCPs not

acknowledging the unique perspectives, needs and concerns of parents and families. This was repeatedly evident in the experiences of parents who were learning of the diagnosis of a fetal anomaly for the first time. The following detailed observation of a specialist's first explanation of a complex fetal heart condition serves to illustrate these findings.

Vignette #3: Rose and Nate

Rose and Nate were referred for an FE after suspicion of a fetal heart condition was raised on a community scan. Several days later, as they waited in the tertiary hospital waiting room for the FE appointment to begin, both parents described feeling "worried about the possibility that something could be wrong with the baby's heart," but they were "hoping for the best". During the FE, the sonographer, Beth, focused intently on capturing the necessary fetal images, providing short explanations such as "I'm getting the head circumference" when prompted by Rose or Nate, but primarily working in silence. Rose and Nate watched the fetal images carefully, sometimes discussing them quietly with each other. Toward the end of the scan, Beth was joined by a pediatric cardiologist, Dr. Jones, who entered the room, introduced himself to Rose and Nate and then quickly proceeded to take over scanning while Beth stood beside him and took note of the cardiac images on the screen. As he started to scan, Dr. Jones explained to the couple, "We will sit down and go over everything we find before you leave today." He then focused on performing the ultrasound, making quiet comments to the sonographer and a medical trainee who entered the room unannounced part way through the FE. At the end of the scan, Dr. Jones verbally noted that the results indicated a "problem with the heart," and the parents were ushered into an adjacent meeting room to discuss the fetal diagnosis in more detail.

In the meeting room Dr. Jones and the parents sat around a small table. He started the meeting by stating that the scan had revealed a major concern with the heart, and that he would try to explain the heart condition and treatment options so that they could "make an informed decision." He noted that "one in approximately every one hundred children are born with a heart defect," and that what their baby had was "on the more severe end of the spectrum." Dr. Jones proceeded by asking if the parents remembered how a heart worked from their high school biology class. Both parents, who were teary-eyed and appeared overwhelmed by the news of the major heart condition, shook their head and stated, "No, not much."

Dr. Jones, in a calm and steady voice and neutral tone, proceeded to use a simple diagram of the heart to describe the normal blood flow through the heart and lungs, including the multiple structures involved, and gave brief explanations of atrial, ventricular and valvular function, as well as descriptions of the changes in blood flow during the transition from fetal to neonatal life. This took approximately seven minutes, with both parents silently listening and staring at the diagram of the heart. Dr. Jones then drew a picture of the heart anomaly identified on the FE using a standard template, reviewing the abnormal structures and hemodynamics as well as taking the time to compare the abnormal components to those on the "normal" diagram. Rose and Nate asked a couple of questions during this review,

including "Is it possible for this chamber to grow bigger prior to birth?" and "How does the blood get from here to there (while pointing with their finger) if the valve is blocked?" However, most of the time both parents sat silently, listening and wiping tears from their eyes while tightly holding each other's hands. This overview took another 10 minutes.

Once the physiological details of the cardiac anomaly were reviewed, Dr. Jones spent 10 minutes reviewing a series of complex staged surgical procedures that were the standard treatment for the cardiac condition, as well as discussing treatment outcomes in terms of survival percentage and incidence of major complications such as stroke, major infection and neurological complications. Over the final three to five minutes Dr. Jones also noted that some parents "choose not to continue the pregnancy," and that some children with this condition become candidates for cardiac transplantation depending on the individual nature of the condition and/or the short or long term outcomes.

When Dr. Jones completed his review of the fetal condition and treatment options, he sat back and asked if the parents had any questions. The parents looked up, slowly shifting their gaze from the diagrams. Rose looked at Dr. Jones and said, "It's a lot to take in," and then asked if the child would be "able to participate in normal activities" once the series of surgeries were completed. Dr. Jones responded by explaining most children with the condition participate in most activities that other children participate in, but generally are not "at the front of the pack" in aerobic activities like running.

Dr. Jones then asked if Rose or Nate had any other questions, to which Nate replied "No, not at this time." Dr. Jones nodded his head and proceeded to provide an overview of "the next steps," indicating that separate appointments had been scheduled for the family to meet members of the genetics and MFM teams later in the day. In providing this overview, Dr. Jones indicated that each team specialized in different parts of the care of the mother and fetus. He noted that as a pediatric cardiologist his role was to discuss "heart matters" with them and that other members of other teams would discuss "other things," like the possibility of doing genetic testing to rule out genetic concerns that are sometimes associated with cardiac anomalies. Dr. Jones wrapped up his meeting with the family by noting the need for a follow-up echocardiogram in six weeks, should the parents choose to continue the pregnancy. Rose responded immediately by asking specifics about how the ultrasound would be booked. As Dr. Jones gathered his things and stood to leave, he handed the parents a card with information on who to contact if they had any questions prior to the follow-up FE. He then excused himself from the room, noting how he was behind in seeing his other patients. As he was turning to go, Rose and Nate thanked him for "going over everything" and "for all of your time."

Overall, the meeting took approximately 40 minutes, of which four to five minutes involved the parents talking or asking questions, and the remainder involved the specialist reviewing detailed diagnostic and prognostic information. In a subsequent interview with the parents, they expressed gratitude to the specialist for the "time he took" in reviewing the complex fetal anomaly, especially given "how busy he was" and "how many other parents he needed to see." However, both parents also indicated that they were too overwhelmed to take in much of the information provided and that they left the initial meeting with many unanswered questions that came to them in the hours and weeks that followed, prior to their next follow-up appointment with the cardiac specialist. They chose not to contact the cardiac team prior to their follow-up appointment, as "it wouldn't change anything—we are not terminating the pregnancy" and "we did not want to bother them." Moreover, they explained that "understanding all of the details" was not as important as their main priority, which was "putting our trust in God to take care of our baby." They also indicated that in hindsight they would have preferred to know more about what it would be like to care for the baby; what differences, if any, to expect in terms of growth and development; how to talk to and prepare their fiveyear-old daughter for the baby's heart condition and neonatal hospital stay; and practical advice and support on taking stress leave from work in the week following the antenatal diagnosis.

Techno-rational approach to information provision and decision-making. An integral component of the surveillance machine was that HCPs expected parents to conform to understanding the nature of the fetal anomaly from the perspective of a biomedical lens and approach pregnancy and treatment decision-making using a techno-rational approach, consistent with standard HCP practice. This approach employed technical and scientific problem-solving to address diagnostic and treatment options. Specifically, the influence of a dominant biomedical discourse and techno-rational approach was apparent in how HCPs: (1) utilized a medical case format of information provision when explaining fetal anomalies to parents; (2) incorporated standard medicalized scripts, which emphasized the inner workings of biological systems; and (3) prioritized quantitative over qualitative information when providing diagnostic and prognostic information to parents.

As was evident in the vignette of Rose and Nate's initial interaction with the health care team related to the diagnosis of a fetal cardiac anomaly, the dominance of the biomedical model and resultant emphasis on fetal physiology and pathology implicitly excluded parents from healthcare discussions because of the extremely specialized knowledge and skill set required. This was evident in HCP-parent interactions that involved gathering objective scientific data through technologically specialized
assessments such as detailed fetal ultrasounds, which one parent described as looking like "a TV screen full of static when the cable goes out" (Eugene, field notes). This was also apparent in HCPs' provision of information related to the nature of the fetal anomaly, which was predicated on a comprehensive understanding of complex biological systems. As described in the preceding vignette of Rose and Nate's experience, HCPs tended to follow a standard medical script when describing fetal anomalies (in comparison to "normal" anatomy) and reviewing associated risks and outcomes. This presentation style was similar to that used by medical trainees when presenting a "case" during medical rounds. Although the script varied slightly from patient to patient depending on the nature of the specific condition, it usually included a review of the incidence of the anomaly; recurrence risk; risk of associated chromosomal/non-chromosomal syndromes or anomalies; ranking of severity, morbidity and mortality risks associated with treatment; and anticipated short- and long-term outcomes. Moreover, as a result of the priority given to fetal pathology and physiology in the discussion of the fetal anomaly, parents were rarely required to speak during the initial "discussion" of the fetal anomaly. Rather, the physiology of the fetus—extracted from prenatal blood work, detailed ultrasounds, FEs, amniocentesis and any other antenatal diagnostic tests—spoke for the parents, thereby reducing the parents to mute and submissive sources of data.

As depicted in the vignette of Rose and Nate, in addition to the use of standardized medical scripts, it was common place for HCPs to prioritize quantitative data when providing diagnostic and prognostic information by incorporating statistical estimates, odds, and rankings of severity in either descriptive form (e.g. severe, moderate, or mild forms of an anomaly) or numerical form (e.g. rating an anomaly at a six on a scale from one to 10, where one is extremely mild and 10 severe). In contrast, qualitative data such

as quality of life (QOL), impact on the family, and caregiving demands were less likely to be reviewed; rather, they tended to be added on at the end of the initial discussion or presented in response to parents' questions. Furthermore, information about anticipated QOL and caregiving demands were often focused on in more detail during follow-up meetings with the healthcare team in response to questions the parents formed after the initial diagnosis during "frantic Google searches" or online discussions with other parents who had children with similar conditions. However, parents who chose to terminate the pregnancy based on the initial information received usually did not meet with the subspecialist team again, and therefore the healthcare team did not review this qualitative information.

A biomedical and reductionist gaze was also evident at an organizational level in how the system was organized such that when a fetal anomaly was suspected or confirmed, parents were automatically booked into separate meetings with different medical subspecialists/teams to discuss the fetal diagnosis from the perspective of each of the medical subspecialities involved. As in Rose and Nate's vignette, parents who received a diagnosis of a fetal cardiac anomaly typically met with the pediatric cardiology, genetics, and MFM teams sequentially on the same day or in multiple appointments over several days, with each team providing information on the diagnosis from the perspective of their medical subspecialty. This was consistent with a dominant biomedical perspective that seemingly reduced the fetus into different biological parts to be serviced by specialized teams and foregrounded the physical nature of the health concern over other components of fetal, maternal or family health. As a result, parents often described trying to make sense of a summary from each team on a specific body part or system, separated from the whole. Parents were then left to reconstruct the nature and extent of the fetal concern from the different puzzle pieces they had been given. Moreover, numerous parents indicated they would have preferred a combined meeting with all the specialist teams (MFM, genetics, pediatric subspecialty, etc.) in order to have an opportunity to directly address HCPs' mixed or conflicting information or perspectives on the diagnosis, prognosis and treatment options.

Rose and Nate's experience also illustrates the impact on HCP-parent communication and parent outcomes when HCPs assumed parents would view the fetal diagnosis through the same biomedical lens and make decisions using a similar technorational approach to the one HCPs employed in clinical practice. Despite providing a comprehensive review of information related to fetal physiology and pathology, HCPs did not explore parents' priorities, concerns or perspectives on what information they viewed as imperative in making antenatal health decisions. In addition, with HCPs' attention and priority fully focused on reviewing the pathology of the fetal condition and associated medical options in an efficient manner, parents' emotional needs were overlooked. Rose and Nate silently wiped away their tears, trying to remain composed as the specialist reviewed cardiac blood flow patterns, a complex fetal anomaly and a series of medical treatments. Other than acknowledging the difficulty of the diagnosis for parents and offering them tissues to dry their tears, the emotional and psychological impact of the diagnosis as well as potential resources and supports to address the full complement of parental needs often went unaddressed until a follow-up appointment several days to weeks later, if then. As a result, many parents described leaving the hospital following the diagnosis of a fetal anomaly with unaddressed emotional and practical needs and feeling information overloaded as they went home to absorb the full impact of the diagnosis and prepare to make critical parenting decisions.

The preceding analysis of how dominant biomedical discourses shaped and influenced antenatal HCP-parent communication and decision-making sets the stage for the analysis of health inequities in Chapter Five, in that it highlights that the full range of parents' health needs were not consistently addressed, as well as draws attention to the differences in parents' experiences due to social positioning and other factors. Furthermore, HCPs' actions that focused on summarizing the objective data gathered on the physical nature of the fetal anomaly served to marginalize the importance of the HCP-parent relationship in antenatal care and decision-making, and ignored the complex real-world problems and concerns parents considered in making antenatal decisions.

Efficiency/Scarcity Discourses

Observations of HCP-parent interactions and detailed interviews with parents illuminated the multiple efficiency imperatives that, together with dominant biomedical frameworks, shaped organizational procedures and processes, often impeding and obstructing individualized, holistic and relational models of care delivery. Dominant efficiency discourses promoted brevity in HCP-parent interactions through organizational protocols that prioritized efficiency in care delivery; streamlining practices that utilized standardized processes and assessment tools; and outcome measures that reinforced and sustained these practices, often with little acknowledgement or consideration of how these practices compromised HCP-parent communication and quality of care as a result.

Finding time: Efficiency-driven practices impeded quality of care delivery. Availability of time was a prominent influence in the delivery of antenatal care. In particular, competing demands on HCP time were a constant focus in antenatal HCPparent interactions. Appointments were scheduled in such a way as to maximize the number of patients seen, and it was not uncommon for staff to accommodate additional patients who were referred for urgent assessment. HCPs often commented they were "working short" or "having to cover" for other providers and/or programs. HCPs' cell phones and/or pagers often rang in the middle of parent meetings, requiring HCPs to temporarily leave the room to take the call. Moreover, multiple observations of the same clinic over many sessions highlighted that these practices and policies were entrenched in the day-to-day functioning of the clinic, rather than sporadic or infrequent events. These and other factors contributed to the intense and constant time pressures HCPs faced in delivering care as efficiently as possible under organizational directives to maximize patient throughput and minimize patient wait times. The gravity and responsibility of needing to provide parents with accurate and comprehensive information about the health of their fetus in order to facilitate potentially life-altering decisions within the timepressured context of an evolving pregnancy appeared to reinforce the emphasis and priority given to time in HCP-parent interactions. In response to these multiple time pressures, numerous streamlining practices and protocols were in place to maximize efficiencies in antenatal care delivery, including: (1) efficiency-driven problem-focused assessments and interactions; (2) standardized task-based checklists; and (3) appointment scheduling that emphasized system efficiency over the needs and time of parents. As will be illustrated, substantial tensions existed between efficiency imperatives promoting brevity in HCP-parent interactions and decision-making (through streamlining protocols and efficient "processing" of patient referrals) and the organizational value placed on providing comprehensive, relational and family-centred antenatal care.

Efficiency-driven interactions prioritized physical elements of care. The underpinning organizational culture and dominant biomedical and efficiency discourses shaped and influenced the priority of antenatal care to focus on the pathology of the fetal

diagnosis, consistent with a biomedical reductionist focus that foregrounded diagnosis and treatment of the fetal anomaly in HCP-interactions. Partly due to the time constraints dictated by the system, health discussions were largely restricted to reviewing physical findings and an overview of treatment options, minimizing the time HCPs were obligated to spend with the family. This reinforced and promoted the idea that there was insufficient time available for detailed assessments of parents' priorities or needs and/or meetings with additional health professionals that could facilitate a comprehensive understanding of the family's unique experiences and provision of psychosocial, emotional, practical and other support. Often medical professionals indicated they had a hunch or a feeling there were other important parent or family issues under the surface that were left unexplored in HCP-parent interactions, but that there was "not enough time to go there," or that it would be "interesting" to have a better understanding of parents' perspectives or non-physical health concerns but, given the time constraints, these were not essential to understand. Inadequate time for parent conversations was a common frustration voiced by many HCPs working in antenatal care, as was the lack of dedicated nurses, social workers and/or psychologists to address the non-physical needs and concerns of parents and families. HCPs often linked a lack of services to limited budgets and the low priority these services and supports were given within the organization. Moreover, although the organizational mission statements and values highlighted the importance and priority of patient-centred, collaborative, and individualized care, in practice the system dictated a set amount of time for HCP-parent interactions following the initial diagnosis of a fetal anomaly, and priority was generally given to describing the fetal pathology and treatment options rather than understanding the parents' unique perspectives, health needs, coexisting stressors, burdens or needed resources. Given the focus on the physical aspects

of care, it was not surprising that when nursing, social work, psychology or other allied health services were available (albeit in limited amounts), the psychological, emotional, and decision-making support potentially available from these health professionals were rarely if ever given priority or foregrounded in antenatal care provision by medical professionals. With the exception of a specialized nurse clinician at one of the two sites who routinely met with parents at the time of the initial diagnosis of a cardiac fetal anomaly and was available for additional support for the remainder of the pregnancy, it was rare for nursing or other allied health services to be consulted to assess parents' needs or offer support. In addition, referrals to social work or nursing were generally made with the explicit request to re-review the physical nature of the disease and/or medical treatment options, or provide practical help with parents' specific one-time requests for support such as financial assistance for meals or transportation or help in finding temporary accommodation near the health centre.

Standardized tasks and checklists reinforced efficient interactions. Many HCP practices were task-oriented, which served to reinforce efficient interactions with parents. For example, HCPs tended to use formalized assessment forms, flow sheets and checklists to guide their patient histories, physical assessments and diagnostic screening examinations. By maintaining a focus on the pre-determined questions and assessments to be completed, HCPs' often focused their attention on the physical and pathological aspects of the fetal condition that were foregrounded in these documentation tools, and away from the broader scope of potential parental concerns or questions, which often went unaddressed. Moreover, HCPs often prefaced their interactions with parents with a comment on the nature of what to expect during their interaction and the anticipated duration or a proviso of how much time they had to meet. In fact, it was rare for an HCP to not mention time (e.g. "The fetal echo should take about 30 to 45 minutes," or "We expect this meeting will take 15 to 20 minutes, during which we will discuss..."). This was effective in setting explicit parameters about what would (and would not be) discussed and reinforced HCPs' ability to control how interactions would unfold. The priority HCPs placed on efficiently working through a specific task was highlighted during detailed fetal ultrasounds when sonographers or medical personnel employed an explicit checklist of images they needed to capture and record for the scan to be considered complete. The majority of HCPs prefaced these interactions with estimated time frames for completion as well as explanations that no specific information on findings would be provided during the scan; rather, all results would be reviewed and discussed after completion by the attending specialist. This was usually effective in preventing interruptions or questions from parents during the ultrasound exam, even though parents (especially fathers) often expressed their frustration to me at the end of the scan that they had hoped to receive a "guided tour" of the fetal images captured by the HCP performing the ultrasound procedure.

Appointment scheduling prioritized system efficiency over quality of care.

The manner in which patient appointments were scheduled often prioritized system efficiency over the needs and time of parents. As previously discussed, patient scheduling for an initial assessment of a suspected fetal anomaly involving multiple subspecialist appointments over the span of several hours was underpinned by dominant efficiency imperatives that prioritized the time pressures of HCPs over the needs and time of parents and families, in that meeting with all of the specialist teams at once would have required HCPs to spend additional time listening to the perspectives and viewpoints of other professionals rather than simply providing their perspective and moving on to the next patient. Parents reported similar scheduling processes for follow-up appointments, which were characterized by a day of short visits with individual professionals separated by long wait times in stress-filled waiting areas. Callie, who required frequent ultrasound assessments over the course of several months for a complex fetal anomaly, emphasized her frustration with this scheduling system that prioritized system efficiency over the care needs of parents and families:

I was put into the regular rotation of appointments with the MFM docs and sort of one of the different sub-teams. And that would be a series of ultrasounds and then a series of appointments and then the series of you know, the sort of what does [the results of] this appointment look like, and then let's do the next one. ... And then they would leave you in the room, somebody would go read the ultrasound, and then sometimes they would come back in and either say, like, 'you're okay, we'll see you at the next series of appointments.' Or someone would come back in and do more readings and talk about what they had seen. Then you leave the ultrasound room, then you go over to the other desk so you show up for an ultrasound, you wait and then you go to the other desk, you know, register, get weighed, sit with everyone else who has any other situation going on, sometimes for quite a while. Then you go into the exam room, you wait in the exam room, and then somebody comes in and tells you about what they've seen in that ultrasound ... sometimes the ultrasound tech didn't tell me. ... And then they stick you in a room and you wait for a really long time and if you are a pregnant woman you often have to pee, so the hard part is like you have to run out and use the restroom and hope that [you don't miss them]. You never know when they are going to swing by (Callie, L 950-976, 997-1000).

The efficiency-based scheduling of patients for multiple appointments with multiple

HCPs or teams also resulted in parents being inadvertently exposed to the emotional distress of other parents, many of whom they came to know while they waited together week after week for their antenatal appointments. Exposure to the emotional distress of other parents who also required antenatal monitoring for a pregnancy and/or fetal concern was often emotionally taxing for parents. Multiple parents commented on this, especially those who were required to have frequent ultrasounds and assessments because of an increased risk of fetal demise. For example, Callie described an event that was particularly distressing for her while she waited for an antenatal appointment:

They left me in a room for forty minutes waiting to get an ultrasound while the woman next door to me was told that she had lost her pregnancy ... and she was just sitting there screaming and rightly so, you would scream. R: Hmm, I can't imagine going through that in your shoes. Callie: The way in which they treat the women and the system in which they bring them in and out of the ultrasounds is not patient-centred because some of those women are going to hear that their children have not survived. And some of those women, like me, are waiting to hear whether or not their children have survived week over week, just [waiting] to find out if they survived this week (Callie, L 1825–1843).

Inflexible appointment times also resulted in prioritizing system efficiency over parental needs. Although the booking system generally allowed for a pre-set amount of time for each appointment, with additional time given for multiple pregnancies (e.g. twin/triplet), not all appointments were "processed" in the scheduled amount of time. Rather, the scheduled time was often taken for granted as a reasonable window of time in which to complete a normal scan or a scan with a minor concern requiring follow-up. In actual practice, ultrasound assessments (e.g. a detailed scan and/or a FE) that resulted in the initial diagnosis of a fetal anomaly often took two to three times longer to complete than originally scheduled, resulting in an almost perpetual feeling from HCPs that they needed to rush in order to catch up. For example, it was not uncommon for an appointment that was scheduled to take 30 minutes to take one to one and one half hours, as additional time was needed to consult with subspecialists, repeat portions of the scan in order to gain clarity on the exact nature of the diagnosis, and meet with parents. This process often resulted in long wait times for parents as HCPs scurried to make up for the lost time associated with a fetal diagnosis. In addition, scheduling imperatives often contributed to HCPs focusing on completing "normal" scans in an even more efficient manner, with little time allowed for parents' questions or concerns given the underlying unspoken assumption that since the ultrasound results were normal, any parental questions or concerns were less of a priority and could be addressed at a later time by the

family doctor or obstetrician, rather than extend the waiting time for parents whose appointments were already delayed. HCPs frequently made statements such as, "The [fetal diagnosis] is making us really behind. We have a lot of catch-up to do if we want to get out of here on time". Delays, "running behind" and "struggling to get caught up" were taken for granted aspects of day-to-day work life for HCPs working in antenatal care.

Interestingly, even when the antenatal clinics were not as busy as usual, and HCPs did not have pressing demands on their time, the nature of HCP-parent interactions rarely changed. The routinized process of adhering to efficiency imperatives was entrenched in the day-to-day functioning of the clinic. As a matter of practice HCPs were cognizant of prioritizing efficiency in every aspect of their practice and sought out ways to expedite patient processing. HCPs' intense focus on staying on time with scheduled appointments while capturing the necessary objective data about the fetal condition often resulted in increasing tensions in HCP-parent communication, especially when more time would have been beneficial in understanding and addressing the broader spectrum of parents' needs and priorities, such as providing emotional support to anxious parents who previously experienced a stillbirth and were undergoing their first detailed scan in a subsequent pregnancy.

HCPs and parents conformed to efficiency imperatives. Parents often commented that they wished for more time to spend with medical subspecialists because they did not have time to ask all of their questions or discuss specific concerns; however, rather than requesting more time or contacting the HCP to set up another meeting, parents tended to conform to organizational imperatives foregrounding brevity and efficiency in HCP-parent interactions. This was evident in multiple parental comments such as, "I don't want to bother them [HCPs] [with a specific concern], they are so busy,"

"I can wait to ask them next time, I don't want to use up any more of their time," and "We were really grateful for the time she did spend. We know how busy she is..." (multiple parents, field notes). Of particular note was that even after the initial fetal diagnosis, when parents described being "overwhelmed," "dumbfounded," "in a daze," and "needing time for the news to sink in," parents were reluctant to contact the medical professionals, and many waited two to six weeks until the next follow-up appointment to have their questions and concerns addressed. Moreover, despite several medical subspecialists providing contact information and indicating at the end of the initial visit that parents should call or email with questions or concerns, most parents remained very reluctant to take up the doctor's time; rather, they described "Googling like crazy," "desperate" and "frantic" Internet searches, and numerous phone calls to families or friends who they felt might provide them with information and insight on the fetal condition or the decisions they faced. Furthermore, parents conformed to organizational efficiency imperatives by generally accepting HCPs' apologies or explanations for delayed appointment starts, interruptions during parent meetings and rushed meetings in order to "move on to the next patient." In addition, the majority of parents quietly accepted and even expected long wait times for appointments and efficiency-based HCP-parent interactions, often commenting on how busy the clinic was or on the number of people waiting to be seen. I did not observe any parents attempt to challenge the system's efficiency directives by requesting more time with HCPs. Rather, it was common for parents to profusely thank HCPs for "squeezing them in" or apologize for "taking so much of your time today," even when the appointments were less than 10 to 15 minutes in duration. At the same time, HCPs were often self-congratulatory on how many diagnostic tests they performed, how many

patients they were able to see and/or how many "difficult" or "complex" consults they had completed.

When parents did express frustration with wait times or inadequate time with HCPs, their frustrations were framed as taken-for-granted assumptions about the inner workings of the system, and not directed at individual HCPs. Parents stated these frustrations in ways that conformed to the system's efficiency imperatives, in that they accepted these limitations as an inherent part of how the system worked. One couple's experience particularly stood out as an example of how parents conformed to the dominant efficiency discourses underpinning and influencing the workings of the health system. Carrie, a health professional who was pregnant with her first child, shared the worry and anxiety she and her partner experienced when a fetal cardiac rhythm abnormality was detected on a routine detailed screening ultrasound performed in their local community. The sonographer performing the scan did not indicate to the parents that an abnormality had been detected (possibly it was not detected until the scan was read by the medical specialist later in the day), and the parents left the appointment excited and happy, recalling the images they had seen of their developing fetus. The parents remained unaware that a fetal concern had been detected until the mother received notice from the receptionist at her family doctor's office that an FE was booked in seven days in conjunction with a referral to see a fetal cardiac specialist because of a "problem with the fetal heart rhythm." No further details about the level of concern or specific fetal rhythm abnormality were provided other than "that's all we know," "Things should be okay," and "We have made sure to get you in [for an FE/consult with a fetal cardiology specialist] as guickly as possible." This phone call resulted in a prolonged spike in parental angst and concern while the parents waited for the appointment with the cardiac specialist. Carrie

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stated, "I worried my baby's heart might suddenly stop," and, "I tried to keep myself calm so I wouldn't cause the baby any added stress, but it was hard, I was scared to death..." (Carrie, field notes). Carrie also noted that she took time off of work because of the level of her emotional distress related to the suspected fetal concern. At the start of the FE several days later, Carrie noted her anxiety and concern about the suspected fetal cardiac concern and was guickly reassured by the sonographer that "everything looks fine today." During her subsequent meeting with the pediatric cardiologist, Carrie was reassured that the results did not indicate a significant fetal rhythm disorder and that what was seen on the community scan was most likely a "normal variant." In my discussion with Carrie afterward, I asked if it would have been helpful for her to have spoken with the medical practitioner who read the community screening ultrasound and referred her for further testing, as they might have been able to provide more information about the level of concern and calm her worries about a risk of a sudden fetal demise. Carrie's response was similar to many other parents who conformed with the efficiency imperatives of the system—"You can't expect the radiologist to give the results [of the community screening ultrasound] to every woman ... they have so many people to see, they can only speak to parents when there is an extreme situation-they just don't have that kind of time" (Carrie, field notes). When asked what she considered an "extreme situation," Carrie noted, as an HCP working in antenatal care, that the only time she was aware a radiologist would be expected to meet with parents at the time of a PNS ultrasound was if there was a fetal demise or a suspected diagnosis that threatened the life of the mother.

Carrie's experience was not uncommon. When questioned about the specifics of the reason for the referral, several parents noted that they had been phoned by their family doctor or doctor's receptionist and told they had been referred for additional diagnostic testing (repeat detailed scan or FE or both, sometimes in addition to a genetic consult) for "a possible concern" or "suspected problem with [a specific body part or system such as the heart, kidneys, or brain]" or "because the team wasn't able to see everything they wanted." The majority of parents did not question the workings of this referral process or expect a conversation with the practitioner reading the screening ultrasounds. Rather, several of them reiterated that when undergoing PNS, "no news is good news." Martha, who was expecting her third baby and who was referred for an FE because of the increased risk of a fetal cardiac anomaly associated with her diabetes, explained, "If you don't hear anything from the doctor's office within a few days to a week after the scan, you can take a sigh of relief and know that everything looked okay. No call is a good thing. It's when they call that you have to worry" (Martha, field notes). In this way, parents conformed with the healthcare system's emphasis on efficient HCP-parent interactions by silently accepting that: (1) it is unlikely HCPs responsible for reading screening ultrasounds will provide information to parents about the ultrasound results; (2) it is acceptable for parents to assume that screening results are normal unless they receive a phone call within a few days indicating it is not; and (3) HCPs are not required to provide detailed explanations to the parents as to the reason for referral for more specialized prenatal diagnostic testing (parents are expected to wait until they are seen by the specialist and should assume everything in the interim will be fine).

Occasionally, the efficiency-driven workings of the broader system resulted in the HCPs at the specialty hospital expressing their frustration and anger with community HCPs who referred women for additional diagnostic testing for a suspected fetal anomaly without communicating this concern to the parents. For example, there were several instances when HCPs expressed their frustration that parents "had no clue" or "had no idea that a [major fetal anomaly] was suspected on the community scan," and "how unfair" it was that "they [the parents] are completely unprepared for a diagnosis of [a complex fetal anomaly]." Moreover, these HCPs expressed their frustration at how difficult it was to have to perform a detailed ultrasound when the parents were completely unaware that anything was wrong, even though suspicion of a fetal anomaly had been raised on a routine screening ultrasound several days previously. They described feeling like the referring team was "passing the buck" or "got out of that one [difficult discussion with the parents]." In addition, the parents involved often described being completely unprepared for the fetal diagnosis and the nature of the multiple meetings with the healthcare team that were planned for the day, using descriptors such as feeling like they had been "hit by a train," "bowled over" or "totally unprepared," as they had only received vague indications for the reason for the referral, such as "We were not able to get all of the images we needed."

Efficiency-based outcome measures reinforced prioritization of physical care. Efficiency-based outcome measures of antenatal care provision emphasized quantitative over qualitative evaluation, serving to reinforce and sustain a narrow focus on the physical aspects of care rather than address gaps in care or acknowledge where quality of care could be improved. For example, over the course of the study, several quality improvement projects and other formal and informal organizational initiatives were started or continued that ultimately aimed to maximize patient "throughput" (the number of patients seen/processed in a given time) or the specific number of diagnostic tests performed (such as the number of detailed scans or the number of amniocenteses completed per day or per week), often couching these organizational goals in patientfriendly terms such as initiating changes with an overall aim to "decrease patient wait times." There was also a high level of formal and informal organizational scrutiny of any actions or processes that impeded efficient throughput of patients scheduled for sequential meetings with multiple care teams in one day, with any HCP or practices that delayed meeting the set timelines usually met with negativity and possible sanctions. For example, there were several instances when parent-HCP meetings went over the scheduled meeting time and the HCP who was waiting to see the parents for their next appointment phoned, paged, or knocked on the door in efforts to expedite the completion of the meeting, indicating the delay was creating a backup of patients yet to be seen. Similarly, there were a handful of times when clinic staff deemed the process of obtaining parental consent to participate in the study would cause unnecessary additional delays in starting the FE, even when parents clearly indicated a desire to participate in the study. During these times, parents were brought in for their ultrasound while I was otherwise occupied, resulting in my inability to observe the fetal scan. Interestingly, this usually occurred when the clinic was ahead of schedule and team members were waiting for the next patient to arrive.

Organizationally driven quality improvement measures focused on quantitative outcome measures, with measures of quality of care generally limited to measures of the quality of diagnostic assessments. For example, in addition to continuous quality improvement strategies to monitor the number of ultrasounds performed within a standard period, there were also semi formalized procedures in place to review antenatal screening assessments for infants born with significant fetal anomalies not detected on PNS assessments. On the other hand, there was a dearth of outcome measures that assessed the quality of HCP-parent interactions or parent satisfaction with care, either formally or informally, within either organization. Moreover, it was rare for HCPs to ask parents about

the nature of their antenatal experience or solicit feedback on how care could have been improved. Interestingly, several parents indicated that a major reason they wanted to participate in this study was that it provided them with an opportunity to tell their story in the hopes that future antenatal care and support could be improved for parents and families.

Individualism Discourses

HCP-parent interactions highlighted the influence of individualism discourses, in tandem with biomedical and efficiency frameworks, in shaping and influencing antenatal care provision. Individualism constructs humans as distinct and rational agents, prioritizing their autonomy, personal rights, self-determination, and freedom to make decisions and act as individuals separate from the greater society. An underlying individualism discourse was particularly evident in HCP-parent interactions related to PNS, diagnostic testing and decisions related to pregnancy and treatment options; in HCPs' intentions of employing a nondirectional approach when providing information and discussing antenatal decisions; and in how the majority of HCPs eschewed paternalistic practices and consistently emphasized that health decisions were the parents', not the HCPs', to make.

Women's participation in PNS can in and of itself be viewed as a means of enacting their autonomy and freedom to learn detailed information about their fetus and thereby make independent decisions related to the pregnancy and/or neonatal treatments. Prior to the introduction of PNS and the availability of legal abortions, women did not have a choice in these decisions; rather, babies with congenital anomalies were born and diagnostic and medical treatment options were reviewed with parents after birth. Technological and medical advancements over the last several decades have led to the development of PNS tests that make it possible to inform women and their partners of the presence of a fetal anomaly, review potential management and treatment options, and prognosticate short- and long-term outcomes. Likewise, political, legal and social changes have contributed to the availability of medical abortions, thereby allowing women to choose to exert their personal right to terminate a pregnancy for any reason, including the presence of a fetal anomaly, prior to approximately 24 weeks gestation.

The documented benefits of PNS include increased reproductive choice and the potential to improve neonatal outcomes. Consistent with this premise, HCPs encouraged women considered at increased risk for a fetal anomaly to pursue additional antenatal screening, with the implicit assumption that antenatal diagnosis of a fetal anomaly would facilitate parental decision-making related to pregnancy management and neonatal treatment options. These decisions, and others, were underpinned by individualism discourses that foregrounded autonomy, personal rights, and self-determination in health decision-making, often minimizing the importance of the unique histories and perspectives of parents and the broader contextual determinants of health in the process. Moreover, a dominant individualism discourse was apparent in the significant emphasis in HCP-parent interactions on the right to know about the presence of fetal anomalies, the right to know about diagnostic and treatment options, and the right to choose. However, there was minimal emphasis in any HCP-parent interactions on parents' right not to know and not to choose, which would have challenged the legitimacy of inherent structures and processes that influenced and shaped parents' behaviours to be consistent with HCP-constructed norms.

Consistent with dominant individualism imperatives guiding professional practice standards intended to safeguard patients and families from paternalistic approaches in

health interactions, HCPs emphasized the importance of parents making independent decisions. Numerous HCPs specifically explained it was outside of their scope of practice to offer paternalistic suggestions or recommendations on antenatal decisions, emphasizing parents' responsibilities and rights in making reasoned decisions about what was best for them based on diagnostic and prognostic information provided by HCPs. Aligned with individualism frameworks, the majority of HCPs described aiming to be nondirectional in their discussion of pregnancy and treatment options. This approach was characterized by unidirectional information flow, objectivity, and neutrality in parent-HCP interactions. However, as will be presented in the analysis of disciplinary and pastoral power in Chapter Five, parents described "reading between the lines" and "trying to figure out what they [HCPs] were saying we should do without directly saying it" (multiple parents, field notes) to explain how parents' decisions were guided by HCPs' often subtle and covert normative prescriptions of what were "good" and "bad" decisions. These findings challenged the commonly held assumption that parents were autonomous individuals enacting their own agency in antenatal health decisions.

Uncritical acceptance of dominant individualism discourses also posed several challenges to HCP-parent communication, in that it decreased the priority placed on seeking input from family members or significant others in making health decisions, as well as limited the value of considering the contextual factors affecting health choices. Parents emphasized that their antenatal decisions were strongly influenced and shaped by cultural, religious and personal factors, yet in HCP-parent interactions HCPs prioritized providing parents with decontextualized information that foregrounded the pathology of the fetal anomaly and associated treatment options with little attention paid to the parents'

unique perspectives, priorities and concerns. In this way, HCPs' actions might have impeded rather than supported parental decision-making.

Responsibilization and Disability Discourses

Antenatal HCP-parent communications and decision-making were also underpinned by responsibilization discourses, which placed increased responsibility and accountability for antenatal health choices on individual parents, empowering them to make their own health decisions, while simultaneously setting expectations that choices be guided by knowledgeable experts and normative prescriptions of what constituted the "best" antenatal decisions. A dominant responsibilization discourse, consistent with neoliberal ideology and engrained in the health consciousness of Western society was a prominent undercurrent in HCP-parent interactions. This was evident in HCP communications that emphasized optimizing health and reducing the risk of maternal and fetal illness through lifestyle changes during pregnancy (e.g. healthy diet, prenatal exercise, stress reduction, smoking cessation, and avoiding alcohol and drug intake), thereby constructing and reinforcing a norm of health-conscious individuals expected to take up healthy lifestyle choices. In this way, "health" and "illness" were largely removed from the domain and authority of individual HCPs and broader health organizations and placed onto the shoulders of health-conscious individuals who were made to feel responsible for their own actions and circumstances. Under this logic, individuals were viewed as both the cause and solution of potential health problems, decontextualized from the unique histories and perspectives of the individuals themselves as well as the broader social determinants of health. A responsibilization discourse was evident in women's descriptions of "doing everything they could" to ensure a healthy baby, including eating a healthy diet, decreasing stress, and for mothers with diabetes, being

"hypervigilant" with their diabetic monitoring and management. This dominant discourse also underpinned many women's initial reaction of assuming they "did something wrong" or somehow could have prevented the fetal anomaly through better lifestyle choices. Similarly, HCP-parent interactions related to antenatal decision-making both reflected and reinforced a responsibilization discourse, in that parents often described feeling pressured to make "responsible" and "accountable" health choices to "prevent" childhood illness, avoid suffering, and ease the economic burden involved in caring for and treating children with complex health conditions through termination of pregnancy. In this way, the discourse of responsibilization became a directive of economic efficiency as well as an ethical obligation of being a good patient, parent and citizen.

Intricately enmeshed with individualism and responsibilization discourses was a pervasive disability discourse, in which parents' rights to make autonomous choices related to whether to have a child with a known fetal anomaly was influenced by a culture in which there is acceptance of people who become disabled but less acceptance of parents who choose not to prevent the existence of a disabled future individual. Moreover, attitudes toward disability were found to be changing in relation to PNS and antenatal diagnosis—where once a child born with a congenital anomaly was accepted as unavoidable, discussions with a number of parents and HCPs indicated a trend toward viewing congenital anomalies as preventable when diagnosed antenatally. Furthermore, there appeared to be an underlying assumption among some HCPs that babies born with antenatally diagnosed disabilities endure needless pain and suffering and create an unnecessary burden on parents and the healthcare system. As will be discussed in detail in Chapter Five, multiple parents who chose to continue the pregnancy described the effect of these assumptions on HCP-parent interactions, and how they enacted their

agency in response to their perception that HCPs and others were viewing them as "contributing to the problem" rather than being part of the solution.

Social Context of Care: Technology-Driven Care and Immediacy of Information Provision and Decision-Making

In addition to the dominant discourses underpinning, shaping and influencing antenatal care, there were two interrelated factors of the social context that impacted the character of antenatal HCP-parent interactions and decision-making, namely the technology-driven nature of healthcare and communication and the immediacy with which information was expected to be gleaned and/or provided and health decisions were to be made. A culture of immediacy of information was part of the underlying social context and was inescapably linked to the technology-driven and technology-saturated nature of current society. For example, whenever a parent was seeking out an answer to a question related to the suspected or confirmed fetal anomaly or associated medical treatments, searching the Internet via a cell phone, laptop or tablet provided an immediate answer. Moreover, the quality of the answer was often given less priority than the efficiency with which it was retrieved using online sources. This was clearly repeated again and again when parents were observed Googling potential fetal diagnoses they overheard HCPs discussing during screening ultrasounds. In addition, the taken-for-granted assumption that the necessary information to make day-to-day decisions was readily available via the Internet contributed to an expectation that health decisions could also be expedited in an efficient manner. A focus on immediacy of information provision and decision-making also placed less emphasis on the process of HCP-parent communication and the need for reflection, debate, and deliberation over important antenatal decisions. Rather, HCPparent interactions, just like Internet searches, focused less on two-way communication in

the form of listening, understanding and responding to parents concerns and priorities, and more on one-way provision of information about the fetal diagnosis and management options. Furthermore, in keeping with a culture of immediacy and technology-driven information provision, many HCPs directed parents to Google the fetal diagnosis or, less commonly, directed parents to specific websites for further information on the fetal condition rather than reviewing this information in detail with the parents in person, with HCPs often commenting that "they [the parents] are just going to go and look it [information on the fetal anomaly and associated treatments] up on the Internet anyway."

A culture of immediacy was woven through much of the antenatal experience and was closely tied to technological advances in healthcare and communication. As depicted in the previous parent vignettes, technology was inescapably linked to antenatal care provision through the sophisticated diagnostic tests and assessments that constituted PNS and formed the basis of antenatal HCP-parent interactions. Parents noted how technological advances contributed to the pregnancy itself through ovulation testing kits, as well as made it possible for women to know they were pregnant only a few days following conception. Moreover, the use of cutting edge technology, in the form of fetal ultrasounds, FEs, sophisticated genetic testing, and a range of other technology-driven services that made the antenatal diagnosis of a fetal anomaly possible, were often taken for granted. This was evident in parents' questions such as, "Why wasn't this [fetal anomaly] picked up on an earlier prenatal ultrasound or screening blood work?" when a fetal anomaly was diagnosed outside of the optimal antenatal window. Part of the driving force behind parents searching out detailed information about their developing fetus was the culture of immediacy of information delivered now, in the present, rather than waiting until 38 to 40 weeks gestation when the baby was born. In addition, technological

advances in healthcare and communication distorted perceptions and expectations to the point that parents came to expect answers to most of their questions in seconds, minutes or hours. This constituted and reinforced a culture of immediacy in antenatal HCP-parent communication and care provision.

Summary

Antenatal HCP-parent communication occurred in a unique care environment characterized by pervasive uncertainty and the time-pressured context of an evolving pregnancy. As demonstrated, PNS and antenatal care provision required extraordinary communication and collaboration between multiple care providers, including community and acute care providers, as well as multiple subspecialist obstetric, genetic and pediatric multidisciplinary teams, each with their own unique set of priorities in addressing maternal-fetal health and antenatal decision-making. Within this complex world of antenatal care, parents faced organizational and societal pressures to conform to the population-based prenatal assessment mechanisms, often unaware, in their excitement over their developing fetus, of the experiences and decisions they would potentially face as a result. Moreover, antenatal care practices were underpinned by multiple, generally unchallenged, dominant frameworks and discourses, including biomedicine, efficiency and individualism, amongst others, which served to shape, sustain and reinforce antenatal communication and decision-making practices in ways that often conflicted with organizational goals foregrounding patient-centred, collaborative and equitable care. The preceding overview of the nature of antenatal care and exploration of dominant discourses underpinning PNS and antenatal care sets the stage for Chapter Five, which expands on this foundational analysis by demonstrating: (1) how dominant and opposing discourses were inextricably enmeshed with the enactment of disciplinary and pastoral

power; (2) how parental agency and resistance were demonstrated within these discursive systems; and (3) the characteristics of parents and families who were particularly vulnerable to inequitable antenatal care practices.

CHAPTER FIVE: ANALYSIS OF POWER RELATIONS, PARENTAL AGENCY AND RESISTANCE, AND INEQUITIES IN ANTENATAL CARE

Foucault's concept of governmentality guided the analysis of health care provider (HCP)-parent communication and decision-making. This analytical lens was instrumental in deconstructing and analyzing the way disciplinary and pastoral power was exercised in shaping individual behaviours by influencing and manipulating the manner in which parents conducted themselves. This deconstruction of power relations builds on the previous exploration of dominant frameworks underpinning HCP-parent interactions highlighted in Chapter Four. Foucault viewed power and knowledge as intricately intertwined (power/knowledge) and emphasized how power/knowledge is employed through discursive practices to govern or regulate the conduct of individuals. In this chapter. I focus on exploring how dominant discourses and associated disciplinary and pastoral power dynamics work together in shaping HCP-parent interactions and decisionmaking, and the resulting consequences for parents and families. I start with an analysis of how pastoral power was enacted in HCP-parent interactions, emphasizing how pastoral power was reflected in the manner HCPs came to understand if parents were "normal" or "deviant" in relation to HCP-constructed norms. This is followed by an inquiry into how disciplinary power was enacted in HCP-parent interactions and decision-making, focusing on the techniques of hierarchical observation, normalizing judgment, and examination, and highlighting how all forms of disciplinary and pastoral power worked together in regulating the conduct of individuals. Building on this, the focus shifts to an analysis of parental agency and resistance in HCP-parent communications, showcasing how opposing and contradictory discourses shape health and health relations and highlighting how neither parents nor professionals are powerless in health interactions. The chapter ends with an examination of how HCPs' unchallenged perspectives and practices

contribute to healthcare inequities leading to increased parental feelings of emotional distress, inadequately informed or biased parental decisions, and unnecessary pressure on parents to succumb to system-centred imperatives.

Deconstruction of Governmentality in Antenatal Care

Pastoral Power

Pastoral and disciplinary power worked in tandem in HCP-parent interactions; it was difficult if not impossible to scrutinize the effect of one without considering the effect of the other. Foucault recognized that the act of guiding individuals involves exerting a form of pastoral power over them that serves to informally and subtly regulate their behaviours, considering these actions as akin to how a shepherd cares for his flock of sheep. The act of "guiding" was inherent to and at the root of all HCP-parent interactions, in that parents viewed HCPs as trusted navigators and tour guides who could steer them through the confusing and overwhelming hoops, obstacles and challenges associated with parents' antenatal journeys. As trusted and respected health professionals in this specialized field, just as a faith-based pastor may be viewed by parishioners as someone who sets an example of actions and behaviours that should be followed, these HCPs were similarly able to wield a subtle form of power over parents' thoughts and actions, often with a great degree of control.

The source of influence for enacting pastoral power for these HCPs was embedded in the nature of the relationships they had with parents, in which health information was shared and multiple potential scenarios and outcomes were explored. In this context, parents viewed HCPs as medical and ethical experts who were applying their expertise to the advantage of the parents. Within this trusting relationship, HCPs encouraged parents to gain a conscious understanding of their knowledge and perspectives related to prenatal screening (PNS) and/or the diagnosis of a fetal anomaly. When parents shared this information, often in follow-up appointments, HCPs came to understand parents' perspectives and actions related to antenatal decisions. From a governmentality perspective, disciplinary power in the form of normalizing judgment was then enacted (seemingly unwittingly) by scrutinizing parents' insights, ideas and decisions to determine if they were normal or deviant in comparison to HCP-constructed norms, with the ultimate goal of reforming deviant behaviours or perspectives through normalizing sanctions. In this way, the enactment of pastoral power in combination with disciplinary power served to idealize certain opinions, perspectives and behaviours in keeping with health-constructed norms, thereby influencing parents in their ostensibly autonomous decisions.

The majority of parents entered into the world of antenatal care uninformed of potential fetal diagnoses and/or pregnancy and treatment decisions they might face as a result of fetal screening, which made them vulnerable to influence by HCPs. As discussed in Chapter Four, parents often entered into PNS naïvely, and were often not focused on or aware of the specific risks of having a baby with a fetal anomaly; rather, they were interested in learning more about the physical features of their unborn baby. Consequently, when parents received a diagnosis of a fetal anomaly, they were often dumbfounded, in a state of shock, and had few if any personal or other experiences to draw on to provide them with an understanding of their possible choices in determining how this journey could unfold. This made parents particularly vulnerable to the influence of HCPs, whom parents viewed as experts and knowledgeable on childhood disease and illness. Parents often verbalized these sentiments in phrases and comments such as, "I was completely reliant on Dr. X, I did not know anything about [fetal diagnosis] or even

the decisions I was facing" (Imogene, field notes). Moreover, as a result of the emphasis on highly specialized knowledge and technical skill in prenatal testing and HCP-parent communications about the fetal condition, HCPs did not generally expect parents to contribute any personal insights about fetal diagnoses or treatment options in initial HCPparent interactions. Rather, the fetal pathology embedded in ultrasound results and genetic analyses spoke for the parents, often reducing them to mute sources of data. This resulted in significant power/knowledge imbalances in which HCPs held expert knowledge, skill and experience and parents either faced a steep learning curve to attain power/knowledge or acquiesced to HCPs' perspectives.

HCPs' abilities to exert pastoral power were underpinned by parental assumptions that HCPs were acting in parents' and/or the fetus' best interests. This involved implicit assumptions that HCPs based their perspectives and decisions on sound medical evidence and ethical standards. It was evident in multiple HCP-parent interactions that parents looked to members of the healthcare team for moral guidance as well as medical expertise. Specifically, parents described wrestling with difficult ethical questions and trying to gain insight into HCPs' perspectives and opinions on difficult moral quandaries such as: What is a reasonable amount of suffering?; Is the pain and suffering my child might undergo in the short-term reasonable if the long-term outcomes are good? (Violet, field notes); "Would my child want me to give him a chance or would he be angry with me that I put him through hell?" (Adnan, field notes); and, When is termination of pregnancy better (more ethically reasonable) than continuing the pregnancy (multiple parents, field notes)? Given the organizational emphasis on brevity and biomedical focus on fetal pathology and treatment options in HCP-parent interactions, these questions were rarely formulated or discussed during initial HCP-parent discussions; rather, parents described

reflecting on and deliberating over them in the days and weeks that followed the initial fetal diagnosis. In addition, since direct HCP recommendations on medical or treatment decisions were rare, parents described reading between the lines as to what a care provider might have indirectly recommended. Specifically, parents described being left with an impression of HCPs' "leanings" toward certain decisions based on the way treatment information was presented, the amount of time spent reviewing one treatment option compared to another, or the emotional tone or body language used. Parents indicated that these impressions significantly influenced their decision-making. Moreover, although some parents were HCPs themselves and several had advanced degrees, none had extensive expertise or knowledge about their fetus' condition or ethical decisionmaking. In addition, most of the parents were not deeply tied to religious or cultural frameworks that provided guidance or direction on these difficult antenatal decisions, and the majority indicated they had never seriously contemplated or discussed how they would approach decision-making related to a diagnosis of a fetal anomaly. Given this set of circumstances, it was not surprising that multiple parents described being in a state of shock and unable to process what to do, and consequently looking to HCPs not only as medical experts in the fetus' physical condition but also as experienced experts and leaders who could credibly guide them in making morally and ethically justified health decisions.

The enactment of pastoral power in HCP-parent interactions was also evident in the narratives of several women who were followed for maternal diabetes during their pregnancy. As maternal diabetes is associated with an increased risk of fetal anomalies as well as increased maternal risks, these women faced increased levels of surveillance and scrutiny over their actions and behaviours related to diabetic management during their pregnancies. They described detailed discussions with diabetic obstetrical specialists who prescribed rigorous surveillance (most women described checking their blood glucose a minimum of six times per day) as well as adherence to strict dietary and activity guidelines, with the aim of staying within very narrow optimal outcome parameters (blood glucose and A1C measurements) in order to decrease the risk of maternal and fetal health concerns. They also described detailed HCP-parent interactions focused on how their diabetic management behaviours compared to an ideal norm. Women described how they "owned up" or "came clean" during parent-subspecialist interactions about not following prescribed diets or "cheating" with an occasional sweet, which resulted in "talking through" and "discussing" these actions in detail and "refocusing" on compliance with the prescribed diet and management routines. When either the mothers' diabetic management behaviours were outside of the ideal or their blood work results were less than optimal, these women described how their medical specialists emphasized the increased risks to both mother and fetus that could stem from "poor control" [of blood glucose levels] and how the specialists "worked with me to get me back on track" or "watched me like a hawk and motivated me to stick to the plan." These women often smiled when they described their diabetic specialist as "rigorous" or "very strict in a good way," and noted, "I am glad to have someone who cares so much about me and my baby," or "[the obstetrical subspecialist] just wants to make sure that I do everything right so that my baby has the best chance" (multiple parents, field notes). These comments indicated women viewed diabetic specialists as acting in the best interests of both mother and fetus. In these examples, diabetic specialists exerted pastoral power by employing techniques of confession, introspection and self-examination in detailed discussions with these women to understand their intentions and behaviours and compare them to HCP-

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constructed ideals, with the primary goal of preventing additional fetal and maternal health concerns through self-imposed adherence to HCP-constructed guidelines.

It was apparent in the accounts that parents often experienced themselves as being guided toward certain antenatal actions and decisions over others. These actions and decisions were further reinforced through the enactment of disciplinary power in the form of normalizing judgment and examination. Examples of how pastoral power was enacted in tandem with disciplinary power in HCP-parent interactions will be incorporated in subsequent sections of this chapter, specific to major antenatal decisions, including whether to pursue additional diagnostic testing and whether to continue or terminate the pregnancy.

Disciplinary Power

From a governmentality lens, HCPs commonly used pastoral power in combination with disciplinary power to govern others by subtly idealizing approaches and decisions aligned with HCP-constructed norms, under the guise of nondirectional care and informed parental decision-making. The enactment of disciplinary power was most apparent when parental perspectives or decisions were incongruent with HCP expectations, resulting in increased tensions in HCP-parent interactions or conscious parental efforts to change their actions to be consistent with HCP-constructed norms, thereby avoiding the stigma and micro-penalties associated with deviance and noncompliance. As will be demonstrated, when HCPs exercised power by shaping parents' perspectives of health and health decisions, even when they tried to be nondirectional in HCP-parent interactions, they failed. This provides an alternative perspective to dominant organizational and HCPs' assumptions that provision of antenatal care is objective, power relations are neutralized, and parental decision-making is free from influence or

manipulation. Consistent with a Foucauldian lens, disciplinary power was enacted through hierarchical observation, normalizing judgment and examination, each of which will be reviewed and illustrated through parent examples and vignettes.

Hierarchical observation: A spotlight on HCPs' priorities. In considering antenatal HCP-parent interactions from a governmentality perspective, surveillance for a fetal anomaly could be constituted as a hierarchical observation coupled with a biomedical lens. HCPs focused the spotlight of their surveillance and assessment on a restricted component of the antenatal experience, mainly fetal physiology and pathology, consistent with dominant biomedical and efficiency discourses underpinning antenatal care provision. Aligned with a biomedical gaze, the methods and foci for assessment prioritized gathering objective fetal-centred data through PNS tests, detailed histories, specialized ultrasounds and genetic assessments and investigations. This was evident in narratives of several mothers who described their experience of undergoing a fetal ultrasound as akin to "feeling like I was simply a carrier ... my baby was the focus-they separated him into parts and examined each one in detail, looking for anything that could be wrong" (Davinder, field notes). This resulted in care provider approaches that often failed to acknowledge and consider the health needs, priorities, concerns, values and belief systems of parents and families.

Parental accounts, as well as my observations of HCP positioning and body language in HCP-parent interactions, underscored HCPs' hierarchical positioning of power in relation to detection of fetal anomalies. This included descriptions of HCPs who "stood over" parents during HCP-parent interactions, as well as those who distanced themselves from parents during ultrasound procedures or conversations by crossing their arms and leaning back in their chairs, not maintaining eye contact, and referring to the mother or fetus in conversations with other HCPs or trainees (in front of the parents) as "cases" or "[diagnoses]" rather than by name. For example, in Anna's experience (Vignette 1, Chapter Four), the sonographer's short white lab coat, positioning of Daisy (the sonographer) over Anna in the taking of the medical history, and the nature of assessment questions asked during the ultrasound exam signalled the hierarchical positioning of the biomedical gaze common in HCP-parent interactions.

The hegemony of the biomedical lens dictated not only the focus of care but also the information obtained and provided to parents as well as the positioning of HCPs during HCP-parent interactions. Callie kept a journal of notes written during her pregnancy that included reflections on her interactions with the healthcare team. She shared these personal reflections as insights into her antenatal experience. Callie's recordings provide insight into parents' impressions of the hierarchical positioning of the biomedical gaze during antenatal HCP-parent interactions, including Callie's specific observations of HCP trainees. The following is a direct excerpt from her journal:

Students/Learners

- 25% of students/learners introduce themselves (name, role, and purpose in room)

~ 75% of students/learners are introduced by staff (name and role)

- Many students do not make direct eye contact with me as the patient, say hello or shake my hand. Often they position themselves where they can see the (ultrasound) screen or where they can see the chart.

- Students often do not sit down in one of the chairs in the room but will stand in the corner. Thus, we have one (often male) medical student standing in a corner while physician, patient, partner, and nurse sit. I would prefer that all students introduce themselves (name, role, purpose in room), make eye contact, shake my hand, and find a seat so they are not standing "over" us during the appointment. - Information is often conveyed to the student/learner about the patient as a particular type of case in front of the patient. Example: "In a case like this we might be dealing with a growth restricted baby or potential [rare fetal anomaly]". This information may be repetitious to the patient and may be a repetition of information that is high stress to receive (Callie, personal notes shared with researcher). Callie's reflections illustrate HCPs' hierarchical positioning of power in tandem with

a biomedical lens focused on fetal attributes in HCP-parent interactions. Callie's estimates

of the introduction patterns for medical and other trainees are consistent with my multiple observations of HCP-parent interactions during fetal ultrasounds and FEs, in which there were multiple HCPs observing the scans, many as trainees or students. In addition, there were numerous instances in which students/trainees and even regular staff entered a room without introducing themselves or otherwise acknowledging the parent(s), proceeded to stand beside or behind the sonographer or specialist performing the scan, observed the ultrasound images, and then exited the room at some later point—often without making any comment to or acknowledgement of the parents. Occasionally, parents would take the initiative to introduce themselves with expectant looks for the trainee to reciprocate; however most parents would simply turn their head and visually make note of the trainee's presence without asking for any introductions or explanations for their presence. Despite organizational and professional mandates and priorities underscoring the importance of collaborative HCP-patient relationships, these examples illustrate how the healthcare team's biomedical and reductionist focus on fetal physiology and pathology often contributed to their not attending to the importance of clear, respectful and collaborative communication in building and facilitating HCP-parent relationships.

HCPs' choices of what information to focus on during HCP-parent interactions was powerful in influencing parents to prioritize certain perspectives and foci of attention as more important and relevant, thereby minimizing the focus on other aspects of care. In this way, HCPs constructed what was important to consider and discuss in HCP-parent interactions and in the provision of antenatal care in general. The focus of HCPs' gaze in HCP-parent interactions was influenced by multiple dominant discourses, not only the predominant influence of the biomedical lens. Efficiency and scarcity discourses, explored
in the previous chapter, determined in part how much time HCPs had to examine or explore broader issues of health (e.g. parents' physical and emotional health needs), as well as the contextual aspects of care (e.g. financial burden associated with travelling to the tertiary centre for additional prenatal testing) and individual factors unique to the family that significantly influenced or shaped their experience and decision-making (e.g. maternal age of 39 with a long history of fertility concerns). The gaze of HCPs was also influenced by individualism discourses that cautioned against medical paternalism and interference with parents' autonomy and free will in health decisions, which might have limited HCP-parent discussions under the guise of "provide the information and let the parents decide" (field notes, HCP-parent observations), rather than risk HCPs being labelled as paternalistic or invested in one pregnancy or treatment option over another.

HCPs' enactment of hierarchical observation in combination with normalizing judgment was effective in creating arbitrary standards where fetal anomalies that HCPs perceived as approximating normal or healthy were described more positively than those anomalies HCPs perceived to be associated with long-term childhood outcomes associated with descriptors such as "abnormal," "chronically unhealthy," "mentally retarded" or "disabled" (field notes, multiple observations). As will be discussed, HCPs' taken-for-granted system of ranking and classifying the severity of fetal anomalies according to how closely long-term prognostications approximated "normality" served to significantly influence and shape parental decision-making.

Perceptions of "normality": Normalizing judgment and examination. Hierarchical observation worked in tandem with normalizing judgment and examination by categorizing fetal anomalies according to perceived level of deviance from healthy parameters and employing rewards and micro-penalties to influence and shape parents' decisions. At a system level, the entire PNS machine involved: comparing fetal findings to standardized "healthy" norms; determining the degree of deviance from this norm (i.e. presence and severity of fetal anomalies); and providing prognostic summaries of potential interventions or treatments, including approximations of future "normality." Fetal anomalies not amenable to "cure" or "repair," such as chromosomal anomalies or those anomalies associated with greater risk of ongoing deviation from healthy standards, were considered more severe and were more likely to be associated with detailed discussions on the option of terminating the pregnancy.

At an interpersonal level, examination involved hierarchical surveillance and corrective normalization enacted in combination with pastoral power in a multi-step process focused on parents' knowledge, actions and decisions related to potential pregnancy and neonatal interventions. As a first step, HCPs evaluated parents' knowledge and understanding of the fetal anomaly, preliminary test results and possible interventions. Given the rare and complex nature of fetal anomalies encountered, parents then faced a steep learning curve wherein HCPs attempted to explain complex fetal physiology and pathology, a range of additional diagnostic tests, and complicated pregnancy and treatment options to parents. Next, HCPs analyzed parents' planned actions in relation to this knowledge and compared them to HCP-constructed health behaviour norms. Finally, HCPs provided rewards when parents' planned actions were aligned with set norms and enforced sanctions when they did not.

In the following four sections I will employ a Foucauldian lens to deconstruct how hierarchical observation, normalizing judgment and examination were enacted in HCPparent interactions and decision-making. Specifically, the underlying power relations of the following four components of parents' antenatal journey will be explored: (1) Parental participation in PNS; (2) HCP-parent communication related to the diagnosis of a fetal anomaly; (3) HCP-parent communication and decision-making related to additional diagnostic testing; and (4) HCP-parent communication and decision-making related to continuing or terminating the pregnancy. Multiple vignettes and insights gathered from participant interviews and my observations will be incorporated throughout this analysis.

Prenatal Screening: Underlying Power Relations

The following vignette of multiple components of Violet and Manuel's antenatal experience was constructed based on detailed field notes of observations and interactions with the parents during Violet's combined detailed screening ultrasound and FE, my observations of the parents' subsequent interactions with multiple members of the healthcare team, and quotes from a follow-up interview with Violet. This vignette has been separated into four parts, consistent with the four components of the parents' antenatal journey and associated HCP-parent interactions highlighted in this analysis, and is employed as a means of illustrating and examining the underlying power dynamics at play and their consequences during these specific HCP-parent interactions.

Vignette # 4: Violet and Manuel. Part One: Conforming to the Expectations of the

Prenatal Surveillance Machine

I introduce myself to Violet and Manuel after they check in for a combined detailed screening ultrasound and FE. We spend several minutes talking while they wait for their appointment to begin. They explain they were referred for an FE because of Manuel's history of a complex heart condition, which required surgical treatment in early childhood, and for which he continues to require ongoing medical follow-up. This is Violet's first pregnancy. The fetus is at 19 weeks gestation. Manuel brings up that his heart condition is very rare and comments, "I don't know if there is any increased risk genetically—it's hard to test for that as there are so few people with it that there probably isn't enough data" (Manuel, field notes). Despite being referred because of the father's complex heart condition, the parents do not verbalize or otherwise overtly indicate concern or worry of a potential fetal heart condition. Rather, both parents describe anticipating the detailed screening ultrasound and fetal echocardiogram (FE) appointment as an opportunity to find

out if they are expecting a boy or a girl and state their hopes to "see" some other physical characteristics of their "baby" including the fetal size and movements.

A month later, during a follow-up interview, Violet recalled her and Manuel's

thoughts and feelings going into the detailed scan:

We thought the big thing that day actually was going to be the sex of the baby. I mean that's what most people are waiting for [laughing]. And like a few people knew that that was the date we were going in, or around that time, so we had some family and friends who were, like, excited to find out too because I guess that's the first sort of thing you find out about the baby that distinguishes it from anything else—starting to get, like, some traits (Violet, L 136–141).

It was taken for granted that parents would participate in PNS as part of the normative process parents undertake when expecting a baby. Consistent with organizational and professional imperatives, as well as dominant discourses of biomedicine and individualism amongst others, HCPs and others reinforced this need to participate in PNS through automatic referrals for detailed screening ultrasounds and blood work. As described in the preceding chapter, it was evident the majority of parents did not fully appreciate the priorities behind the healthcare system's edict to participate in PNS; rather, parents conformed with the system's mechanisms of surveillance in exchange for "more information" about their fetus. These findings challenge system and HCP assumptions that parents consciously choose to participate in PNS to determine the presence of a fetal anomaly. Rather, parents' naivety concerning the purpose of PNS and their unquestioning compliance with screening recommendations often resulted in unexpected exposure to increasingly sophisticated forms of fetal surveillance and scrutiny and decisions they had not previously considered. This was evident in Violet and Manuel's experience in that, even though the father had a significant congenital cardiac condition that prompted the referral for a FE, the parents were unaware of their fetus'

increased risk of having a cardiac anomaly, focusing instead on gleaning insights into the physical "traits" of their fetus. In addition to the suggestion of a possible gap in Manuel's understanding of the heritability of his congenital cardiac condition, Manuel and Violet's description of their experience also highlights that parents' priorities for entering into PNS rarely aligned with the PNS surveillance machine's priority of identifying fetal anomalies. In addition, several parents described screening referrals that were put in place as a matter of course; parental discussions with healthcare providers about the reason for undergoing PNS, the pros and cons of participating, and the level of accuracy associated with screening results were rarely discussed in detail, if at all. Moreover, parental compliance with PNS protocols was often enforced by HCPs through the use of micropenalties, such as stigmatizing comments and pejorative labels for those parents who hesitated or considered not participating in PNS. This was evident in parents' descriptions of HCP-parent interactions in which questioning the necessity of PNS blood work resulted in HCPs making parents feel like they were being "irresponsible" or negligent in "not wanting to know all the details," which generally resulted in parental compliance, albeit often uninformed, with PNS protocols.

The Initial Diagnosis of a Fetal Anomaly: Underlying Power Relations

Vignette #4: Violet and Manuel. Part Two: "There is a problem"

The ultrasound appointment was booked for 9:00 a.m.; however, the parents waited in the waiting room until 10:35 before they were escorted into the dimly lit ultrasound room. Violet lies down on the exam table, lifting her blouse to expose her pregnant belly while Chloe, the sonographer, carefully drapes a towel over her lower abdomen to provide some privacy. Manuel takes a seat in the chair to the side of the exam table. The room is small with the exam table and ultrasound machine taking up most of the available space. I sit in a chair against the wall, facing the parents, and with a clear view of the sonographer's ultrasound screen. The family is able to view the fetal images on a large screen on the wall opposite them. A curtain is pulled across the doorway. There are hushed voices in the hallway outside as other patients come and go from the adjacent assessment rooms.

Chloe, the sonographer, takes a brief history, which she started as she escorted Violet and Manuel down the narrow hallway to the ultrasound room, and completes simultaneously with applying ultrasound gel to Violet's abdomen. Chloe asks about any family history of heart disease, to which Manuel responds by providing a succinct description of his specific congenital cardiac condition, including a brief list of cardiac surgeries he underwent in early childhood. Chloe clarifies the name of the cardiac condition and writes it down on the assessment form. Next, she asks about any previous ultrasounds, to which Violet responds that the last ultrasound was a "dating ultrasound" at seven weeks, noting, "There was not much to see—the baby was so little." Manuel adds, "Yes—we couldn't make anything out—not big enough."

The ultrasound starts immediately thereafter, with Chloe beginning by taking the fetal heart rate, and then proceeding to capture a cross-sectional image of the fetal brain. She measures the head circumference, indicating she is "getting the hat size" and the "ear to ear" measurement. Manuel jokingly asks, "Is there lots [of brain]?" which results in everyone sharing a smile and a short laugh. Chloe states a number and says, "It's good."

Next, Chloe captures images of the face. The image projected on the screen shows black eye sockets, a smaller black circle where the nose would be, and the skeletal outline of the face and skull in various shades of grey and white. Chloe notes this view is "not the parent favourite" and explains she is specifically looking for a cleft lip. She pauses and then comments, "It looks good." Manuel, who is leaning forward and watching the screen intently, exclaims, "You can look for that already? Wow!"

Chloe proceeds to capture initial views of the heart and aortic arch. She does not indicate to the parents what she is imaging at this point. Chloe continues on to views of the stomach, commenting on its location on the screen as "the bigger black spot." A medical trainee enters the room and stands behind Chloe, looking intently at the ultrasound machine's screen, viewing the images. The trainee does not introduce herself or acknowledge the parents, silently looking at the images on the screen, arms crossed, a neutral expression on her face. Chloe notes her presence with a nod and continues to scan. The parents looked up when the trainee walked in the room, but neither say anything or address her. While the medical trainee is looking at the sonographer's screen, Chloe opens up a checklist on her personal screen and marks an X across from "abnormal four-chamber cardiac view" and "abnormal outflow tract" [this screen is not visible to the parents as they are only able to view the fetal images on the large screen on the wall]. Chloe does not comment on the detection of these abnormal findings.

Chloe continues her detailed scan, focusing next on the lower extremities with measurements of the femur—"knee to hip measurements." She comments that the baby is kicking a lot and smiles when she says this makes getting the measurements more difficult. The parents are keenly watching the fetal images on the large screen, grinning as they watch the fetus kick and move around. Manuel asks Violet if she can feel the kicking. She feels her rounded belly and tentatively replies, "I don't think so." Chloe finishes her measurements of the lower extremities with a measurement of the big toe to heel and images of the fetal toes.

Chloe turns to Violet and asks if she had any first trimester screening. Violet responds, "Yes, I had SIPS (serum integrated PNS)," and comments that the

results "were negative." Chloe measures the back of the neck and indicates, "It's thin—good." She then does a quick scan of the genitalia, not making any comments to the parents, followed by measurements of the tibia and fibula. Manuel asks a question about the red and blue colours on the screen and Chloe explains the different colours indicate the direction of blood flow—toward or away from the probe. Next, Chloe assesses the structures of the spine, commenting afterward that it "looks good."

Chloe continues to take various measurements while the parents watch the screen intently. She comments, "Baby sure is wiggling a lot, it's hard to tell what's what ... Sure is busy." Her voice is upbeat as she continues to inform the parents of different fetal structures she is imaging and measuring. Violet asks if it's true that there is increased fetal movement after the mom eats sweets. Chloe shrugs, "Its normal [for the fetus] to move a lot. We worry more about the ones that don't move very much."

At 10:50, 15 minutes into the scan, Chloe states that she will now focus on capturing more detailed images of the heart. She comments that she hopes the fetus will turn, as it is not in a good position for the cardiac images she is seeking. She moves through select views, including colour flow Doppler, which looks like blue and red smears on the screen. Shortly after, four members of the medical team enter, including an MFM specialist, a cardiac specialist and two medical fellows. The perinatologist introduces himself and his colleagues to the parents. Chloe stands up and the perinatologist sits in the sonographer's chair and readies the equipment for him to take over the scanning. He explains to the parents the results will be reviewed at the end of the scan. Violet asks if they can find out the sex of the baby. The perinatologist notes, "Under the circumstances, we will tell you the sex." He adeptly focuses the probe on the fetal genitalia and within less than a minute or two notes in a friendly tone, "It's a boy." The parents take in the news quietly, smiling at each other.

The medical specialists and trainees gather around the ultrasound screen, taking in the images as the perinatologist systematically scans and captures a series of images. The cardiologist notes to his colleagues, "It looks like HLHS" [hypoplastic left heart syndrome]. The cardiac fellow asks questions about the orientation of the heart in the current image, which prompts a group discussion with the different HCPs pointing at the screen and making note of specific structural landmarks, their descriptions largely made up of abbreviated medical terms and jargon. They note the baby is in breech position. The parents continue to stare silently at the screen. The perinatologist continues to scan and the group discusses the images on the screen amongst themselves: "Tricuspid valve looks competent ... Is the PFO [patent foramen ovale] patent? ... Flow is PA [pulmonary artery] to duct to transverse arch, retrograde to ascending aorta..." Early on in the medical discussion, the perinatologist turns to the parents and says, "I know this is hard, we are having a very technical discussion, but we will explain everything at the end." Shortly after, the cardiologist turns to Manuel and asks him specific questions about his cardiac condition and past treatment. The specialist's tone is friendly and inguisitive, and Manuel appears relaxed and smiles as he provides a more extensive history than he gave to Chloe, noting he was a young child when he underwent most of the surgical procedures and explaining he has had to rely on what his parents told him about his cardiac treatments. The medical team

continues to scan and discuss the FE images for the next 10 to 15 minutes, referring to different structures with medical terms and acronyms. When the team agrees they have captured all of the necessary images, the perinatologist puts the probe away and wipes the gel off Violet's round abdomen while informing the parents the scan is completed and that the cardiologist will meet with them in an adjacent meeting room in a few minutes.

A few minutes later, Chloe ushers the parents into a small meeting room down the hall. The cardiologist and the cardiac fellow who observed the FE accompany them, and a cardiac nurse clinician joins the meeting about ten minutes after it starts. The parents sit side by side around a small table, the cardiologist sits opposite them, and the nurse and fellow sit on opposite sides. I sit in a chair to the side of the table. The cardiologist, Dr. Smith, starts by indicating that the team found "a problem with the baby's heart" and that he will review the findings with the parents and explain the diagnosis so they can understand it. Dr. Smith reviews normal fetal circulation using a standard diagram. He draws arrows on the diagram to indicate direction of blood flow, starting at the right atrium and following the blood flow through the cardiac chambers and out the left ventricle into the aorta. He makes note of differences in fetal circulation compared to newborn circulation. Dr. Smith uses soft tones and a quiet voice. He smiles frequently and looks directly at the parents as he is speaking. He asks the parents if they understand the diagrams he has presented, and they nod and say yes. Neither of them asks any questions. Dr. Smith then takes out a coloured handout labelled "Hypoplastic Left Heart Syndrome (HLHS)," which includes a brief description and multiple coloured images of the condition and a series of three surgical treatments. He spends the next few minutes reviewing the altered blood flow and structures in HLHS, individualizing the illustration on the handout with his pen to describe the specific nature of their fetus' form of HLHS. Next, he sequentially reviews the series of three surgeries required to treat the condition, noting that because the left-sided cardiac structures are small, surgical treatment is not considered a "cure," but rather a re-routing of the blood flow so that the right and left (pulmonary and systemic) circulations are separated at the end of the three surgeries. Dr. Smith does not provide specific statistics regarding surgical success, but notes, "The majority of infants survive and do well." Dr. Smith spends the most time (four to five minutes) reviewing the first surgery and one to two minutes reviewing each of the second and third surgeries, primarily focusing on the changes in blood flow and the pre- and post-surgical physiology. The nurse clinician and medical fellow listen quietly, their eyes predominantly on the handouts being reviewed, occasionally looking up at the parents' faces. While Dr. Smith is reviewing the information, the parents keep looking at the medical diagrams on the handout, nod their heads, and occasionally look up at him. Once he has completed going through all of the information, Manuel asks him how severe the condition is compared to his own. Dr. Smith explains it is a similar condition but, in general, what the fetus has is considered more severe. Violet looks surprised by this, but does not ask any specific questions. At this point, Dr. Smith briefly notes that not all parents want their fetus to go through all of the surgeries, and parents have the option of termination. He then notes that if they continue, he would recommend a repeat FE in four weeks. Dr. Smith starts to talk more quickly, looks at the closed door and

indicates that he has to go to see the next patient, but that the nurse clinician, Kyla, will review the information with them as it is a lot to take in.

Kyla, the cardiac nurse clinician, reintroduces herself and apologizes for entering the meeting late. She initially asks the parents a few questions including if this is their first baby, specifics about the father's heart condition, what the parents do for work and where they live. She then spends the next 15 minutes reviewing the nature of the heart condition and the three associated surgeries, going through each of the surgical procedures again, taking more time than Dr. Smith and adding additional details about length of hospital stay with each surgery and specifics about the nature of recovery and infant monitoring in the timeframes between surgical repairs. The parents ask very few questions; both look like they are having difficulty taking in the information. At the end of the meeting, Kyla gives them her contact information and encourages them to call with any questions, noting that "it's a lot to take in," and that parents often come up with questions once they have time to review the information on their own. Before leaving, Kyla informs Violet and Manuel of their appointment with the genetics team in the afternoon and encourages them to go and have some lunch prior to this appointment.

During a follow-up interview a few weeks later, Violet described her excitement in viewing

the first recognizable images of her fetus during the detailed scan. She explained she did

not realize there was a concern with the baby's heart until the end of the scan when the

cardiologist told them there was a "problem."

I felt pretty good during that time [the beginning of the detailed scan]. It seemed like the tech was sort of nodding along and mumbling like this looks good and good head, good legs. She said something about five fingers, five toes at the end ... So yeah, that was good and when they called in the specialist I mean that wasn't alarming at all for us because it was planned that we were going to do an echo ... so it was the two doctors then and they were talking to one another through the whole thing. Now, they told us it was a boy right at the start, so I was kind of just thinking about that while they were doing the heart scan and they were saying a lot of words that I, I knew some of the words, but I didn't know what they were talking about so I kind of blanked out ... I was just busy thinking about what we would do with a boy and going over our names and stuff. And I guess it went on for a while, but I mean I don't really have a frame of reference for how long it's supposed to take so I didn't, I wasn't really concerned at all until they outright told me there was a problem at the end (Violet, L 145–208).

In comparison to Violet's experience, Manuel's past history of a heart condition helped

him to pick up the HCPs' concern of a fetal heart condition during the ultrasound exam.

He told me he picked up on it [the concern with the fetal heart] quite a bit earlier than I did because the terminology makes more sense to him and he could see they were talking about something that was not a normal heart. And also he's done [had] echocardiograms...So he's more familiar with what they were talking about, although he didn't like precisely know what they were saying, but for me it was closer to gibberish...I mean, because I'm sure they were trying to keep their tone neutral so I couldn't pick up on it, so if you don't know what's what ... (Violet, L 253–288)

Violet also described the priority the cardiologist placed on providing physiological details

when describing the fetal anomaly for the first time, as well as other "more pressing"

information she would have preferred the cardiac team to review.

[After the parents were given the fetal cardiac diagnosis] At that point the cardiologist started talking about, well, he said there is three surgeries and he got into the technicalities of it pretty quickly. And he had diagrams and stuff and, like, he was explaining it fairly patiently. What I kind of found after, though, after all that, because he didn't have a lot of time with us, that I would have rather had more, I don't know how to say it, but well, just in terms of learning about exactly what's going on, the blood goes in here and we have to make this, and during the operation it goes like this [gesturing how Dr. Smith explained the different blood flow patterns]. I didn't feel that was like the most pressing thing. For me, I was more concerned about, like: What does this mean? What is the survival rate? Is it a condition where children suffer greatly? ... And more about, What is this going to mean for you? and What is the quality of life like? (Violet, L 332–342)

Vignette #5: Lexi and Logan

Observation of Lexi and Logan's interactions with the healthcare team during and

following their detailed scan and FE provided additional insights into how HCPs'

descriptions of a fetal anomaly and/or its treatment can serve to influence parents'

understanding of the condition and their subsequent decisions. This vignette will be

referred to in each of the following sections to illustrate the nature of HCP-parent

interactions and factors influencing parental decision-making.

Lexi and Logan were referred for a detailed scan and FE at twenty weeks gestation after a regular screening exam in their local community indicated "a tear in the diaphragm (diaphragmatic hernia) or a mass in the heart." During my initial meeting with the couple prior to the start of their scan, Lexi stated when she initially heard the suspected fetal diagnosis from the community physician that "it was like a slap in the face—I wasn't expecting it." She went on to explain that having three healthy children at home had led her and Logan to assume this baby would be healthy as well. Following a lengthy detailed scan that took over an hour and a half to complete, the couple met with an MFM specialist, Dr. Lopez, who was accompanied by a medical fellow.

Having been told at the end of the scan that the ultrasound exam had confirmed the presence of a diaphragmatic hernia, the specialist asked the parents to explain their understanding of the fetal diagnosis based on the preliminary information they had been given by the community physician who met with them after the initial PNS ultrasound. Lexi provided a clear and concise summary: "There is a tear in the diaphragm with the bowel and stomach pushed up through it into the chest, which is making the heart pushed over to the right." Dr. Lopez listened, and then provided additional verbal details of the nature of the condition, including an overview of the different levels of severity of diaphragmatic hernia and an analogy to squeezing an opened tube of toothpaste in the way the abdominal contents were pushed up into the chest. Dr. Lopez proceeded to provide mortality statistics for "isolated LDH [left diaphragmatic hernia]" versus those associated with a genetic anomaly, "which we think this [the fetal anomaly] is" [i.e. isolated/not associated with a genetic anomaly]. She indicated that over the past 25 years the survival rate has been 40 percent. She then indicated new data from the Canadian Pediatric Surgical Database Registry ("which you are now a member of," she noted with a smile) are much better, with survival at around 80 percent. However, "we can't be too specific-it's somewhere between 40 and 80 percent." She then went on to state, "But if you are dead, you are dead and if you are alive, you are alive, you can't be 40 percent dead." During this discussion, the parents listened to the specialist quietly, without interjecting or asking any questions.

Next, Dr. Lopez provided a brief description of postnatal treatment of diaphragmatic hernia, prefacing her description with a comment that she would not provide a lot of detail, since her last pediatric rotation had been many years ago. She did not specifically address how the congenital anomaly was repaired. Rather, she focused on providing a brief description of the care needs in ICU postoperatively, including a "breathing tube to inflate the lungs" and possible time on a "heart and lung machine," which she later described as extracorporeal membrane oxygenation, "ECMO for short," indicating this was needed in approximately 10 percent of cases.

Following the specialist's description of the anticipated postnatal course, Logan asked, "If the baby gets through the neonatal treatment, what then?" Dr. Lopez responded, "I will answer that question, but first I want to explain other options," and went on to explain the parents' option to terminate the pregnancy in detail. In describing this option, the specialist started with emphasizing that the institution was "very pro-choice," and adding that she knew of TOP services that had been provided for several women who "were walking around with placards outside the building [alluding to women who had been involved in anti-abortion demonstrations]," two of these because "it was an inconvenient time." She added, "You should not feel like it's not an option for you—what you are dealing with is much more significant." Dr. Lopez then discussed how she thought termination of pregnancy (TOP) could be seen as "one of the most compassionate and kind acts a parent could do," noting, "Women don't choose termination because they are not compassionate, they choose it because they are—they are trying to prevent suffering." This discussion was followed with a detailed description of how TOP would be performed.

Dr. Lopez did not specifically go back to answer the father's question concerning post-treatment outcomes; however, she did indicate that "should they choose to continue," they would meet with a neonatologist and/or a pediatric surgeon at 35 weeks of pregnancy, at which time they would also need to temporarily relocate to be close to the specialized hospital where neonatal treatment would occur. At this time the team would also review the anticipated plan for labour and postnatal treatment and arrange a tour of the intensive care unit where the baby would be cared for after birth.

Following this, Dr. Lopez discussed the option of amniocentesis, noting she would "suggest this test." She indicated a one in two hundred risk of miscarriage and noted that in deciding whether to go through with an amniocentesis, the parents should consider how they would feel if they decided to pursue neonatal treatment of the diaphragmatic hernia and "ended up with a mentally retarded child [from an unknown chromosomal anomaly]." Dr. Lopez then noted having an amniocentesis would provide the parents with information about possible chromosomal anomalies in addition to the diaphragmatic hernia "ahead of time," inferring this was an important consideration in deciding to continue or terminate the pregnancy. Dr. Lopez noted that given the parents were from out of town, the amniocentesis could be expedited and performed later in the day.

At this point, Lexi became very teary-eyed and asked, "How common is this?" Dr. Lopez noted an approximate incidence of one in five thousand. Lexi noted, "Wow, it's not very common." Dr. Lopez nodded, and noted that the fetal anomaly was not caused by anything the mother did, noting, "You don't look like you took crystal meth or cocaine, but if you did it is unlikely to have caused this, although it may have increased the risk. However, I know many women who use and don't have this happen."

Dr. Lopez then ripped a piece of paper towel from the holder on the wall and wrote down three possible websites she thought "might be helpful" for the parents to look up, including the Canadian Pediatric Surgery website and the March of Dimes website. She also noted she was in "full support" of peer support, and that other families found peer [parent-to-parent] support very helpful, but she didn't know if it existed for diaphragmatic hernia specifically. In response, Lexi responded, "Google is my crack," and described having a hard time "not looking up everything," and that it was difficult to know what was relevant or good information. At this comment, Logan responded by nodding his head and noting, "It's hard to keep her off," commenting that sometimes Googling exacerbated rather than diminished Lexi's worries. Dr. Lopez nodded in response, and then started to gather the charts. As she was preparing to leave, Dr. Lopez noted that the parents had a subsequent meeting with the genetics team, with whom the parents could further discuss the option of amniocentesis and arrange for an "amnio" later in the day if they chose to do so.

As the preceding vignettes illustrate, HCP-parent interactions following initial diagnosis of a fetal anomaly generally involved the provision of complex diagnostic and prognostic information as well as pregnancy and treatment options in the form of what parents described as "speeches" or "huge downloads" of information rather than two-way discussions that included parents sharing their insights or perspectives. As previously described, the first step of examination involved evaluating parents' knowledge and understanding of the fetal anomaly and associated diagnostic tests and interventions. Inevitably, parents' understanding of the fetal condition was very limited. Even when parents were health providers or had done pre-reading on a suspected fetal anomaly, they described having a very generalized understanding of the nature of the fetal condition but lacking clarity on specific treatment options or outcomes. As a result, the first phase of examination involved a steep learning curve during which the healthcare team attempted to explain the complex fetal pathology and pregnancy and treatment options to parents. Once parents were informed as to the nature of the fetal anomaly and associated pregnancy and treatment options, HCPs could enact the second stage of examination, which involved analyzing and comparing parents' planned actions in relation to this knowledge to HCP-constructed health behaviour norms.

Using a Foucauldian lens, the "speeches" and "lectures" HCPs provided on the nature and treatment of fetal anomalies can be seen to have been constituted and shaped by underlying dominant discourses of biomedicine, efficiency, and individualism amongst others. Specifically, the preceding vignettes illustrate the priority many HCPs placed on providing health information from a biomedical framework, their brevity in communicating complex information to parents, and their underlying assumptions that parents would view fetal anomalies and make decisions from the same biomedical lens

and techno-rational approach HCPs employed in clinical practice, without acknowledging parents and families' unique circumstances or priorities related to antenatal decisions. In many of my observations of initial HCP-parent interactions, it was as if HCPs were attempting to give the parents a crash course in the nature and treatment of the fetal anomaly. Given the rare and complex nature of many of the fetal anomalies, and given that most parents entered into prenatal testing focused on learning exciting and positive news about their fetus, the vast majority of parents described being unprepared for the complexity of the initial information they received on the fetal anomaly, and feeling dumbfounded as they listened to complex physiological details and treatment options associated with the fetal anomaly minutes after they viewed "exciting" and "happy" pictures of their fetus on the ultrasound screen (field notes, multiple participants). The majority of parents listened to the complex diagnostic and prognostic information quietly, often wiping away tears or trying to regain their composure while staring with dazed expressions at HCPs as specific pathology was reviewed, rarely asking questions or interrupting HCPs' explanations. Callie, who was pregnant with twins, described feeling like she was receiving a one-way "speech" during some HCP-parent interactions, rather than a two-way dialogue about the fetal condition and pregnancy and treatment options.

So there are a number of speeches, and I say speeches because there is not a dialogue between the patient and the provider, it was sort of like your child, you know, your children look unwell. Here are all the, you know, things that we should talk about. We should talk about terminating your pregnancy. We should talk about the different risks. We should talk about what is occurring right now. We should talk about what surgery looks like, you know what I mean? Like, there is sort of a suite of like twelve things that we should probably talk about at some point with this family (Callie, L1111–1118).

When HCPs emphasized potential negative outcomes associated with the fetal anomaly or neonatal treatments, parents commonly commented on their assumptions that HCPs were covering themselves from a professional liability standpoint by ensuring HCPs provided parents with adequate information on the full range of potential risks and complications. However, many parents described how the litany of "things that can go wrong" was emotionally distressing and unnecessary, especially if it was repeated after parents had made a decision to continue the pregnancy. For example, Callie asserted:

You don't need to scare the shit out of them [parents who have received a fetal diagnosis]. At that point [once parents have decided to continue the pregnancy and seek neonatal interventions] like, you have given them the choice; you have given them the information. I wonder if people [HCPs] are scared that they are going to get sued and so they feel like they need to hit people [parents] over the head. Just, like, here are all the ways that things can go wrong (Callie, L 1290–1294).

When HCPs shaped parents' perceptions of fetal diagnoses and treatment options, thereby influencing parental decision-making, this too could be understood as enacting pastoral power in combination with disciplinary power. Given the parents' limited understanding of the fetal anomaly and their assumptions HCPs were acting in their best interests, parents turned to the healthcare team to provide medical and moral expertise on the best options for their fetus. Although direct recommendations from HCPs were uncommon, almost all parents described sensing HCPs were guiding them, "leaning toward" or "pointing toward" specific antenatal decisions through such indicators as the amount of time spent on one option over another, the emotional tone or body language used, and the order in which options were reviewed. From a governmentality lens, this provides an example of how HCPs enacted pastoral power to guide parents toward certain antenatal decisions over others. For example, in Lexi and Logan's initial meeting about the nature of the fetal anomaly, the MFM specialist provided information on the fetal condition, emphasizing the option of terminating the pregnancy over surgical treatment, as was evident in the comparatively greater amount of time spent on this option, the HCP's priority in addressing this option first even when Logan specifically asked about outcomes associated with surgical repair, and the specialist's description of TOP as

"sometimes the most compassionate option." On the other hand, in her review of the surgical treatment of the fetal anomaly, the HCP did not actually address the specifics of how the condition was surgically repaired, but rather emphasized the wide range of surgical success (40 to 80 percent) and the complex nature of the immediate postoperative period, including the possibility of extreme life-saving measures such as extracorporeal membrane oxygenation. The specialist also did not provide any positive short- or long-term outcomes associated with the fetal condition. In contrast, in Manuel and Violet's experience, the time pediatric cardiac team members spent on pregnancy and treatment options was dedicated almost exclusively to a detailed review of a series of surgical repairs, with only a brief comment at the end of the meeting related to the option of terminating the pregnancy. In a follow-up interview several weeks later, Violet discussed how she and Manuel interpreted this information, and their confusion and frustration with how it was conveved:

And they [the pediatric cardiac team] also kind of vaguely mentioned something about, they were talking a lot about the surgeries and they kind of offhand mentioned, like, termination or palliative care I think, or comfort care, or something about if you just don't go through with the surgeries ... and I mean that's fine if what they are trying to say is the survival rate is really good now, so we recommend the surgery, but it was a bit confusing because afterward we are like, okay, they have talked and talked about the surgery and they mentioned these two things. Should we be thinking about them? Like why? Why did they mention them? They must be an option but then they didn't talk about them... you get the vague idea that we had some sort of choice, but we weren't sure why or how to make the decision, or if they were trying to suddenly point us in one direction (Violet, L342– 360).

As evident in Violet's comment, parents were often placed in positions where they

tried to read between the lines to decipher HCPs' suggestions and recommendations

related to pregnancy and treatment options from the manner in which specific information

was conveyed and the content of diagnostic and prognostic information provided.

Moreover, whereas HCP-parent discussions of medical and surgical treatment options of postnatally diagnosed congenital anomalies are often framed in terms of medical evidence supporting one specific treatment over another, antenatal decisions differed significantly because of the uncertainty of the evolving fetal condition and the option of TOP. Specifically, the option of TOP resulted in parents attempting to ascertain not only which option was best from a medical perspective, but also which was "best" from a moral and ethical perspective. Perhaps because of these moral and ethical decisions at play, some HCPs spent little time on reviewing the option of TOP, instead emphasizing the parent's right to make free and independent decisions based on the "objective" information provided by the healthcare team. However, parents often expressed their difficulty and frustration with decisions related to pregnancy and neonatal treatment options because HCPs directly or indirectly idealized certain treatments or options based on the nature of the fetal condition itself, with different teams often idealizing different options, decontextualized from parents' unique perspectives, beliefs, priorities and circumstances. When HCPs did not acknowledge these and other factors parents viewed as imperative in making health decisions for their fetus, parents often described feeling misunderstood by the healthcare team and unsupported as they prepared to make critical antenatal decisions.

Communication and Decision-Making Related to Additional Diagnostic Testing: Analysis of Underlying Power Dynamics

Vignette #4: Violet and Manuel. Part Three: Under the Magnifying Glass: Additional Assessments of Parental and Fetal "Normality"

Following their initial meeting with the pediatric cardiologist, Violet and Manuel had a break for lunch and then met with members of the genetics team. I did not observe this interaction; however, Violet described their interactions with the healthcare team in a

follow-up interview a few weeks later.

Violet: Okay, so first we just met with the one genetic counsellor by herself, just the three of us. And she started off by just probably doing what she does with most people she has never met before—it was more of just like a broad series of questions about our personal medical histories in detail, our family histories. She went really into detail with Manuel, and with me only up to parents and asked if there was anything else alarming [in other family members]. But with him she went up to grandparents. So it was all pretty broad of course. Manuel talked a bit about his heart condition and she asked if there were other heart conditions that he knew of in the family.

R: And were there?

Violet: Not that he is aware of, no, but then, in my family she kind of skimmed over it a bit more. I mean I got the sense they were much more, you know, it was pretty obvious that they are highly suspecting it from Manuel. There is no reason they would look at my side first when there is nothing. Although we did talk about a couple of other things, like, way back up my grandma's cousin had cystic fibrosis because they were asking about any genetic things. They asked if there were any intellectual disabilities of note in either family, so stuff that is not related to the heart. So that was fine, although we were at that point, really anxious to get someone to answer our questions. We had been through lunch in an hour or two then, and we were trying to process this and thinking of all of this stuff.

R: This was after just learning about the heart condition, and then a break, and then going to that [the meeting with the genetic counsellor]?

Violet: Yes, but, she clearly wanted to start just by getting a broad overview of our history, so that was fine. Then shortly after that the geneticist and genetics fellow came in. And we were talking a little bit more specifically about the baby's heart condition at that point. And let's see, they were talking about amniocentesis. That seemed to be a big thing. They were trying to explain to us about it. They kind of explained how chromosomes work and why they wanted me to have it. They talked about an increased risk of chromosomal things and they were linked to heart problems. Even though my SIPS [serum integrated PNS] came back negative, I guess it's not a hundred percent ... I felt like they [the genetics team] also spent quite a lot of time talking about sort of technical things. The way the surgeon [pediatric cardiologist] went over the surgery, a lot of time trying to make us understand chromosomes and how we're supposed to have two of each and there could be a problem if there's a little bite out of one of them or three, what makes Down syndrome or something—which, I think that is interesting and stuff, but again, I don't feel like it was the first priority, and especially because, really, I was a pretty low risk for that being the problem. Like, having done the SIPS test and it came back negative, having [no] family history, I mean they were pretty sure and nothing, nothing came up on the ultrasound as well. They also marked down, like, no other markers of [fetal anomalies], so, yeah, so it seemed like a long time spent on that when that was fairly, relatively improbable.

R: And did you have the sense that they were encouraging you to have the [amniocentesis]?

Violet: Definitely.

R: It wasn't an option? It was a suggestion so to speak?

Violet: Yes, I mean they made it clear that it is not mandatory, but they were strongly suggesting we do it. They were also saying, like, at that point they were saying something about a heart transplant and, you know, they will prioritize you on the list if you don't have chromosomal problems or something, and so that was a bit confusing too because that was almost like, this was a new option we were hearing and we were trying to understand how heart transplant worked in the whole thing.

R: Because Dr. [Smith, the cardiologist] had not really talked to you about it at all? Violet: I don't know if he got to that or if he did he didn't have a chance to talk about it very much (Violet, L 430–437, 439–450, 452–463, 465–483, 642–653).

At the end of the day, Violet and Manuel described leaving the hospital "dazed," confused

and frustrated with multiple unanswered questions and conflicting prognostic and

treatment information received from different HCPs. Moreover, their request to meet with

a pediatric cardiology team member to clarify conflicting information received from

multiple subspecialists was dismissed.

Violet: So, I would say that takes us to about the end of the appointment and at that point we were pretty, pretty dazed and we were saying [to the genetics team] like, are you sure we can't talk to the cardiologists or anyone else? And they were off, I don't know doing surgery or whatever—like, definitely not today. R: So, they didn't offer to page somebody? Violet: No, no, they were pretty defensive. Like, no, this is it for you for the day (Violet, L 674–682).

As illustrated in the preceding vignette, once a suspicion or confirmation of a fetal anomaly was raised, parents were often subjected to the aforementioned multi-step process of normalizing judgment in tandem with examination in relation to decisions concerning additional diagnostic testing such as amniocentesis. Breaking this into individual steps, step one involved parents meeting with members of the genetics team, including genetic counsellors and geneticists who reviewed parents' understanding of the fetal anomaly and addressed the possibility of additional anomalies associated with the structural fetal anomaly already identified. Next, consistent with a biomedical lens, step two involved HCPs providing parents with detailed information such as: the science of chromosomal testing including details about normal genetic findings; a range of possible chromosomal and non-chromosomal syndromes specifically associated with the fetal anomaly; and additional testing that could confirm or negate the coexistence of a genetic anomaly. Similar to the "speeches" parents described receiving about the nature of the fetal anomaly and associated treatments, many parents described their initial meeting with members of the genetics team as akin to receiving a "lecture" or "mini-course" (field notes) in chromosomal analysis, as was evident in Violet's comment that the genetics specialists spent "a lot of time trying to make us understand chromosomes," reinforcing the unidirectional nature of information flow from HCP to parent and the priority HCPs placed on framing parental decisions from a biomedical lens. Following this presentation of detailed information on a possible genetic anomaly, HCPs segued into presenting parents with the option of pursuing genetic testing, usually in the form of amniocentesis.

For many parents, information about genetic testing options was often not provided in an objective manner that included a review of the pros and cons associated with each option, but rather as HCPs' suggestions or recommendations. In addition, increased concern raised by HCPs about genetic anomalies in the context of previously reported normal screening results often caused parental bewilderment and frustration, such as Violet verbalized when she expressed her confusion over HCPs' recommendations for additional genetic testing when previous PNS blood work had "come back negative." The priority HCPs gave genetic testing was also evident in their offers to "fast-track" or "expedite" an amniocentesis, emphasizing this would facilitate parents' "informed" decision-making in a timely manner.

In the third and final step of examination, parents described being subjected to HCPs' normalizing judgment in the form of positive or negative feedback on their decision. Those parents that made decisions in agreement with HCP-constructed norms to pursue amniocentesis described HCPs' responses: warm and supportive natures in organizing and sometimes expediting an amniocentesis; collaborative tones in HCP-parent interactions providing the impression parents and HCPs were "all in this together" (field notes, Abra) and encouraging parents to call with any additional questions or concerns; and reassurance amniocentesis results would facilitate parents' decision-making. In contrast, the few parents who chose not to pursue amniocentesis described receiving the impression HCPs thought they "made a mistake" or a "poor parenting decision" (multiple parents, field notes). For example, parents who chose not to pursue amniocentesis described some HCPs who appeared perplexed when told of the parents' decision and continued to re-review the information to "make sure they understood" (multiple parents, field notes) the potential consequences associated with this decision. Parents perceived HCPs' repeated questioning and repeating of the potential "negative consequences" as questioning the parents' decision, despite parents indicating their reasoning and rationale, which was generally based on either: (1) not wanting to risk a miscarriage for additional information that would not alter their decision to continue the pregnancy; and/or (2) their perception that the risk of a genetic anomaly was low given that other antenatal testing results (i.e. screening blood work, detailed ultrasound) had not raised increased suspicion of a coexisting genetic anomaly. In this way, HCPs' verbal and nonverbal reactions to parents' decisions pertaining to additional genetic testing served as micro-rewards or punishments to idealize and potentially influence parents toward actions consistent with HCP-constructed norms.

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A Foucauldian lens also helps to shed light on what could be understood as how pastoral power was enacted in HCP-parent interactions concerning decisions related to additional diagnostic testing in the way parents perceived HCPs as acting in their best interests and in how parents looked to HCPs for medical and moral expertise and guidance on these antenatal decisions. In general, parents' participation in additional noninvasive diagnostic testing was taken for granted—HCPs assumed parents would view additional non-invasive testing favourably if it provided greater insight into the specific nature of the fetal anomaly. Hence, additional testing in the form of fetal MRI, 3D ultrasound or other specialized non-invasive testing was usually presented by HCPs as a means of gaining a greater understanding of the nature of the anomaly, with parents generally conforming to this expectation, often without even realizing participation was a choice. However, given amniocentesis posed a small but not insignificant risk to the fetus, some parents deliberated over whether it was acceptable to risk a miscarriage in order to determine antenatally if a chromosomal anomaly was present, with many parents looking to the healthcare team for guidance on this decision. As depicted in Lexi and Logan's vignette, occasionally HCPs suggested or recommended parents pursue amniocentesis for specific reasons. However, as in the case of Violet and Manuel, the majority of HCPs did not make specific recommendations; rather, they influenced parents' decisions by emphasizing certain actions or outcomes over others. Moreover, HCPs often backed up their direct or indirect recommendation to pursue amniocentesis with arguments that underscored the benefits of the procedure (e.g. Violet was told that the absence of a genetic anomaly on amniocentesis could help with prioritizing the baby for a neonatal cardiac transplantation), or by painting a picture of how amniocentesis could help the parents avoid negative outcomes by pursuing TOP if amniocentesis results indicated a

chromosomal condition associated with what the HCP framed as negative outcomes. For example, in Lexi and Logan's experience, the specialist came across as acting in the parents' best interests in the way she presented the option of amniocentesis by framing the possible outcome of uncovering a chromosomal anomaly associated with an intellectual disability in a manner that encouraged parents to consider amniocentesis as a priority. Specifically, from a governmentality lens, the specialist employed pastoral power through the use of introspection and self-examination in tandem with a negatively framed potential outcome when she encouraged the parents to consider how they would feel if they "ended up with a mentally retarded child."

Both HCPs and parents viewed the choice of whether or not to pursue amniocentesis or chorionic villus sampling (performed earlier in pregnancy, usually between 10 and 13 weeks gestation) to determine the presence or absence of a genetic anomaly as a critical antenatal decision. Several parents commented that test results indicating a chromosomal anomaly such as Down syndrome would be a deciding factor in choosing to terminate the pregnancy. For parents who had already thought through and discussed what they would do in the event that a fetal anomaly was detected antenatally, parents described their decision as more straightforward, often agreeing immediately when the option was raised, thereby truncating the need for a more detailed HCP-parent discussion. For other parents who did not view TOP as an option for them, additional diagnostic testing was valuable in determining definitively whether a chromosomal anomaly existed with the intent of "knowing what they were dealing with" and "being prepared" in order to fine tune their preparation for what to expect after the baby's birth. Other parents chose to pursue amniocentesis because a significant chromosomal anomaly could have ruled out the option of neonatal treatment, and they preferred to

know this ahead of time so they could plan palliative care for their child after birth, allowing them potentially more time with their baby in a hospice or home setting rather than waiting in hospital for results of postnatal genetic testing to determine possible treatment options. From a governmentality lens, pastoral power was enacted in relation to these parental decisions in how HCPs posed potential hypothetical outcomes to parents and then observed and discussed parents' reactions to these possibilities. In most cases, HCPs guided parents toward the choice of pursing amniocentesis by presenting the option of amniocentesis in ways that would be aligned with most parents' perspectives and viewpoints. It was uncommon (approximately one in 20) for parents to refuse amniocentesis unless the diagnosis was made at a late gestational age, when complication risks were increased and TOP was no longer an option.

The enactment of disciplinary and pastoral power continued to play out in HCPparent interactions as parents moved forward in their antenatal journey from choosing whether to pursue specific diagnostic tests and procedures to making pivotal pregnancy and neonatal treatment decisions. The following section provides an analysis of power relations underlying HCP-parent communication and decision-making specifically related to continuing or terminating the pregnancy. The section begins with the fourth and final part of Violet and Manuel's vignette to illustrate and provide insight into the nature of this aspect of their experience.

A Pivotal Turning Point: Parents' Decisions to Continue or Terminate the Pregnancy

Vignette #4: Violet and Manuel. Part Four: Considering Options

Part two of Violet and Manuel's vignette described how Dr. Smith, the pediatric cardiologist, raised the option of TOP during his initial discussion of the fetal anomaly.

Later that day during their meeting with members of the genetic team, Violet and Manuel

sought clarity on this option.

Violet: And then we asked them [members of the genetic team] about this option of termination. We were trying to get more information on that, like why did they [the cardiac team] bring it up? Like, why is that an option, in terms of, you know, how serious this is? Can you tell us if there is a poor quality of life? But, I don't think they knew too much about it, they didn't want to say much I guess. [They] didn't want to say something wrong. They did tell us, they did say several times that the survival rate was, like, 70 percent, and that was sort of vague again. Like, the survival rate of what, right? I don't know. I think when you are talking about cancer they use a five year survival rate, but we didn't know if [they were referring to] the first operation, all of them through childhood, or...? But, again, I don't think they knew. I think they had sort of a vague overview.

R: And was that similar to the impression you had from Dr. Smith [the cardiologist]? Violet: Well, he had really only said "the majority of cases," so we couldn't tell if he was trying to gently say 51 percent or like 95.

R: He didn't give any specific statistics?

Violet: No, he didn't, no. So, we kind of took that number, I mean that was not great, but also, it's more than 50 percent ... It was not the worst thing. ... But when we came back and saw Dr. Jones [another pediatric cardiologist] a few weeks later, he was like saying, no, the survival rate now, here, is like 94 percent, like during the three surgeries, and then really strong through childhood, and they can't really comment on what happens in middle age because they don't have enough survivors. But he gave us something much more specific and optimistic and that was more like what we had, we had found a bunch of different stuff, different papers on the Internet and basically what he seemed to be quoting was, like, the most optimistic studies we had seen...

R: So, going home with maybe 51 or 70 percent at first, and then waiting a couple of weeks at least until you met with Dr. Jones?

Violet: Yes, two weeks or so, yes.

R: It's a different sense all together in terms of outcomes, I would think? Violet: Yes, yes. I don't know. We also found they [the genetics team] were not super helpful, like, saying much about the different options. Although they did mention, like, factually, like, you can get a termination up to 24 weeks or something without, without questions asked or anything. You know, it's quite easy ... for any reason, I think that's what they said.

R: And so that was clear after that point?

Violet: That was clear, we just were not really clear on, I don't know, like why, why do people choose it? I know it's kind of a personal thing, and you can't get someone to tell you, yes, you should do it, but sort of, yeah, it was confusing in the decision-making process because, and maybe, that is just for us, [but] we thought if there is a 70 percent chance of survival, then, why not? But then we were like, well, then maybe there is a quality of life problem that nobody has told us about yet. So, so we kind of went home with unanswered questions that nobody seemed to be able to really get into. The genetic team didn't. I don't think they knew, and the

cardiologist, I think he just didn't have the time to get into it (Violet, L 529–591, 593–604).

As Violet indicated, multiple HCPs noted the parental option of TOP; however, she and

Manuel were left with many unanswered questions about this potential decision,

especially given they had not considered it before.

Violet: We were just confused. And, of course, for us this was a planned pregnancy. The wanted baby. And we had never bothered to consider or talk much about abortion because there was no relevance to it. We knew there was a vague possibility there could be something wrong with the baby, but we figured, like, it was so slight [that] we could just talk if it came up. So, you know, I don't know, I guess we didn't know how to approach it. R: It's not something you had considered, making that decision? Violet: No, we had never. I don't think I've ever really thought about it. We never really [did] (Violet, L 625–636).

Continuing or terminating the pregnancy was a pivotal decision most parents faced following antenatal diagnosis of a fetal anomaly. For the majority of parents, this decision was associated with intense deliberation and contemplation of multiple intersecting factors. The majority of parents had never considered the option of termination because the pregnancy was "planned" and "wanted." In this context, several parents took a similar stance to Manuel and Violet in seeking out clarification and further specifics about the full range of possible options and associated outcomes prior to making a definitive decision. This included seeking specifics about the statistical success rate of treatment options, quality of life (QOL) indicators, and the degree of pain and suffering their child would experience. For those parents who deliberated over the decision to continue or terminate the pregnancy, many described it as one of the most difficult and emotionally distressing decisions they ever confronted. Moreover, for several parents, this already taxing decision was further complicated by their perception that HCPs' indirect or direct recommendations were in opposition to the parents' personal beliefs and values. For example, Yolanda and

Zane described the emotional angst and intense deliberation they underwent in deciding

to continue the pregnancy (at 20 weeks gestation), despite HCPs' strong suggestions to

pursue TOP because the fetus was not expected to survive the pregnancy.

Zane: [The MFM specialist] said that either your baby is going to die in the time that he spends in the womb, like the next couple of weeks, or your baby is going to die of termination, which is the best option anyway because it's painless. And those are kind of like the options that he painted for us. And then he said, like, if we kept our baby in there, and the baby survives, I guess, like, you know, like, almost, it would be miraculous, like, it's not even possible, like, the survival rate is extremely low.

R: You just used the word "painless." Were you given the impression that if the baby did die in utero that there would be suffering or pain involved?

Zane: Yeah, because he basically said, like, it would be like heart failure, right, and you know the baby is going to be in a lot of pain. And then we were talking about it and the big thing that came up is, like, you know, our baby is going to suffer, you know, he's going to die from heart failure, you know. We didn't want him to experience pain and that's why he presented termination that, you know, it's painless and it's quick and it's easy, you know, we can inject him in the heart and baby is gone.

Yolanda: Yeah, when I heard that, inject him in the heart, I'm like, wow, like that is so cruel, like how could that be painless?

Zane: Yeah, I thought that was ruthless, right, so I'm like, ah, I don't think so. And then we talked it over and like, two days later, we're like, no, we're not going to take that option.

Yolanda: ...That same day we went home and, of course, I was like, I didn't get any other options. Everything was just, like, he's going to die, like, everything was so negative that I, I think that that was the best option—to terminate. R: Hmmm.

Yolanda: ...Yeah, so, I was, like, that whole night, I was like, I think I should do this [termination] because the baby is going to die and termination is a better option, but then there was something in me that was telling me that, that wasn't right for me to do so ... And so, then we went back home, and on the way back home in the car, I was like, you know what, I'm not going to do that because I can't live with that guilt for the rest of my life. I don't know, I will have to like do this to the baby and then I will have to give birth to that baby [i.e. a still born baby as part of the termination process] and I'm like, I don't want to do that ... So, it was really hard to make the decision, but I was, like, I'm not going to do it and if my baby has to die, God will make the decision, and if God will know, okay, this is your time and you are going to live, then I'll take it, but I'm not going to *do* [emphasis in the original] it (Zane and Yolanda, L 389–437).

In contrast to parents who faced intense deliberation and emotional angst in deciding whether to continue or terminate the pregnancy, some parents (approximately 30 to 40 percent) described the decision-making process as less difficult because of firmly held personal beliefs or values that provided clear and definitive guidance, or because they had already mapped out clear decision trees as to "if this, then that" scenarios, which they relied on and enacted when confronted with this major life decision. For example, Renee, who received a fetal diagnosis of a common heart defect associated with excellent short- and long-term outcomes following surgical repair, described "not getting too attached" to the baby until the amniocentesis results came back as normal. She explained how the genetic team indicated the fetal heart defect was associated with an increased possibility the baby would have Down syndrome and how she and her partner had decided prior to the pregnancy that in the event of a major chromosomal anomaly they would choose to terminate the pregnancy, noting, "After the diagnosis, we decided we could deal with the heart problem, but not Down syndrome" (Renee, field notes). Renee attributed this decision in part to having worked extensively with children with intellectual disabilities in her career and understanding the multiple challenges they faced. With this decision already made, Renee indicated waiting for the amniocentesis results was one of the most difficult times of her life, noting, "It was like my hope was put on hold ... I didn't allow myself to get excited about the baby until I knew we would be keeping it" (Renee, field notes). In contrast, another small group of parents (approximately 20 percent) indicated TOP was not an option because of conflicting religious, cultural and/or personal beliefs. Hence, these parents described not deliberating over whether to continue or terminate the pregnancy because "it wasn't a decision ... we were not terminating" (Rose, field notes). These parents also described intense feelings of worry

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and angst as they waited for the results of diagnostic tests and the birth of their baby, with several of them noting they "had to accept" whatever happened and describing how they focused on "hoping for the best," and for some, "kept praying that everything would be okay" (multiple parents, field notes).

Navigating unspoken rules of engagement and the elephant in the room. Parents' descriptions of initial HCP interactions following an antenatal diagnosis of a fetal anomaly indicated an awareness of the power relations and underlying organizational manipulations at play, which determined how subsequent HCP-parent interactions unfolded, including when, which and if additional specialists would meet with the parents. Moreover, parents repeatedly described unspoken rules of engagement and indirect methods the healthcare team employed to ascertain and guide parents' decisions to continue or terminate the pregnancy. Parents often described feeling like this topic was handled like "the elephant in the room," in that it was the obvious question HCPs wanted to determine the answer to, but it was rarely asked outright. One father, Jesse, described the healthcare team's multiple attempts to gain certainty about whether the parents intended to continue the pregnancy before setting up additional meetings for the parents with a pediatric specialist to explain potential treatment of the complex fetal anomaly as well as a meeting with a perinatologist to review high-risk obstetrical care. In his description, Jesse underscored how HCPs' attempts to determine the parents' intentions to continue or terminate the pregnancy were made simultaneously with HCPs' descriptions that emphasized the "potential increased negativity" that would result if they chose to continue the pregnancy.

There is this stage where the hospital, after they give a [fetal] diagnosis, you know, they want to, they kind of want to, like, ask you very soon if you want to keep your baby or not. There is a sort of process, right, it's like, it's so, they are so professional about it but at the same time they are very, it's like that really kicked in

as soon as the diagnosis was given it seemed, because that really was the crux of the conversation on the next appointment [i.e. the meeting with the healthcare team after the initial diagnosis of the fetal anomaly]. The next appointment after the diagnosis was with this genetic counsellor and her colleague-that was sort of the wheel that was activated, you know. Like, hey, let's talk with the parents if they want to keep their baby, you know, and sort of talk about that kind of stuff. And talk about the genetic, oh yeah, and then the amniocentesis and further testing all sort of around the thought of do we want to, do you as parents want to search out, find out more information about what seemed to me the potential increased negativity of, or consequences of having this child. So, all those little wheels are put into place, which seem to have to happen, needed to happen, before you can see the pediatric surgeon, before you could have more of an in-depth discussion with the perinatologist. That [the determination by the healthcare team regarding the parents' intent to continue or terminate the pregnancy] was a stage, which just got immediately activated. And it was a whirlwind of tension and anxiety, so that was part of the roller coaster there (Jesse, L 768-789).

Parents perceived this HCP-led process to ascertain parents' intentions concerning

pregnancy intentions as "needing to happen" before meetings with pediatric and other

subspecialists were set in place. Several parents perceived that the impetus for this was

the system's protection of specialists' time, because a meeting with pediatric team

members might be perceived by HCPs as unnecessary if parents had already decided to

terminate the pregnancy. This description exemplifies how dominant efficiency discourses

were taken up by HCPs. In contrast, from the parents' perspective, the specific,

comprehensive and up-to-date information parents gleaned from pediatric experts

involved in the postnatal care of infants and children with the same fetal anomaly as their

child often provided parents with answers to many of their unanswered questions, which

parents indicated was (or would have been) extremely valuable in making the decision to

continue or terminate the pregnancy. As Jesse indicated,

By that time [when they met with the pediatric specialist several weeks after the initial diagnosis], we had done a lot of research on the Internet already, but certainly meeting with the pediatric surgeon was an immense relief and confidence booster and hope booster. Yeah, I mean for sure, it would have been great to meet [the surgeon] even sooner (Jesse, L762–766).

HCPs idealized continuing or terminating the pregnancy in the manner information was conveyed and the content of information provided. The majority of parents described paying close attention to what was and was not said during initial HCPparent meetings, and indicated that their perceptions of HCPs indirectly (and sometimes directly) guided their choice to continue or terminate the pregnancy. This perception was based on the manner in which treatment and prognostic information was presented that idealized one option as better than the other. Sometimes these forms of power were enacted in subtle and nuanced ways to influence parents' decisions to continue or terminate the pregnancy. For example, several HCPs appeared to make an unquestioned assumption, in keeping with health-constructed norms associated with the fetal diagnosis and treatment outcomes, that the family would be continuing the pregnancy. In these instances, the option of terminating the pregnancy was either not raised at all, was given as an option but not reviewed in detail, or was raised in a way that dismissed it as a valid option given the positive treatment outcomes. This was evident in Violet and Manuel's meeting with the pediatric specialist, who idealized the option of continuing the pregnancy in that the bulk of information they presented focused on the option of surgical treatment, underscoring the fact that most children survived and did well. In contrast, only a brief comment was made at the end of the session about the option of terminating the pregnancy. From a governmentality perspective, this could be understood as HCPs enacting disciplinary power in the form of normalizing judgment and examination in combination with pastoral power to idealize specific parental decisions related to pregnancy options.

In contrast, Lexi and Logan's interaction with the MFM specialist idealized the option of terminating the pregnancy. This was evident in: (1) the amount of time the

specialist dedicated to TOP compared to neonatal treatment; (2) the multiple comments which directly and indirectly indicated the HCP's "pro-choice" stance; (3) the priority given to discussing the TOP option first even when Logan asked a direct question about post-surgical treatment outcomes; (4) the inference that surgical treatment could involve considerable pain and suffering that could be taken from the comment TOP "might be the most compassionate" option; and (5) the spotlight on the complex postoperative care needs rather than a balanced approach that included potential positive outcomes associated with treatment. In both scenarios, it was striking that treatment and prognostic information was provided in a fairly one-sided manner that idealized one option without explicitly making a recommendation.

Several parents described being shocked or surprised at how quickly during their initial meeting with HCPs the option of TOP was raised. Moreover, this choice was often combined with a description of the fetal anomaly that emphasized potential negative postnatal outcomes. For most parents, this bias was not directly stated but covertly woven into the manner in which information was conveyed and the content of information provided. For example, Jesse described being unprepared for how quickly the MFM specialist spoke about the option of TOP in tandem with an emphasis on "bad news" rather than a "balanced" approach to providing prognostic information.

No, no we weren't really prepared. Although we thought we, we suspected that there would be talk about that. I don't know if you're supposed to prepare for that, but it was, it was definitely a shock, and a shock personally how, how quick, you know, they sort of built that card [the option of terminating the pregnancy]. You know, like, how quickly they sort of present that as an option. Now on the flip side I guess I can understand, I suppose, I can understand why they need to establish that question or deal with that question right away because they don't want to have to deal with that question later on, or they want to make sure the parents are sure ... but, nevertheless, with the speed, and with how quickly, how almost focused they were on dealing with that kind of question, it was shocking to me actually. You know, it would have been less shocking if it was, if it was that discussion and at the same time, on the same day, there was also some other discussion about once again, you know, this is how it could, you know, this is how successful things could occur. You know, like it was just basically bad news and it was basically the worstcase scenario that day, no other discussion ... Thea [Jesse's partner] and I were talking about this—we said there should be a more balanced approach to providing information about a diagnosis and the treatment. There should be, like, when you get the information on what it is and what are the consequences, it should be delivered in a balanced approach. This is the best-case scenario, this is the worst-case scenario, instead, you know, it was just, it was just like worst-case scenario ... There was no hope in any of those discussions, so much so that, you know, we were, we were just glad that we were done talking to those, those people. Nothing against them at all, they were doing their job and they were, like, strictly, like, like really professional and really understanding. But the news that they had, that they have to deal with is just not the kind of words you want to hear from them (Jesse, L 796–813, 833– 839, 854–860).

Jesse went on to explain that although HCPs did not directly state or suggest they should

terminate the pregnancy, nonetheless he perceived a significant bias.

I would say whatever that notch is [where an HCP directly presents a biased perspective toward TOP], maybe one, okay, it depends on how many notches there are in the scale [laughing], but you know, like notches like a hundred percent, you know, if it was a hundred percent bias towards ending the pregnancy that would be, like, ten out of ten, I would say it would be like seven or eight [out of ten]. It's sort of that direction ... They stopped short of suggesting anything like that but they certainly... present to you that decision and everything to do with that decision right up front so that is why I say seven, eight in terms of that scale of bias (Jesse, L 1078–1091).

In providing prognostic insights, HCPs relied on their current understanding of the

evolving fetal anomaly, often working on "hunches" or "best guesses" as to how the severity and complexity of the fetal anomaly would change from diagnosis to birth (i.e. some forms of fetal anomalies became less severe and were associated with improved mortality and morbidity outcomes from diagnosis to birth, while others became more severe). In addition, the detail of prognostic information varied, with some HCPs providing prognostic information based on their professional expertise and experience and others providing information based on published reports and discussions with subspecialists rather than first-hand experience. However, parents often had not considered the possibility that different HCPs might provide different prognostic scenarios until the

parents experienced dissimilar or divergent prognostic perspectives. Upon realizing not all

HCPs presented similar perspectives on pregnancy and neonatal treatments and

outcomes, parents often described their evolving awareness of their vulnerability to the

bias and influence of expert opinion. For example, Yolanda and Zane described how

initial information they received from an MFM specialist about a complex fetal lung

anomaly was provided in such a way as to strongly influence them toward termination,

and that subsequent meetings with other HCPs led them to understand the different

opinions HCPs held on the fetal prognosis.

Zane: ...We look back in retrospect and we kind of talked about how, like, their [MFM specialist and fellow] attitude at the time was more, like, termination. They didn't really, like, they didn't really have the facts, they kind of gave us, like, a very broad, like, I don't know, explanation of what was going on ... and their first, what they really wanted [us] to do was terminate right away, and that's the best option, like, the baby was going to die in two weeks [in utero] anyways. They said, well yeah, he's going to have, he's going to have heart failure and expect the worst. But then after [at a subsequent appointment one week later] talking to the other doctors they kind of said, like, no the [fetal measurement of the lung anomaly] has gone down ... After that we talked to [the pediatric specialist] and they had a different attitude, they had way more statistics and a lot more facts and a lot more concrete evidence... (Zane, L 65–78)

Zane: One of the things he [the MFM specialist at the first meeting] said to us that really stuck out was, like, "I'm not a betting man but if I was to bet," he was like, "I'd bet on the side that your baby is going to die pretty soon" ... He kind of basically painted a picture in our mind that our baby is going to die like in two weeks. Yolanda: In two weeks, yeah [shaking her head and looking down and rubbing her pregnant belly].

Zane: You're better off, like, you know, terminate, now.

Yolanda: Yeah, terminate, like next week.

Zane: It will be better.

Yolanda: Yeah, he was like, I'll give you time, like a few minutes, to make a decision. That's what he told us. And then we went to the car because we had to pay for the parking. And then when we went there, then I didn't want to. I didn't want to go back in there because, like, I mean after what he was saying. So, I stayed in the car and then Zane went back by himself to tell him that we were going to think about it. We can't say yes, like, right now to terminate. So then, he was like, okay, you guys can have another appointment next week... (Yolanda and Zane, L 102–127)

At the subsequent meeting the following week, Yolanda noted a different specialist had a more positive outlook on the fetal prognosis, which provided them with hope for their unborn baby's future, and Zane added how in hindsight he tried to make sense of the perspective of the initial specialist, while underscoring the importance of HCPs providing a balanced discussion of pregnancy options.

Yolanda: This other doctor, her name is [Dr. Smythe], I think she was so much, like, nice, like, she explained. And she did say, like, everything was in a better way, and she wasn't, like, all your baby is going to die, your baby is going to die. She was, like, you still have, yeah, like hope. She was really positive. And I know that probably that's her job as a doctor, and I felt like we had hope. Zane: Well, you know, it's not so much of a negative, I guess negative or positive over neutral. I guess in the moment, you know, we understand maybe they are trying to be as professional as possible, and like, you know, the facts are showing us it appears, you know, that the best option in this situation would be termination, right? So I guess, I don't, it's not like I don't hold anything against it, but, I think it's kind of part of their job to explain it, but the way we took it was, like, okay, you only gave us one option, whereas, you know, we went home, we did our own research and that is kind of what led us to like, I don't really think that termination would be the best option... (Yolanda and Zane, L 132–146)

Using a governmentality lens, Yolanda and Zane's experience underscores how

HCPs employed pastoral power to shape parents' perceptions of prognostic information, and thereby had the potential to significantly influence parents' decisions to continue or terminate the pregnancy. In their initial meeting with the healthcare team, the presentation of "worst-case scenarios" associated with the fetal lung anomaly, combined with an emphasis on the option of TOP, exerted considerable influence toward shifting the parents' perspectives toward termination as "the best option". In contrast, Yolanda and Zane spoke about how their own research into treatment options and the prognostic indicators given by the second specialist contrasted with the initial information they received and gave them hope about their fetus' future, which ultimately contributed to their decision to continue the pregnancy.

Enforcement of micro-penalties for not conforming to HCP-constructed norms related to pregnancy decisions. HCPs imposed micro-penalties when parents' decisions to continue or terminate the pregnancy were not in keeping with HCPconstructed norms, resulting in subsequent HCP-parent interactions being more fraught with conflict and tension. As the majority of parents interviewed chose to continue the pregnancy, for the participants in this study the majority of conflict centred on HCPs' verbal and nonverbal reactions that were perceived as attempts to influence parents toward terminating the pregnancy. HCPs who continually emphasized a "litany of negative outcomes" associated with the fetal anomaly, or who guestioned parents' understanding of the complexity and/or severity of the fetal anomaly, were viewed by parents as using these subtle forms of negative feedback to try to manipulate and influence them toward TOP, even when parents made their plans to continue clear to the healthcare team. Specifically, many parents described HCPs who focused on the potential negative outcomes associated with the fetal anomaly rather than providing a balanced approach of positive and negative outcomes related to treatment of the fetal anomaly. Potential negative outcomes reviewed by HCPs included: unnecessary pain and suffering; lengthy hospitalizations; multiple surgical procedures with significant morbidity and mortality risks; "poor" quality of life; high care-giving burdens; and increased strain on the parents, siblings and broader family unit. Parents also perceived HCPs who continued to foster dread and despair by repeatedly giving the "child will die" speech as disrespectful of and in conflict with parents' decisions, especially when parents had verbalized a conscious effort to "put their trust in God" or "focus on the positive" and "hope for the best." In addition, several parents described feeling stigmatized and made to feel they would be making irrational and emotionally-based decisions if they chose to continue the pregnancy.

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In this way, from a governmentality lens, HCPs' verbal and nonverbal responses to parents' plans to continue the pregnancy acted as micro-penalties and served to idealize parental decisions consistent with HCP-constructed norms to terminate the pregnancy, thereby influencing parents to make "independent" and "informed" decisions toward this end. In contrast, HCPs used micro-rewards in the form of positive feedback and the expression of hopeful outcomes when parental decisions to continue the pregnancy were aligned with HCPs' health constructed norms. Not surprisingly, these HCP actions were viewed by parents as supportive, caring and demonstrating faith in the fetus' survival and long-term health as well as the parents' ability to make "good" parenting decisions.

Analysis of Parental Agency and Resistance

Building on the preceding exploration of the enactment of disciplinary and pastoral power in antenatal interactions and decision-making, the following section shifts the focus onto examining parents' enactment of agency and resistance within these complex power relations and discursive systems. A governmentality lens helps expose competing and contradictory discourses shaping HCP-parent interactions and illuminate how power operated through knowledge embedded within discursive frameworks that constituted and shaped antenatal care delivery. Parents took up these competing discourses when they enacted agency as a means of resisting and challenging the authority of dominant frameworks shaping and influencing HCP-parent communication, antenatal care provision and health decision-making. Parents were not challenging specific dominant frameworks such as biomedicine, efficiency and individualism, but rather emphasizing how an exclusive focus on these discourses in HCP-parent interactions minimized or negated HCPs' ability to focus on parents' unique histories, needs and priorities as well as the contextual determinants of health. In the following section I will discuss parents' nascent

enactment of agency, which was characterized by a shift from being relatively passive to an engaged and active parent. Agency was constituted in those parental actions that challenged the legitimacy of the organizational and system-wide compulsory structures that compelled and influenced them to think and behave in certain ways and guided them toward specific health decisions. Specifically, parents took up opposing discourses emphasizing comprehensive and holistic care as well as thoughtful, reflective and balanced approaches in communication of diagnostic and prognostic information.

There was a seismic shift in parents' self-identity from "pregnant" to "parent" that was expedited following the initial diagnosis of a fetal anomaly, and that involved nascent enactment of parental agency and resistance to perspectives not aligned with the parents' views or values. When parents' and HCPs' perspectives were in alignment and parents perceived their needs and priorities had been met, there was less need for parents to resist or challenge dominant organizational frameworks impacting their care, and consequently less tension and conflict in HCP-parent relationships. For this reason, amongst others, there was considerable variability in how parents took up the role of "parent" and manifested their agency related to antenatal decisions.

Although they initially took up and conformed to the hegemony of biomedical frameworks and rarely questioned system-dictated efficiency imperatives, as parents absorbed the initial shock of the fetal diagnosis, they consciously became aware of system inadequacies and inconsistencies. At this point, there was a concomitant change in parental agency from subjects of assessment and recipients of information to active parental agents attuned to information and decisions related to fetal health concerns. Parents used phrases such as "The blinders came off," "We lost faith in the system", "We were disillusioned," and "We were triggered into action" (multiple parents, field notes) to

denote their awareness and realization of the need to resist and/or challenge system shortcomings and institutional priorities that served to minimize or negate their unique experiences, perspectives or priorities, and/or that they perceived influenced them toward decisions not aligned with their values, beliefs or best interests. In this role, parents described enacting initial parenting decisions and taking an active role in advocating for and, at times, protecting the well-being of the fetus. Parents enacted agency in multiple ways including: (1) maintaining and fostering hope; (2) raising their voices to draw attention to fetal, parent and family needs and priorities; (3) arming themselves with information; (4) seeking out additional medical expertise; and (5) searching out parent-toparent support.

Parents Maintained and Fostered Hope

Hope and parental agency were inextricably linked in that hope played a pivotal role in fostering parents' abilities to enact agency in HCP-parent interactions. Conversely, despair or diminished hope related to the fetal prognosis often resulted in diminished parental agency to question HCPs' prognostic information. This was evident in the experiences of several parents who initially considered TOP because they perceived the fetal prognosis was "hopeless" or associated with "no good outcomes" or "zero hope." For example, Yolanda and Zane described how their initial HCP-parent meeting centred on the high probability of fetal demise. The parents explained that the hopelessness "painted" by the HCP conveying this prognostic information resulted in parental feelings of being "trapped," "hypnotized," and "under a spell"; they could see no other option than the one strongly recommended by the specialist, which was to terminate the pregnancy, even though this was contrary to their personal beliefs.

Zane: ...When we look back in retrospect, like, how, like, why would we even entertain that [considering TOP] thought?

Yolanda: Yeah.

Zane: What was wrong with us? Like, we were under a spell or something. It almost felt, like, but we just got, I mean, we were just kind of basing our decisions I guess at that point, kind of on the information that we had got at the time, right, so, I mean, it almost seemed, like, you know, like, you [looks at Yolanda] said, between the sword and the wall, that either way you're going to lose, right? R: It was like a dilemma?

Yolanda: [Nodding in affirmation] Because you think everything, like, there is no hope. Like zero hope...

Zane: It was like she was hypnotized or something.

Yolanda: Yeah, like...

R: Oh, when you were in the meeting with them [the specialist]?

Yolanda: ...No, when I got home. Like, why that is insane, like, it's just like I didn't have a chance to see, like, farther, like [to see] other options. I was like, just like that [raises her hand up a short distance from her face to indicate she could only see a very short distance].

Zane: It's almost like we felt trapped. Like, you know, the picture that was painted for us, without realizing that, you know, we could escape that picture and go on the Internet and find out some new information, right?

Yolanda: I was in a dream. Like, I don't know...

Zane: Tied up or something.

Yolanda: Yeah, like, just that, [accepting] that this [specialist] is right, and that [TOP] is what we have to do. And then even I talked to my mom that day over the phone, and I was like, yeah, we have to terminate... (Yolanda and Zane, L1477–1517)

Given the parents' understanding that the fetal prognosis was associated with

"zero hope," Zane and Yolanda described how they turned to their Christian faith as a

source of hope and support, which in turn led them to focus on the positive as one

strategy to maintain their sense of hopefulness for a better outcome for their fetus.

R: So, you mentioned hope and I am curious, what that's been like, because I know when I talked to you on the phone, I think you used the word, that first meeting [the initial meeting with the specialist who provided them with information on the fetal diagnosis] sort of "destroyed" you in a way in terms of hope, and just if you can talk a bit about that...

Yolanda: Yeah, it was a big difference, like, when we first went, as I told you, we heard all like negative things, like [they kept] going through my head [gesticulates with a circular motion around her head], my baby is going to die in another two weeks, and it's hard and this [fetal lung anomaly] is so huge and all those other things...and then as I told you, we are Christians, so we went to, we went to the elders in the church and we tell them what was happening and they prayed with us. And we have the baby, the baby is still in prayer with the prayer team that they have at church. And they pray with us and we believe, and we know that God is in

charge, and even though we know that, that's okay, we know that, that God is the one that has the last word and he will say yes or no. So, we're, like, we're going there because we know we need to go to the hospital because everyone there knows everything, but our hope would be lost. Like we, we respect [the HC team] and everything but we were trusting that God will, will help us through this... (Yolanda and Zane, L 755–773)

Similarly, Callie described how her upbringing in the Hindu faith gave her direction to

focus on "doing what is in front of you," which allowed her to focus on staying positive and

"doing the best I can with what I have in front of me":

Callie: And where the Hinduism comes in is that there is, there's a school of thought that says there's many roads up the same mountain. And there are many lives we're here to live. And there's a pretty strong sort of argument to be made that you do what's in front of you. You know, and you see through what's in front of you, and you are all, you are all on your own journeys. And if you are on your own life journey, then my job is to do the best I can, you know, to kind of do the best I can with what I have in front of me (Callie, L 173–179).

Callie also indicated how she enacted agency by asking others to hold her and her

unborn children in their thoughts and meditations in accordance with Buddhist tradition:

Callie: I was raised Hindu ... and then I went to a Buddhist temple ... So, they have something in the Buddhist tradition where you hold someone in your thoughts and meditation and so you can sort of ask different people to be held in your thoughts. So, I actually contacted my own temple in [city], the temple at [city] and another temple. And I asked them to put myself and my children on there, sort of like a registry of people that people are praying for essentially. So, I sort of reached out to this larger community because I felt like I wasn't capable of myself, of like, sort of deeply holding my own self and my own thoughts for my own wellness and my own children. So, I felt, I felt like there was a community of people out there that were, that were holding me in their thoughts and they were sending me their positive support ... I sort of said, "shit, things are going sideways, this is what I need, I need to know that there are, that there are positive thoughts being sent to my children and if I can't create them in myself I'm going to find a community that can." And I actually sent that out to, like, everyone I knew so that, like, people that I was not associated with their religion, like Catholic people that I work with that were, like, can my church put you on the prayer list? And I was like, yes, like, I'll take all comers, like, I wanted a maximum... (Callie, L 1613–1644)

In addition to finding hope in their faith, a higher power, or a greater purpose,

several parents also described how they fostered hope by connecting with their fetus,

often through talking to the fetus or otherwise transmitting positive energy in their daily

parent-fetus interactions. For example, Zane and Yolanda described regular fetal

interactions and positive mindsets they actively fostered as a means of maintaining hope

for their fetus' well-being. They also emphasized the importance of avoiding pessimistic or

negative thoughts, which they described as "like swallowing poison" in that they perceived

these as toxic to maintaining a hopeful stance.

Zane: ...I read psychology and different things, right, [it] talks about ... where focus goes, energy flows, right? So, I'm like, I can't focus on things that I don't want to, because if you don't want them and you focus on them, it's kind of like you're giving them more energy, your life would sort of gravitate toward those negative things. ... I focus on what I want, you know, and I just want to concentrate on that in, like, my own mind ... [I try to keep] a positive mindset ... I think if we went in with the mindset of like, no, if we kind of based our approach, like a hundred percent on what the, on our first appointment, ... I don't think the baby would be doing this well... I think our attitude has a lot to do with it, like a positive mindset. Like, I told my wife, ... you're at a place where you've got to think for the best. And then, you know, just kind of like focus on what we want and not on what we don't want. And I mean if you worry too much about the bad things, I think that's just too much negativity. It's kind of like, I don't know, swallowing poison.

R: And do you [looking at Yolanda], do you try to do the same thing in terms of focusing on the positive?

Yolanda: Yeah, well it's hard. It's not that easy, but that's what I try, and I talk to my baby, and I tell him that everything is going to be okay. That he's fine, that he's growing, and that, that everything is going to be okay. We know and as Zane told me, I have to try to transmit—

Zane: Yeah, transmit.

Yolanda: Transmit that to the baby, like, transmit that everything is going to be okay... (Yolanda and Zane, L 821–873)

Parents also described resisting the "litany of negatives" and "the shattering of

hope" in HCP communications of prognostic information by aligning themselves with

alternate frameworks and approaches aligned with hope for positive fetal outcomes.

Rather than taking up and conforming to biomedical models foregrounding high morbidity

and mortality rates associated with neonatal treatment and less than ideal long-term

outcomes, several parents described focusing on the positive and "going with their gut"

rather than conforming to techno-rational approaches modelled by HCPs. For example,

Callie described how she and her partner considered prognostic information conveyed by

HCPs as well as their own detailed search of the literature, and ultimately, despite

multiple HCPs' emphases on "the litany of bad things that could happen in the pregnancy"

(Callie, L 463) and the uncertainty of how things might unfold, they enacted their hope for

their unborn children by taking a leap of faith akin to jumping off a cliff.

Callie: There is a distinct moment, we were sitting on the blue couch in our living room, ... and he's [Dan, Callie's partner] like, you know, I think we should go for it. And I was, like, prepared for where this might go and he's like, you know, I think we should do it. I think he was even more confident than me at the time and I think he's sort of like, yeah, we should go ahead. And he sort of likened it in the same way that people jump off cliffs. I mean, like he didn't know where this was going, like, and he was prepared that we might be jumping off a cliff...

R: So, what comes into my mind when you say that, and it may not be, but what I'm thinking about is a leap of faith.

Callie: Totally. A leap of faith, totally, totally. And I think what's useful for you to know is that after that second appointment with Dr. [MFM specialist] when they sort of gave us, this is the situation ... [Dan] went on the [specific university] website and did a whole bunch of research, so he had read the latest articles on [fetal diagnosis], he did a whole bunch of research, he pulled a whole bunch of stuff. And he shared with me those highlights. I found that I couldn't go on there. I found that going to the analytical literature about the odds of the situation made me so emotionally unstable. And I felt like I was, I was growing people and I needed to respect the people that I was growing and, you know, I need to sort of hold my shit together. ... And I think that is why we work as a couple is I'm like, yeah, let's do it, and then, like, I don't know if we should do it, I don't know, and he's like, you know, and then he is like, so, this is what I know, this is what we don't know. I think we could jump, okay, let's jump (Callie, 670–697, 755–762)

Finally, parents attempted to maintain a hopeful stance by focusing on benefits to

child and family in relation to potential pregnancy and neonatal treatment outcomes.

Parents did not necessarily hope for fairy-tale endings of perfect neonatal results; rather,

they described the potential for personal growth and parental resilience stemming from

their antenatal experience, and rewards associated with caring for children with complex

congenital anomalies. For example, Jesse described how "hope became a real word" for

him when he came to understand the "immense love and caring" mothers of children with the same condition as his fetus described as part of their parenting experience.

Hope became a real word for us when we started reading the stories in this group [Facebook group specific to their child's rare fetal anomaly] ... I haven't even experienced my child yet, but I think the love that you can get from your child, no matter how challenging it is, it's pretty powerful I think ... I think I'm picking that up from the Facebook group because once again, all these mothers and some fathers who, who have expressed this feeling basically throughout a lot of the post. It's just something that you look forward to because they lived through this and through all the posts that we read, you know, we are getting a good snapshot of the potential of a healthy child. And even if it's not super healthy, just the love, the immense love and caring that a lot of these mothers are expressing towards their child, don't give up on that (Jesse, L 924–25, 1343–1358).

Parents Raised their Voices

Several parents described finding it particularly frustrating to fight or struggle to have their physical, emotional, psychological and practical needs met when the organization's mission and value statements, as well as its public image as portrayed in the media, highlighted family-centred, individualized and holistic care provision. In contrast, parents perceived these frameworks to be largely excluded or delegitimized in HCP-parent interactions. Numerous parents used phrases such as "raise my voice," "fight for," "stand up to," "maintain control," and "resist" (multiple parents, field notes and parent interviews), to describe instances when they reached a point where they actively resisted or challenged HCPs' priorities and approaches. Parents did this by challenging the dominant underlying discourses of biomedicine and efficiency, amongst others, by emphasizing opposing discourses aligned with acknowledging parents' central role in antenatal decision-making and addressing holistic and contextual needs of parents and families in HCP-parent interactions.

Although only a few parents described seeking additional health services, of these parents, the majority described needing to manage "emotional distress," "overwhelming

stress," or "the emotional trauma" they experienced in association with the diagnosis of a

fetal anomaly. This subset of parents was well educated (university undergraduate degree

or higher), often worked in health-related fields, and/or had previous experiences that

exposed them to potential parental resources and supports. Accessing additional support

was often not an easy task, as evidenced by parents' descriptions of the "fight" and

"struggle" they experienced in accessing additional supports including psychology,

reproductive psychiatry, and social work services not routinely offered as part of antenatal

care. For example, Callie described her struggle to access personal support for the

emotional trauma associated with elements of her antenatal experience.

Callie: ...At some point one has to acknowledge that ... the women, the men, the families [who receive an antenatal diagnosis of a fetal anomaly] are at incredibly high odds of experiencing a traumatic event ... They, they will experience the traumatic event of choosing to terminate that pregnancy or the traumatic event of choosing to carry those children to term and having them not survive or the traumatic event of having them survive and be okay. But at some point, you look at the situation and you know that these children are very unlikely to walk out this door and it, it's more of a question of what type of trauma they have as opposed to whether or not they have a trauma ... I actually went to a counsellor, I went to a private counsellor and I was like, I need someone to talk to, right? And one of the things that the counsellor said in passing, which I don't think she realized what she was saying was, like, you can always have another child. R: Em, em.

Callie: And I just, actually just went to the supervisor of that counselling group and I was just, like, I cannot see that person, like you just need to find me something else [crying].

R: Em, em, I'm sorry.

Callie: I'd rather talk to a pillow than this. But like, she just didn't understand, like, you know, it's not about [having another baby]. Anyway, in addition, I got a referral to reproductive mental health and ironically their wait list is so long that I didn't see them until after the children had been born... I went to that group, it was super fascinating but it's not the same thing as, as me. I had a traumatic experience. I described [my experience] and I think everyone sort of was, like, oh shit, well we're not doing so bad, you know what I mean? Like, I think they got more out of the experience than I did... (Callie, L1275–1286, 1328–1362)

In addition to raising their voices to access additional supports for unmet needs,

many parents described enacting their agency by "speaking up" to "maintain control" and

not allowing HCPs to dictate what the parents should or should not do. One father, Sam, who had a complex congenital anomaly himself, provided insight into the importance of speaking up to maintain control.

...And the other thing, the other advice, something I've learned, maybe learned the hard way or through my own experience is that you are in control of your own health and I think if you are having your baby, the baby can't do anything, right, so you are also in control of the baby's life. And no doctor can take over that control. It doesn't matter how good they are. You can't expect the healthcare system to take control for you. So, you have to be informed. You have to have more general insights than anybody else in the system in order to be in control and to be able to make whatever decisions need to be made. Listen to the advice of the professionals of course, but at the end of the day you are the one making the decision, you are the one who is going to have to live with those decisions (Sam, L 1172–1182).

Similarly, Thea described how preparing a list of questions ahead of time for

specialist appointments was an effective means of making sure her voice was heard,

which she perceived as valuable in "creating as much control as you can in a world where

you have no control."

Thea: [We learned] don't panic until you have all the information. And you know, we learned to write down questions. Like, we would always with those specialist appointments; we would always come with, like, a list of questions that we prepared before.

R: I remember you were referring to the questions on your phone during the meeting, right? You had your questions on your phone?

Thea: That's right. Because it's like, I guess at the end of the day you have so little control over the situation, but if you can at least prepare yourself and ask questions, and feel like you know what's going on, like, then you are kind of creating as much control as you can in a world where you have got no control (Thea, L 898–909).

Parents also described resisting HCPs' focus on the constant potential negatives,

particularly in the context of parents' "mini-celebrations" of positive feedback on their fetus'

progress and/or when they had clearly made the decision to continue the pregnancy. As a

result, parents described reaching points where they "had enough" or "reached their limit"

(multiple parents, field notes) in relation to HCPs' perceived negativity and/or offers of diagnostic tests that would not change the parents' decision to continue the pregnancy or add any additional value to postnatal decisions. For example, Thea described reaching the point where she had "had enough" and declined additional genetic fetal testing because she perceived it was more of an "academic exercise" than an investigation likely to provide diagnostic information valuable in guiding their baby's postnatal course or

helping them make future decisions.

There was, like, so many milestone moments where we go, we were waiting for news and we received it, like, ... the NIPT test, or the result of the initial part of the amnio. And then it was the results of the fetal echo, and every stage we got good news, but there was always, like a but [emphasis in original], like, so you'd get some news, and you were like on a little bit of a high, and then it was like, and then they'd kind of, like, take you crashing back down, you know, like it was a feeling that you weren't allowed to relish in the good news that you were given. So for example, for when I got the results from the first part of the amnio for the trisomies, it was like, okay, well, you know, good news, you don't have trisomy 18 or 21 or the other one, but [emphasis in original], you know, the microarray might still show us about the deletions or additions and those could result in, like, you know, developmental or mental issues and we won't know yet until those come in. ... So it's, I mean, I know they're trying to be thorough, and in some way, in some cases, like, I know our understanding of genetics is a bit limited, so even if we had gotten maybe, like, some result about a deletion ...nothing is known about all these types of variations... it might not have given you any information, it might have just caused you to worry. And, and my last conversation with the geneticist was basically ... we think it's an isolated [fetal diagnosis] but we still have your baby's genetic material. Do you want us to keep it because we could test for one more syndrome, [X] syndrome? And I was like, well, like, can you tell me more about that? She said, well, the results are only 80 percent accurate and it will be obvious at birth and its, it's not a, you know, these are the results of it or this is sort of the symptoms of it, it's not, it doesn't have to be, it's not life threatening, blah, blah, blah. And I'm like, one more test, so all of a sudden, I would have had one more thing to worry about and I didn't want to put myself through waiting two more weeks to get an answer that was only 80 percent accurate. So, it was kind of a point where, you sort of reach a level of like, you have enough information and it's almost like you've made a decision to go ahead with the pregnancy, and knowing more at a certain stage is not very useful because every, every little bit of information that you have carries a potential of it being something else to worry about. Whether it needs to be worried about is a different story. So, I found that was very, like, we weren't allowed to sort of celebrate our sort of successful moments or our positive moments for very long because there was always some

other bit of information or some new genetic test that was threatening to, like, bring you crashing down again (Thea, L 222–268).

Finally, several parents described resisting and challenging health information that

they perceived as biased toward specific decisions not aligned with their values, beliefs or

priorities. For example, Yolanda and Zane shared how they reached a point where they

asserted their agency to continue the pregnancy based on their underlying values and

beliefs, despite strong recommendations from HCPs to terminate the pregnancy as the

best option.

Yolanda: Yeah, I guess my, my soul was, like, that night when we got home was ... like I didn't, I'm, like, I don't want to do this [terminate the pregnancy]. Should I? I don't want, like, there was a part of me that really didn't want to do that. And the next morning when I woke up I told my mother-in-law ... I know better. I'm not going to do this because I ... won't believe in what he [the MFM specialist] told me, like I went home with that, like, there is no hope for my baby. And he even told me that the earlier you do it [terminate the pregnancy], is better because there is no attachment to the baby. ... And he was like rushing me, like-Zane: Yeah, like the sooner the better, you know ... And then I remember, we were talking about it too and it's, like, ... we are not going down that road. Like, screw him, like, we are not doing that, right? And one of things that really stuck out to us was, like, you know, ... the picture I had in my mind, like I'm doing it. Like, a needle in my hand [i.e. referring to performing the ultrasound guided intra-cardiac injection of potassium chloride as part of the TOP process], like, I was just picturing that, like, you know, let's say 10 years down the road, like, just remembering that, like, reminiscing, it's, like, wow, ...you know, our baby, and now he's dead, and he might have had a chance. That's the biggest thing too, we are like, you know what, if our baby can fight it out? Why not give him a chance? Like, why take that opportunity from him, you know, at the end of the day too, it's like we are Christians and we don't believe in abortion, right? And it's kind of like, I can't go back on what I believe ... I don't want to take that road and I think it would be wrong down the road because I'd feel guilty (Yolanda and Zane, L 890–926)

Parents Armed Themselves with Information

Enacting parental agency by raising their voices went hand-in-hand with parents

taking an active role to "arm themselves" with information about the fetal anomaly,

pregnancy options, neonatal treatments, and the nature of anticipated parental caregiving.

Parents varied in the degree to which they actively searched for information, although all

but one set of parents interviewed indicated they searched for information on some element of the fetal diagnosis, related care, or potential supports. The majority of parents described "a steep learning curve" and spending "countless" hours on the Internet (the primary source of additional information for all parents interviewed) Googling different websites for specific information, with varying degrees of success. Most parents described starting with general searches and then "fine-tuning," "drilling down" and "narrowing" (multiple parents, field notes) their searches as they came to understand the finer details of the fetal diagnosis, treatment options and parental caregiving experience. The impetus to actively seek information varied from parent to parent; however, the majority described one or more of the following reasons as their primary stimulus: (1) Feeling "shocked," "overwhelmed" and "on information overload" (multiple parents, field notes) during the initial review of the fetal diagnosis, which impeded their ability to initially take in all or part the information provided; (2) Conflicting diagnostic and/or prognostic information from different HCPs; (3) Significant gaps in information received; (4) Distrust of HCPs perceived to be attempting to influence them toward a particular decision; (5) The perception that HCPs were not fully disclosing the nature of the condition or its treatment; and (6) Perceived lack of access to HCPs for timely answers to their questions (e.g. follow-up appointments in two to six weeks, or meetings with the pediatric specialist or multidisciplinary team not being scheduled for weeks to months).

Particularly when parents received minimal information on the fetal condition or diagnostic and prognostic information they perceived as biased toward a pregnancy or treatment option contrary to their personal beliefs or values, parents described feeling strongly motivated to seek "balanced" information from the Internet, other parents (through online blogs, parent chat rooms etc.), and family members and acquaintances in the health field. In particular, for those parents who initially deliberated over whether to continue or terminate the pregnancy, they described not only searching for hopeful or encouraging information, but also focusing on finding "unbiased" information or "information from multiple perspectives" (multiple parents, field notes) about the fetal condition, parenting demands, and short- and long-term outcomes. For example, Jesse described his and Thea's search for information following their initial fetal scan when the MFM specialist provided limited information on the fetal condition with a proviso that a detailed HCP-parent meeting would be set up the following week.

We were googling left, right and center about [fetal condition]. And arming ourselves with, with the knowledge as much as possible. ... I would say that our reaction to this news was to learn as much as we could about it. We went straight to it, as quickly as possible, to just arming ourselves with knowledge and like making sure we had all the good questions and found out as much as we could. We didn't shy away from that part, you know. Did it help us? It maybe helped us because it gave us a focus for what to look up I guess. We didn't get any pamphlets on it [the fetal diagnosis], of course, at the hospital, nor did we expect any pamphlets, but we were given nothing really after that, after that initial diagnosis other than having them write down on a piece of paper the spelling of it because it's such a complicated-sounding word (Jesse, L 652–653, 663–673).

In contrast, Kath described a supportive relationship with a knowledgeable and

accessible pediatric specialist team with whom she met on a weekly basis (in conjunction with weekly FEs). Kath noted that the clear and updated information she received during these meetings was more than adequate in meeting her and her partner's information needs about the fetal cardiac anomaly, associated medical management and anticipated neonatal treatments. Of all the couples interviewed, Kath was the only one that did not describe a search for additional information following the diagnosis of a fetal anomaly.

Kath: We were at 19 weeks when we found out the problem, so she [fetus] was at 20 weeks when we finally diagnosed the problem and since then we went in for weekly ultrasounds. So, it was like 20 weeks and then until 35 weeks, like, that's how many we did, so one per week.

R: Wow!

Kath: ...We saw Dr. X [pediatric cardiologist] and Dr. Y [pediatric cardiologist] most often.

R: Okay.

Kath: ...It was really nice actually, like, seeing them because, and then I really liked both of them, you know, like, I think in the beginning, especially, like, each time they saw us, they kind of, they explained to us again, you know, like, what the issue is, the [treatment], like, just kind of going over, like every single, every time. R: Hmm.

Kath: For the first little bit, for the first couple of weeks actually, which was really nice because ... I didn't really recall a lot of like, I can tell some things about the [treatment], but I don't really remember exactly what they were—they were a little too long for me. And then it was really nice ... I didn't feel like I couldn't ask a question ... I didn't get the feeling, you know, oh, such a dumb question to ask. I always got the feeling that, oh, if I ask them the same question or whatever, because I don't remember, like, you know, they have never been, like, oh, I explained this to you, you know, what's wrong with you? ... They'd just explain it again...

R: And did you find that you sought out other forms of information? Like, a lot of parents for instance talk about searching the web and looking for information on there. Was that your experience?

Kath: Actually, it's funny, because, I think I searched on the web once and I think I Googled, like [fetal diagnosis], but then I had no idea what I was reading, you know, all the medical terms, so I was even more confused. And then I know from an experience my husband had,[that] what's on the web is usually the really serious cases ... and they could just be blowing it completely out of proportion or whatever. So, I was really careful and did not go on the web ... I knew that this thing [the fetal condition] was a big deal, but I didn't need to really scare myself any more than what I was already afraid of ... What I did more was if I had a question, like Dr. X and Dr. Y were always there and we were there every week, so I kind of figured that getting information from them was so much better than what was online. Plus, I knew that there was no point because of how rare the condition is. Dr. X had explained to me, like, how rare it is and even there is not much literature for them [pediatric cardiac specialists] to go on. So, to me it was like, if they are having a hard time finding things to refer to, there is no way I will be able to find it on the Internet with such a broad search (Kath, L 491–584).

Parents Sought Additional Medical Expertise

Parents also enacted agency through actively seeking out expertise on fetal

conditions, treatment options and prognostic outcomes by requesting consultations with

medical experts. This action was often triggered by parents' dissatisfaction and frustration

with mixed or conflicting prognostic outcomes or treatment options, and/or the desire for

specialized information from medical specialists anticipated to be involved in their child's

care after birth. Although for some parents these subspecialist consultations were a formalized standard of care within the institution (e.g. pediatric cardiologists performed and/or read all FEs), this was not the case for all forms of fetal anomalies. Moreover, given the dynamic nature of many structural fetal anomalies, meetings with pediatric subspecialists were often not scheduled until a few weeks prior to delivery to facilitate provision of the most up-to-date diagnostic/prognostic information prior to the baby's birth. Parents sought additional expertise from medical specialists to: (1) gain additional diagnostic or prognostic insight into the fetal anomaly such as specialized information a fetal radiologist could provide from fetal MRI assessments or geneticists could provide on rare chromosomal anomalies; (2) gain up-to-date, detailed and comprehensive anticipatory guidance about postnatal treatment plans or options from pediatric specialists, such as pediatric surgeons or medical specialists who were directly involved in medically or surgically managing the care of children with the same or similar congenital anomalies; and (3) seek the opinions of medical experts with whom they had established relationships and trusted to provide individualized input into pregnancy and treatment options.

Sam, a father who had significant congenital heart disease (CHD) and whose partner's previous pregnancy had ended in stillbirth, had the following recommendations to other parents about seeking out expert medical advice:

Get expert advice when it's needed. It might be that you don't have any complications and then in that case it doesn't really matter but as soon as something happens or there is something unforeseen then that can make a big difference. And I mean I appreciate that from my own experience, I always seek out the experts. And I understand the advantage of having interaction on that level (Sam, L1163–1168).

Multiple parents described receiving prognostic information from pediatric specialists that was "up-to-date," "specific," "comprehensive," and comparatively "less extreme" (multiple parents, field notes) compared to information provided by HCPs less familiar with their child's condition. Moreover, parents described pediatric specialists as providing specific examples and stories of other infants or children with the same anomaly whom they had cared for, including details on the nature of care provided, the most common complications and treatments, and potential resources and supports available to families. For example, Yolanda and Zane sought out a consultation with a pediatric specialist for additional information on treatment options following a fetal diagnosis of a complex lung anomaly. Although this consultation was part of the general plan of care, it was usually scheduled closer to the delivery date, and thereby only available to those parents choosing to continue the pregnancy. Yolanda and Zane described preferring to have specific information from a pediatric specialist prior to making their decision to continue and pushed for this in their interactions with the MFM team. Both parents emphasized the multiple benefits of meeting with a pediatric expert on their child's rare fetal anomaly in terms of detailed diagnostic and prognostic information received, increased confidence in the specialist's knowledge and expertise on their child's rare fetal anomaly compared to MFM specialists they initially met with, and strengthened hope for a positive outcome for their unborn baby.

Zane: He [the pediatric specialist] knew everything, like, honestly, we went in there and we were like, wow, I mean I think him and Dr. X [another pediatric specialist] were kind of the ones that answered our questions, like everything we asked, we got an answer for ... Dealing with the first, the first doctor [MFM specialist] we had ... he didn't really know what he was talking about versus Dr. [pediatric specialist]. If we had a question, like, he had an answer and when we went to his office it almost felt, I don't know, the environment was more inviting too, like, I wanted to ask him everything, right? The kind of questions to ask [a pediatric expert in his specialty]. Yeah, I mean we left there, though, and he honestly, I mean he didn't really solve the problem, but he definitely clarified a lot of questions that we had and a lot of doubts we might have had too...

Yolanda: Yeah, it was different because the first one [the meeting with the MFM physician] I walked out crying, and with this other one [meeting with the pediatric specialist] I was, like, smiling. I was, like, well there's hope for my baby. ... He had a way that was respectful and polite, but at the same time it was very, I mean we felt comfortable there. Whereas the first time it almost seemed like we were being pushed into, like, you know, the baby is going to die, you know (Zane and Yolanda, L 698–737).

Although this was not as common, a few parents also emphasized the importance

of seeking out additional input from a health professional with whom they had an

established and trusting relationship and who understood the unique histories and

contexts of their health decisions. For April and Abra, this expertise came from their family

doctor with whom they shared a long-term relationship and who they trusted would

consider pregnancy and treatment options with their best interests in mind.

R: ...If you were to give advice to other people in a similar situation, so another grandma that was in your situation or another mom that was in April's situation, what advice would you give them about this experience?

Abra: ...Always get a second opinion.

R: Okay, always get a second opinion. So, would you say that your first opinion was that first ultrasound in [month] when you first found out about the baby's diaphragmatic hernia and then the second opinion would be...? Abra: My family doctor.

R: Oh, your family doctor, so...

Abra: I believed him. I believe in him more than anyone....

R: So, his input was valuable to you?

Abra: Yeah...He always told me, he told me right from the get-go that it's [the fetal anomaly] fixable. It's going to be, you know, a couple of complications, the heart, the lungs is one of them. And that everything was going to be fine if I believed in myself. You know because I, I didn't want to go by, you know, I just met these people [MFM specialists] and, you know, they, I was telling them, they were telling us this, they were telling us that [uses a hand motion of slicing her hand across her neck to indicate the recommendation to terminate the pregnancy], he [the family doctor] goes no, no, no, it's fixable (April and Abra, L 1529–1616).

For parents given the opportunity, the coordination of a multidisciplinary meeting

with a team of medical specialists and allied health professionals involved in antenatal

and anticipated postnatal care was viewed as a valuable opportunity to ask questions of

the entire team, clarify previous conflicting information, and establish consensus on delivery and treatment plans. For example, Kath described how a multidisciplinary meeting with members of the MFM team, pediatric subspecialty team and neonatal team was extremely helpful in settling discrepancies and communicating a clear delivery and treatment plan, as well as determining which HCP was ultimately "in charge."

Kath: And then later on when we all got together [in a multidisciplinary meeting], Yeah, you [referring to the researcher] were at the meeting as well where we all sat in that conference room ... And then that particular perinatologist [who had previously indicated the baby would likely be delivered between 39 and 40 weeks] wasn't there. This other dude was there, and I think that we asked the same guestion and then that doctor was saying ... it actually looks good and everything now, you are probably going to deliver at 39 to 40 weeks-that's what we are going to plan on for you. And then Dr. [pediatric subspecialist] stepped in and said, 'Oh, no ... It's going to be earlier, it's going to be 37 to 38 [weeks gestation], you know, because we found statistically or whatever the babies have a better chance if they come out, you know, more between 37, 38 and not to wait til the full 40. And then, after Dr. [pediatric subspecialist] said that, the other doctor just kind of went, okay, like [laughter].... it's always what the [pediatric subspecialist] says—that is what we are going to do ... Because ... there are all these different doctors and everything and, you know, whoever is not a [pediatric subspecialist] could say what they wanted to say, and we realized that at the end of the day, like their opinions don't matter (Kath, L 1626–1652).

Parent-to-Parent Support: "The More Hopeful Side of Hoping"

Parents also searched for additional information on the fetal anomaly and associated parenting considerations by seeking out support from other parents who experienced an antenatal or postnatal diagnosis of a fetus with the same or similar health condition. Occasionally (approximately one in every eight parents/sets of parents) the healthcare team suggested websites or provided contact information regarding general or condition-specific parent-to-parent support programs or associated online resources. However, most parents described searching out parent blogs or Facebook groups specific to their child's health condition on their own. In general, parents described these Internetbased resources as very helpful in providing balanced information and insights on the specific nature of the fetal condition and associated parenting experiences. Jesse described the parent-organized, condition-specific Facebook group that he and Thea joined as a "lifesaver" in helping them have a realistic perspective of what to expect after their baby was born, as well as in maintaining a hopeful outlook for their fetus. Similarly, Thea indicated how parent-to-parent connections helped her feel "less alone" and more hopeful.

[The Facebook site specific to her unborn baby's anomaly] was super helpful, like, just because it was, like, real experiences by real people, both good and bad ... So, because you see the full gamut of, like, kids who have small [fetal condition] and they were repaired within a couple of days to kids that, like, have huge medical issues well beyond the [fetal condition], like it sort of gives you, it gives you hope. There is like a lot of hope on the website and a lot of practical advice, so you feel like you are not alone. ... Seeing this forum you kind of feel, okay, there's other people who have gone through the same thing, you know, and I posed a few questions, like, you know, have any of you been asked to get your baby tested for [genetic syndrome associated with fetal anomaly], and you know, I saw what the responses were. A lot of them were like, don't worry about it, like it's totally not life threatening, it's not a big deal, you know ... like don't stress about it. So, you know, it gives you the, maybe the more hopeful side of hoping, yeah (Thea, L 473–500).

Similarly, Yolanda described the "truth" she found in connecting with other parents of

children with the same rare fetal/postnatal condition, and the support and hope that she

and Zane received from these interactions.

Yolanda: ...I find the truth in Facebook [on the parent blog] and I read all the stories, I went through all these things and they are, like, very positive, these babies are fighters, these babies are strong, [fetal diagnosis] babies are really special, and they are fighters. So that was such a big help (Yolanda and Zane, L 773–781).

For some parents, the connections they made with other parents on Facebook or

other parent blogs/social media sites were a regular, even daily, connection. Online

parent-to-parent connections were particularly valued by parents who had received a fetal

diagnosis of a rare fetal anomaly where face-to-face meetings with other parents would

have been logistically difficult, given the extremely limited number of children with the same condition in a given geographical area.

Parents enacted agency through multiple approaches underpinned by holistic, relational, and collaborative frameworks, amongst others. These parental actions were forms of resisting the dominance of biomedical and efficiency discourses that foregrounded fetal pathology and treatment outcomes in HCP-parent interactions. In this way, many parents were able to: (1) resist and challenge system and organizational shortcomings, as well as HCP priorities that parents perceived were not in their best interests; (2) actively engage in strategies to address gaps in health information or antenatal care; and (3) challenge HCP bias or influence in health decision-making. Building on this analysis, the final section of this chapter underscores the inequities in health communication, antenatal decision-making and provision of antenatal care, including the weighty consequences for parents and families.

Inequities in Antenatal Care

Not all parents had equal opportunities or abilities to challenge or resist gaps in care or HCP bias in health communications related to pregnancy and neonatal decision-making, which resulted in significant inequities in health communication, antenatal decision-making and provision of antenatal care. For example, the impact of a dominant biomedical lens in tandem with efficiency imperatives, which minimized the importance of parents' psychological, emotional, physical and practical needs in HCP-parent interactions, was magnified for those patients that were more vulnerable due to such factors as age, class, language skills, education level, and financial security. Similarly, a responsibilization discourse that shifted the responsibility from HCPs to parents to meet their own health and health information needs resulted in health inequities because some

parents were better equipped to take up this challenge than others. Those with additional support (including physical, financial and personal resources) were in a better position to address these challenges; however those who were more vulnerable—such as those living in poverty, those with mental health or additional physical concerns, or those with competing social demands (e.g. seven other children to care for, or dependent elderly parents)—scrambled to find resources on their own, often unsuccessfully. Where some parents had the opportunities, personal resources, abilities and/or experience to resist the dominance of biomedical, efficiency and other discourses and the enactment of pastoral and disciplinary power in health interactions, other parents and their families faced additional challenges including: (1) unaddressed emotional, psychological and physical needs; (2) uninformed decisions; and (3) pressure to succumb to bureaucratic and system-centred patient "processing" imperatives. Moreover, parents who were vulnerable to health inequities because of their social positioning related to factors such as class, ethnicity and financial security were often presented by HCPs as problematic, in that they challenged the "ideal" and required more time and resources. This was at the core of the inequities in antenatal care and the struggle parents faced when seeking additional supports and resources.

Unaddressed Parental and Family Needs

A reductionist approach that placed a spotlight on determining the presence and nature of fetal health concerns and reviewing pregnancy and treatment options from a techno-rational perspective often served to minimize parents' health needs, priorities and concerns, as well as the interplay between fetus and mother, and mother and partner/family. Doing so created the potential for health inequities in antenatal care provision, in that there was unequal opportunity for parents to have their health needs (emotional, psychological, physical and practical) addressed. For example, all parents interviewed described experiencing some degree of emotional distress following the diagnosis of a fetal anomaly and the additional emotional and psychological strain associated with making "difficult" and "life-and-death decisions" in the time-pressured environment of an evolving pregnancy; however this parental distress was rarely acknowledged or addressed in any detail in initial HCP-parent interactions. In addition, priority was given to scheduling parent meetings with multiple medical subspecialists, whereas referrals to those HCPs whose focus was on providing emotional, psychological, practical or social support, including nurses, social workers or psychologists, were usually only offered on follow-up visits (nursing support only), or when pushed for by parents or HCPs. Furthermore, information provision in HCP-parent interactions was predominantly unidirectional (HCP to parent), with HCPs usually focusing on reviewing complex information on fetal pathology and treatment options and rarely spending significant time addressing parents' perspectives, priorities, or contextual factors such as concomitant stressors or the additional burdens parents faced. There were also significant differences in how prepared and supported parents felt in relation to the delivery of the baby and early neonatal treatments. Specifically, as the majority of newborns required complex surgery and care in neonatal or pediatric intensive care settings after birth, parents had multiple questions and concerns about postnatal care, including: (1) the anticipated plan of care from delivery to initial discharge home; (2) newborn care needs before and following neonatal surgical procedures; (3) the postnatal role of parents in care provision; (4) resources and supports available to provide breast milk to the baby after birth; and (5) potential approaches and available resources to balance the needs of siblings and other family members with those of the newborn in the postnatal period. Those parents who

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received antenatal support from a formalized pediatric-MFM collaborative program, such as those with fetal diagnoses of cardiac anomalies, often received more support, including detailed written and verbal information and anticipatory guidance from members of the healthcare team on what to expect after delivery, as well as tours of labour and delivery areas and intensive care settings, which the parents described as "very helpful" and "invaluable" in helping prepare emotionally and practically for the perinatal and early neonatal periods. However, other parents, especially those with minimal antenatal contact with pediatric subspecialists, described receiving very limited guidance on anticipated postnatal care, which they perceived as significantly contributing to increased parental uncertainty, anxiety, and a "loss of control" over what would happen or how to best prepare for the postnatal period. In this way, parents who received less needed more.

Those parents who "raised their voice" or otherwise pressured HCPs for additional support were generally successful, albeit often with difficulty; however, those who assumed no support was available or did not know how to access or ask for additional help received significantly less support, with negative health consequences commonly following as a result. For example, Tara described her initial interaction with the healthcare team following the antenatal diagnosis of an oomphalocele as a brief interaction focused on fetal physiology and pathology, suspected level of severity, and anticipated neonatal treatments. With the bulk of information centred on the fetal health concern and provided unidirectionally from HCP to parent, Tara indicated that her history of anxiety and depression and the significant emotional distress she was feeling related to the fetal anomaly were never acknowledged or addressed in HCP-parent interactions until she sought additional support for maternal-fetal bonding concerns and signs of postpartum depression after the baby was discharged from hospital following neonatal

surgical repair. In addition, Tara noted that HCPs she met with antenatally emphasized the fetal oomphalocele was on the "less severe end of the spectrum," implying she should be relieved that it was "easily treatable." Tara expressed that the limited information she received, in tandem with HCPs' emphases on positive outcomes associated with the fetal anomaly, made her feel less comfortable discussing her feelings, worries and concerns, as she was given the impression she should not worry and should be grateful her fetus did not have a more severe form of the anomaly.

Tara: Even during finding everything out, it was always that these are the problems but, you know, we've [the health providers] seen worse, like, everything that he is presenting with is very minor in comparison to what is out there ... It was very reassuring for us to know that his [her unborn son's] case was not like a severe oomphalocele, you know, there's kind of a range, he's got an oomphalocele, it's a very small one. They [the healthcare team] didn't foresee any difficulty with it and so it was, it was kind of just, you know, like small potatoes on their big potato radar ... And [Jack, Tara's partner], yeah, you know, I'm a little bit more doom and gloom than [Jack] [laughter], so he found it very, very reassuring to himself because he just was, like, yeah, they are not worried about it ... He's got a small oomphalocele and so then everything was set and there was a plan, and it was just a matter then of getting it done... (Tara, L 102–105, 238–262)

Despite Tara initially stating that it was reassuring to hear her fetus had a less severe form of oomphalocele, she went on to explain that over the remaining course of the pregnancy she continued to feel sad and worry about the possibility of the fetus experiencing complications or difficulties, which resulted in what she described as "selfprotection mode kicking in," in that she was reluctant to attach to her fetus because of worries he might die. As these feelings of sadness continued over the course of her pregnancy, Tara indicated she did not voice these concerns and worries to the healthcare team for several reasons, including: (1) the fetal anomaly was detected in the third trimester, and follow-up appointments prior to her delivery involved ultrasounds and stress tests but not additional meetings with those HCPs who initially provided information about the fetal anomaly; and (2) the multidisciplinary team she initially met with had reassured her that neonatal treatment was associated with very good outcomes, which was inconsistent with Tara's feelings of sadness, anxiety and her "doom and gloom" tendencies, making her feel that the healthcare team would not understand or would minimize her concerns. After the baby's birth, Tara described how her lack of preparation concerning what to anticipate following the delivery, and lack of time to bond with the baby at birth before he was "whisked away" for observation and treatment, added to the worry, anxiety and sadness she was already experiencing. In hindsight, Tara, similar to several other parents, indicated it would have been helpful to be prepared for a range of possible scenarios at birth, including specific details about the nature of delivery and postnatal care and available supports. Instead, information conveyed to the parents during the multidisciplinary meeting was limited to a brief description of the neonatal surgery and anticipated postnatal course. Tara described her impression that the healthcare team did not spend a lot of time going over more details or provide opportunities for follow-up meetings with the healthcare team because the fetus had a less severe form of oomphalocele. Notably, Tara described increased emotional distress and anxiety after her son's birth, despite these favourable prognostications, his stable postnatal condition, and his successful neonatal treatment.

Tara: So, we went in [for a planned C-section] in the morning and everything was good, and then he was born, and he was really good, he scored nine on the Apgar, and ... he was big ... I was really emotional the morning of the [planned] C-section, just because I knew it had been talked about in the multidisciplinary meeting that he'd be taken [to the NICU] quite quickly [after birth]. R: Hmm.

Tara: And I would maybe only have like five minutes with him, but I didn't even get that ... I got like, I got like, a hey, here's your kid as he was whisked by. R: Oh, so hard, so hard.

Tara: Yeah, and so I was like, super emotional. I was crying and then I had a Csection from hell and so, you know, I only got to see him, he was already bundled in the incubator to be transported when I got to touch his hand ... I understand that they've got to get him out, that they've got to keep him stable, they've got to stuff like that, but at the same time, like, I really wish that I could have had a little bit of contact with him, just a little bit of time, even though I literally was having a C-section from hell ... and then I saw him [the next day] in the NICU and ... he had a breathing tube ... and IVs and all sorts of stuff ... it was overwhelming. I came in bawling.
R: Hmm. It's pretty overwhelming ... And did they, did you feel like you sort of knew what to expect when you went in?
Tara: No ... no. I knew nothing. I knew nothing... (L. 489-521, 647-652)

Tara noted several factors that contributed to her anxiety, sadness, and difficulties in bonding with her child postnatally including: "the self-protection mode" she went in after the fetal diagnosis; not being able to hold or breastfeed her newborn son in the early neonatal period; and her lack of understanding on how postnatal and postsurgical care would unfold. Moreover, rather than the healthcare team addressing Tara's emotional and psychological needs and concerns proactively in the antenatal period, she described experiencing feelings of sadness and anxiety throughout the remainder of her pregnancy, having a "panic attack" the first time she was left alone to care for her baby in hospital prior to discharge, and the need to start antidepressants several weeks after her baby was born. Tara's experience illustrates how the psychological needs of parents were often overlooked in the midst of HCPs' central focus on fetal pathology and neonatal treatments, as well as how HCPs' assumptions about the severity of a fetal anomaly were not necessarily consistent with parents' reactions to the diagnosis or the degree of parental support required.

In contrast with Tara's experience of receiving very limited anticipatory guidance on what to expect and how to prepare for the neonatal period, Callie described how a collaborative and trusting relationship she developed with her primary MFM specialist was paramount in helping her and her partner understand and prepare for a range of potential fetal and neonatal outcomes without adding to the worry and concern they were already experiencing.

Callie: And so, the first time that I saw [MFM specialist] and they had us in for a [specialized] ultrasound, [the specialist] reviewed what we were seeing, they have amazing, amazing communication. I would just, if you want to know what good quality communication looks like, you know, between her and [another specialist]. like, I would just record them and be like [gesticulates as if presenting something to someone]. Specifically, what they did is they taught us what they were seeing, what they were looking for, what the markers were, they showed us a little picture of [fetal anomaly] ... and she educated us ... Yeah, and they said, you, you guys are going to be the experts and they actually talked about the rest of the team, they are like, you know, this is a rare situation, not everyone sees twins, not everyone sees these types of [fetal diagnosis], like you will be seeing stuff that looks like this more often than the ultrasound techs. And this is what you're going to see, and this is what it means and ... what they did do specifically, they walked us [through it], so they are just a very approachable sort of person and they chatted with us. And sort of talked about what was, what was happening, what the decision points would be, if things were to deteriorate what that would look like, and if they deteriorated to that point, at that point, what those choices would be.

R: So, it was very clear for you. It was like a road map as to what to anticipate or expect, and a bit of an algorithm as to, if this then that? Callie: Right, and what was really good is that they sort of said, I am the person who does [specialized fetal procedure] if what you are seeing right now deteriorates to that point. But we are not there yet, you know what I mean, like, that was the good part is they sort of said, this is what's in front of us right now. Here's what we know. And they also, they were transparent as well, they were also very good, they didn't sort of repeat the babies will die scenario because you don't need to do it, we really, I really think most women get, get that message. You don't need to scare the shit out of us, we're, we're plenty scared you know, before you even tell us we're having twins we're scared (Callie, L 525–572).

Callie, like all of the parents interviewed, also described feelings of sadness and

worry following the diagnosis of a fetal anomaly. Callie eventually resorted to a private counsellor for additional support given the limitations of the system, including excessively long wait times for a reproductive mental health referral, indicating that her background in healthcare and her past experience having a sibling with a significant health concern provided her with additional motivation, expertise and experience in ensuring her emotional distress was addressed effectively. While Callie could afford to pay for a private counsellor, not all parents who would have benefitted from this form of support had the necessary financial resources available to do so. Tara's and Callie's contrasting experiences in terms of the amount of anticipatory guidance and emotional support they

received point to inequities in accessing and receiving antenatal care that addresses the full range of parents' health needs, and the substantial negative consequences for parents' overall health and wellness that can potentially result from these inequities.

Uninformed Parental Decisions

Parents faced significant inequities in accessing the necessary health information to make informed antenatal decisions, highlighting entrenched structural inequities when parents were charged with the responsibility of ensuring that their own health information needs were met. Many parents described their perceptions of receiving incomplete, "conflicting," "unbalanced," "biased," and "persuasive" (parent interviews, multiple parents) diagnostic, prognostic and/or treatment information. As a result, parents often felt uninformed about the full range of pregnancy and/or neonatal treatment options available and forced into the position of being responsible for researching this information on their own in order to feel confident they were making fully informed antenatal decisions. This created potential inequities amongst parents, because some parents did not question or challenge HCPs' presentation of information and assumed HCPs were indirectly or directly recommending certain decisions because they were acting in the parents' best interests. Moreover, some parents were better able to search out additional information on diagnostic, prognostic and treatment options than others due to age, language fluency, education, and socioeconomic factors, amongst others. For example, several parents with higher levels of education or experience in health-related fields described proficiency in researching condition-specific "case studies", "Mayo Clinic reports" and comparative analyses of different treatment options. In contrast, other parents with comparatively low levels of health literacy or those burdened with significant competing demands described additional challenges in accessing and understanding health information about the fetal

diagnosis, related decisions and potential outcomes. In comparison, these parents were disadvantaged in terms of making informed antenatal decisions, as well as less equipped to challenge information biased toward certain health decisions.

Parents' experiences raised particular concerns about potential health inequities when information was conveyed in a manner where parents perceived there was only one pregnancy or treatment option, such as Yolanda and Zane described when their initial meeting with a specialist left them with the impression that their only option was to terminate the pregnancy. As this example illustrates, parents were sometimes placed in vulnerable positions where they were pressured to make life-altering decisions, such as choosing to continue or terminate the pregnancy, based on incomplete or biased information. This vulnerability was further emphasized in how parents' perceptions of whether to continue or terminate the pregnancy changed once they met with the pediatric team, which they found "more positive", "more hopeful" and more knowledgeable about current treatment options. In this way, those parents who were not referred to or did not push for consultations with pediatric or other subspecialists were potentially disadvantaged in terms of the specificity and comprehensiveness of information received about pregnancy and postnatal treatment options.

Delivery of diagnostic and prognostic information often focused on potential or confirmed abnormal findings and quantitative outcomes, such as length of stay in intensive care and estimated total days in hospital, as well as morbidity and mortality outcomes associated with specific treatment options, often framed as statistical percentages. Often minimized or left out of these interactions was information on qualitative aspects of the parents' and child's experience, such as QOL indicators, the nature of suffering or pain endured, and insights from other parents and/or children and young adults living with the health condition. When the healthcare team did not provide this information, parents either made their pregnancy and treatment decisions without considering this information or took the initiative to seek it out on their own. This process was easier and more effective for some parents compared to others, with parents who were more vulnerable because of health literacy, language fluency and socio-economic factors having the most difficulty accessing information relevant and individualized to their unique situation. For example, Amena and Adnan described the increased frustration and difficulty they faced in trying to research information on a suspected fetal diagnosis of Down syndrome, given that English was their second language, they were relatively new immigrants to Canada, and they were not familiar with available services or resources for people with childhood disabilities in their new country.

When someone tells you your baby might come with Down syndrome, this is not just about us, but about the baby. What kind of future he would have? We have to make hard decisions. Should we keep him or let him go? It is not easy for parents, do you know what I mean? ... If we let him live, would he be happy? Would he have a happy life? Would he find a partner or would he be mad at us because we give him the life? That is really a hard question, but to be honest with you, we were close to let him go more than keeping him. Because we are new in the countrywe don't know how much services will be provided for those people with Down syndrome. Some of my friends told me that they have centers for them and some of them get married and act like normal children, but still there is no guarantee, you know what I mean? It will be hard for us that he would have lots of disease, like maybe heart problem, kidney problem, vision problem, and he won't live for long. So that was really painful for us to hear all of that and also [the HCP] kept telling us very confidently he would have so and so, and so and so, and both of us [Adnan and Amena] were crying actually ... We don't need like weak boy or weak baby, so we came to, you know, like if for some reason it was confirmed it was Down syndrome its almost certain we would let him go (Adnan, L 39–61).

Similarly, Adnan described how as new immigrants he and his partner did not understand

cultural differences between Canada and their native country in terms of how individuals

with certain disabilities would be viewed or treated by the larger society. Although the

healthcare team did not address it, this was a significant factor in the couple's decision-

making as to whether or not to continue the pregnancy.

Adnan: In [country of origin] many people think it's a shame to have a baby with Down syndrome.

Researcher: Hmm.

Adnan: You know what I mean? They are concerned for the future. If I have, like, three babies, [and] one of them with Down syndrome, the other babies might not find someone to marry with.

R: I see.

Adnan: Some people think that disease, might, you know, transfer between generations. They might have the chromosome that is totally wrong ... (Adnan, L 608–619)

Finally, health inequities were also associated with how diagnostic, prognostic and

treatment information was often presented in the same way to every parent using rote

scripts individualized to the specific fetal anomaly but decontextualized from the unique

perspectives, experiences and priorities of individual parents. In these instances, parents

were left to make sense of how to individualize the information to their unique

circumstances and how to access any additional supports they required. Moreover,

without coming to understand the parents' and family's unique histories and perspectives,

HCPs were often unaware of additional stressors or burdens parents and families

struggled with, and the impact these had on their personal and family health. For example,

April, who was sixteen and in high school when she received a fetal diagnosis of a

diaphragmatic hernia, decided with her mother's support and advice to stop going to

school and stay at home until after her baby was born. In my initial interview with both

April and Abra, they described several stressors that they found challenging about their

antenatal experience, including: the perceived stigma associated with a "teenage

pregnancy"; the social isolation and loneliness April was experiencing as a result of being separated from her friends and peers; and the significant financial concerns the family anticipated in relation to April and Abra's need to temporarily relocate for a minimum of two to three months to the city where specialized maternity and pediatric care was planned. Although soft-spoken and guiet, letting her mother answer most of the guestions during the bulk of the interview, April expressed that her main fears were related to the possible pain and suffering her child might experience and what involvement she could have with her baby when the baby was being cared for in an intensive care setting after birth. In addition, Abra was very concerned about how her partner would manage to work and care for their seven other children on his own. April and Abra noted they had not discussed these concerns with the healthcare team, as the focus of their previous discussions had been outlining the nature of the fetal anomaly and treatment options, with HCPs reassuring the family that more specific information on the anticipated postnatal course would be reviewed by pediatric specialists in a meeting tentatively scheduled for 34 to 35 weeks gestation. In the end, the baby was born prematurely, and the family never had the opportunity to meet with the specialist or tour the ICU prior to the baby's birth. In speaking with Abra and April after the baby's birth, they described feeling "overwhelmed," "nervous," and "scared" of "all the tubes, wires, breathing machine, and monitors," and the overall fragility of the baby's condition. April and Abra's experience underscores how providing generic, non-individualized information on prognostic and treatment information contributed to health inequities, in that some parents were able to fill in the gaps of missing information and supports better than others. It also illustrates potential consequences of providing decontextualized prognostic and treatment information that failed to address the unique fears, concerns and needs of parents, and left them ill-prepared to face the emotionally and physically taxing experience of pregnancy and neonatal care following the antenatal diagnosis of a fetal anomaly.

Succumbing to Institution-Centred Patient-Processing Imperatives

In addition to inequities related to holistic care provision and informed antenatal decision-making, inequities were also apparent in the experiences of parents who acquiesced to institution-centred patient processing imperatives compared with those able to challenge or navigate around the push and pull of these policies and protocols. Parents used words such as "a living nightmare," "an emotional roller coaster," and "emotional trauma" to depict elements of their antenatal experience made unnecessarily more difficult because of contentious HCP-parent interactions or frustrations navigating an unsupportive, foreign, and HCP-centred system. Parents were constructive in their feedback, generally indicating perceptions that most HCPs were well intentioned but hampered by system constraints. This was evident in the multiple examples already presented where parents described their frustrations navigating the system, yet emphasized that HCPs were "professional," "tried their best," or "seemed to care," even when parents found the outcome of HCP-parent interactions unsatisfactory.

Although the majority of patients interviewed expressed frustration with nonpatient-centred aspects of the system, such as long wait times before and between appointments, scheduling of multiple appointments with multiple specialists or teams over a full or half day rather than one meeting with all of the professionals together, and nonrelational approaches to patient care, most parents conformed to taken-for-granted patient-processing imperatives underpinned by dominant biomedical and efficiency discourses. Numerous parents discussed frustrations with "the system" over these and other organizational shortcomings in providing patient- and family-centred care; however, most parents did not challenge these limitations or discuss their frustrations with the healthcare team. Those parents that did resist or challenge institution-centred patientprocessing imperatives, or those who received additional HCP support or assistance with care coordination, generally reported multiple benefits including greater satisfaction with antenatal care, effective HCP-parent communication, and streamlined and individualized antenatal and postnatal care provision.

As previously described, organizational structures and procedures, which necessitated parents having multiple specialist appointments in a serial manner rather than one appointment with multiple health professionals, were frustrating and exhausting for parents. In comparison, families who had the opportunity to meet with multiple specialists simultaneously in a multidisciplinary team meeting were able to review the same material in less than one hour (not including the time spent performing the FE and initial genetic assessment), with opportunities to clarify conflicting information and seek additional information on specific areas of concern, ultimately leading the parents to express greater satisfaction with the health communication and care coordination they received.

There were significant differences in parents' experiences of care coordination and preparation. Some parents described HCPs who served as "go-to persons," "navigators," "advocates," or "liaisons" (field notes, multiple parents) that provided care coordination and parent education related to antenatal and immediate postnatal care. HCPs fulfilling this role varied across the group of parents and included nurses, MFM specialists and pediatric medical subspecialists. For those parents who had "someone in their corner," they described collaborating with the healthcare provider(s) to "work around" system shortcomings or institution-centred processing imperatives, whereas other parents accepted these shortcomings without question and struggled through bureaucratic hoops on their own. As a result, those who received additional support navigating the system

ultimately experienced less frustration with care provision and more individualized and streamlined care than others. For example, a commonly repeated parental concern was "getting different answers to the same question" from multiple specialists. Numerous

parents described this frustration in relation to multiple aspects of their antenatal care,

ranging from understanding available pregnancy and treatment options, to learning

specifics about neonatal treatment outcomes, to determining optimal delivery plans.

Those parents who had an identified HCP to contact to help them work through and clarify

conflicting information generally described this support as incredibly helpful. However, the

majority who worked through these frustrating scenarios on their own described struggling

to access relevant information and trying to "figure out who was in charge." For example,

Kath described her and her partner's frustration with the multiple different responses to

their question of when to expect their baby with a complex heart problem to be scheduled

for delivery.

And of course, with each doctor that you see, Oh, when do you think we may deliver? ... Ask them the same question. And then like different doctors have different experiences, right? And then I remember that first doctor [perinatologist] we asked, like, oh yeah, you know, the baby's growth seems to be doing fine, you know, you seem to be on track, you know, you are probably going to deliver, you know, 39, 40 weeks, so we have to wait til then. And at which point, okay, oh that's really nice, right, you know, full term, right? ... And then you know, the next day, then it was like, oh no, no, no, it's 37, 38 because that is what [pediatric subspecialist] said. And so, it would be changing. I don't know if it's because we maybe shouldn't be asking all of these doctors the same question and getting a lot of different answers ... But then, yeah, I seriously had it. It was just like because one doctor, like, they just all have different opinions (Kath, L 1615–1622, 1659–1665).

Finally, Callie, whose antenatal care included at least one ultrasound each week to

monitor the health of her twin fetuses, described a similar frustration with the system-

centred patient processing imperatives that she described as initially being shuffled from

one test to another, with long wait times "corralled" in stress-filled waiting areas in
between appointments, often taking several hours to complete each appointment even though the actual procedure and meeting with the specialist took less than an hour. In response to these frustrations, Callie and her primary MFM specialist created an individualized plan that worked around system shortcomings and allowed Callie to be "fit in" for ultrasounds on days the specialist was working—shortening the time she needed to be at the hospital for follow-up ultrasounds by several hours each week.

Callie: The situation was sort of poor for quite a while [with long waiting times for follow-up appointments in stress-filled waiting areas], so here's the interesting negotiation of the system. I became the [fetal diagnosis], you know, under [the specialist]. And so, what they would do is fit me in where they could and so they would have me come in and I wouldn't sort of have an official appointment in the system, I wouldn't officially be seeing the nurse or the doctor, the whole thing. They would just have me come in and see them when they were in the ultrasound, so when they were reading the ultrasounds. And then they would come back in and see me quite quickly, so it was a huge benefit (Callie, L 517–525).

Summary

Foucault's concept of governmentality guided the preceding analysis of HCPparent communication and decision-making. This analytical lens was foundational in helping to understand how power/knowledge was employed through discursive practices to govern and shape HCP-parent communication and decision-making, and in considering the resulting consequences for both parents and families. Specifically, using a governmentality lens facilitated an understanding of how pastoral power was enacted in tandem with disciplinary power in HCP-parent communications and parental decisionmaking. In addition to analyzing parents' participation in PNS, I explicitly explored the underlying power relations in HCP-parent communication and decision-making in relation to three specific HCP-parent interactions emphasized by parents. This analysis of power relations in antenatal care therefore created a platform for discussion of parental agency and resistance in HCP-parent interactions, highlighting parents' power to challenge and resist dominant frameworks by aligning with opposing and alternative discourses shaping health and health interactions. Building on this analysis, in the final section I underscored how HCPs' unchallenged perspectives and practices contributed to health inequities and led to unaddressed parental feelings of emotional distress, inadequately informed or biased parental decisions, and unnecessary pressure on parents to conform to systemcentred imperatives. The analysis of the nature of antenatal care and deconstruction of underlying power relations in HCP-parent communication and decision-making provided in Chapters Four and Five set the stage for an analysis of parents' emotional responses to the diagnosis of a fetal anomaly in Chapter Six.

CHAPTER SIX: PARENTS' EMOTIONAL RESPONSES TO THE DIAGNOSIS OF A FETAL ANOMALY

As described in the preceding chapters, antenatal diagnosis of a fetal anomaly had a life-altering impact on parents. Parents described this as one of the most difficult and emotionally distressing experiences they had ever faced, with significant and potentially long-term consequences. Having provided a broad and detailed overview of the nature of antenatal care and an analysis of power relations, parental agency, and inequities in antenatal care in the preceding chapters, in this chapter I provide an in-depth examination of parents' emotional reactions to the diagnosis of a fetal anomaly, highlighting my understanding of the multiple integral components shaping, influencing and characterizing parents' reactions. This analysis will serve as the foundation for the development of a preliminary framework aimed at providing insight into the complexities of parents' emotional reactions to the diagnosis of a fetal anomaly, as well as a tool to guide health care providers' (HCPs') provision of individualized and comprehensive parental support, which will be detailed in Chapter Seven. The chapter begins with an exploration of the antenatal parental grief reaction triggered when a fetal anomaly was suspected, which often persisted even when further prenatal testing results were "normal." This is followed by an exploration of the nature of the parental grief response stemming from a confirmed fetal anomaly and the associated loss of the anticipated and hoped for "perfect" baby. The parents' emotional responses were distinctive in that they occurred within the context of an evolving pregnancy and were intertwined within what I found to be a complex matrix of emotional responses. This matrix was comprised of prominent emotions vacillating between four intersecting continua: (1) dread/despair-hope; (2) powerlessness-control; (3) self-stigma-self-respect (and associated social isolation-social integration); and (4) low parental-fetal attachment-high parental-fetal attachment. The dominant emotions

experienced as part of this dynamic emotional vortex, as well as the time-pressured nature of an evolving pregnancy, motivated and influenced parents to respond in ways that promoted their emotional stability, addressed decision-making dilemmas and managed the perceived reactions of others. Specifically, parents described as supportive those actions, initiated by themselves or others, that allowed them to move their emotional stance toward hope, control, self-respect (and associated social integration), and higher levels of parent-fetal attachment. As they grappled with the fetal diagnosis and their first parenting decisions, parents moved through what they depicted as four distinct phases of parental response to a fetal anomaly: (1) Overwhelmed: A whirlwind of conflicting emotions; (2) Treading water: Looking inward and considering options; (3) Taking control: Looking forward and enacting parenting decisions; and (4) After the pregnancy ends: Now it's real. Each of these phases will be explored in detail, highlighting prominent parental emotional responses and actions common to each phase.

A Unique Grief Response: Loss of the "Normal" Pregnancy and/or the "Perfect"

Baby

From the instant suspicion of a fetal anomaly was raised, parents described the pregnancy as permanently and irrevocably altered. Parents expressed sentiments of loss of the "perfect" or "healthy" baby and "normal" pregnancy and an associated grief reaction, which was triggered as soon as HCPs introduced the suspicion of a fetal anomaly. For most parents, the grief associated with a suspected or confirmed diagnosis of a fetal anomaly was exacerbated by the fact that it was unanticipated. As previously described in Chapter Four, the majority of parents entered into prenatal screening (PNS) with a naïve assumption that testing would indicate a healthy fetus and had not seriously considered the ramifications of a potential diagnosis of a fetal anomaly. Specifically, when parents

were first told of a suspected fetal anomaly, they described feeling "shaken to the core" and "in a state of disbelief" (field notes, multiple parents). During the period between initial suspicion and learning the results of definitive antenatal testing, parents described "fearing the worst," "jumping to worst-case scenarios," and "playing out their worst fears" (field notes, multiple parents). These fears and worst-case scenarios varied from parent to parent and included sudden fetal demise, neonatal death, and images of caring for a child with a serious, lifelong health condition characterized by suffering, difference and disability. Moreover, even when parents received reassuring news that additional antenatal testing was "normal" and a fetal anomaly was essentially ruled out, they described an inability to return to the "blissful ignorance" and "naivety" they experienced before the suspicion of a fetal anomaly was raised (field notes, multiple parents).

For those who initially received a confirmed diagnosis of a fetal anomaly or for whom a suspected fetal anomaly on a community scan was confirmed with additional testing, parents described a similar initial parental grief reaction in response to the loss of the anticipated "healthy," "perfect," "wished for," and "dreamed of" baby. This subset of parents described experiencing a complex emotional reaction to the loss of a "healthy" baby within the unique context of an evolving pregnancy. This grief reaction was unique in that parents grieved the "anticipated" baby, the "imagined" baby, the baby they described feeling kick, punch and somersault inside the womb, but whom they had never met face to face. In this way, parents grieved what they had hoped for but not physically known outside the womb. Furthermore, parents described experiencing profound loss and grief within the context of a pregnancy in which there were no outwardly discernible differences to the pregnancy from the pre-fetal diagnosis stage to the post-fetal diagnosis stage.

Parents compared their emotional reactions to those of friends or family members who had "normal" pregnancies, or to their own previous pregnancies in which PNS had not detected any suspicion of a fetal anomaly. Importantly, parents explained the loss of an anticipated "healthy" baby was compounded when they compared it to the joy and naïve bliss experienced by their friends and family members who were not exposed to the emotional angst and turmoil associated with a suspected or confirmed diagnosis of a fetal anomaly. Moreover, several parents described the suspected or confirmed diagnosis of a fetal anomaly as interrupting the standard script of what to expect during pregnancy, which itself was associated with feelings of loss. For example, many parents compared their experience to how most parents "do" pregnancy in the modern era, emphasizing how it was the norm to find out the fetal sex during PNS and subsequently focus considerable time on preparing a gender-specific baby room, purchasing gender-specific clothing and having gender-themed baby showers. Others described it as the norm to anticipate taking home their first photos of their (healthy) baby to share with loved ones and treasure as important keepsakes of their pregnancy. Parents anticipated and expected these normal and joy-filled activities of the pregnancy experience, which allowed them to follow in the same steps as pregnant friends or family members. However, when parents were told of a possible fetal anomaly, it interrupted this typically happy and celebrated time and ejected them off the normal pregnancy path and onto an unforeseen and emotionally taxing path, which they described as contributing to their feeling isolated, stigmatized and rejected. In this way, parents' feelings of isolation and rejection were not necessarily attributable to the specific actions of others; rather, they resulted simply from deviating from the norm. Parents' comparison of their experience to normal pregnancies added to parents' sense of loss and associated feelings of grief. In addition, once parents started on the alternate

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route from that of a normal pregnancy, they lacked the usual guideposts of what to expect and described feeling guarded and unprepared for what to anticipate or how to respond.

Parents' Emotional Responses to the Diagnosis of a Fetal Anomaly

Parents generally viewed a suspected or confirmed diagnosis of a fetal anomaly as a critical event or turning point in their lives. They described this experience as comprised of a unique grief response associated with the loss of an anticipated and hoped-for baby within the context of an evolving pregnancy. Based on parents' descriptions of their experience, this response was conceptualized as representing a complex matrix of emotional responses involving prominent emotions vacillating along four intersecting and simultaneously occurring emotional continua. The suspected or confirmed diagnosis of a fetal anomaly changed parental perceptions of the pregnancy, the anticipated baby, and their family's future. The diagnosis also initiated reframing of what it meant to be a parent. Parents described this time as one of deep reflection and soul-searching as they focused on the emotional turmoil associated with the fetal diagnosis, decision-making dilemmas, and how to respond to others' reactions. In addition, throughout this process parents described exploring and determining effective means of integrating the diagnosis into their everyday lives in ways that allowed them to move forward out of their initial emotional turmoil and angst.

The parents' response to a diagnosis of a fetal anomaly was conceptualized as representing a multidimensional construct comprised of four intersecting planes representing different emotional continua: hope–dread/despair; control–powerlessness; self-stigma–self-respect (and associated social integration–social isolation) and high parent-fetal attachment–low parent-fetal attachment (see *Figure 3*, A Multidimensional Construct of Parents' Emotional Responses to a Diagnosis of a Fetal Anomaly below).

The four dimensions of response represent the dominant parental emotions expressed. Parents expressed other emotional responses (such as guilt and anxiety), but not as consistently or as prominently. As depicted in the following illustration, the four dimensions are not expressed in isolation; rather, they intersect with each other, indicating all four emotional continua influence and are shaped by the other dominant emotions. Moreover, it is impossible to completely separate any of the emotional continua



Figure 3. A Multidimensional Construct of Parents' Emotional Responses to a Diagnosis of a Fetal Anomaly.

from the influences of the others. The dominant emotions experienced as part of this dynamic emotional matrix, as well as the inherent nature of the evolving pregnancy, motivated and shaped parents to respond in ways that promoted their emotional stability,

addressed decision-making dilemmas and allowed them to address the perceived reactions of others. Parents described as supportive those actions, initiated by themselves or others, that allowed them to move their emotional stance toward hope, selfrespect, control, social integration, and higher levels of parent-fetal attachment.

There are several basic assumptions about emotions underpinning the conceptualization of parents' emotional responses to a diagnosis of a fetal anomaly that provide a framework for this section. These assumptions are based on previous theoretical and research literature and are included here to provide insight into the overall conceptualization of parents' complex emotional responses. These assumptions include: (1) emotions are short-term feelings that are expressive and purposeful (Campos, Campos, & Caplovitz Barrett, 1989; Sroufe, 1997); (2) emotions support individuals in adjusting to the opportunities and challenges they face (Campos et al., 1989); (3) thought is a necessary condition of emotion, and emotions prioritize behaviour in ways that optimize adjustment to the demands individuals face (Barrett & Campos, 1987; Frijda, 1986); (4) emotions reveal what is valued to the individual and provide a measure of performance in relation to values, goals and beliefs (Frijda, 1986); (5) emotions express the nature of our relationships with others (Campos et al., 1989; Fogel, 1993); (6) emotions can affect interpersonal relationships both positively and negatively (Fogel, 1993); (7) emotional control is associated with successful adaptation to stressful life events (Campos et al., 1989; Fogel, 1993) and (8) emotions are not expressed as simple discrete responses but rather involve continued tuning and modulation (Fogel, 1993).

Dread/Despair–Hope Continuum

A prominent parental reaction to the diagnosis of a fetal anomaly occurred along a continuum between dread or despair and hope. When parents were first informed of a

suspected or confirmed diagnosis of a fetal anomaly, they often reacted with feelings of dread and/or despair, yet the majority retained some sense of hope that further testing would rule out a fetal anomaly, or the fetal condition could be successfully treated or "cured" postnatally. As described in Chapter Five, parents resisted and challenged their feelings of dread and despair through actions and approaches that provided them with hope. As previously described, parents searched for hope in multiple ways including: focusing on the positive; prayer and putting faith in God or a higher power; resisting the "litany of negatives" in HCP communications of prognostic information by aligning with alternative sources of information that allowed for the possibility of positive fetal outcomes; and connecting with other parents with a child with a similar health condition.

Initial dread or despair associated with the fetal diagnosis. Parents commonly described their initial emotional reactions to the fetal diagnosis as one of angst and dread. An important distinction was parents' description of dread as it compared to despair. Parents used words such as "shocking," "discouraging," "threatening," "distressing," "intimidating," "alarming," and "daunting" to refer to the parental fear caused by the diagnosis of a fetal anomaly. Despair, on the other hand, was associated with the "loss of hope" and was described by parents using descriptors such as "zero hope," "hopeless," "agony," "misery," "mournful", "depressed" and "resigned." Parents generally described their feelings of despair as the polar opposite of hope, whereas dread was framed as a fear of what might happen, but not a situation devoid of hope. Similarly, parents described initial emotional reactions of shock, alarm, fear, and unease, but rarely described a sense of resignation or a situation in which all hope was lost except, as in Yolanda and Zane's initial experience (as described in Chapter Five), the prognosis was such that the fetus was not expected to survive the pregnancy. In their initial response to the fetal diagnosis,

parents were actively involved in making sense of the diagnosis and what it might mean for both themselves and their future child. Although coming to understand the nature of the fetal diagnosis was often associated with distressing thoughts and feelings related to potential treatments and outcomes, parents' initial responses were generally not associated with immediately giving up hope for their anticipated baby. Rather, as previously described, parents described being "guarded," "in limbo," "not committed," and in "self-protection mode" but not without hope for a positive outcome, albeit possibly a different one than they had anticipated.

On describing the initial shock of the fetal diagnosis, Jesse clearly described his automatic reaction to think "the worst," and how this sense of "despair" was exacerbated when information provided by HCPs focused on "worst case scenarios," rather than a "balanced" approach including a range of best- and worst-case scenarios. Specifically, Jesse described how HCPs' descriptions of a complex fetal anomaly and accompanying worst-case scenarios contributed to his initial sense of despair that made it difficult for him to be hopeful.

I mean the news was so shocking that I guess it's a human tendency to, I don't know, think about the worst, the worst case, I guess, I mean I think that it is a natural tendency for us to be like, gosh, this is bad news, "oh no" in your mind. Just it goes into the worst possible scenarios and you sort of fall into a bit of a despair, which just prevents you from looking at, looking towards hope. Which again, this brings it back to how information should be delivered to us in a more balanced way. When you are presented with all the talk about what the worst- case scenario would be, how can, how can one be hopeful? (Jesse, L 1251–1260)

In contrast to the above example, Tara received a fetal diagnosis of a small oomphalocele and was reassured by the healthcare team that the baby's prognosis would be very good. Despite the positive prognosis and the healthcare team's reassurances, Tara remembered the moment that the "suspected diagnosis" was confirmed, and her feelings of sadness associated with it:

[Before the appointment] there was always still a hope that it really was nothing, it was going to be nothing. So, when I found out that it was the oomphalocele, I phoned, you know, my partner and told him ... I think we were both just sad, like, that was, like, the biggest emotion. It wasn't really scared, it wasn't really anything else (Tara, L 176–179).

Tara went on to explain that despite the healthcare team's reassurances she continued to worry for the rest of her pregnancy about the possibility her baby might die and the baby's upcoming delivery and postnatal care. Similarly, several other parents described, "hoping for the best" in response to their initial feelings of dreading the worst. In this way, parents enacted hope to offset the dread they experienced.

Parents' reactions to initial despair and dread: Searching out hope. Parents

indicated their initial feelings of dread and/or despair prompted them to learn more about the fetal diagnosis as a means of understanding what they were facing and "to try to make sense of it all." Parents also described searching for information that would provide them with a sense of hope for their fetus' future. Parents described multiple "Googling" sessions and "exhaustive searches for anything relevant" as they struggled to accept the reality of the fetal anomaly and their feelings that "this was not the scenario we were hoping for." One father described how "searching out good news," "best case scenarios" and other parents who had experienced a similar diagnosis all helped to ease his initial feelings of despair and shift his perspective towards a more hopeful stance in relation to his unborn child's future.

Certainly, finding the [Facebook parent group] sooner would have been a good thing, searching out good news, searching out best-case scenarios, searching out people that have [fetal diagnosis], of course we didn't know anyone else that had this problem, right, so looking for people that are in the same boat as you is a good thing to do. Finding these things earlier so that you can get out of the sort of

negative world and the negative feeling of despair sooner—that's a good thing too, ... finding out the best-case scenarios (Jesse, L 1314–1323).

Parents also described counteracting their initial feelings of dread and despair by focusing on the hope associated with positive news about the progress of the pregnancy and the available treatments for the fetal anomaly rather than dwelling on the risks associated with the pregnancy, fetal condition or treatment options. Hope was derived from multiple events and findings including the: feel of the fetus' strong kicks and movements; visualization of "normality" on subsequent ultrasounds; normal amniocentesis results; the "ruling out" of associated medical concerns; and successfully continuing the pregnancy to full term. Each risk averted and each bit of positive news following the diagnosis provided hope. Moreover, parents described consciously celebrating mini-accomplishments and/or positive feedback about their fetus, which reinforced their hope for a positive outcome. For example, Callie and her husband scheduled a major celebration with friends and family when their twins reached the gestational age of viability, and multiple parents described the "mini-celebrations" they had when they received "good news" from amniocentesis results. Common physical indicators of health also provided hope-regardless of their basis in medical fact. For instance, for parents with fetal heart anomalies, a "regular" heartbeat on follow-up exams provided reassurance the fetal heart was "strong" and "doing well," despite the known presence of a complex fetal anomaly. Similarly, mothers described feeling strong fetal kicks as reinforcing their image of a physically healthy and resilient fetus that they referred to using descriptors such as "tough" and "a fighter." All of these positive results and physical indicators served to provide parents with hope for their fetus' well-being.

For many, hope was derived from a change in perspective. For example, Abra shared the following insight into how focusing on the positive helped her through the

emotionally difficult time when her daughter was told of a complex fetal anomaly.

It just made me really think, like it was Friday and I was talking with my husband, and he was like honey, you always remember, you go to sleep with positive thoughts and you wake up with a positive. And then I was like, it made me think, like that is true, right? If we want positive outcomes we've got to think positive. Don't think, oh no, they [care providers] are going to say this, no, they are going to say that, you know? It really made me think when he said that (Abra, L 1142–1147).

Abra also had the following advice for other parents facing a similar antenatal experience:

"Always have a positive attitude. It is hard to come by ... It's very hard, you know" (Abra, L

11557–1569). Similarly, Sara, who experienced a stillbirth of her daughter in a previous

pregnancy and faced concerns of a suspected fetal anomaly in her current pregnancy,

emphasized finding hope by focusing on enjoying the moment rather than worrying about

potential negative outcomes.

We can't control what happened and the time that we got to spend with our daughter when she was, when I was pregnant with her was really special, we were really, really happy and we really enjoyed getting to know her and there's no reason why we can't do the same with this one depending on the outcome or not. I mean he is still a little person to us and we really, you know, we are really happy and excited and we are hoping that we get a good outcome and we get to meet him properly ... I think I realize that I don't have any answers of what happened and there is nothing that I can do, so there is no point in being concerned about this. This is a new baby and what happens, happens. We will have to face it (Sara, L 393–402).

Powerlessness–Control Continuum

Hand in hand with their initial feelings of dread and/or despair, the majority of parents initially experienced a transient phase where they described a sense of powerlessness. This was expressed in multiple ways including: "We felt like we lost control of the situation"; "I felt helpless"; "We felt powerless to change anything"; and "We were no longer sure what to do" (field notes, multiple parents). A shift from powerlessness to a building sense of control was triggered as parents learned more about the diagnosis and started to map out tentative algorithms and decision trees related to antenatal and postnatal care. In general, the more certain parents were of their decisions related to the fetal diagnosis, the greater the sense of control and the lower the sense of powerlessness they exhibited. Moreover, a greater sense of parental control went in tandem with a growing conviction in their decisions and choices.

Powerlessness–Control intertwined with uncertainty and the complexity of the fetal anomaly. Parents described finding the uncertainty inherently associated with an evolving fetal diagnosis particularly difficult and frustrating given the current social context characterized by a culture of immediacy and technology-driven information provision. Uncertainty was a taken-for-granted aspect of pregnancy, regardless of the presence of a known fetal anomaly. This was evident in parents entering into their PNS ultrasounds with questions such as Will it be a boy or girl? Who will the baby look like? When will I deliver? What will we name the baby? Parents often viewed the unknown answers to these questions as part of the excitement and anticipated "happy surprises" associated with pregnancy. Modern technology in the form of ultrasounds, 3D ultrasounds, amniocentesis and genetic testing provided families with antenatal answers to some of these common questions. For many parents this was perceived as adding additional excitement and joy to the pregnancy experience by allowing them to prepare for a girl or boy or have a sense of what the baby would look like before they were born. Adding clarity to antenatal uncertainties also provided parents with a greater sense of control and power over their experience. The existence of a fetal anomaly was a major change for parents as they adjusted from the uncertainty of two or more positively viewed possibilities (e.g. boy or girl, resembles Dad or Mom) to hoping for the best of the possible

negatively viewed scenarios (e.g. fetal demise or high-risk neonatal surgery). The inherent uncertainties associated with a fetal anomaly also reinforced the powerlessness and lack of control described by many parents.

Almost all of the parents observed and/or interviewed emphasized their sense of powerlessness in response to the situational and emotional uncertainty inherent to the experience of a diagnosis of a fetal anomaly. Parents found both the situational uncertainty (lack of information about an event) and the emotional uncertainty (the feeling of "not knowing") aversive and an emotional state they appeared strongly motivated to reduce. Parents faced uncertainty about many facets of the antenatal diagnosis experience and its aftermath. Specifically, parents faced uncertainty related to the exact nature of the fetal anomaly and how it would manifest in their child. Even when parents were provided with a clear diagnosis, they were generally informed that the condition occurred along a spectrum of severity and infants and children with the same condition could have varying levels of success with neonatal and future interventions. Other common areas of parental uncertainty included: (1) the exact nature of neonatal and future treatments (i.e. parents were often given an algorithm involving an "if this, than that" scenario); (2) potential associated co-morbidities not specifically identifiable antenatally (e.g. learning or behavioural disorders or associated chromosomal anomalies if definitive antenatal genetic testing was not completed); and (3) the impact on parents and family members from associated caregiving challenges.

HCPs' descriptions of fetal diagnoses and/or prognoses were often framed in terms of possibilities, probabilities, and "risks of," consistent with language used by HCPs when describing medical diagnoses. Although in many cases the healthcare team were certain of the general nature of the fetal diagnosis, it was common for parents to be told " minor/small defects may be missed" during antenatal screening, and that there were "no guarantees that the diagnosis is 100% accurate" or that "complete [diagnostic] information will not be available until the baby is born," Although HCPs described needing to review these exceptions as part of fully informing the family as to the state of what was known and not known about the fetal diagnosis as well as covering themselves from any liability concerns, these statements were often perceived by parents as adding to the overall uncertainty of their antenatal experience.

In general, the greater the complexity of the fetal anomaly, the greater the uncertainty associated with the fetal diagnosis and prognosis. In situations where the fetal diagnosis was rare or complex, HCPs often prefaced their discussions with phrases such as "We are still working on coming to a clear diagnosis," "We don't know for sure," and "Our best guess or hunch is..." In general, fetal diagnoses associated with greater complexity and uncertainty such as complex oomphalocele, severe heart disease, and diaphragmatic hernia were associated with parents' descriptions of intense feelings of powerlessness and/or lack of control over their experience. Parents who received complex fetal diagnoses such as this were often placed in a position where they were required to make antenatal decisions from a range of best- and worst-case scenarios rather than one associated with greater certainty of the nature of postnatal diagnoses, neonatal treatments, or treatment outcomes.

Parents exhibited and described less powerlessness (greater control) following the diagnosis of a fetal anomaly when they perceived pregnancy or neonatal treatment decisions necessitated less deliberation on what the "best" decision was, or the nature of the fetal diagnosis was associated with HCPs' and parents' perceptions that there was only one real option. In these situations, parents generally were less likely to question

prognostic information or search for additional information on pregnancy or treatment options. For example, Claire and Ethan described leaving their initial screening ultrasound with the impression termination of pregnancy (TOP) was the only "reasonable" option, as the complex fetal diagnosis was associated with "no hope" (despair) for their fetus, and continuing the pregnancy with the intent of providing palliative care to the newborn at birth would place unnecessary risk on maternal health and therefore was not advised by the community provider, given the baby was expected to die within a few days after birth. Similarly, Yolanda and Zane described a similar prognosis of "zero hope" for their fetus and were initially encouraged that termination of pregnancy (TOP) was the "best" option. In these examples, TOP was presented by HCPs as the only reasonable option, and therefore there was no impetus for parents to search out additional information on the diagnosis or other possible options. This was more likely if the diagnosis was presented with prognostic outcomes of a very limited life span, considerable pain and suffering associated with medical treatments, and/or a poor quality of life. Fetal anomalies associated with positive prognostic outcomes in tandem with initial diagnoses of fetal anomalies at an advanced gestational age that precluded TOP as an option were also associated with an increased sense of parental control and less deliberation over antenatal decisions. Similarly, if parents perceived a fetal anomaly was clearly associated with a high rate of successful treatment and excellent long-term outcomes, they generally perceived a higher degree of prognostic certainty and described feeling more in control of their experience.

Parents' responses to feelings of powerlessness and lack of control. In response to their initial feelings of powerlessness, parents described seeking out means of increasing their sense of control. How parents responded was strongly linked to their

perception of the uncertainty or certainty associated with the fetal diagnosis. In general, parents searched for increased certainty even when the situation appeared uncertain. This included seeking out information to improve their understanding of the fetal diagnosis, treatment options, future implications and available supports. It was common for parents to reflect back to the initial fetal diagnosis and make comments such as "We didn't know anything about [fetal diagnosis], we needed time to make sense of things," or "We needed to become more informed before we knew what we would do." For example, Thea described the priority she placed on understanding the diagnosis and anticipated treatments, repeatedly expressing that "knowledge is power." Alternatively, some parents described realizing "things were out of our control," and coming to a point where they came to terms with what they could not control in relation to the fetal diagnosis. The turning point for these parents was not their situation becoming more certain or that they expressed more emotional certainty, but rather they expressed a greater sense of control over their situation. For some, this perception of an increased sense of control resulted in part from a greater understanding of the diagnosis, prognosis, and anticipated management plan. For most, they described their sense of control increasing once they came to an agreement concerning pivotal decisions such as which forms of additional prenatal testing they would participate in or whether to continue or terminate the pregnancy. In general, once parents were able to chart their future course in relation to the fetal diagnosis, they experienced greater certainty and clarity about their decisions. That is, parents' emotional certainty was enhanced by having a planned response to the fetal anomaly, despite the situational uncertainty related to the fetal diagnosis and future treatments remaining high until after the baby's birth or the TOP.

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Powerlessness–Control and parental conviction. Closely tied to parents' sense of powerlessness or control was their sense of conviction over their decisions and parenting behaviours. Through my observations and interviews with parents, it became apparent it was necessary to understand and differentiate between uncertainty parents faced related to what they *could* do (which was related to their sense of power or control over the situation) and uncertainty parents felt about what they should do (i.e. their moral convictions), as well as the inherent situational certainty associated with their current or anticipated experiences related specifically to the fetal anomaly. Parents appeared to have a greater sense of control over their situation when they filtered out things that were out of their control and focused on those things that were within their control and power. Parents' sense of control increased not necessarily because their level of control shifted or the certainty associated with fetal outcomes improved, but rather, because of this shift in focus. Conviction, on the other hand, had to do with parents' perceptions of whether their antenatal decisions or behaviours were "right," "moral" or consistent with their values and beliefs.

Parents' convictions that they were "doing the right thing" had to do with feeling in alignment with the morality of their own behaviour, which was in line with their sense of control over the situation. In the initial period following a diagnosis of a fetal anomaly, parents faced uncertainty about what would happen but also uncertainty about what they should do. The shock of the fetal diagnosis, situational uncertainty associated with the diagnosis, and the parents' lack of experience in similar situations were all factors contributing to initial feelings of powerlessness and "lack of control". As parents moved forward through the experience, searched for and understood the fetal diagnosis and its implications, and found support for the decisions they made (from medical experts, other parents, or family members), the majority emerged with both a greater sense of control and a greater conviction their decisions were "right for them." Moreover, as was exemplified in the previously described example of Zane and Yolanda's ultimate decision to continue the pregnancy despite HCPs' concerns of a high probability of fetal demise, parents who came to express a greater sense of control over their experience often had stronger convictions that their parenting decisions and behaviours related to the fetal anomaly were consistent with their beliefs and values and hence perceived as morally "right". This was the case regardless of whether parents considered or chose TOP or continued the pregnancy. Conversely, parents who were morally and ethically torn about their decisions, or felt pressured into a given decision, often experienced a lower level of conviction and a lower sense of control. In this way, parents' convictions were linked to and representative of the ethical nature of decisions or dilemmas faced following diagnosis of a fetal anomaly. Decisions were not simply based on systematic and purposeful processing of pros and cons of a given decision, but also involved reflection and reflexivity regarding what parents believed and valued to be morally correct. The more parents believed their decisions were moral, ethical and consistent with their worldviews, values and beliefs, the stronger their conviction in their decisions. In turn, the stronger parents' convictions their decisions were right for them, the greater their sense of satisfaction with their decisions and the greater their sense of control.

Parents who described making antenatal decisions more quickly and with greater ease had often thought through what they would do in the event of a diagnosis of a fetal anomaly and/or had very strong convictions as to what were morally "right" decisions for them. In addition, parents with strong moral convictions were less likely to describe feelings of powerlessness. From the time of the initial diagnosis of a fetal anomaly, this subset of parents was more certain of their decisions and appeared to have greater emotional control in HCP-parent interactions. Many of these parents described that their decisions were guided by their faith or religion, or a moral conviction of what was "right". Moreover, many of these parents described previously considering what they would do in a similar scenario and as a result needing less time to deliberate over their response. Self-Stigma–Self-Respect Continuum (and associated Social Isolation–Social Integration Continuum)

In addition to dread/despair and uncertainty, parents also faced stigma and associated social isolation in relation to the diagnosis of a fetal anomaly. Specifically, the diagnosis of a fetal anomaly changed parents' perceptions of the pregnancy from normal to abnormal, which left them vulnerable to self-stigma and critique. In addition, many parents described worrying over how others would perceive or define them as parents and judge their antenatal decisions. Parents also expressed concerns family or friends might reject them or their child as a result of the fetal anomaly or parental decisions made in relation to pregnancy or neonatal treatment options. In response to this self-stigma, the majority of parents described a period of social isolation following the initial fetal diagnosis while they deliberated major decisions such as whether to continue or terminate the pregnancy.

Parents described isolating themselves from others as a means of shielding themselves from potentially stigmatizing reactions, in addition to needing time to sort through their feelings and decisions related to a suspected fetal anomaly. This selfisolation sometimes put parents in the difficult situation where they distanced themselves from the very people to whom they usually turned for emotional, informational, practical, financial and others forms of support. For some parents, this initial emotional and physical distancing from others in their social network was tied to a concern over how they would be perceived by others as a result of the fetal diagnosis. Some parents (such as two mothers who faced a higher risk of having a baby with Down syndrome because of older maternal age, or a mother who described one episode of drinking excess alcohol prior to realizing she was pregnant) commented they worried family or friends might silently or overtly question their responsibility for the fetal anomaly. Other parents described anticipating negative reactions to the suspected or confirmed fetal diagnosis from close friends or family members, which would add to and potentially exacerbate their emotional distress rather than allow them to focus on coming to terms with the diagnosis and making important decisions free from unwanted outside influences. Inherent to the social isolation following the diagnosis of a fetal anomaly was parents' evolving realization that their fetus was potentially "not normal," coupled with their worries about others' stigmatizing perspectives and discriminating actions against people with disabilities. This was a particular worry if friends or family had previously demonstrated thoughts or actions that reinforced stigma of children or adults with disabilities. For example, several parents described being reluctant to share the fetal diagnosis with certain family members, including their parents and grandparents, because of negative and stigmatizing perspectives on childhood disabilities these individuals had shared in the past, such as referring to children with Downs syndrome as "mentally retarded" or "mongoloids." In this way, parents described stigma as a major factor in determining whether they self-isolated or sought social support from their existing networks following the initial diagnosis of a fetal anomaly. That is, if parents perceived others were likely to discriminate against them, make them feel somehow responsible for the fetal anomaly, or add to their emotional distress, they were less likely to turn to these individuals for support. For example, one

mother described how she worried she would be differentiated within her friend group as "the mom with the baby with the [fetal anomaly]" (Renee, field notes). Similarly, Abra described wanting to keep her sixteen year old daughter, April, who was pregnant with a baby with a complex fetal anomaly, "safe" at home—away from public scrutiny. She described keeping April home from school after learning of the fetal diagnosis as a way of protecting her:

You know, every parent wants their kids to finish school. She should have been doing Grade 11 this year, but after we found out she was pregnant I put tight strings on her. I keep her close to me. I keep her home ... because of what's wrong with baby. Safe. (Abra, L 810–821)

For this family, as the birth of the baby approached, April described feeling supported by her mother and protected from the stigmatizing gaze of others who she felt judged her for being pregnant at a younger age and/or for continuing the pregnancy following the diagnosis of a complex fetal anomaly. At the same time, April also expressed her unhappiness and the loneliness resulting from her isolation from friends and peers who had been one of her major sources of support. These preceding examples highlight that parents often self-isolated based on what they perceived others would say or do, not necessarily on actual stigmatizing actions of others specific to the fetal diagnosis or the parents' decisions.

In contrast to the preceding examples, some parents described self-imposed isolation after a suspected diagnosis of a fetal anomaly to prevent family members and close friends from detecting their angst or worry, with the rationale that they did not want loved ones to needlessly worry in the event definitive antenatal testing indicated normal results. This was the case for several families who described waiting for amniocentesis results to determine the presence of a suspected chromosomal anomaly such as Down syndrome. This subset of parents described similar experiences comprised of a whirlwind of emotions and decisions, from the initial "joy" and "happiness" associated with anticipating a healthy baby to the "shock" and "overwhelming" feelings associated with PNS results indicating a suspected fetal anomaly to the "sitting on pins and needles" and "hanging in limbo" (field notes, multiple parents) associated with waiting for amniocentesis results to definitively determine the presence or absence of a fetal chromosomal anomaly. For the majority of parents this whirlwind of emotions occurred over a very short period of time, often within a few days or weeks. For example, several parents described a similar timeline for learning of the results of additional diagnostic tests in the context of a suspected chromosomal anomaly, such as the results of a detailed ultrasound, raising initial concerns on a Monday, undergoing amniocentesis on a Tuesday, receiving preliminary amniocentesis results the following Monday, and definitive results within two weeks. The majority of these parents described a self-imposed period of isolation, which allowed them time and space to "get their feet underneath them" or "their heads wrapped around" the suspected fetal diagnosis, because they did not want to be influenced by close friends and relatives while they were considering their own perspectives and beliefs and making what they viewed as significant life decisions. Specifically, parents described needing focused time to deliberate their choices and come to a consensus. For example, Adnan and Amena did not inform their family or friends of a suspected fetal diagnosis of Down syndrome arising from PNS blood work. They described their initial emotional reaction to the suspected diagnosis of Down syndrome as "a living nightmare," "hell," and "stressed beyond anything we had experienced" (field notes, Adnan and Amena), yet described how they isolated themselves from their close-knit extended family members by staying in their car for three days (only to return home at night to sleep) while awaiting the preliminary amniocentesis results so as not to worry their extended family who lived with

them, as well as to avoid being influenced by them regarding antenatal decisions they "should" make.

As illustrated by Adnan and Amena's experience, parents' self-isolation was tied to how parents perceived they would be viewed or judged for their antenatal decisions. For example, two mothers specifically described how they shared the news of a suspected chromosomal anomaly with their own mothers because they knew their mothers would support them in their decisions to either continue or terminate the pregnancy (one mother had decided to terminate the pregnancy if the amniocentesis indicated Down syndrome, while the other mother had decided to continue if the amniocentesis indicated Down syndrome). However, several other parents indicated they specifically did not share the news of a suspected chromosomal anomaly with their parents—either because they felt their parents would disagree with their decision to continue or terminate the pregnancy, or because they wanted time to deliberate the decision themselves and come to a decision without the influence of their parents or other family members. In addition, when parents did share their decision with family and/or friends, parents tended to frame the nature of the fetal anomaly in a way that validated their decision to continue or terminate the pregnancy. For instance, some parents described telling family and friends they wanted to "give the baby a chance" by continuing the pregnancy, whereas others indicated they would share decisions to pursue TOP with close family members from the perspective of "having no other choice to avoid suffering." Moreover, several parents described a plan to tell family and friends they "lost the baby" or "had a late miscarriage" rather than face the "stigma" and "judgement" of others or "have to justify" their choice to terminate the pregnancy (multiple parents, field notes). For example, Adnan and Amena noted that during their time of self-isolation, while they awaited preliminary amniocentesis results,

that they discussed tentative plans for how they would explain a decision to terminate the pregnancy if amniocentesis results confirmed a diagnosis of Down syndrome.

Adnan: Maybe I will tell my mom, but for friends, I don't think I will tell them that we get rid of the baby because of Down syndrome. R: How would you have explained it to your friends then? Adnan: Just the baby died ... for no reason. Without interference, without interference, yes. (L 680-684)

Parallel shifts from self-stigma to self-respect and social isolation to social

integration. Once the initial period of intense learning about the fetal anomaly and deliberation over major decisions was completed, those parents who continued the pregnancy described starting to feel more comfortable sharing details of the fetal diagnosis, associated decisions and anticipated experiences with their close family and friends. Parents indicated this often involved a shift in their personal perspectives or understanding of the cause of the fetal anomaly. It also involved a shift from self-stigma to self-respect in relation to their views of themselves and their antenatal decisions. For example, as previously noted, several mothers described their feelings of guilt and uncomfortableness in relation to their perceptions that they did something or did not do something that could have prevented the fetal anomaly, which led them to avoid reaching out to others for support (self-stigma). Parents indicated that reassurance from HCPs, their own research on the Internet, and discussions with others knowledgeable about the condition often helped to ease the self-blame and self-stigma contributing to their initial self-imposed isolation. Other parents described "coming to terms with" or "accepting" their child's health condition, noting this was "a big hurdle" or "huge step" (field notes, multiple parents) in moving forward to share the news of the fetal diagnosis with their closest family and friends and then gradually to tell others in their social network. For those parents who continued, they described—and I observed—an increased confidence in

their decisions over the remainder of the pregnancy as they prepared for the birth of their baby. In addition, for this subgroup of parents, they described the relief associated with sharing their decisions with family and friends and being able to move forward with their social network intact to help them through the remainder of the pregnancy and neonatal period. In most cases, parents described this reintegration with their social network as helpful and supportive in their ongoing journey. Unfortunately, I was not able to reconnect with any parents who terminated in the weeks to months following their TOP; therefore, I am unable to describe the nature of their experience in terms of their social reintegration into their existing support network.

Factors influencing and shaping self-stigma–self-respect and associated social isolation–social integration. Parents' self-imposed isolation was influenced and shaped by the situational uncertainty associated with the fetal diagnosis and associated parental feelings of powerlessness. Parents faced significant antenatal decisions based on possibilities and probabilities, rather than the definitive medical information provided to parents who experience a postnatal diagnosis of a congenital anomaly. This contributed to parents' sense of powerlessness over their situation, which they reacted to with a "frantic search for information," "steep learning curves" and intense deliberation over possible choices, which most parents preferred to do in isolation from their social network. Parents described that this self-imposed social isolation allowed them time to better understand the fetal diagnosis and explore their options together before sharing the fetal diagnosis with others.

Parents who had considered and discussed what they would do if a fetal anomaly was detected, or had a clear conviction of the "right" decision based on their personal values and beliefs, were less likely to experience self-imposed isolation and more likely to share the fetal diagnosis with close friends and family members sooner than those who needed more time to consider their options and make decisions. In addition, parents who perceived that family members and friends would support them in their antenatal decisions were less likely to self-isolate from their support system. Moreover, several parents noted that the perspectives of family members, such as their own parents, influenced their antenatal decision-making. Several parents who described seeking advice from family and friends tended to make decisions consistent with their perception of what these individuals would want them to do. In contrast, those parents who perceived family or friends might attempt to influence them toward alternative decisions. This resulted in those parents whose perspectives were aligned with their immediate social network receiving early support in their decision-making and those parents whose perspectives were potentially in conflict with their social network receiving less support.

Low Parent-Fetal Attachment–High Parent Fetal Attachment Continuum

Parents' responses to a fetal anomaly were also characterized by a fourth intersecting continuum focused on parent-fetal attachment, which shaped and was influenced by the other three emotional continua previously described. As all parents described some degree of attachment to their fetus, this continuum was conceptualized as ranging from low parent-fetal attachment to high parent-fetal attachment. Both mothers and fathers described feelings of fetal attachment. The majority of parents also described how their attachment to the fetus increased as pregnancy progressed and childbirth approached.

My observations of and in-depth interviews with parents led to my conceptualization of parent-fetal attachment (PFA) as a multidimensional construct

influenced by multiple variables, including internal factors such as developmental stage of pregnancy and parental emotional and cognitive factors, as well as other factors such as number of pregnancies, cultural background, and parents' perception of the nature of the fetal diagnosis. In addition, parent-fetal attachment also influenced and was influenced by other dominant emotional reactions. For example, parents who described feeling more attached to the fetus also described "searching for hope" and a more hopeful attitude toward their fetus than those who displayed less PFA (parent-fetal attachment) and a less hopeful attitude in general.

Impact of quickening: "The pregnancy became more real." Mothers consistently reported maternal-fetal attachment was enhanced once quickening, the ability for mothers to feel fetal movements, occurred. Given that screening detailed ultrasounds were generally booked between 18 and 22 weeks gestation and quickening is usually first detected between 13 and 22 weeks gestation, many of the women were already sensing fetal movements at the time of the initial diagnosis of the fetal anomaly. Several women described how their ability to sense fetal movements changed their perception of the fetus and influenced their decisions related to pregnancy and neonatal treatment options. For example, Violet, whose fetus was antenatally diagnosed with a complex heart condition, noted her ability to sense her unborn baby "kicking" influenced her decision to continue the pregnancy.

...In that time [in the midst of decision making about whether to continue or terminate the pregnancy] the baby started kicking, and I mean that's, you know, the pregnancy is progressing kind of thing, like, it became even more real and sort of less like we wanted to do an abortion or something. But also, more thinking about the child's life and [questioning], is it going to be short and terrible, or normal, or whatever in between? (Violet, L 839–843)

Violet also described that "feeling the baby," as well as viewing the baby's evolving

development on ultrasound images, influenced her perception toward continuing the

pregnancy, in that she and Manuel "came to think of the baby much more as a person":

I would say things definitely changed as soon as I could feel the baby ... And I thought, like, that's [TOP] just going to be terrible, like, we might as well give it a chance if there is a survival chance. It's not like, you know, having a six-week abortion where, I don't know what that's like either, it's probably quite unpleasant for some people, but a fairly obvious difference ... I guess in the interim period [between the first and second appointment with the cardiology team], just because of when it was [the timing coincided with the mother first feeling the fetal movements], we came to think of the baby much more as a person (Violet, L 853–871).

Fetal images promoted attachment/bonding. Given differences in antenatal

health facilities, parents were not always able to view fetal images during ultrasound

procedures, however when this option was available all but one parent expressed interest,

excitement and delight in viewing the images of their fetus, and most asked specific

questions or sought out additional information and clarification about the images being

viewed. Many parents expressed that the opportunity to view real-time images and

movements of their fetus provided reassurance their baby was doing well. Parents also

expressed that these images supported their bonding process with their fetus.

Seeing him on the ultrasound screen is amazing, that's an amazing thing to see your baby—being able to watch the baby during the ultrasound even though you don't know what you're looking at, that's, I think that's really good ... you get to see the little person, and then you get to see them, you know, doing his thing and they're playing with their toes or they're sucking their thumb or something and it, it is, there is definitely a connection there. The last ultrasound I had I didn't get to see him ... I don't know if there wasn't a TV in there or they just didn't have it turned on ... So I didn't get to see him in that last ultrasound and that made me sad because I got used to seeing him. And that was right before he was born and so I didn't, the last pictures I got of one of his ultrasounds was of his face and he had super chubby cheeks and that made me happy (Tara, L1154–1181).

Alterations in parent-fetal attachment. Both mothers and fathers described an

evolving attachment to their fetus at the time a fetal anomaly was initially diagnosed, and

how this diagnosis altered and interfered with the parental attachment process in different ways. There were multiple intersecting variables that influenced and shaped PFA, including individual beliefs and values and the gestational age when the fetal anomaly was diagnosed, amongst others, making it impossible to separate out all of the intersecting factors influencing the impact of the diagnosis of a fetal anomaly on PFA. Rather, common reactions and perspectives concerning PFA will be reviewed with examples from those parents who described growing PFA and guarded PFA, as well as those who considered or chose TOP and the associated impact on PFA.

Reframing. Parents who continued the pregnancy and pursued neonatal interventions for their baby described reframing their perspectives from expecting a healthy baby to adjusting to the new reality awaiting them following the baby's birth. This change in perspective on the anticipated baby occurred in tandem with reframing of parent-fetal attachment. Parents described this change in perception using phrases such as, "It may not be what we were expecting, but we will love him/her just the same"; "Making the most of the time we have together"; "Loving her for the time we have her"; and "We will love the child we are given" (multiple parents, field notes). For these parents the attachment process was altered and reframed as they came to understand the nature of the fetal anomaly and anticipate future parent-child relationships and interactions.

Guarded attachments: Self-protection mode. For some parents the diagnosis of a fetal anomaly interfered with the parental-fetal attachment process. As previously discussed in Chapter Five, the diagnosis of a suspected fetal anomaly resulted in some parents voicing a resistance to "committing" or "overly attaching" to their fetus because of fears that becoming more attached would make it more difficult to cope with an unplanned miscarriage, still birth or neonatal death, or, alternatively, to cope with the emotional aftermath of choosing to pursue TOP. Tara, who received a fetal diagnosis of an oomphalocele, discussed the "self-protection" mode that she experienced following the diagnosis of the fetal anomaly.

Yeah [sighs], I guess, like, I'm not one of those pregnant people that felt really ooey gooey about being pregnant and about, you know, the baby-to-be. I think it's more of a kind of, like, self-protection thing that it's like, you know what, I'll be happy when the baby is in my arms and it's here and it's alive—that's [when it will be] good ...So, yeah, I would say that knowing that there was a health concern with him early on made that self-protection mode kick in even more (Tara, L 728–737).

Parent-Fetal attachment alterations in the context of considering TOP.

Parents who considered or chose TOP continued to describe an attachment to the fetus. However, increased tensions existed between parents' and HCPs' perceptions of PFA and the option of TOP, and the actual experience as described by parents. As previously reviewed in Yolanda and Zane's description of their antenatal experience, discussions between parents and HCPs, as well as between the researcher and a range of maternalfetal and pediatric HCPs, indicated an underlying HCP assumption that TOP was generally less difficult earlier in pregnancy when parent-fetal attachment (HCPs focused on maternal-fetal attachment) was lower compared to later stages of pregnancy. In contrast, several parents commented that they "couldn't imagine making a TOP decision this late" (i.e. after 18 to 20 weeks gestation), due in large part to their evolving attachment to the fetus. In addition, parents who considered or chose TOP described it as "one of the most heart-wrenching decisions to have to consider" given the level of PFA that already existed and the gravity of the situation. Parents described considering the choice of TOP as the best parenting choice for their baby, despite their growing attachment. That is, these parents did not consider or decide to terminate the pregnancy within a context of low PFA. Rather, for these parents, their first priority was the fetus;

they framed their consideration of TOP in ways such as "not wanting the baby to suffer" or be exposed to high levels of "pain or suffering" with "no guarantees" of a healthy or long life at the end of it, and "not wanting our baby to hate us" for giving him life (multiple parents, field notes). In this way, these parents described their love for their fetus as the impetus for considering or choosing TOP.

Parents who perceived that they "had no option but to terminate the pregnancy" described experiencing profound despair about the anticipated loss of their baby while still pregnant because they perceived they "had no option but to terminate the pregnancy." As illustrated in the vignette of Kara and Karina in Chapter Four, many parents took a more guarded approach to parent-fetal attachment as soon as suspicion was raised about a fetal anomaly. In comparison to parents who described going into a "self-protection mode" or "not getting too attached to the baby" as a means of self-protection because of worries of fetal demise or newborn death related to the fetal anomaly, one mother, Claire, described "trying to detach" because she perceived the only option available was TOP. Claire and her partner, Ethan, who lived in a remote community, were told after a routine PNS ultrasound in their community that their fetus had a complex heart lesion. Perhaps because of the remote community and the time delay in seeking a confirmed diagnosis by pediatric experts, the local medical practitioner responsible for reading the PNS ultrasounds informed Claire and Ethan that their fetus had a complex heart lesion associated with "no successful treatments" and "kindly" advised the family that TOP would be the best option (field notes, Claire and Ethan). During my observation of the detailed scan and fetal echocardiogram (FE) at the tertiary centre, Claire requested the viewing screen displaying the fetal images be turned off, stating, "I don't want to see anything-it's too hard." The paradox of the family's experience was striking to observe. On the one

hand, Claire appeared to be displaying emotions consistent with an intense and acute grief reaction, noting in our pre-ultrasound discussion her assumption of the certainty that TOP was the only option available and her understanding that the repeat scan was only being done to confirm what the couple already knew from the results of the community screening ultrasound. On the other hand, fetal images on the sonographer's screen indicated a regular heartbeat and normal baby movements, including kicks and hand movements. Throughout the 45-minute scan Claire laid rigidly on the exam table, her eyes squeezed shut and tears running down her cheeks. Ethan sat quietly by her side, holding her hand, looking down at the floor, both parents avoiding looking at the fetal images on the sonographer's ultrasound screen. In the meeting with the pediatric cardiology team immediately following the FE, the parents were advised a complex heart condition did exist but the diagnosis and prognosis were different than the one initially reviewed by the community practitioner. The revised diagnosis was reviewed in detail along with specific prognostic information including best and worst case scenarios, and morbidity and mortality statistics indicating an 85 to 90 percent chance of survival and a "reasonable chance" of a "good" quality of life. In my discussion with the parents following this meeting, Claire explained she had started to "try to detach" from the baby, as a way of preparing herself for the perceived need to terminate the pregnancy, something she had thought she "would never even consider," but given the local practitioner's review of prognostic information had come to believe was "the only reasonable option." Information concerning the change in fetal diagnosis and prognosis was initially received by the parents with disbelief, then anger and questioning as to why incorrect information had been given. The parents stated feeling like "our hope for our baby was taken from us," and that in the ten days since the community scan they had been consumed by an

intense and devastating emotional reaction they now understood to be unwarranted. This was followed by outward signs of emotional distress and statements of guilt for "giving up" on their baby, while at the same time asking multiple questions to clarify the basis for the change in diagnosis and seek reassurance that the new diagnostic and prognostic information could be trusted. Several weeks later, Ethan described their decision to continue the pregnancy and reported feeling hopeful for a positive outcome for their anticipated baby. He described a "steep learning curve" to understand the complexity of the heart condition, required treatments and expected outcomes, as well as the support they had received from a parent network of other families of children with congenital heart disease (CHD) who had provided "valuable insights" and "tremendous hope" about their anticipated baby's future.

Claire and Ethan's experience demonstrated the parallel changes in parental emotions that occurred with a change in PFA. A change in the certainty of the fetal outcome to one of "no hope" was associated with profound despair and a sense of powerlessness to avoid terminating the pregnancy. Woven into this experience was parents' conviction based on the initial prognostic information provided that TOP was the "best" and perceived to be "only" decision available. Upon being informed of the revised diagnosis, in addition to their immediate feelings of disbelief, anger and betrayal, the parents also displayed and voiced a tentative renewing of hope for their fetus and his future, which continued to grow and rekindle as the pregnancy progressed toward delivery. In summary, as a result of the revised diagnosis, parents shifted from despair to hope, from powerless to a growing sense of control, from decreasing PFA to guarded but growing PFA, and from social isolation (as they pondered what they would do and kept their decisions between themselves) to reintegration with their social network and social
supports after making the decision to pursue neonatal surgical intervention for the complex heart defect.

Phases of Parents' Responses to a Diagnosis of a Fetal Anomaly

As parents struggled with the diagnosis of a fetal anomaly and faced their first parenting decisions, four distinct phases of parental reactions were commonly observed and described: (1) Overwhelmed: A whirlwind of conflicting emotions; (2) Treading water: Looking inward and considering options; (3) Taking control: Looking forward and enacting parenting decisions; and (4) After the pregnancy ends: Now it's real (see Table 1, Phases of Parents' Responses to a Diagnosis of a Fetal Anomaly on the following page). The initial phase was triggered by suspicion or confirmation of a fetal anomaly, was relatively short in duration (hours to days), and was characterized by a whirlwind of conflicting emotions resulting in an overwhelmed emotional state that challenged parents' abilities to take in information or make decisions. This phase was guickly followed by a phase of "treading water," characterized by a period of time lasting days to weeks in which parents looked inward to consider their personal values and beliefs, as well as searched for additional information to make sense of the diagnosis while they considered the decisions they faced. During this deliberation phase, parents considered additional antenatal testing to gain further insight into the nature of fetal health concerns and rule out additional fetal anomalies. The final antenatal phase involved a noticeable shift from the contemplative previous phase, and was characterized by an orientation toward the end of the pregnancy and a readiness to enact parenting decisions. Parents' efforts during this phase focused on moving forward in pursuing TOP or, having decided to continue the pregnancy, starting to focus on preparing for the baby's delivery and postnatal care. The fourth and final phase, After the pregnancy ends: Now it's real, occurred in the initial post-pregnancy

	Phase One	Phase Two	Phase Three	Phase Four
Parental Response	Overwhelmed: A Whirlwind of Conflicting Emotions	Treading Water: Looking Inward & Considering Options	Taking Control: Looking Forward & Enacting Parenting Decisions	After the Pregnancy Ends – Now It's Real
Emotional	Overwhelmed	Absorbing Meaning of Diagnosis Inward Reflections	Reframing the Diagnosis to Move Forward	Adjustment from Anticipated to Real/ Uncertainty to Certainty
Cognitive	Difficulty Processing Information	Making Sense of the Diagnosis Deliberating Decisions	Preparing and Anticipating for Birth/TOP	Individualized Learning Curves – Not Prepared For Everything
Action	Immobilized	Preparing for Action	Enacting Decisions	Caregiving/Care for Self (actual vs. anticipated)

Table 1. Phases of Parents' Responses to a Diagnosis of a Fetal Anomaly.

period (following TOP or following delivery and continuing into the early neonatal period). This phase focused on facing the reality of antenatal parental decision and adjusting to the multiple and diverse burdens associated with this phase, regardless of the nature of decisions made. In the following section, I will explore each of these phases in detail, highlighting the nature of the parental emotional responses and actions common to each phase.

Phase One – Overwhelmed: A Whirlwind of Conflicting Emotions

Parents described their initial emotional reactions to the diagnosis of a fetal anomaly as characterized by an immediate overwhelming vortex or whirlwind of conflicting emotions. Although each initial parental reaction was unique, as illustrated in the multiple vignettes and examples provided in Chapters Four and Five, the vast majority of parents described similar emotional responses triggered by initial suspicion or confirmation of a fetal anomaly: shock and disbelief while searching for reassurance; searching for hope while dreading what the diagnosis might mean for their unborn baby and family unit; worry and guilt that their actions, inaction or genetic makeup were possibly responsible for the fetal anomaly, while also grappling with the need to take in complex information and make life-altering decisions; powerlessness while trying to regain control; and fear and profound sadness while trying to control their emotions and not overreact. Inherent in this emotional whirlwind were feelings of emotional turbulence and instability. Juxtaposed with this conflicting and consuming emotional vortex, parents described a temporary inability to process or make sense of the information provided, describing the overall experience in phrases such as "physically and mentally numb," "frozen," "paralyzed" and "unable to take it in."

The initial diagnosis of a fetal anomaly was often not relayed to parents definitively at a specific point in time. Rather, it generally unfolded as a building worry or suspicion that stemmed from antenatal screening indicating "potential" concerns. Initial concerns were often downplayed by HCPs with reassurances of "something that may be nothing," but nevertheless expectant mothers were referred for further investigation. A typical scenario involved referring the mother for further antenatal testing, such as a detailed ultrasound with a focus on the area of concern by a maternal-fetal (MFM) subspecialist and/or a referral to a genetics team to investigate the possibility of a chromosomal anomaly. Depending on the nature of the concern, a comprehensive fetal diagnostic workup could take days to weeks from first suspicion to completed fetal assessment, with the final prognosis continuing to be guarded with uncertainty as to the fine details of the fetal condition and how it would manifest after birth.

There was a range of parental reactions to the initial suspicion of a congenital anomaly. Parents generally described taking cues from the spoken and unspoken reactions of the HCPs providing the information—if the HCPs appeared concerned, the parents tended to be more concerned that further testing would confirm a fetal anomaly. However, if the HCPs referral was not associated with overt alarm or concern, parents described feeling less anxious and troubled about what further testing would reveal. Several parents made comments such as, "The doctor didn't seem to think it was anything, so we decided not to panic until we knew for sure." Moreover, for many parents it was the initial suspicion, not necessarily the confirmation of a fetal anomaly, which triggered an overwhelming emotional reaction. This was especially the case if the healthcare team described the presence of a fetal anomaly as "likely" or if their referral for additional testing was associated with words such as "high risk" or "urgent."

Parents who received a confirmed diagnosis of a fetal anomaly described needing time to let the reality of the diagnosis be absorbed and processed. As previously described, many parents indicated their initial feelings of shock and disbelief were intensified because they had not seriously considered the potential for PNS to result in a suspected or confirmed diagnosis of a fetal anomaly; rather, they described excited anticipation of what the PNS would reveal. Violet vividly recalled the interactions with the healthcare team when she and her husband were initially given the fetal diagnosis of a complex heart condition. Despite knowing there was an increased risk of a fetal heart anomaly given her partner's medical history, Violet described her initial feelings of not wanting to overreact and how this evolved into her ultimate realization of the gravity of the fetal diagnosis in their lives.

Well, so initially when they told us there was a problem with the heart, that the heart doesn't look normal, I didn't really panic off the bat because I know there are lots of minor heart conditions and that was sort of in my head when I set up the appointment, that because what [my partner, Manuel] has is obscure [rare], I thought maybe, and it [Manuel's heart condition] is kind of several problems in one, or something, I somehow thought maybe like one of the problems would get passed on, or, you know, a minor defect, something manageable or even, even if they did get the same condition, I mean we know [Manuel] went through it and he's fine. He's had a good life and also that was [many] years ago so we'd have to assume that the techniques are better, the survival rate is higher and that. So ... it wasn't a super concern for me I guess, I didn't panic immediately. I think when it kind of got bad was when Dr. X said it was similar to what [Manuel] has but worse, I got it, like, okay, well that's really not good because he was a toddler getting open heart surgery and if it's going to be worse than that... Yeah, well that's the point where suddenly it's like, well, life is not going to be the same anymore. That is the thing you realize (Violet, L 299–328).

In comparison, Jesse vividly described his emotional reaction to the initial fetal diagnosis

of a complex fetal anomaly, emphasizing his inability to immediately process the news in

his initial state of shock.

But when the news came, it was instant, just such a great shock and everything like that all at once ... So when it came to the moment [of AD] it was massive but it didn't hit as hard as I thought ... When individuals are faced in a situation where they are shocked, I don't know if its tendency for humans to be just kind of like being in a bit of a lull or something like that, you know what's going on, you're processing it, and your trying to figure things out, but it's, there's a bit of a dull lull in my head (Jesse, L 139–141, 154–161).

Jesse's experience illustrates the delayed emotional response described by many parents

when they were first told of the suspicion of a fetal diagnosis. Parents described a blunted

emotional reaction to the life-altering news, which they attributed to the co-existence of a

feeling of disbelief and their inability to take in all the information and process what it

meant for them and their fetus. Both participant descriptions and my observations indicated it was not until the fetal diagnosis was absorbed and became more real that parents expressed more overt emotions. Parents' facial expressions changed from shock and disbelief to silent crying or outright sobbing, turning their faces away and hiding their expressions in their hands; they were visibly shaken and emotionally distraught. The delayed and dampened initial parental emotional response was an important consideration, as HCPs often appeared to interpret the parents' initial response as an indication parents were adequately processing diagnostic and prognostic information and it was reasonable to charge ahead with even more medical details. As previously described, HCPs often appeared to assume parents were emotionally and cognitively able to take in detailed medical information without checking to see if the parents needed a break or to clarify parents' emotional state or understanding of the health information provided.

Parents were not the only individuals who experienced an overwhelming reaction to the initial fetal diagnosis. Grandparents and other family members who accompanied the parents to their FE appointment also described an intense emotional reaction to the diagnosis of a fetal anomaly. Abra, the mother and main support of a sixteen-year-old mother who received a fetal diagnosis of a complex lung abnormality, described her disbelief when she was told of the fetal diagnosis: '[I was] shocked when I found out. I was really hoping it was just a dream ... I cried" (Abra, L 728–744). As the grandmother of the fetus and primary advocate for her daughter, April, Abra described her struggle to take in the medical information while emotionally grieving not only for her unborn grandchild but also for her daughter who had to face this difficult experience at a young age. Despite parents' descriptions of being "numb," "frozen" and "hoping it was a dream," many parents recited incredibly vivid memories of the first time they were told of the suspected or confirmed diagnosis of a fetal anomaly. Many parents remembered the exact words HCPs used in describing the condition, even when they did not necessarily understand their meaning, and had extraordinarily clear memories of the physical setting in which the information was given to them including vivid details of the room and clothing HCPs were wearing. However, paradoxically, despite parents' abilities to describe vivid and exact descriptions of these initial antenatal encounters, they also described having difficulty understanding the medical details and significance of the suspected or confirmed fetal diagnosis. One father poignantly recalled the moments when he and his wife were first told of a complex fetal diagnosis, including his vivid recollection of the setting as well as the reaction of the student who was in the room with them, her facial expressions mirroring his own emotional reaction.

I definitely remember that moment [when initially informed of the fetal anomaly], of course, when we found out ... and I picture things very well too ... I remember the room, I remember how there was a student with us. ... She was in there with the ultrasound technician and I remember, I remember the shock on her face, her feeling like, I don't know, if it was like a first, one of the first times she had to sort of be around bad news, or, you know, news like that. I remember how she, I think I'm bringing that up because it was like that sort of added to the dumbfoundedness because she was almost, [like] kind of a mirror of me in a sense ... Obviously she didn't have the connection to our child, but I guess I was so cognizant of that because it was in a bit of a shock too. But she was very professional and I remember her saying after, after we had been given the diagnosis that, you know, she wished us well and she was emotional too and once again a bit of a mirror of how I was feeling a bit of a mirror of how I was feeling and how I was feeling and how I was feeling and I remember her saying after, after we had been given the diagnosis that, you know, she wished us well and she was emotional too and once again a bit of a mirror of how I was feeling too, trying to keep it together (Jesse, L 173–206).

Parents identified different phases in their emotional reactions to the diagnosis of a

fetal anomaly. The initial phase of overwhelming conflicting emotions was the beginning

of what many described as the "emotional roller coaster." Parents described staying in

this phase for a relatively short period of time, often only minutes to hours, although many people described walking in a haze of disbelief and shock for several days. As parents absorbed the diagnosis, they could generally clearly articulate moving on to the next phase of parental response, which focused on starting to process their new reality, considering the meaning of the fetal diagnosis in the unique context of their lives, and contemplating the decisions they faced.

Phase Two - Treading Water: Looking Inward and Considering the Options

For most parents, the second phase of parental response to the diagnosis of a fetal anomaly was a contemplative time described as akin to treading water; emotionally they were staying afloat, but they were not actively making definitive decisions in one direction or another. During this phase parents were motivated to reduce the intense emotional reaction inherent to the initial phase, in which the diagnosis of the fetal anomaly was the central focus. A common parental focus in this second phase was generating a deeper understanding of the fetal anomaly and its implications for the fetus, parents and family unit. Seeking out additional information and asking for clarification and details on the diagnosis, associated prognosis, caregiving demands, and the overall impact on the family appeared to calm the overwhelming vortex of emotions described in the initial phase and help parents prioritize their next steps. It is during this phase that parents searched for additional information and deliberated over the multiple antenatal decisions previously described, including whether to: (1) pursue additional diagnostic testing; (2) continue or terminate the pregnancy; and (3) pursue potential neonatal treatment options.

During phase two, parents focused on understanding the meaning and significance of the fetal diagnosis and taking time to absorb its meaning and ramifications for them and their family. The parents' understanding of the fetal anomaly was not static; it continued to evolve as more details were gleaned through the parents' own "research," as well as through their ongoing interactions with HCPs for follow-up imaging (e.g. ultrasound or fetal MRI) or meetings to discuss the results of genetic testing. For many parents, enacting their own agency by informing themselves about the fetal diagnosis and pregnancy and treatment options was effective in providing an increased sense of hope and control over the antenatal experience and decreasing the situational uncertainty associated with the diagnosis. Parents' actions to inform themselves about the fetal anomaly were strongly motivated by their initial feelings of being "overwhelmed," "not able to take in anything," "confused," and/or having many unanswered questions. Parents moved through this phase with different levels of ease or difficulty, which was dependent on multiple intersecting factors such as parents understanding of the fetal anomaly and diagnostic and treatment options, degree of HCP support and communication, and coexisting burdens and responsibilities.

The second phase was also associated with parents looking inward and reflecting on and considering their own worldviews prior to enacting decisions. Most parents described taking the time to absorb and make sense of available options individually and then to discuss these as a couple. Specifically, they described considering their personal beliefs, values, what they "could live with," and what was "right for them." The looking inward component of phase two was consistent with the tendency for parents to isolate themselves from close friends and family members as they took time to absorb the diagnosis, make sense of it and deliberate over decisions away from unwanted outside influences. Parents described deliberating the most over two antenatal decisions: whether to have an amniocentesis, and whether to continue or terminate the pregnancy. The contemplative nature of the second phase also involved considering how the fetal diagnosis fit within the context of the parents' lives, including how it intersected with coexisting personal or external stressors, and setting priorities for next steps. As parents began to adjust to the initial shock associated with the diagnosis of a fetal anomaly, they started to process the meaning of this information and its anticipated impact on their current and future lives. For some parents this included prioritizing decisions to be made and considering means of minimizing coexisting stressors in the family's life. For example, one father described how coexisting life events, such as a recent marriage and a plan for a major move, added to the couple feeling stressed and overwhelmed. He explained how he and his partner tried to decrease any significant additional external stressors following the diagnosis of a complex fetal anomaly.

When the news [diagnosis of a fetal anomaly] came ... it was just such a great shock ... we obviously decided to just focus on our child. So we halted the sale of our place and halted looking for a new place so all that real estate stuff stopped (Jesse, L139–143).

Parents identified a clear transition from the second emotional phase of looking

inward, contemplating the meaning of the fetal diagnosis and the associated decisions

they faced, to a third phase where they looked to the future, enacted parenting decisions

and, for some, began to look forward to the birth of their baby. As one father noted:

The day of the diagnosis and then the sort of weeks that followed after that, that's sort of one stage and then now we are sort of in the stage where thankfully things are stable and where we are focused on, you know, the excitement of our baby coming. But, certainly the weeks after [the day they were told of the fetal anomaly] were gosh, were mammoth. It was challenging for sure. I mean, man, something you can't prepare for, and it is such an emotional roller coaster ride (Jesse, L 617– 624).

Phase Three - Taking Control: Looking Forward and Enacting Parenting Decisions

In this third and final antenatal phase, most parents had completed the bulk of searching for information related to the fetal anomaly and shifted their focus to enacting parenting decisions. During phase three, parents made decisions about terminating or continuing the pregnancy, assuming the diagnosis was made at a gestational age where this was an option. For those parents who continued the pregnancy, a shift in focus was evident in terms of starting to prepare for the baby's delivery and anticipated postnatal care. In this way, phase three was characterized by a change in parental focus from contemplative and deliberative to taking action and looking toward the future. Although the number of parents interviewed following a decision to terminate the pregnancy was very limited, both parents who pursued TOP and those who continued the pregnancy described a sense of relief and satisfaction in having made a major life decision. Moreover, parents described preparing to face the "next steps," which, for those who continued, included planning details, such as adjusting personal and work schedules and organizing alternative caregiving for dependent family members in preparation for the baby's delivery and neonatal treatments at a specialized hospital. In this way, parents often described the start of this phase as a clear turning point in their perspective concerning the fetal diagnosis and how they chose to approach their management of it.

For some parents there was a very clear turning point where they made a decision to either continue or terminate the pregnancy. For many of these parents, the result of an amniocentesis was viewed as a deciding factor in how they proceeded. For example, one father indicated a critical turning point in the couple's antenatal journey was associated with "good news" from the amniocentesis results. I think things started to turn around when, well actually when [my partner, Thea] had her amniocentesis. That put the wheels into motion pretty quickly with the good results that we got back which was maybe, maybe two weeks later, okay, actually it took a little bit longer than we expected, but anyway ... I remember talking to my partner and saying if [genetics counsellor] calls us get her to say like is it good news, is it good news you want to hear or is it bad news you don't want to hear? If it's bad news that we don't want to hear—don't tell us, we will come in. If it is good news, tell us on the phone. So it was good news—there was no further signs of any other problems. I remember, I was at work and I found out. I was so relieved. We were both obviously very relieved with that (Jesse, L 869–885).

For other parents, abnormal amniocentesis or other antenatal assessment results were associated with a decision to terminate the pregnancy. As devastating as these results were for parents to hear, once parents had time to take in the information, they generally expressed a sense of relief they had discovered this information antenatally and had the choice to end the pregnancy. Parents also described relief in knowing their course ahead was clearer than when they were waiting for results and deliberating over what to do.

For those parents who continued the pregnancy, the third phase was often associated with framing the diagnosis in a way that provided hope about the baby's condition and the family's resilience to face this challenge. Common parental phrases characteristic of this phase included "We just have to hope for the best" and "It is in God's hands" (field notes, multiple parents). Similarly, for the small number of parents recruited who pursued TOP, parents described viewing their decision in a positive light, such as helping their unborn baby avoid "suffering and pain" or "a life full of medical tests and procedures." This subset of parents described the possibility of "starting over" and looking forward to a "healthy" pregnancy (field notes).

A changed perspective toward the birth of the baby: The "good uphill." For those parents who continued the pregnancy, the Looking Forward phase involved taking control of those decisions within their power, such as planning accommodation and travel plans for the baby's delivery, and letting go of those elements parents perceived to be out of their control. Parents also described focusing on fostering hope through their belief in God, in the healthcare team, and others they perceived to have power or control over their child's and/or family's fate. One father indicated three factors that converged together to provide the hope the parents were seeking to change their emotional perspective from a phase of angst and deliberation toward a new phase where they began to look forward to the birth of their baby. He referred to this new phase as "the good uphill."

[A major turning point for us was] very specifically the time when we discovered, when we started with the amniocentesis [results] onward. That's probably the, let's call it the uphill, the good uphill. It started to go up, the amniocentesis results the focus was on the positive, the stories we read online, and the meeting with the pediatric surgeon. That was sort of those three points mapped out up the hill if you were to draw the line, those three points helped us reach the peak, the point where we need to be, you know, and looking forward to our baby coming [as compared to the despair previously felt] (Jesse, L 1224–1231).

Interestingly, as described by several parents, this self-identified turning point associated with the "good" news from the amniocentesis results "motivated a change" in how these parents searched for further information about the fetal diagnosis. It was as if the "good news" from the amniocentesis fostered a search for information that reinforced the hope they were seeking. For example, in this context, Rose and Nate, as well as Yolanda and Zane, described maintaining and fostering their hope by focusing on the "positive stories" on the Internet of children with similar complex heart conditions.

For those parents who continued the pregnancy, the third phase involved taking time to learn more about the diagnosis and preparing for when the baby was born. Searching for information during this phase was significantly different from the earlier searches parents described in the time immediately following the diagnosis of a fetal anomaly, in that they were more focused and specific to the baby's and family's needs during the perinatal and early newborn period. The third phase was also associated with taking on the burden of parenting decisions. For example, many parents who lived outside the immediate vicinity of the treatment center were directed to temporarily relocate at around 34 to 36 weeks gestation to facilitate optimal delivery and neonatal interventions. This was often a financially, emotionally and physically taxing time for parents and significant others, as family members were often separated from each other and their support networks. Although making the decision to continue the pregnancy and look forward to the birth of the baby with hope was associated with relief and renewed optimism, at the same time new parental worries arose as the future course was tentatively mapped out. These worries often intertwined with the personal sacrifices parents faced in order for their baby to receive needed medical treatments and supports after birth and beyond. For example, Abra described the increasing burden of needing to relocate with her daughter, April, to be close to the specialized hospital where her anticipated grandchild's delivery and neonatal treatment for a complex lung anomaly was planned.

Abra: Moving over here, yeah, moving here—financially, and physically, emotionally—it was hard.

R: Tell me a bit about that in terms of some of the things you struggle with, just being here now and waiting for the baby to be born.

Abra: [Date] is when we first seen the specialist here and, you know, they told us the bottom line, this is where they want baby born, and her [April's] cervix is really short and so, that was the long weekend ... We had stuff to organize and everything was challenging, you know.

R: And you have seven other children to think about, so how did you manage to organize that?

Abra: You know, financially, it's the second time I could say I left everything up to my husband. I had to leave [other commitments] to be over here ...It's a big challenge. I've never been away from my kids like this, my husband, my support... It's an every day thing where I try not to miss them and think of them... R: And how is your husband doing at home with [the other children]? Abra: He's surviving ... He's finding it hard (Abra, L 339–421).

Phase Four - After The Pregnancy Ends: "Now It's Real"

The fourth and final phase—After the Pregnancy Ends: Now It's Real—occurred in the early neonatal period following the birth of the baby. This phase focused on dealing with the outcomes of decisions made and learning to adjust to the multiple parenting burdens inherent to this phase, regardless of the antenatal decisions made. During this post-pregnancy stage parents described major shifts in their emotional, cognitive and behavioural responses compared to the antenatal phase. Most of these shifts related to the inherent adjustment from the imagined or anticipated outcome to the certainty of the post-pregnancy phase. For example, whereas in the antenatal period parents had an image of what the birth and postnatal period would be like, in the postnatal period they dealt with the reality of that experience. A noted limitation of this study was that I was not able to capture insights on the nature of parents' experiences beyond the termination of pregnancy because of the very limited number of parents who participated in the study who chose TOP, and for those that did, a lack of follow-up interviews in the weeks and months following termination. For this reason, the description of this phase will only focus on the experiences of those parents who continued the pregnancy following the diagnosis of a fetal anomaly.

Parents who continued the pregnancy and sought neonatal interventions for their baby described a shift (on the despair/dread-hope continuum) from the uncertainty of the antenatal phase, in which they had hoped for the best, to the reality of delivering the baby and becoming immersed in the reality of varying levels of success with neonatal interventions. It also involved a shift (on the powerlessness-control continuum) from a struggle for power and control over uncertainties to negotiating power and control with a new healthcare team involved in providing neonatal interventions within an intensive care setting. In addition, there was a shift on the social isolation–social integration continuum from sharing information of the anticipated baby with the parents' social network to the reality of integrating the baby and their care demands into the family's social lives. Finally, there was a fourth shift on the PFA continuum from an evolving bond with the "anticipated" and "dreamed of" baby to the introduction of a reciprocal, physical and emotionally evolving connection with a newborn baby, albeit initially in the foreign environment of an acute care hospital setting.

"The hardest thing - I didn't think it would be this hard." The eight families interviewed after the pregnancy all described the post-pregnancy stage as more difficult than they anticipated. Specifically, several parents described the emotional angst, fear, and concern associated with the uncertain and fragile nature of their newborn's condition and the overwhelming nature of visiting their child in an intensive care unit setting. Parents described learning "a new set of rules" and forging relationships with new professionals actively involved in caring for their child. Those who had done extensive reading and researching about what to expect or who had been guided through this process by HCPs described this anticipatory guidance as helpful in the early days of "adjusting" and "getting used to" life after their baby's birth. Those who were less prepared for what to expect postnatally, such as April and Abra or Tara, described how the neonatal period was much more challenging than anticipated. For example, Tara's newborn son required reparative surgery within the first few hours of life, several postoperative days in intensive care, and additional care needs with feeding and monitoring once discharged home. Tara also described facing additional challenges in the postnatal phase related to her physical limitations because of the need for a repeat caesarean section, as well as the additional emotional distress of leaving her older toddler in the care of relatives while trying to juggle her newborn's care demands and care for

herself. She emphasized:

Awful, it's awful. Like, you know, this, it's naïve of me to think that this is the hardest thing I'm ever going to go through in my life, but right now it's the hardest thing I'm ever going to go through, it's the hardest thing I've ever gone through ... I feel like I knew what to expect, I knew that it was going to be hard and I did, I just didn't think this hard (Tara, L870–886).

Similarly, Callie emphasized the difficult adjustment from the antenatal world of

anticipating twins with fetal health concerns to the overwhelming postnatal reality of being

present and actively involved in caring for infants with medically fragile conditions who

required complex and continuous care in an intensive care unit setting.

The minute the children were born, you know, there was, they [the healthcare team] were, here [gesticulates the action of being given a baby to care for]. There was action to be taken, you know, decisions to be made, you know, breast milk to be pumped, like, there was things to do. I could do skin-to-skin and that could help them grow, I could read books to them and they would hear my voice and, you know what I mean? Like, there were all these things that I could be doing (Callie, L 1847–1851).

Finally, Thea explained her baby's long postnatal course in hospital including over seven

weeks in an intensive care unit setting, plus several additional weeks on an acute care

ward requiring extensive medical support. In particular, she described being unprepared

for the challenges and frustrations she faced in needing to be an advocate for her baby

within the complex healthcare system:

[What we learned] is that we had to be advocates for him, which is something I never really thought about or really conceived, although in retrospect the Facebook group did talk about parents raising issues with their healthcare providers on various different things. But the whole parent as advocate was really quite astonishing, like, you know, when to ask questions or not even to question things but just to kind of like, in some ways especially like in [acute hospital care area] maybe you're the person who sees things, you're there all the time, and the nurses come and go. So whether they are doing the dressing differently than what you've seen it done or whether you've seen some people do things in a way that's better than what you are witnessing that day, you know, you're kind of the advocate. You're always asking the questions, like, why does my son need another blood test? You already did two this week, like why do you need to poke him so many times? ... Why are you using the Kangaroo pump differently? Like, why? Why is so much of my [breast] milk wasted, like why? Like you're always kind of like either the eyes and ears or you're the advocate for the child. And so it's been kind of more of a bigger role maybe than I thought, like than I would have thought prenatally. I think, yeah, the healthcare provision, like, really does rely on the parent to be there (Thea L 672–695).

After neonatal intervention: A new reality. Parents who were interviewed

following their baby's discharge home from hospital consistently indicated there was an

expectation from others in their social support system that, given the baby's survival and

improved health status following neonatal intervention, the parents should also be

recovered or recovering emotionally and physically from the experience. However,

parents described their emotional recovery as continuing long after the baby's birth and

initial neonatal treatment. One mother, whose child required an oomphalocele repair

within the first few hours of life, noted that HCPs, family members and friends inferred that

she was over the "big hump" and that she should be doing better. However, she

described finding this "completely unfair" and underscored that the emotions caught up to

her after the "roller coaster ride" in the hospital. She shared her perception of this

postnatal phase:

[After the baby's initial discharge from hospital] you are homebound [due to baby's care needs], you're physically bound [due to strict activity guidelines after the C-section], and then emotionally taxed ... Baby is home and now, now it's real. Now, this is the hard part (Tara, L 1336–1356).

Similarly, Kath and Callie described how, several weeks to many months after their baby/babies were discharged home following neonatal surgery, they continued to work through their emotions associated with the "whirlwind" and "roller coaster" of the diagnosis of a fetal anomaly, neonatal treatment and ongoing care needs, and/or extra vigilance of their child's health condition after initial treatment. They noted that once they were no longer in "adrenaline mode" and had time to think through and reflect on their experience. they continued to have intense feelings and reactions to their antenatal and early neonatal experiences. Indeed, many parents described being extremely appreciative of the opportunity to tell me the story of their postnatal experience because they were thankful for "someone to listen," "someone who cared about what it was like to go through such a difficult time," and "the opportunity to tell our story." In addition, several parents indicated their perception of the significant long-term emotional effects their antenatal and early postnatal experiences would have on their ongoing health. Moreover, many of these parents also emphasized the invisible nature of the emotional "trauma" they experienced that continued to significantly impact their lives. For example, Callie noted:

I am going to carry this [antenatal and early postnatal experience] around for the rest of my life, like and I am going to be, you know, turning to my child and be like, oh, it's, you know, it sucks what the world did to me, that everyone judged me for the pregnancy I had. And now I have two healthy children and most people upon looking at me or my children would not know the trauma of the experience that I've been through (Callie, L 1873–1880).

Summary

Parents described the antenatal diagnosis of a fetal anomaly as having a profound and life-altering impact on their lives. Parents described the "emotional trauma" and their other intense emotional reactions to the diagnosis of a fetal anomaly, and the associated antenatal and early post-pregnancy care experiences. Specifically, parents faced a unique grief response associated with the loss of the anticipated and hoped-for baby within the context of an evolving pregnancy. This parental response was comprised of a complex matrix of emotional responses involving prominent emotions vacillating between four intersecting continua: (1) dread/despair–hope; (2) powerlessness–control; (3) selfstigma–self-respect (and associated social isolation–social integration) and (4) low parental-fetal attachment –high parental-fetal attachment. Parents described as supportive those actions, initiated by themselves or others, that facilitated movement of their emotional stance toward hope, control, self-respect (and associated social integration), and higher levels of parent-fetal attachment. As they grappled with their emotional response to the fetal anomaly and their nascent parenting decisions, parents moved through four distinct phases of parental response to a fetal anomaly: (1) Overwhelmed: A whirlwind of conflicting emotions; (2) Treading water: Looking inward and considering options; (3) Taking control: Looking forward and enacting parenting decisions; and (4) After the pregnancy ends: Now it's real. Building on the exploration of the nature of antenatal care and analysis of power relations, parental agency, and inequities in antenatal care in the preceding chapters, this analysis of parents' emotional responses to the diagnosis of a fetal anomaly, and subsequent antenatal and early post-pregnancy experiences, will serve as the foundation for the development of a preliminary framework aimed at providing insight into the nature of parents' emotional reactions to the diagnosis of a fetal anomaly, as well as a tool to guide HCPs' provision of individualized and comprehensive parental support, which will be detailed in Chapter Seven.

CHAPTER SEVEN: DISCUSSION AND IMPLICATIONS

This study offers a deep understanding of health care provider (HCP)-parent communication and decision-making related to prenatal screening and the diagnosis of fetal anomaly. A Foucauldian governmentality lens informed the method of inquiry and facilitated scrutiny of the discourses, counter discourses and power relations underlying, shaping and influencing HCP-parent interactions and decision-making. Moreover, this theoretical perspective oriented the focus on disrupting taken-for-granted assumptions and challenging practices and structures contributing to health inequities in antenatal care, with the intent of prompting needed change in practice, education, and policy aligned with improved patient care and health equity.

A Foucauldian governmentality lens was specifically and purposefully chosen to guide this research and facilitate inquiry into the research question. A strength of this theoretical perspective is that it guides and facilitates the exploration of dominant discourses, power relations, and other organizational and system frameworks that influence and shape health delivery, HCP-parent communication, and patient/family outcomes. In this way, a governmentality lens provides considerable insight into the nature of antenatal communication and decision-making. However, it can also be problematic. It may obscure the role of other factors that undoubtedly also influence and shape antenatal care, including those aligned with biomedical perspectives, such as the neurocognitive underpinnings of decision-making or the physiological stress response of parents following the diagnosis of a fetal anomaly. Notwithstanding an awareness that there are multiple factors that influence and shape antenatal communication the confines of this study, in the following discussion I will focus on three areas that this theoretical orientation brought to the

forefront, specifically: (1) the characteristics of parents' emotional responses to the diagnosis of a fetal anomaly; (2) the dominant discourses constituting, influencing and shaping antenatal care and HCP-parent communication practices; and (3) the nondirectional intentions and directional impacts of HCP-parent communication and decision-making. Each of these will be discussed and interpreted in relation to existing theoretical and clinical knowledge. Whereas in the preceding chapters I presented the research findings beginning with the overall nature of antenatal care in order to illustrate the broader social context prior to describing the influences on HCP-parent interactions and subsequent parents' responses, in this chapter I discuss the findings in reverse order. I begin with discussing the parents' emotional responses in order to set the stage for recommendations at the HCP-parent level. I then widen the discussion to consider how the multiple and intersecting health and societal discourses shape antenatal communication and decision-making. I also consider the effectiveness of nondirectional approaches in antenatal communication, a discussion that sets the foundation for the broader organizational and societal implications I recommend later in the chapter. Following the discussion on these three broad areas, I provide an overview of the implications for practice, policy development, education and research stemming from this research, including an overview of study limitations.

Parents' Emotional Responses to the Diagnosis of a Fetal Anomaly Proposed Conceptualization of Parents' Emotional Responses

Results of this research contribute to new insights into the nature of parents' complex emotional responses to the suspected or confirmed diagnosis of a fetal anomaly. I conceptualized these responses as a complex matrix of prominent emotions vacillating between four intersecting continua: dread/despair_hope; powerlessness_control; self-

stigma-self-respect (and associated social isolation-social integration); and low PFAhigh PFA. The dominant emotions experienced as part of this dynamic emotional vortex, as well as the time-pressured nature of the evolving pregnancy, appear to motivate and influence parents to respond in ways that promote their emotional stability, address decision-making dilemmas and manage the perceived reactions of others. Parents described as supportive those actions, initiated by themselves or others, that allowed them to move their emotional stance toward hope, control, self-respect (and associated social-integration) and high PFA. In addition, findings from this study build on these and other previous findings to offer a new conceptualization of parents' emotional responses as characterized by emotions not experienced as discrete states in which parents feel either hope or despair (or control or powerless and so on). Rather, parents' emotional responses are complex, fluid and relational in nature, with, for example, the experience of dread/despair and hope vacillating between these two points on an emotional continuum, highlighting that it is possible to experience varying degrees of both hope and dread/despair simultaneously. These new insights into parents' emotional responses bring another layer of understanding to Araki's (2010) findings of parents' "ambivalent" reactions following the diagnosis of a fetal anomaly (for example, maintaining hope while experiencing periods of despair and hopelessness). These emotions are perpetually influenced and shaped by the intersecting emotional continua of powerlessness-control, low PFA-high PFA and self-stigma-self-respect (and associated social isolation-social integration). This nuanced understanding of the complex nature of parents' emotional responses highlights the dynamic and interrelated nature of emotions evoked by a diagnosis of a fetal anomaly, rather than such responses being viewed as static or discrete. These findings also draw attention to how parents are motivated to enact agency to move toward the emotions of hope, control, high PFA, and self-respect, opening the door to potential HCP interventions informed by this understanding of the nature of parents' emotional responses to the diagnosis of a fetal anomaly.

New insights from this study build upon our understanding of the psychological and emotional distress strongly associated with the diagnosis of a fetal anomaly. In particular, previous research findings have emphasized the parental feelings of worry, grief, sadness, and anxiety associated with the diagnosis of a fetal anomaly (Araki, 2010; Hedrick, 2005; Lou et al., 2017; Rempel et al., 2012) and have highlighted the experience of posttraumatic stress (PTS) symptoms and depressive disorders in a significant percentage of parents (both men and women) following the diagnosis of a fetal anomaly (Cole et al., 2016; Horsch et al., 2013). However, the findings of this study differ in that rather than identifying discrete emotions that are prominent in this clinical context, parental emotions are here described as fluid, dynamic, interrelated and occurring along multiple intersecting emotional continua.

New Insights into the Experience of a Suspected Fetal Diagnosis

The new insights gleaned from this study extend our understanding of parents' psychological and emotional responses to the *suspected* diagnosis of a fetal anomaly by drawing attention to the feelings of emotional distress, angst, and worry that often remained heightened, albeit to a lesser extent, even when additional antenatal testing indicated normal results. Previous research findings have focused primarily on the heightened maternal anxiety associated with false positive prenatal screening (Baillie, Smith, Hewison, & Mason, 2000; Thomas, Roberts, & Griffiths, 2017), including residual feelings of anxiety even after normal results are known. This has been attributed to continued fears of an undetected fetal anomaly as well as a generalized feeling that

something else unexpected could threaten the pregnancy (Baillie et al., 2000). Findings from this study concur and add to the understanding of this experience by drawing attention to the feelings of anger and angst, in addition to anxiety, that prospective mothers and fathers expressed in relation to the perceived threat to the pregnancy. The findings also show how parents reserved emotional investment, using expressions such as "living in limbo" and "self-protection mode" as they deliberated over potential pregnancy and treatment options while awaiting definitive results. Parents emphasized the inherent discrepancies in HCPs' reassurances about normal results, which were often provided by way of a quick phone call, in contrast to parents' significant worries and concerns that often had multiplied and increased in intensity over the course of waiting for definitive results, and which generally went unaddressed in the sharing of "normal" results.

Differences Between Parents' Initial Feelings of Dread Compared to Despair

Findings from this study add to our understanding of parents' emotional responses to a diagnosis of a fetal anomaly by emphasizing that parents experience dread in response to the diagnosis of a fetal anomaly, which is different from the feelings of grief and despair described in previous research. Past research has highlighted parents' initial feelings of grief and despair as a primary response to the diagnosis of a fetal anomaly (Araki, 2010; Cole et al., 2016; Horsch et al., 2013; Wool, 2011); however, feelings of dread in relation to the diagnosis of a fetal anomaly have received little (if any) attention. Therefore, these results draw attention to seemingly subtle but important differences between dread and despair in parents' emotional responses, and highlight how dread is characterized as a fear of what might happen but not a situation devoid of hope, in comparison to despair, which parents described as the loss of hope. These insights into parents' experiences have implications for new ways of thinking about, acknowledging and responding to parents' emotional responses to a diagnosis of a fetal anomaly, as well as the potential for developing HCP-initiated interventions tailored to addressing parents' experiences of dread (instead of despair) in relation to a suspected or confirmed diagnosis of a fetal anomaly.

Differences in HCPs' and Parents' Responses to Medical Uncertainty

The findings from this study shed light on the difference between HCPs' perceptions of medical uncertainty in relation to diagnostic, prognostic and treatment parameters associated with a fetal anomaly and parents' fluctuating feelings of powerlessness and control in response to this inherent medical uncertainty. Specifically, they highlight how HCPs foreground the uncertainty associated with the medical diagnosis, treatment options and prognosis while they are simultaneously searching for and indirectly and/or directly recommending options to increase medical certainty of the fetal diagnosis and future treatment options. HCPs' emphasis on the medical uncertainty associated with a fetal diagnosis was apparent in the manner in which diagnostic information was presented to parents in terms of "best guesses" and "hunches," as well as the use of provisos and complex algorithms (e.g. "if this, then that" scenarios) when providing parents with prognostic information related to neonatal treatment of complex fetal anomalies. In keeping with this medical uncertainty, HCPs highlighted potential diagnostic tests that could provide parents with greater medical certainty of the specific nature of the fetal diagnosis, and thereby greater clarity on potential treatment options, such as pursuing amniocentesis to determine the presence of an associated chromosomal anomaly or fetal MRI to gain greater certainty of the pathological nature of a fetal lung mass. In contrast, although parents reiterated HCPs' statements of the uncertainty associated with the fetal diagnosis, prognosis and treatment options, many

parents did not take up HCPs' biomedical stance of searching for greater medical certainty, choosing instead to consider alternative perspectives such as enacting faith in a higher power, focusing on the power of prayer or positive thoughts, and adopting an approach consistent with "living in the moment" to gain a greater sense of control over their uncertain situation. Parents' emotional responses were consistent with this stance, often emphasizing their fluctuating feelings of powerlessness and control in relation to the inherent situational uncertainty of an evolving fetal diagnosis. This was evident in parents' statements such as "It was out of my hands," "It's in God's hands—I have to have faith," and "All we can do is pray and hope for the best," and in their descriptions of strategies they employed to "try to have control in a situation where you have no control," such as preparing detailed lists of questions to ask HCPs at upcoming medical appointments.

Results from this study provide new insights into the differences between HCPs' perspectives, which foreground medical uncertainty while searching for medical certainty in the context of a diagnosis of a fetal anomaly, and parents' perspectives, which emphasize powerlessness and a search for control. This differs from previous research findings that have highlighted the idea that uncertainty is a pervasive feeling associated with parents' experiences of a diagnosis of a fetal anomaly (Araki, 2010; Hedrick, 2005; Rempel, 1993; Rempel et al., 2004; Titapant & Chuenwattana, 2015). In addition, although many of the parents in this study perceived that gaining greater certainty related to the nature of the fetal diagnosis and prognostic predictions on survival and quality of life (QOL) outcomes was helpful in informing their decisions to continue or terminate the pregnancy, parents also emphasized the increased emotional distress they experienced as a result of the continued scrutiny and vigilance associated with ongoing medical searches for greater diagnostic and prognostic certainty. In particular, HCPs' continued

focus on searching for greater and greater medical certainty, sometimes to the point where it made no perceivable difference to the parents' experience or decision-making, had the potential to squelch parents' hope and impede their ability to celebrate the minimilestones of an evolving pregnancy by maintaining their focus on "the constant potential negatives" associated with the fetal diagnosis.

In this study, differences in perspective between HCPs and parents in relation to the uncertainty inherent to the diagnosis of a fetal anomaly were often a source of increased tension and conflict in HCP-parent interactions and contributed to stymied HCP-parent communication when parents did not take up HCPs' biomedically focused priorities of approximating diagnostic certainty and thereby prognostic accuracy. Understanding these differences in HCPs' and parents' reactions to the uncertainty that inherently intertwines with a diagnosis of a fetal anomaly provides new insights into our understanding of the nature of parents' and HCPs' antenatal experiences, and has implications for developing strategies to improve HCP-parent communication and decision-making support.

Proposed Relationships Between Self-Stigma–Self-Respect and Social Isolation– Social Integration

The new understandings gleaned from this study expand on previous research findings to propose that parental self-stigma occurs along an emotional continuum with self-respect and is strongly associated with a parallel continuum of social-isolation–socialintegration. These findings build on previous research that has highlighted issues of stigmatization in how parents assumed that friends, family, HCPs and society would perceive them negatively because of their antenatal decisions (Araki, 2010; Lou et al., 2017). Findings from this study are consistent with Araki's (2010) results that have described women's perceived stigma related to the fetal anomaly and/or related parental decisions as associated with greater isolation from their social support systems. Current findings also build on research that has found women isolate themselves from friends and family out of fears their decisions will be influenced toward termination of pregnancy (TOP) or against disabled children (McCoyd, 2008; Redlinger-Grosse, Bernhardt, Berg, Muenke, & Biesecker, 2002), as well as research by Aune (2012) that has demonstrated the relationship between social pressure and stigma in that women described selfisolating because of perceptions that others would have difficulty accepting their decision to continue a pregnancy following a fetal diagnosis of Down syndrome. Understanding the nature of these relationships between self-stigma, self-respect, social isolation and socialintegration within the broader range of emotions evoked by a diagnosis of a fetal anomaly, as well as the contextual and personal factors influencing and shaping these emotional and behavioural responses provides HCPs with additional insight into the nature of parents' struggles with perceived stigma and associated social isolation, as well as direction for potential HCP-initiated interventions to ensure parents and families receive the support they need for optimal decision-making and ongoing health.

New Insights into PFA in the Context of a Diagnosis of a Fetal Anomaly

Findings from this study draw attention to the multiple personal, contextual and structural factors that influence and shape PFA, such as the content and delivery of diagnostic, prognostic and treatment information; personal factors such as a parental history of mental health concerns; and perceived support from personal support networks and HCPs. Moreover, study findings emphasize that these personal and contextual factors appear to play a prominent role even when neonatal treatment is associated with favourable prognostic outcomes including low morbidity and mortality rates as well as

excellent QOL. These findings underscore the importance of HCPs explicitly addressing PFA in all ongoing HCP-parent interactions *and* considering the personal and contextual factors influencing parent-fetal bonding, rather than only targeting those parents diagnosed with severe fetal anomalies as potentially in need of increased support related to PFA concerns, as is commonly assumed in clinical practice. This is particularly important given the potential deleterious short- and long-term emotional and psychological consequences for both parent and child.

Finally, results from this study provide new insights into PFA in relation to parents' decisions to continue or terminate the pregnancy. Specifically, parents who considered continuing as well as those who considered termination of pregnancy (TOP) described doing so from a perspective of having an existing bond with the fetus and prioritizing what was the best option for the baby, often weighing the anticipated QOL with the amount of suffering, pain and challenges they perceived the child would face. That is, in comparison to common clinical perspectives and previous research suggesting TOP for a fetal anomaly in the first trimester is associated with less maternal psychological distress as compared to those women who undergo TOP at a later gestation (Daugirdaite et al., 2015), parents in this study, regardless of their ultimate decision or the timing of that decision, emphasized that their experience of considering and/or choosing TOP was "one of the most difficult" decisions they had faced, describing their decision-making process using terms such as "agonizing" and "torturous." Although further study is required to delineate the relationships among the multiple intersecting variables such as planned versus unplanned pregnancy, severity of the fetal anomaly, gestational age at diagnosis, and numerous personal and contextual factors, results of this study emphasize the need for HCPs to acknowledge the emotional difficulty of this decision for all parents, both

mothers and fathers, and seek out ways to provide ongoing support to parents, regardless of their decisions.

Similar to previous research, findings from this study indicate that for those parents who continue the pregnancy, PFA is a significant factor in their decision to continue or terminate the pregnancy. For this subset of parents, the majority of expectant mothers and fathers indicated a growing attachment to the fetus that influenced their decision to continue the pregnancy. Consistent with the findings of a previous qualitative study that found prenatal maternal attachment occurred in spite of the mother's knowledge of a fetal anomaly (Hedrick, 2005), the majority of parents in this study described their evolving attachment to their fetus as the pregnancy continued. Moreover, this attachment was strengthened by deliberate positive interactions with the fetus, including regular interactions such as talking to, reading to, and sharing positive hopes and dreams with the fetus. Furthermore, findings from this research highlight that both expectant fathers and mothers described evolving attachment to their fetus, and that men as well as women indicated that their attachment to the fetus influenced their desire for the pregnancy to continue.

In contrast to Hedrick's (2005) study, which found women who received a diagnosis of a fetal anomaly perceived that preparing for the intensity of complex neonatal tests and treatments supported maternal-fetal attachment (MFA), this was not the case for all parents in this study. Rather, many parents described their attachment to their fetus was interrupted, "put on hold," or that they went into "self-protection mode" after the diagnosis of a fetal anomaly. Parents described these attempts to limit any further emotional investment into the parent-fetal bond as ways of protecting themselves from

even greater emotional distress in the future, in the event of the loss of the fetus/infant through TOP, fetal demise or neonatal death.

In summary, analogous to theoretical perspectives of the grief work precipitated by the death of a child, findings from this study highlight the intersecting and interrelated emotions commonly triggered by a diagnosis of a fetal anomaly. In addition, they extend this knowledge by describing proposed relationships among prominent emotions evoked, and the parental actions aimed at moving from feelings of dread or despair to hope, powerlessness to control, self-stigma to self-respect (and associated social isolation to social integration) and low PFA to high PFA. These findings provide new insights by proposing a framework that highlights the intersecting nature of emotional continua and how emotions are influenced and shaped by other prominent emotions commonly triggered by the diagnosis of a fetal anomaly. These new understandings have significant implications, not only for contributing to a complex understanding of parents' emotional responses to the diagnosis of a fetal anomaly, but also for prompting the development of specific and practical supportive interventions that acknowledge common parental reactions and help to mitigate parents' emotional distress following the diagnosis of a fetal anomaly. Moreover, study findings provide a deeper understanding of the personal, contextual, and broader organizational and system structures and practices that influence and shape parents' emotional responses, highlighting the multiple factors that contribute to differences in parents' experiences, as well as potential health inequities that can result in those who need the most support receiving the least. Specifically, findings from this research draw attention to differences in parents' physical and mental health, language fluency, age, and geographic location, amongst other factors, that can contribute to health inequities, thereby providing direction for needed change in health policy and practice.

Dominant Discourses Constituting, Influencing and Shaping Antenatal

Communication and Decision-Making

Nurses have been criticized for perpetuating apolitical perspectives in relation to health discourses (Holmes & Gastaldo, 2002). By maintaining this view, nurses fail to acknowledge and challenge how dominant discourses and power relations create and sustain current health communication practices, and how nurses' and other HCPs' unchallenged perspectives and practices contribute to health inequities, uninformed or biased patient/parent decisions, and professional practices that serve to meet the goals of healthcare institutions and HCPs rather than the needs of patients and families. A unique contribution of this study is that it employed a critical perspective to examine the dominant discourses and power relations underpinning antenatal communication and decision-making, thereby encouraging reflexivity about how knowledge is constituted and the role of these dominant structures in shaping antenatal HCP-parent interactions and, ultimately, health outcomes.

Biomedical Discourses

Findings from this study draw attention to how antenatal HCP-parent communication and decision-making are significantly influenced and shaped by dominant biomedical perspectives in tandem with organizational efficiency imperatives. This was evident in HCP-parent interactions related to the provision of diagnostic, prognostic and treatment information that centred on "crash courses," "one-way speeches" and "mini lectures" on fetal pathology and physiology, with limited time available for exploration of parents' needs, priorities, questions and concerns. For some parents, especially those who shared HCPs' biomedical perspectives and had the necessary resources and supports available to navigate the healthcare system and any coexisting stressors, this approach provided detailed and comprehensive information about treatment options, albeit decontextualized from the parents' priorities and worldviews. However, for the majority of parents, the combination of an emphasis in HCP-parent interactions on complex fetal physiology and pathology together with limited time available for discussion of parents' questions and concerns reinforced that HCPs' priorities were focused on providing medical information. The healthcare team assumed such information would facilitate parents' antenatal decision-making, as evident in their minimal emphasis on providing emotional, practical or decision-making support in relation to the parents' overall antenatal experience. Moreover, the use of an objective and value-neutral tone and approach by some HCPs when performing diagnostic tests and delivering emotionally distressing health information related to the presence of a fetal anomaly often served to further promote parents' perceptions that these HCPs were similar to "robots" who performed their duties well but were not engaged or invested in developing therapeutic relationships centred on supporting parents through an emotionally distressing life event. These findings are consistent with work by Anderson (1999), who emphasized that a dominant biomedical perspective and nondirectional HCP approach in antenatal care creates tensions in professional-parent interactions by minimizing the importance of developing genuine relationships that foster understanding of families' unique illness narratives and the broader social contexts in which health-related behaviours take place and perceptions of health and illness are formed.

Consistent with previous literature and research findings (Orsini, 2007; Rapp, 1988), results of this study indicate that when parents' values and perspectives diverge from the dominant biomedical and techno-rational approach employed by HCPs, communication is often stymied, HCP-parent interactions are associated with greater

tension and conflict, and as a result parents perceive HCP-parent communication as less than satisfactory. A dominant biomedical perspective and techno-rational approach is evident in the manner and content of HCP-parent antenatal communication, including the presentation of factual diagnostic and prognostic information relayed in value-neutral tones; an emphasis on the use of severity scales and numerical data in presenting morbidity, mortality and other prognostic information; and a preference for employing a rational problem-solving approach when considering antenatal decisions. Most HCPs appeared to take for granted the use of a biomedical perspective and techno-rational lens in discussing antenatal health decisions, and in so doing established this approach as their expected standard for parents' antenatal decision-making. This creates tensions in HCP-parent communication when parents do not share this perspective or approach and/or when HCPs' exclusive focus on this approach results in the wider range of parents' needs and/or concerns not being addressed. This is consistent with findings from an early ethnographic study of antenatal communication between genetic counsellors and parents that explored the use of amniocentesis for prenatal screening of genetic anomalies (Rapp, 1988). Rapp found that "the vocabulary of biomedicine describes pregnancy and birth, abortion and disability in ways that may result in a tug-of-war of words" (p. 149), with the use of medical terminology and simplified statistics contributing to muffling the anxietyprovoking nature of the possibility of a chromosomal fetal anomaly (Rapp, 1988). Moreover, Rapp found that "the codes, genres, and assumptions of biomedicine construct the limits of the conversations genetic counselors may have with their patients ... [and that] the language of biomedicine also limits communication by locking counselors into a discourse in which technical language dominates, despite a sincere desire on their part to reach out to patients" (p. 151). Similarly, findings from this study demonstrate how a

dominant biomedical perspective, with its focus on fetal physiology and objective prognostications, contributed to a disconnect between HCPs' perspectives and priorities and those of parents and families, many of whom left their initial meeting with unanswered questions and concerns. Furthermore, based on the findings of her study, Rapp (1988) emphasized that the use of medical jargon and simplified numerical prognostic indicators may "sit comfortably with information-seeking, medically compliant patients, especially those with some advanced education (that is, middle class), but they often gloss over the reality of less privileged women" (p. 149). Likewise, results of this research suggest parents who were more educated, particularly those who were health professionals themselves, were often satisfied with the way in which medical information about a fetal anomaly was provided, albeit decontextualized from their unique experiences and perspectives. In contrast, those parents who were less educated, had coexisting stressors or physical or mental health concerns, or those who were less familiar with the Canadian healthcare system and/or for whom English was not their first language, often expressed greater dissatisfaction with the nature of information provided and more frustration related to their unaddressed concerns following initial HCP-parent interactions.

Multiple Discourses Underlying Women's Participation in Prenatal Screening

Study findings also provide insights into how dominant individualism, responsibilization, disability and biomedical discourses (amongst others) underpin HCPs' actions and behaviours that espouse parental responsibility and autonomy to make independent antenatal decisions and eschew paternalistic behaviours that involve making overt recommendations to parents about pregnancy or treatment options. In particular, study findings draw attention to the influence of underlying individualism and disability discourses in HCPs' encouragement of women's participation in prenatal screening as a
means of enacting their reproductive choice to know about the presence of a fetal anomaly and the right to independently choose from a range of pregnancy and treatment options. Furthermore, findings indicate that HCPs and others presented the option of prenatal screening (PNS) in positive terms, indicating it was the "right" thing to do and a "normal" part of antenatal care, implying PNS could have potential positive benefits for both the mother and child. The majority of women described participating in PNS not necessarily as a result of a conscious decision, but more as a personal responsibility, consistent with societal and health discourses equating participation in PNS as synonymous with making "good parenting decisions". In contrast, there was minimal emphasis in HCP-parent interactions on parents' right not to participate in prenatal screening and to choose not to know about the presence of a fetal anomaly.

These findings are consistent with previous work by Hunt and colleagues (2005) that found that HCPs emphasized the benefits of pursuing amniocentesis as a means of prenatal screening and enacting personal autonomy related to reproductive choices, while disparaging the decisions of women who chose not to pursue amniocentesis as being based on irrational emotions. Similarly, McCabe and Holmes (2011) noted that PNS technologies are intertwined with broader health and social discourses that may "glorify normalcy and pathologize the abnormal" (p. 77). Likewise, in a British qualitative study of PNS for Sickle Cell Disorder (SCD), Berghs, Dyson and Atkin (2017) found that parents did not see PNS as an option; rather, they viewed it as a personal responsibility. They described how parents were motivated to participate in PNS because of the fetus' increased "risk" of SCD and the perceived potential benefit to both the mother and unborn child, noting that these decisions were largely influenced by institutional priorities and professional ideologies that framed PNS and "informed" choices as a moral good, leading

the authors to question whether women were really given "choices" when participating in PNS was framed as the "right thing to do" (Berghs et al, 2017, p. 184).

Consistent with the results of this study, several scholars have theorized that the fact that PNS is offered universally and is government-administered provides legitimacy to the idea that it is an inherent good, and therefore a necessary intervention in which pregnant women should participate (Browner & Press, 1995; Tremain, 2006). Tremain asserts that without the PNS tests that make the calculations of "risk" possible, there would be no risk in pregnancy, in that risk does not exist apart from the rationalities, practices and technologies that make risk calculable and attach it to certain objects. Consistent with a governmentality lens, she further argues that to describe the possibility of a particular future event as a "risk" is to label the actual occurrence of the event with a negative value, and to imply certain actions should be taken to avoid it. Similarly, to recommend parents participate in PNS to "reassure" them nothing is wrong is to imply there would be a problem requiring action if testing revealed a concern. In applying this logic, Tremain contends, "when the constitutive efficacy of risk is appreciated, the eugenic impetus behind prenatal testing and screening becomes evident" (p. 49).

Understanding PNS practices through a governmentality lens allows us to understand how prenatal disability is constituted in ways that go beyond discussions of medical paternalism or women's rights to make autonomous reproductive decisions. This lens allows us to understand PNS as a system of surveillance, a form of disciplinary power, in which HCPs, who are viewed as experts and authorities in health, use binary labels such as "abnormal," "normal," "good," and "bad" to create categories of individuals, which allows the possibility of determining movement away from the norm (McCabe & Holmes, 2011). Within this system of surveillance, the pregnant woman disciplines herself in accordance with a set of socially constructed norms, and engages in the internalization of these norms and self-discipline, which may involve participation in PNS (generally considered "good") and continuing or terminating the pregnancy, depending on the results as they are communicated by the medical experts (McCabe & Holmes, 2011). In this way, a Foucauldian lens allows for a comprehensive analysis of antenatal communication and decision-making, in that it does not merely assume women and their partners are coerced into certain modes of action by HCPs or other external powers, nor does it imply that any particular decision is ethically or morally wrong. Rather, a governmentality lens allows examination of these practices in ways that indicate how the practices and technologies of disciplinary and pastoral power in tandem with discursive practices constitute certain subjectivities. As Tremain (2006) asserts, a governmentality lens indicates how practices of liberal governmental power have "constituted subjects whose actions are governed through the exercise of their own capacity to choose in accordance with the norm(al)" (p. 50).

Disability Discourses—The Elephant in the Room

Results of this study highlight how individual perspectives on disability often go unstated in HCP-parent interactions, acting as the proverbial "elephant in the room," yet play a central role in antenatal communication and decision-making, including parents' decisions to participate in PNS and whether to continue or terminate the pregnancy in the context of a diagnosis of a fetal anomaly. A strength of this research is that the use of a critical lens allowed for analysis of the effect of disability discourses in antenatal care to be considered not in isolation, but rather in how they intersected with multiple other dominant discourses, including biomedicine, efficiency, responsibilization, and individualism, to shape and influence antenatal communication and decision making.

Findings from this research suggest that HCP communications about prognostications related to the QOL of children with fetal anomalies are sometimes based on questionably negative assumptions about living with a disability and the impact of a disabled child on the lives and futures of parents and families. Several parents in this study described experiences in which HCPs provided "unbalanced" prognostic information that emphasized the "litany of negatives" associated with the diagnosis of a fetal anomaly, including the potential pain, suffering and poor QOL their unborn child would endure and/or the daunting caregiving burden and potential deleterious effects on the parents' and family's futures. Other parents emphasized their perceptions that HCPs, friends and family members were trying to influence them toward TOP as the "responsible" thing to do. In addition, some parents took exception to HCPs' portrayal of individuals with disability, noting an overly negative approach that emphasized the undesirable attributes and care burden associated with individuals with disabilities, rather than providing a balanced approach that emphasized potential positive and negative outcomes. These findings are consistent with previous theoretical and research literature emphasizing the idea that PNS exists within a broader sociocultural context of "taking personal responsibility for risk control," leading expectant parents to consider potentially difficult choices and to shoulder the burden of responsibility for reproductive outcomes (Kelly, 2009, p. 93).

Findings from this study indicate that many parents make decisions about continuing or terminating a pregnancy based on their perceptions of the impact of the potential disability and what the child's and family's life would be like if they continued. Notably, parents who had positive personal experiences associated with living with a disability themselves or through a close friend or relative with a disability often described being more open to the possibility of continuing the pregnancy. In contrast, parents who were not familiar with the nature of the fetal anomaly described being more dependent on the guidance and expertise of HCPs for prognostic estimates of what the future might hold for their unborn child. In the absence of certainty, parents described basing their decisions on what they imagined or perceived their child's life would be like. In addition, several parents reported receiving mixed messages about the anticipated QOL associated with different fetal anomalies, with several parents commenting on the overly negative perspectives some HCPs shared about their unborn child's anticipated QOL or the burden of raising a child with a disability, which was not consistent with their personal searches for information on the Internet or their conversations (online or other) with parents who had a child with a similar condition.

Similar to the findings from this study, France and colleagues (2012) have found that parental decisions related to continuing or terminating a pregnancy with a known fetal anomaly are influenced by parents' perceptions of the "imagined fetus." Parents' decisions are shaped by their imagined scenarios which take into consideration the degree of physical and emotional suffering anticipated, the day-to-day prognosis; the nature of caregiving resources and services available, and the stigma associated with the disability. In this way, parents' decisions related to TOP are based on perspectives and assumptions that are open to influence by how prognostic information is provided. In comparison, this prognostic information may not correlate with the actual lived experience of individuals with disabilities and their families. For example, in a review of challenges with genetic counselling in the modern era, Minear and colleagues (Minear, Alessi, Allyse, Michie, & Chandrasekharan, 2015) noted the lack of empirical data on public opinion about Down syndrome (DS) and highlighted that public misconceptions about the nature of the disability may influence parents' decisions to participate in PNS and/or choose TOP

in the event of a prenatal diagnosis. They reported conflicting findings in the research in that the majority of individuals living with DS reported being happy with their lives, and the parents of children with DS reported feeling love and pride for their child, with only four percent expressing regret over having the child. In comparison, they noted that 64 percent of Dutch women perceived that raising a child with DS would be a burden, and that women who decided to terminate a fetus affected with DS feared these children would have excessively difficult lives because of the nature of health conditions associated with DS, as well as the stigma and lack of value society has for people with a disability (Minear et al., 2015). Given that there is conflicting information available on the experiential knowledge of disability, and given that the manner in which prognostic information is presented appears to significantly influence parents' decisions related to pregnancy options, we must question whether parents would make different decisions if they had accurate, balanced and comprehensive information available to them. Or, is it that parents positively frame the outcomes of their antenatal decisions in ways that reinforce their perception that their decision was the right decision for them?

Multiple Discourses Shaping Women's Choices to Continue or Terminate the Pregnancy

Findings from this research also illuminate the dominant individualism, biomedical, responsibilization and disability discourses influencing and shaping parents' decisions related to continuing or terminating a pregnancy subsequent to the diagnosis of a fetal anomaly, decisions and dilemmas that women and their partners did not need to consider prior to the advent of PNS and the legalization of abortion. In particular, study findings demonstrate how dominant individualism and disability discourses influence the dilemma many parents described that involved choosing either to continue the pregnancy (and

parent a child with a significant and often lifelong disability) *or* live with the emotional and psychological consequences of enacting their reproductive right to terminate a planned pregnancy. In particular, women who did not view TOP as an option, for religious or other reasons, described periods of angst and extreme emotional distress when they perceived HCPs were "steering" them or "encouraging" them toward TOP, a choice and right they had, but one they preferred not to consider. Furthermore, findings from this study provide a nuanced understanding of the additional burdens that parents took on in enacting their reproductive rights, in that when parents' decisions and choices were not respected or valued by HCPs, family members or others, parents faced increased emotional distress as well as guarded and tense future interactions with these individuals.

These findings are consistent with research and theoretical literature previously reported. For example, in some of the early ground-breaking work done in the area of prenatal screening, Rapp (1999) highlighted the multiple dilemmas women face within the dominant Western biomedical model of pregnancy, noting that in the early days of PNS women who faced these challenging decisions acted as moral pioneers. Rapp asserts,

... I came to think of the women who submitted to the discipline of a new reproductive technology in order to reap its biomedical benefits as moral pioneers. At once conscripts of techno-scientific regimes of quality control and normalisation, and explorers of the ethical territory its presence produces; contemporary pregnant women have become our moral philosophers of the private (p. 306).

Similarly, Kerr (2004) has noted that by giving parents choices about whether or not to participate in PNS, HCPs also give parents the responsibility for these choices, which can be viewed as a burden. Moreover, giving women the choice to participate in PNS, combined with the choice of TOP, places the responsibility for preventing disability on the shoulders of individual parents, or should PNS be declined, facing the future of caring for a disabled child (Kerr, 2004). Likewise, Rapp (1999) emphasizes that the construction

and routinization of PNS situates women on the frontier of biomedicine's expanding capacity to diagnose prenatal fetal anomalies and forces them to "judge the quality of their own fetuses, making concrete and embodied decisions about the standards for entry into the human community" (p. 3).

A critical perspective facilitated an examination of the dominant disability discourses and associated power relations underpinning parents' decisions to continue or terminate a pregnancy in the context of a known fetal anomaly. In particular, findings from this study highlight potential ethical concerns about the role of eugenics in the way medical information about a fetal anomaly is presented to parents. These findings bring new understandings to the burgeoning body of knowledge on this topic, much of which has been limited to discussions specific to prenatal genetic testing. Within this literature, critics from both bioethics and disability rights perspectives emphasize that the routinization of technologies that provide parents with the option to choose against "abnormal" or "defective" children has troubling ramifications for societal perspectives on parenthood and parent-child bonds, and sends a negative message to society by facilitating actions aimed at avoiding the birth of a child with a disability (Parens & Asch, 2000). Similarly, Shildrick (2004) asserts that the assumption behind PNS is that decisions are made based on the results of testing; "decisions that will act to eliminate those that are deemed defective" (p. 154). Moreover, in drawing attention to how PNS leads to selective abortion of fetuses with known health concerns, members of the disability rights community argue that scientific advances should be directed at supporting and improving their lives, not preventing them (Parens & Asch, 2000; Saxton, 1988). In a position statement by the Disabled Peoples' International - Europe (DPI-Europe) (2000), a human rights organization whose primary goal centres on the protection of the rights of

disabled people and the promotion of their full and equal participation in society, they argue that disabled people are threatened by the promises of genetic testing and prenatal screening, since what is actually being offered are tests for characteristics that are perceived as undesirable, noting that people with disabilities often are considered passive subjects in ethical and scientific debates on bioethics and human rights. Furthermore, in their most recent position paper DPI-Europe (2000) assert the organization's support for women's reproductive rights, but "deplore" the context in which these decisions are often made, noting that there cannot be informed choice when genetic counselling is directive and misinforms parents about the experience of disability; there can be no free choice if women are under social pressure to participate in PNS and as long as the myths, fears, stereotypes and discrimination against disabled people continue; and there can be no real choice until women feel they can continue with a pregnancy assured they will be bringing their child into a welcoming society that provides comprehensive systems of support (p. 6). Their position statement also outlines several specific demands to ensure the protection of disabled people's rights, highlighting the need for healthcare interactions to be based on "strong principles of justice, ethics and non-discrimination with a respect for diversity, autonomy and fully informed choice" (p. 7). Consistent with these recommendations, findings from this study have significant implications for HCP-parent interactions, which at a minimum include the need for societal and healthcare perspectives to be more respectful and inclusive of those with disabilities.

Dominant Efficiency Discourses

Study findings clearly demonstrate the significant tensions between dominant efficiency discourses that pressure HCPs to promote brevity in HCP-parent interactions and relational care models foregrounded in organizational mission statements and professional standards. On the one hand, organizational efficiency imperatives emphasize standardized care delivery protocols and efficient patient processing; on the other hand, organizational mission statements and HCP standards uphold relational care models that support HCP-parent communication and collaboration based on comprehensive assessments, compassion, trust and mutual understanding. Given these conflicting tensions, HCPs are put in an impossible position where, despite their best efforts, they are hard-pressed to be able to comply with efficiency imperatives in healthcare delivery while at the same time meeting the expectations set forth in their professional standards and the organization's public image, which promotes HCPs' abilities to provide family-centred, holistic and comprehensive care.

Findings from this study provide new insights, specific to the area of antenatal care, related to how efficiency-driven organizational imperatives often work in tandem with dominant biomedical perspectives to restrict the role of HCPs and limit HCP-parent interactions largely to one of HCP as medical expert and parent as receiver of specialized medical knowledge. Specifically, findings from this study emphasize how time was a predominant factor shaping HCP-parent antenatal interactions and how organizational efficiency imperatives significantly compromised HCPs' abilities to provide quality care. This was evident in participant observations, in which a near obsession with time permeated the culture of antenatal healthcare delivery. Specifically, it was common for HCPs to refer to "time constraints," "a lack of time," and the need to "make up time" in relation to their interactions with parents and families. In addition, although parents and family members expressed gratitude for the time HCPs did spend with them and an appreciation of the time pressures faced by HCPs, they also noted the considerable time

spent waiting for their appointments to begin and described being "herded" from appointment to appointment with significant wait times in between.

Prioritizing the provision of medical information over addressing other parents' needs and concerns also serves to minimize the time HCPs feel obligated to spend with families, thereby allowing HCPs to be able to see all of the patients scheduled on a given clinic day, but at the same time limiting the time available for providing parents with psychosocial, emotional and practical support. An organizational emphasis on efficiency also encouraged HCPs to "stick to the facts" and foreground diagnostic and prognostic information in initial HCP-parent interactions rather than delve into potentially more time-consuming topics such as parents' histories, concerns, and psychological reactions to the diagnosis of a fetal anomaly. These findings are consistent with the results of several studies in other adult care settings that have highlighted the deleterious effects on healthcare delivery and patient outcomes related to organizational efficiency imperatives (Melon, White, & Rankin, 2013; Nash, Zachariah, Nitschmann, & Psencik, 2007; Ng, Vail, Thomas, & Schmidt, 2010).

Findings highlight that the majority of HCPs express considerable regret over "not having more time" to foster relationships with expectant parents that allow for an understanding of parents' unique histories, coexisting health concerns or challenges, and/or health priorities. Moreover, HCPs indicate that the inadequacy of available time for patient interactions is a major frustration and contributes to job dissatisfaction and, for some, considerable moral distress. In addition, findings from this work also shed light on the influence of efficiency imperatives in promoting and reinforcing the idea that there is insufficient time for detailed HCP-parent discussions. As a result, initial HCP-parent interactions are characterized by predominantly one-way exchanges of information from

HCP to parents in the form of "lectures," "downloads" and "speeches" on what HCPs assume is important for parents to know in the limited time available. In addition, the healthcare system's unchallenged emphasis on efficiency (not effectiveness) in healthcare delivery results in a lack of time and priority for detailed HCP-parent discussions that could facilitate an understanding of the broader factors influencing parents' antenatal decisions and abilities to manage pregnancy and/or neonatal outcomes (e.g. parental history of mental health concerns, financial stressors, language and cultural fluency concerns). As findings from this study have shown, this can lead to increased tensions and conflicts in HCP-parent interactions, unaddressed parent and family needs, and inequities in antenatal care.

Although the influence of efficiency imperatives on antenatal care has not been well addressed in the literature, findings from this research are consistent with studies in other care settings that have highlighted the deleterious effects on patient outcomes when the efficiency imperatives promoted by provincial and regional healthcare systems and individual health organizations become the driving force in healthcare delivery and practice (Crawford & Brown, 2011). Specifically, HCPs cited inadequate time as the reason behind discrepancies between the care they valued and the care they were able to provide. This is similar to the findings of previous research in other care contexts that has found efficient processing of patients compromises and devalues nurses' abilities to address psychosocial, emotional and nonphysical (such as discharge coordination and anticipatory guidance for medical procedures) care needs of patients and families, even during devastating events such as the death of a child or the diagnosis of a life-threatening illness (Rodney & Varcoe, 2011).

Study findings are also consistent with previous theoretical and research literature demonstrating that the corporate models currently responsible for guiding healthcare resource allocation and organizational efficiency imperatives have seriously disrupted the culture of healthcare delivery, with deleterious effects for both patients and HCPs (Heggen & Wellard, 2004; Melon et al., 2013; Shannon & French, 2005; Storch, 2005; Varcoe, 2001; Weiss, Malone, Merighi, & Benner, 2002). In particular, Melon and colleagues (2013) have drawn attention to the effects of healthcare restructuring in the 1980s and 1990s, which has been associated with a steady increase in Emergency Department (ED) wait times, and has resulted in a sense of urgency and a demand for narrowly focused solutions aimed at moving patients in and out more quickly in order to solve the problem of excessive wait times. Moreover, healthcare organizations evaluate these short-term solutions by making certain that attention is focused on those aspects that ensure order, such as the use of audit tools and quantitative assessments that serve to reinforce the "smooth operation" of the system and provide a defensible argument that the system itself does not need fixing (Rudge, 2011, p. 172). In addition, a fixation on time as an indicator of quality in the ED diverts attention from the larger concerns that may adversely affect patients, nurses, and the entire system of care, including the root cause of errors, nurse staffing and patient outcomes, as well as numerous factors that affect nurses 'abilities to practice safely, attentively, and holistically (Varcoe, 2001; Weiss et al, 2002; Shannon & French, 2005; Storch, 2005).

Findings from this research also indicate health administrators target the inefficient use of time as a source of reducible healthcare expense, which was evident in their support of multiple quality improvement projects focused on increasing the number of antenatal patient assessments per day and/or accelerating patient flow through multiple maternal fetal medicine appointments. Emphasis on accelerating patient flow appears to be largely driven by the sense of urgency to complete specialized prenatal assessments in order to provide definitive information about the presence or absence of a fetal anomaly, thereby ensuring women and their partners are given the opportunity to make timesensitive decisions related to continuing or terminating the pregnancy. This pervasive sense of urgency also prompts administrative measures to "squeeze in" and "accommodate" as many urgent patient assessments as possible into a clinic day in order to facilitate the detection of fetal anomalies in a timely manner. Moreover, scheduling of patient appointments appeared to be based on arithmetic predictions of minimum staffing levels that foregrounded the quantity of assessments performed, without accommodating for the potential need for HCPs to spend additional time with parents in the event of a diagnosis of a fetal anomaly or the extra time some parents may require to address concomitant health concerns, issues with language fluency, or other contextual issues affecting health decisions. As a result, HCPs often described feeling "pressed for time," "hurried," and "frustrated" as they tried to deliver complex diagnostic and prognostic information in as efficient manner as possible, knowing that they were not able to address the full range of parents' needs, while struggling to address the backlog of patients still waiting to be seen. HCPs' constant sense of needing to "pay attention to time" and the pervasive culture of aiming for efficiency in HCP-patient interactions also appeared to contribute to HCPs being reluctant to engage in detailed discussions with parents that would have allowed for a greater understanding of and ability to address parents' priorities and concerns.

Study findings are also consistent with previous research indicating the dominance of efficiency discourses over those aligned with holistic and collaborative care delivery practices (Heggen & Wellard, 2004). For example, in the antenatal setting the emphasis on increasing the number of patients seen per day (patient throughput) was often equated by hospital administrators with an increase in quality, yet parents consistently reported leaving HCP-parent interactions emotionally unsupported, with unanswered questions, and lacking clarity on pregnancy and neonatal treatment options. Efficiency discourses, in and of themselves, are not the issue; it is the tendency for efficiency discourses to be taken up in ways that subordinate other discourses, thereby acting to determine what is valuable and appropriate in healthcare delivery and practice (Heggen & Wellard, 2004).

Insights gained from this research suggest that much of the work done by HCPs in antenatal care is invisible to hospital administrators and decision makers. Rather, consistent with efficiency discourses as one of the driving forces underpinning health delivery, the predominant focus of administrative evaluation consists of quantitative numerical information including patient wait times, number of patients seen, number of screening ultrasounds performed and other quantitative measures related to patient visits, which becomes the authorized knowledge reviewed by hospital administrators and decision makers within the broader healthcare system. In contrast, quality of care including holistic assessments and comprehensive care is largely unaccounted for by program managers and health administrators who, in line with dominant discourses and imperatives, are focused on how they can "fit in" and "squeeze" more patients to be seen and/or how to minimize "missed fetal anomalies," which might expose the organization to unwanted litigation and negative publicity.

These study findings are consistent with the work of Melon and colleagues (2013), whose critical examination of nursing care in EDs shed light on how much of the care provided in EDs is dependent on the educated decisions and critical interventions of nurses; however, this work is invisible to hospital managers invested in improving ED wait times. In this way, only certain patient characteristics and actions of nurses become administratively "knowable" such as the "neat and tidy" statistics and other quantitative measures captured in administrative and continuous quality improvement projects such as acuity scores and wait times which become the reified knowledge that makes its way into the hands of decision makers who are working to understand and reform patient waiting times and the risks associated with ER care (Melon et al, 2013, p. 229). In contrast, the time and resources required for effectively responding to the needs and priorities of patients, as well as the physical resources needed to accomplish this care, are not visible or measured by hospital systems (Melon et al., 2013). Moreover, Rudge (2013) describes the underlying mechanisms that compel HCPs, specifically nurses, to feel drawn to organizational imperatives where productivity, efficiency and effectiveness are the purported gains, emphasizing how nurses take up these operations of management and government with an intention and desire to have more time to provide holistic and individualized patient care, only to have these efficiency imperatives result in less time to provide care as they immerse themselves in the role of governing productivity measures.

Finally, a unique contribution of the findings of this study is that it draws attention to how organizational efficiency imperatives commonly dictate the nature and amount of parental support available from nursing and allied health professionals, thereby creating opportunities for influence and bias toward certain treatment options and inequities in terms of access to and provision of care and support. Specifically, such opportunities are shaped by the availability and accessibility of pediatric and other specialized services and resources, which varied considerably depending on the nature of the fetal anomaly and the organizational resources and supports in place. Furthermore, there were significant discrepancies in the antenatal care received across different subsets of parents, with those parents who were supported by a formalized antenatal care team comprised of both MFM and pediatric HCPs generally benefitting from significantly greater support including ongoing contact with pediatric and obstetrical specialists as well as specialized nursing and social work services. In contrast, parents whose fetus was diagnosed with a less common but equally or more complex/severe anomaly, but who did not have access to support from formalized MFM-pediatric teams, were often left to find additional resources on their own and/or faced greater challenges and burdens related to unaddressed personal, family or practical needs. Little has been written in the research or theoretical literature about these structural inequities in antenatal care. However, Kett and colleagues (2017) recently reported the benefits of a multidisciplinary fetal centre in providing a unified source of obstetrical and specialized pediatric clinical expertise for women who receive a suspected or confirmed diagnosis of a fetal anomaly (Kett, Wolfe, Vernon, Woodrum, & Diekema, 2017). They point to the benefits of this approach in addressing the multiple and diverse care needs of patients and families who receive a diagnosis of a fetal anomaly, indicating parents sought out emotional and practical support from the multidisciplinary care team in addition to health information related to the fetal diagnosis.

Findings from this study provide new insights from a critical perspective on the impact of dominant discourses in influencing and shaping HCP-parent antenatal interactions that has previously received little attention in the research literature on antenatal communication and decision-making support and is often taken-for-granted in clinical practice. Although previous studies in antenatal care have highlighted that ineffective HCP-parent communication and inadequate parental support can lead to magnified parental distress and decreased satisfaction with care (Hodgson et al., 2016; Lou et al., 2017; Rempel et al., 2004), these studies focused on the nature of the parents' experience and/or decision-making but did not take into account the broader discourses and power relations impacting and shaping HCP-parent interactions.

A Foucauldian lens is helpful in exploring how dominant discourses in healthcare and society construct and shape the nature of HCP-parent/patient interactions and contribute to how we structure our "realities". Discourses "form the constraining grids that give rise to the way we think and act" (Heggen & Wellard, 2004, p. 295). An enhanced understanding of the often taken-for-granted underlying structures and processes influencing and shaping parents' prenatal screening decisions and antenatal care is the requisite first step in developing potential strategies and interventions to address the identified gaps in patient care.

Nondirectional Intentions and Directional Impact on Antenatal HCP-Parent Communication and Decision-Making

The governmentality lens employed in this study facilitated an understanding of the tension and conflict in HCP-parent interactions arising from HCPs' seemingly wellintentioned communications focused on providing the requisite diagnostic, treatment and prognostic information HCPs perceived parents required to make "informed" decisions, which contrasted with parents' perceptions that HCPs were directing them toward specific antenatal decisions. Multiple underlying discourses, organizational frameworks and power relations contributed to this commonly described scenario in which HCPs intended to be nondirectional yet were perceived as guiding parents toward specific pregnancy or treatment options.

Nondirectional Antenatal Communications About Pregnancy and Treatment Options

Findings from this study highlight that HCPs' intentions of providing antenatal health information in a nondirectional manner is consistent with an underlying biomedical perspective and techno-rational approach in which diagnostic and prognostic information is provided in a neutral and objective manner. Moreover, study findings highlight that diagnostic and prognostic information is often presented in biased ways-sometimes with subtlety and seemingly unwittingly and sometimes overtly. HCP communications that parents perceived as indirectly guiding them toward certain antenatal decisions included the amount of time HCPs spend on reviewing one option over another, the order in which options were discussed, nonverbal communication indicating a positive or negative tone associated with certain options, and an unbalanced emphasis on positive (or negative) outcomes associated with certain diagnostic/treatment options. In addition, HCPs' verbal and nonverbal feedback can serve to indicate to parents that the parents' antenatal decisions are not aligned with HCP-set norms, thereby seeming to encourage parents to reconsider their decisions. This includes HCPs' repetitive questioning about whether parents understood the consequences of their decisions in combination with verbal and nonverbal indicators that HCPs disagreed with parents' decisions. In this way, even when HCPs profess to be nondirectional in their approach, their communications related to antenatal decisions, including additional diagnostic testing such as amniocentesis or pregnancy and neonatal options, ultimately lead parents to perceive HCPs as biased toward specific options consistent with HCP-constructed norms.

Findings from this study also underscore a lack of clarity in HCP-parent communications related to pregnancy and treatment options that contributes to parents'

perceptions that HCPs are directing them toward specific antenatal decisions. This was evident in how different HCPs and healthcare teams emphasized different pregnancy and/or neonatal options in individual HCP-parent discussions and/or provided conflicting information concerning prognostic outcomes and/or neonatal treatments. Additionally, unacknowledged divergent HCP and parent assumptions related to the option of TOP, in combination with unclear messaging related to this pregnancy option, contributed to parents' perceptions that HCPs were indirectly guiding them toward specific pregnancy options. HCPs and parents often entered into HCP-parent interactions with different assumptions about TOP. On the one hand, consistent with an underlying individualism discourse in healthcare, HCPs often assume that women are aware of their right to terminate the pregnancy for any reason up to approximately the 24th week of pregnancy. On the other hand, women and their partners often are unaware of this option and/or assume that HCPs only raise TOP as an option when a fetal anomaly is considered severe or life limiting. As a result, HCPs and parents' perceptions related to the option of TOP are frequently misaligned, which can contribute to parents' confusion and frustration in HCP-parent interactions. Furthermore, HCPs are not consistent in how they raise the option of TOP with parents, with some HCPs reviewing it in detail, others only briefly mentioning it as an option, and some not raising it at all, which adds to parents' confusion related to pregnancy options and heightened concerns about whether HCPs are attempting to influence their antenatal decisions.

Study findings also provide insight into how parents' perceptions of HCPs' directiveness (whether indirect or direct) in HCP-parent communications leads parents to be guarded in subsequent HCP-parent interactions and to feel the need to research diagnostic and treatment options for themselves. In particular, parents expressed great frustration and anger toward HCPs who they perceived to be presenting antenatal options in terms of non-options; who squelched parents' hope by focusing on a "litany of negatives"; or who appeared to indirectly pressure parents toward certain decisions in the way information was delivered or the content prioritized. This resulted in parents searching the Internet for other sources of "balanced" information. This was especially the case when parents perceived that the information HCPs provided skewed toward a pregnancy or treatment option that was not aligned with parents' worldviews or beliefs. Interestingly, in these circumstances parents' anger, frustration and disappointment with antenatal communication was more pronounced because they expected HCPs, as health experts and leaders, to act as health advocates and take the parents' best interests into consideration. Parents' disenchantment with HCPs resulting from encounters in which they perceived they were being steered or directed toward certain antenatal decisions contributed to a guarded approach in subsequent HCP-parent interactions.

Research findings provide new insights into antenatal HCP-parent relationships from a critical perspective. In particular they highlight that parents prefer a balanced discussion of diagnostic and pregnancy/treatment options, in which both negative and positive outcomes of antenatal options are discussed and contextualized to the specific nature of the fetal condition and parents' unique situations. This is not to imply that parents expect every HCP to have detailed conversations about their priorities and concerns, especially at the time of initial diagnosis; however, parents do indicate a preference for communications that acknowledge their unique circumstances and inquire about their priorities in relation to the diagnosis of a fetal anomaly. In contrast, when HCPs act on the assumption that they know what information parents need to make reasoned and informed decisions, they impede their abilities to provide individualized care. Strikingly, parents often perceived HCP-parent interactions as "robotic" rather than supportive when HCPs interactions with parents were limited to providing one-way diagnostic, prognostic and treatment information, in ways that did not involve investing in a relationship in which parents' unique perspectives and concerns were understood and health information was personally or contextually individualized. In contrast, when HCPs approached HCP-parent interactions with a caring and engaged stance that involved dialogue with parents and an overt intention of understanding the parents' and families' unique perspectives and priorities as well as the broader contexts in which health decisions occurred, there was an immediate and observable change in tone from a formal interface, in which the HCP was in charge and the parent listened, to one in which sharing of information was encouraged and parents felt more understood and supported. In this way, supportive HCP-parent communications were predicated on HCPs' caring engagement in their interactions with parents.

Consistent with previous research indicating that women make uninformed decisions related to PNS in that either their decisions were not based on relevant or accurate information or their decisions were not aligned with their personal values and beliefs (Dixon & Burton, 2014; Fransen et al., 2010; Jaques et al., 2005; Shea, 2017), results from this study draw attention to parents' concerns that information related to prognosis and treatment options were often not provided in a balanced manner, but rather often were biased toward specific pregnancy or treatment options.

In summary, findings from this study provide a unique critical perspective on HCPparent antenatal communication and decision-making, highlighting how dominant discourses and power relations shape how health communication is conceptualized and enacted in antenatal HCP-parent interactions. The results of this study provide multiple insights into the organizational structures, policies and priorities that constrain antenatal health communication and ultimately parental decisions and health outcomes, opening the door to implications for practice, policy development, education and research to consider and develop alternative strategies to challenge existing barriers to health communication and improve parent and family outcomes.

Implications for Practice, Education, Research and Policy

Study findings have significant implications for expanding the scope of nursing and interdisciplinary practice related to all levels of antenatal communication and decisionmaking support. In particular, study findings draw attention to the need to address the broader contextual elements, including dominant discourses and power relations that can serve to impede the provision of relational and comprehensive care and/or lead to inequities in antenatal HCP-parent communication and decision-making support. In this section, I will start by presenting my recommendations for change at the broader organizational and system levels, including: (1) proposed recommendations for PNS education and support; (2) promotion of a collective critical and reflective analysis of antenatal communication and support; (3) strategies to prioritize patient and family care over organizational efficiency imperatives; (4) recommendations for demonstrating and fostering respect for individuals with disabilities; and (5) strategies to address inequities in antenatal care. This is followed by specific recommendations for change at the level of individual HCPs in clinical practice, highlighting specific practice implications for the delivery and content of health information and support, and reviewing potential practice implications stemming from the proposed conceptualization of parents' emotional responses described in Chapter Six. Next, specific implications for HCP education and future research initiatives are explored, highlighting the complex and interrelated factors

influencing antenatal health communication and decision-making support, and pointing to the multiple research questions yet to be explored. The chapter ends with an overview of study limitations and final conclusions on the contributions of this research.

Recommendations for Change at the Healthcare System and Organizational Levels

Results of this research point to the need to consider multiple structural, policy and procedural changes at an organizational level. Specifically, study findings highlighted gaps in antenatal care delivery; HCP-parent interactions that were associated with and/or resulted in increased tension, conflict, and parental emotional distress; inequities in healthcare delivery and health outcomes; and the difficulties, frustrations and emotional and moral distress that HCPs experienced in addressing the communication challenges and complex care needs of patients and families. Furthermore, this research emphasizes that despite HCPs' best intentions and efforts, they are often set up to fail because of the underlying discursive practices and interrelated organizational structures and policies (or their absence) that compromise the ability of HCPs to provide quality patient care.

Changes to PNS education and support. Research results reinforce that parents often enter into prenatal screening naively, without having thought through the potential implications arising from a screening result that indicates or raises suspicion of a fetal anomaly. Findings also suggest that uninformed choices related to PNS can potentially expose women to unnecessary additional psychological distress, shock, frustration and time-pressured decision-making in the inherently emotionally distressing context of learning of a suspected fetal anomaly. Participating in *and* not participating in PNS should be an informed choice. There is an obvious need for improved education and support for women and their partners related to PNS. In addition to further research to more fully understand the nature of parents' and HCPs' experiences related to PNS, HCPs involved

in prenatal counselling, and/or responsible for referrals for PNS, need to facilitate parents' understanding of: (1) their choices related to prenatal screening; (2) common fetal anomalies detected by screening exams; and (3) potential decision algorithms parents could face if prenatal screening results in an abnormal finding, including consideration of additional diagnostic testing such as amniocentesis and options of continuing or terminating the pregnancy. To augment HCP-parent discussions on this topic, care providers need to be aware of and provide parents with relevant written information as well as links to online resources that can offer guidance and direction for parents on making informed prenatal screening decisions (for example, see "BC Prenatal Genetic Screening Program: An aid to decision-making.," 2016 (May)`). Furthermore, I recommend that these resources be given out as a standardized part of care to every woman who is considering PNS—either as the discussion arises with individual HCPs or, at a minimum, as part of the material provided when women are referred for specific PNS tests. Finally, based on a comprehensive mixed method review and quality criteria analysis, Diadori (2016) draws attention to the potential benefits of Internet-based decision support aids specific to PNS. Online decision support aids have been shown to hold considerable promise, with recent evidence of their effectiveness in supporting decision-making and decreasing decisional conflict in other areas of healthcare delivery, including safety and health interventions for women experiencing intimate partner violence (for example, see Eden et al., 2015; Ford-Gilboe et al., 2017). Hence, findings support further exploration and discussion of the possibility of developing and/or adapting a decision support aid as a potential tool to facilitate parents' informed decision-making related to PNS.

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Promote a collective critical and reflective analysis of antenatal

communication and support. Nurses and other HCPs must develop and hone their abilities to critically analyze the effects of biomedical, efficiency, disability and other dominant discourses in healthcare delivery and practice. HCPs must also develop the skills to speak out and act against efficiency and other organizational imperatives that, in the absence of attention to patient outcomes, jeopardize the quality of patient care and result in health inequities in which vulnerable patients and their families receive suboptimal care. Rudge (2013) asserts that when nurses take up organizational imperatives focused on "productivity and virtual circles of improvement," they become entranced in the "dance of efficiencies and effectiveness and the bottom line" (p. 210), and are set up as governors of the multiple processes of organizing hospitals, thereby taking up the desire to align with organizational imperatives to be "productive." Rather than turning their gaze toward and critiguing the discursive regimes and social organization of the practice setting, they focus on this endless self-propelling loop of governing organizational efficiency imperatives that takes away from the essence of HCPs' clinical practice-their interactions with patients-thereby reinforcing and sustaining the perception that they have a "lack of time" to provide comprehensive and compassionate care. Only by critically analyzing the underlying discourses and power dynamics at play, and understanding how their actions can ultimately have deleterious effects on patient and family care, can nurses (and other HCPs) assert their agency as subjects, not objects in the organizational machine focused on improving productivity (Rudge, 2013).

Acquiescence to efficiency discourses maintains their influential position in the delivery of healthcare services. Nurses and other HCPs are in a position to resist the

dominance of any discourse, thereby shifting its power and influence and providing opportunities for other discourses to gain prominence. Several authors have recommended the need for *collective* action to resist the dominance of efficiency discourses in healthcare delivery and services (for example, Rankin, 2009; Heggen & Wellard, 2004; Rodney & Varcoe, 2012). Although it is a worthy exercise in and of itself, it is insufficient for individual HCPs to passively consider and reflect on the organizational constraints we experience in providing care to antenatal patients and their families. Effective and long-term change of entrenched organizational structures and processes will take a concerted effort from a team of dedicated and motivated HCPs, patients and organizational leaders who hold strong convictions about the need for improvements in antenatal care and communication. Rankin (2009) joins multiple other critics (Dingwell & Allen, 2001; Gordon, 2005; Murray, Holmes, & Rail, 2008; Rodney & Varcoe, 2011; St-Pierre & Holmes, 2008) in encouraging nurses to open a collective dialogue focused on developing strategies for nurses to "talk back" and "act back" against the powerful authoritative ideological practices for healthcare reform that have serious negative consequences for nursing practice and patient outcomes (p. 275). Similarly, Heggen and Wellard (2004) assert that in order to reduce the general acceptance of the dominance of efficiency discourses, nurses (and, I would argue, all HCPs) need to be courageous and speak out about their concerns; facilitate and encourage debate about strategies that will support nurses to be more resistant to dominant discourses; and assist in making the invisible influences of these dominant discourses more visible (Heggen & Wellard, p. 297).

Prioritize patient and family care over efficiency imperatives. Findings indicate that provincial healthcare systems and organizations need to reconcile the individualized, comprehensive, and collaborative care emphasized in their mission statements with the

dominance of efficiency imperatives that compromise the abilities of well-intentioned and capable HCPs to deliver quality care consistent with their professional standards. Observational and interview data point to gaps in providing holistic care and a lack of relational care practices, factors that influence parents to make uninformed antenatal decisions and contribute to suboptimal health outcomes. Moreover, study findings draw attention to how these practices create, reinforce and sustain health inequities in care delivery, such that those individuals and families who are vulnerable because of physical and mental health, financial status, language fluency, and other differences, face an increased risk of unaddressed health concerns. The need for change is apparent in parents' accounts of HCP-parent interactions; parents spoke about HCPs who were "professional" in what they did, fulfilling the duties of their job (e.g. completing an FE, providing medical information), but who were not necessarily caring, engaged or otherwise supportive in HCP-parent interactions. HCPs need to temper their expert stance and tendency to lecture with approaches that acknowledge the emotional difficulties associated with the diagnosis of a fetal anomaly and facilitate an understanding of parents' unique perspectives and priorities in relation to the diagnosis of a fetal anomaly. Specifically, changes at the organizational and system level must include structural, cultural and policy changes that facilitate HCPs' abilities to prioritize parents' and families' needs and concerns over institutional efficiency imperatives.

Building in efficiency measures to optimize the use of tax-payer funded, government-run health organizations is an important and necessary goal; however, these measures become *unproductive* and *inefficient* when they compromise HCPs' ability to provide the care required to optimize patient and family health outcomes and minimize health inequities. Therefore, system and organizational efficiency imperatives that jeopardize HCPs' abilities to address the full range of parents' needs and/or contribute to inequities in antenatal care need to be challenged, reconsidered and addressed. These changes need to occur at the broader organizational level as well as at the level of individual HCP-parent interactions. Providing an exhaustive list of recommended organizational structural and policy changes is beyond the scope of this paper. However, a practical example stemming from this research is the need to rethink the use of efficiency-driven patient scheduling policies in which parents are scheduled to meet with multiple HCPs/subspecialist teams in separate appointments over the course of several hours or multiple days. Instead, there is a need to consider the multiple benefits of scheduling multidisciplinary HCP-parent meetings to review the nature of the fetal diagnosis, prognostic information, and pregnancy and treatment options as well as provide opportunities for discussion of parent questions and concerns. There is growing evidence in the literature of the effectiveness of multidisciplinary approaches to fetal care in providing a unified source of clinical expertise that addresses the full range of parents' health concerns, including their informational and decision-making needs, in addition to providing emotional and practical support (Kett et al., 2017; Loyet, McLean, Graham, Antoine, & Fossick, 2016; McNamara, O'Donoghue, O'Connell, & Greene, 2013). Furthermore, Loyet and colleagues point out the multiple advantages of a specialized nursing role—a fetal care team nurse coordinator—the focus of which is to: (1) provide supportive nursing care including informational, emotional and practical support; (2) facilitate consistent and accurate diagnostic, prognostic and treatment information across the multiple MFM and pediatric care teams; and (3) support parents in navigating the complex healthcare system. Preliminary research indicates that this specialized nursing role is effective in providing enhanced communication, improved comprehensive support

throughout the pregnancy and early neonatal period, navigation assistance within the complex healthcare systems, and improved continuity of care delivery (Loyet et al., 2016). As this example demonstrates, change does not necessarily need to involve healthcare organizations spending significantly more money on healthcare delivery; rather, it involves collective brainstorming of creative solutions that prioritize the needs of patients and families over other organizational goals.

Findings provide direction for both antenatal care providers and organizational leaders to consciously re-examine and address policies and procedures that foreground organizational and HCP priorities over the needs, concerns and health outcomes of parents and families. In addition to rethinking patient scheduling policies, other efficiencydriven system processes and policies also need to be challenged, such as those previously described that result in parents waiting anxiously for the results of PNS results under the directive that "no news is good news" or interactions in which women are sent for additional diagnostic testing for suspected fetal concerns without a clear understanding of the reason for the referral, thereby potentially exposing parents to unnecessary emotional distress as they anxiously wait for the results of further testing. Numerous policies such as these are taken for granted by both clinicians and administrators in their focus on keeping up with the demands and time pressures associated with the delivery of antenatal care. System administrators and HCPs providing these services need to collaborate to identify alternative patient-informed strategies that ensure the provision of clear and timely HCP-parent communication about prenatal screening results.

At a structural and policy level, healthcare organizations also need to address system-level issues that contribute to HCPs having insufficient time and resources to explore the personal and contextual factors shaping parents' antenatal experiences, as well as to provide and/or coordinate additional supports and resources needed by patients and families. Specifically, it is recommended that administrative leaders and decision-makers recognize and optimize the roles of professionals within their organization, such as specialized nurses, social workers, and psychologists, who have the requisite education and skills to provide the emotional, psychological and practical support many parents require but few receive. Moreover, these HCPs need to be formally recognized as part of the antenatal care team, with dedicated, organizationally mandated time to specifically address the needs of this subpopulation of patients. This will facilitate proactive, multidisciplinary and supportive interactions that can help parents address and minimize the emotional, physical and practical burdens associated with the diagnosis of a fetal anomaly, and thereby reduce the potential for health inequities. For example, by prioritizing the need to understand a woman's personal history of depression and anxiety, and her need for support during the inherently emotionally distressing time following the diagnosis of a fetal anomaly, antenatal HCPs can implement proactive interventions and referrals to community and tertiary support services as one strategy to help to support the woman's mental health and antenatal decision-making process. This may ultimately prevent the extreme emotional distress and progression of mental health concerns that were described by parent participants in this study. Similarly, members of the antenatal healthcare team can provide proactive support and facilitate informed decision-making by, for example, reviewing community resources and specialized services available to children with disabilities with parents who are contemplating their pregnancy options following a fetal diagnosis of Down syndrome. These examples illustrate how a

multidisciplinary team of HCPs has the potential to address some of the existing gaps in care delivery that contribute to health inequities in antenatal care.

Demonstrate and foster respect for individuals with disabilities. The inherent dangers of organizational and societal recommendations for PNS for all women include the potential for fetal anomalies to be viewed as something that prospective parents can prevent, in both the interests of the child (by avoiding "needless" pain and suffering) and the common good (by reducing the burden on society of caring for, treating and supporting those with disabilities). That is, even in the way PNS systems are set up and orchestrated to highlight the detection of an "anomaly" as a means of providing an option of TOP (and thereby avoidance of the birth of an "unhealthy" baby), messaging is created and facilitated that contributes to the devaluing of people living with disabilities. In addition, these guidelines and standards produce organizational and system changes that can serve to reinforce the stigma associated with disability and promote the perspective that childhood disability is something that can (and should) be avoided. This observation aligns with the experiences of multiple parents who chose to continue the pregnancy, despite their perceptions that HCPs were clearly trying to influence them toward TOP, and as a result of these interactions described being made to feel that their unborn child's life was not valued and/or that they were making an egregious parenting decision that could result in unnecessary suffering as well as a preventable and substantial burden on society. Parents described these interactions as some of the most emotionally distressing moments of their overall experience, often continuing to be visibly emotionally upset as they retold their experiences several months later. Moreover, parents explained that their emotional distress associated with these interactions was more pronounced because they had trusted that HCPs, as health experts who care and advocate for individuals with

disabilities, would have been supportive and understanding of their choice. In a country such as Canada that celebrates its emphasis on reducing barriers, increasing opportunities and guaranteeing equal rights for people with disabilities (Government of Canada, 2018), it is unacceptable that parents feel that their decision to choose to give birth to a child with a congenital health condition is not respected and/or that their child is not welcomed in our society. A societal and healthcare system view that is more respectful and inclusive of those with disabilities, both in action and in word, is required. Furthermore, it is essential that HCPs, whose professional lives are dedicated to promoting health for all individuals and, in particular, advocating and caring for those with disabilities, must also demonstrate respect and support for parents' choices to support the life of an unborn child with a known health concern. These recommendations are not intended to negate or take away from women's right to terminate a pregnancy, as I believe these choices should be equally upheld and respected; rather, they are put forth with the intention of sensitizing HCPs and others to the need to address the findings of this research that suggest that HCPs indirectly or directly, unwittingly or consciously, stigmatize those with disabilities in covert and overt ways.

Tackle inequities in antenatal care. The findings of this study demonstrate that inequities occur in antenatal communication and care provision, and also provide a beginning understanding of how such inequities arise. Specifically, whereas some parents had the opportunities, personal resources, abilities and/or experience that allowed them to resist the dominance of biomedical, efficiency, disability, responsibilization and other discourses and the enactment of pastoral and disciplinary power in health interactions, other parents and their families faced additional challenges, including unaddressed psychological, physical and practical needs; uninformed and/or potentially biased antenatal decisions; and pressure to succumb to system-centred patient processing imperatives. This analysis suggests that those who were financially, socially and environmentally disadvantaged faced greater obstacles in meeting their health care needs. Moreover, it underscores how these health inequities were reinforced and sustained by a complex network of entrenched structures, power dynamics and discourses that operated throughout the organization, reflected the wider society and were taken up by both HCPs and parents to varying degrees. Therefore, tackling inequity will require attention to these elements throughout and beyond the healthcare setting. The goal of addressing these elements is achieving health equity, which is aligned with the goals of social justice and focuses on striving for the highest possible standard of health and healthcare for all, giving special consideration to those who are at the greatest risk of poor health, and paying particular attention to the economic, social and environmental influences on health and access to healthcare (Braveman, 2014).

Recommendations for tackling inequities in antenatal care draw upon Browne, Varcoe, Ford-Gilboe and Wathen's (2015) intervention to guide organizations in enhancing their capacity for equity-oriented services (referred to as the EQUIP healthcare intervention), which includes the following ten strategies: (1) explicitly committing to equity; (2) developing supportive organizational structures, policies and procedures; (3) re-visioning the use of time; (4) attending to power differentials; (5) tailoring care, programs and services to local contexts; (6) actively countering racism and discrimination; (7) promoting meaningful community and patient engagement; (8) tailoring care to address interrelated forms of violence; (9) enhancing access to the social determinants of health; and (10) optimizing the use of place and space. These interventions focus on enhancing the capacity for equity-oriented care at both the staff and organizational level and include strategies to enhance HCPs' knowledge, attitudes and practices related to equity-oriented care (Browne et al, 2015). This intervention utilizes a participatory approach to foster shifts in organizational structures, policies and practices to boost the capacity to deliver equity-oriented care, improve care practices and shift client outcomes to more favourable results (Browne et al, 2015). Ford-Gilboe and colleagues (Ford-Gilboe et al., in press) empirically demonstrated that the greater the extent to which patients felt they received care characterized by an equity orientation, the better their health outcomes were over time, particularly for those living in marginalizing conditions.

As a means of addressing the inequities demonstrated in this study, it is recommended that organizations involved in providing specialized antenatal care services take up the EQUIP intervention and associated strategies for enhancing capacity for equity-oriented services. Although EQUIP interventions were initially developed for primary healthcare settings, I believe they could also be beneficial to hospital programs delivering specialized services including antenatal care. Browne and colleagues (2015) do not provide detailed protocols for implementing the EQUIP intervention; rather, they emphasize how to enhance the capacity of health organizations to optimize their responsiveness to the diverse needs of populations whose health is influenced by intersecting forms of structural inequities. This involves a combination of staff education and practice facilitation aimed at supporting practice and policy changes at the organizational level. As described by Browne and colleagues, staff education involves a blend of workshops and interactive learning activities, which ideally involve a practice consultant to facilitate staff discussions in ways that incorporate staff experience and knowledge specific to the practice setting (Browne et al, 2015). In applying the EQUIP intervention in antenatal care, the ultimate goal would be to enhance HCPs'

understanding of existing health inequities in antenatal care as well as optimize their abilities to provide equity-oriented care.

Specific to the inequities demonstrated in this study, this intervention would involve collaboration between hospital administrators, managers, HCPs involved in direct patient care and patient advisory committees to identify and incorporate specific strategies to maximize the delivery of equity-oriented care (Browne et al, 2015). Specifically, Browne and colleagues recommend optimizing opportunities for organizational ownership of the intervention through such strategies as maximizing staff input and encouraging care providers to identify their own entry points and areas where learning and skill-building are necessary. For example, based on the inequities demonstrated in this study, two strategies that seem particularly relevant to explore in relation to guiding organizations to enhance their capacity for equity-oriented antenatal care services are re-visioning the use of time and attending to power differentials. Although it is important for specific strategies to be brainstormed at each clinical site, an example of a potentially valuable tool is the use of equity talk pocket cards. These pocket-sized cards contain cues to reframe HCPparent communication in ways that promote health equity (see EQUIP Healthcare Website). For example, a equity talk pocket card could be tailored to the unique context of antenatal care by cuing HCPs to address the multiple intersecting personal and contextual factors impacting the antenatal experience of parents and families, thereby helping to offset the dominant biomedical focus in HCP-parent interactions that minimized the broader needs and priorities of parents and families. Similarly, multiple tools and structural/process changes could be identified and incorporated into practice with the goal of addressing the inequities identified in this study, such as parents' unmet psychological, physical and practical needs and/or parents' uninformed and/or potentially biased
antenatal decisions. In this way, multi-layered strategies could be developed by HCPs to address specific practices that contribute to health inequities at both the organizational and individual HCP level.

Delivery and Content of Health Information: Practice Implications

In addition to the multiple system and organizational implications for change stemming from this research, there are also numerous implications for change at the level of individual HCP-parent interactions. Specifically, study findings support a shift to a relational inquiry approach to HCP-parent interactions. Furthermore, a caring and engaged approach was pivotal to HCP-parent interactions that parents perceived as supportive. There are also several practical recommendations for practice arising from the findings concerning the content and delivery of diagnostic, prognostic and treatment information related to a suspected or confirmed fetal anomaly. Specifically, health information that was accurate, consistent, balanced and individually tailored to the needs and preferences of parents was viewed as supportive to antenatal decision-making and the parents' antenatal experience in general.

Relational inquiry approach to HCP-parent communication.

A relational inquiry approach (Hartrick Doane & Varcoe, 2015) provides an important foundation for future nursing and interdisciplinary HCP-parent antenatal interactions in that it goes beyond an emphasis on HCPs' professional knowledge and communication skills to explicitly address the intrapersonal, interpersonal and contextual factors shaping patients' experiences. This approach is grounded in inquiry and acknowledges the dynamic complexity of the human health experience, thereby enabling HCPs to consider the meaning of any health experience for each individual within their unique context, address the complexities of that experience, and utilize multiple forms of knowledge simultaneously to enhance the effectiveness of health-related interventions (Hartrick Doane & Varcoe, 2005a, 2015). Consistent with this approach, and in addition to promoting a critical and reflective analysis of antenatal communication and support at the broader organizational and system levels of care, practice recommendations challenge individual HCPs to approach antenatal interactions from the perspective of critically considering the structures, discourses, ideologies and procedures that shape and influence healthcare provision (Hartrick Doane & Varcoe, 2007).

Consistent with a relational inquiry approach, findings from this research provide direction to individual HCPs on how to improve antenatal communication and decisionmaking support by prioritizing the parents' unique histories, perspectives, concerns and priorities in HCP-parent interactions. To gain insight into parents' priorities and concerns relevant to their antenatal experience, HCPs might consider asking open-ended parent/family-centred questions such as: (1) What is your priority in coming to this appointment today? (2) What do you feel is important for me to understand about your antenatal experience and/or your values, beliefs and priorities about this pregnancy? (3) What questions or concerns are you hoping our team can address during our meeting? and (4) There is a range of options available to you, from your right to terminate the pregnancy to the possibility of learning more about the nature of the condition and/or other associated concerns such as a chromosomal anomaly, to medical treatments following delivery. Which would you like me to go over with you first?

HCPs also need to consider and discuss existing or potential personal, family and/or other contextual factors impacting parents' antenatal experiences. These include their access to support services, language and cultural fluency, financial security, faithbased beliefs, existing physical and/or mental health concerns, and geographic location (e.g. living in urban or remote areas). Rather than focusing initial HCP-parent interactions on fetal physiology and pathology, HCPs need to address the potential stressors and strain associated with a diagnosis of a fetal anomaly, including the emotional burden on parents as well as the practical and financial strain that can result from multiple appointments and temporary relocations to a distant city for antenatal monitoring and neonatal treatments.

Insights gleaned from this work suggest antenatal HCPs need to reorient their approach from a focus on biomedical and efficiency imperatives to consider the broader intersecting personal and contextual elements shaping parents' antenatal experiences. For example, HCPs can both acknowledge and encourage discussion of the multiple factors influencing parents' antenatal experience as well as facilitate shared brainstorming of potential supports by employing combined statements and questions such as: (1) The diagnosis of a fetal [specific diagnosis] can be a very stressful time for parents. We realize that the diagnosis of [specific fetal anomaly] affects each family in unique ways and we want to understand how we can support you. What has this process been like for you? What personal or family challenges do you think you might need support with given this antenatal diagnosis? (2) What is your biggest priority related to the diagnosis of [specific fetal anomaly]? To whom have you turned for additional support in the past? Are they available to help you with [specific concern/challenge]? and (3) The following resources are available to you (e.g. bioethics consultant, First Nations advocate, social worker, psychologist, reproductive mental health team). What other resources/supports do you think might help?

A relational inquiry approach also directs HCPs to critically consider how organizational factors such as efficiency imperatives may deleteriously influence antenatal care and patient outcomes. A relational inquiry approach involves attending to the interplay between individuals and the contexts of health and health experiences in order to better understand and respond to the differences among people (Hartrick Doane & Varcoe, 2015). For example, after their initial meeting with HCPs about the fetal health condition, it was common for parents to be emotionally overwhelmed and overloaded with information. However, parents were often reluctant to contact HCPs with unaddressed guestions and concerns because they had witnessed how "busy" and "overworked" the HCPs were and did not want to "add to their workload." Based on these findings, rather than encouraging parents to "call if you have any questions," it is recommended that antenatal care providers consider scheduling regular in-person, phone, or video conference meetings with parents to allow time for parents to review information, seek clarification, and discuss their priorities and concerns related to the diagnosis of a fetal anomaly. The frequency and nature of follow-up HCP-parent interactions can be individualized to the needs of specific parents and families, with a minimum of a follow-up meeting scheduled a few days following the initial meeting. Moreover, a team approach that optimizes the roles of advanced practice nurses and other non-medical health professionals such as specialized social workers, psychologists, and genetic counsellors to build parents' capacities and address parents' concerns will help to facilitate a shared multidisciplinary approach to comprehensively and holistically address families' educational, emotional, and practical needs rather than placing this responsibility fully on individual medical practitioners. These recommendations are consistent with feedback from multiple parent participants who indicated it was or would have been immensely helpful to have prescheduled HCP-parent meetings to discuss the full range of their specific concerns and questions in the initial days and weeks following the antenatal

diagnosis, and to have these interactions continue at regular intervals throughout the pregnancy. Moreover, in the instances where parents received additional support from specialized nurses, social workers, spiritual care providers and or psychologists, the majority of parents indicated that they found this support helpful in addressing the broader range of their health concerns and priorities.

HCPs also need to consider how individualism and disability discourses influence and shape HCP-parent interactions and antenatal decision-making. In addition to the previous recommendations related to demonstrating and fostering respect for individuals with disabilities, there is also a need for HCPs to be upfront and clear in discussing *all* pregnancy and treatment options, and why they are being offered, so that parents do not have to try to read between the lines to determine if HCPs are suggesting one pregnancy or treatment option over another. This will help to minimize the parental confusion and frustration associated with HCPs' communications that result in unclear or inconsistent information on antenatal options, such as briefly raising the option of TOP at the end of a lengthy presentation on neonatal interventions, or not clarifying that TOP, within a specified gestational period, is an option for any woman regardless of the presence of a fetal anomaly.

Parents' emotional responses to a fetal anomaly: Direction for practice. The proposed conceptualization of parents' emotional responses to a diagnosis of a fetal anomaly has significant implications for HCPs' understanding of the intersecting and interrelated emotions commonly triggered by the diagnosis of a fetal anomaly. Specifically, it has the potential to provide a framework to guide HCP-initiated assessments and interventions by: (1) acknowledging common parental responses, and using this as a starting point to discuss parents' unique emotional responses; (2) addressing potential

barriers, constraints and challenges influencing parents' experiences and emotional responses; and (3) identifying potential strategies, resources and interventions to support parents in moving toward an emotional stance characterized by hope, control, self-respect, social integration and high PFA, thereby minimizing the emotional distress stemming from unacknowledged feelings of dread/despair, powerlessness, self-stigma, social isolation, and low PFA. For example, in initial and ongoing antenatal interactions with parents, HCPs could employ this framework as a starting point to address parents' unique emotional responses to the diagnosis of a fetal anomaly, asking specific questions related to parents' feelings of dread/despair-hope, powerlessness-control, self-stigma-selfrespect, social isolation-social integration, and the perceived level of PFA. This approach provides an opportunity to acknowledge and address parents' emotional wellbeing following the diagnosis of a fetal anomaly, as well as the potential to initiate a proactive discussion related to personal and contextual concerns that may exacerbate parents' emotional distress and/or provide resources and supports aimed at supporting parents to move toward a more positive emotional stance.

Delivery of health information and support: Caring engagement. Consistent with a relational approach, findings from this study support HCP-parent engagement that is sincere, caring and genuine. Findings indicate parents perceive HCPs demonstrate support by: (1) actively engaging with them in a kind and caring manner; (2) listening to and inquiring about their perspectives, values and personal stories; (3) getting to know them on a broader level beyond that directly related to the diagnosis of a fetal anomaly; (4) initiating discussions about personal and contextual factors influencing and shaping their health and health decisions; and (5) being understanding and respectful of parents' decisions. Moreover, findings reinforced that it did not necessarily take a lot of time for HCPs to sincerely demonstrate a desire to engage with the parents and/or enact concern for their well-being; rather, an HCP approach characterized by caring engagement was embedded within HCPs' words and actions that evoked parental impressions that HCPs "truly cared," were "concerned" and/or "took the time to understand." Furthermore, parents emphasized that HCPs demonstrated kindness and caring in small but significant ways such as going out of their way to ask how the parents were doing emotionally, pausing in the middle of a discussion of the fetal diagnosis to let the parents compose themselves, making eye contact, asking about other family members, and demonstrating hope for their child's future and the family's ability to manage upcoming hospitalizations and treatments.

Content of health information: Individualized, accurate, consistent and **balanced.** Study findings provide specific suggestions for what many of these parents perceive as helpful in relation to the content of health information specific to a suspected or confirmed diagnosis of a fetal anomaly. In particular, parents indicated that they preferred individualized, accurate, consistent, and balanced health information. Consistent with previous research by McCoyd (2008), research findings strongly suggest that parents prefer health information to involve "situated" knowledge related to one's societal and familial context, social supports, and the parents' coping capacities, as well as an image of how a potential child might be affected by the health condition. In addition, for parents whose initial discussion of the fetal anomaly focused primarily on fetal pathology and/or the specific details of complex neonatal treatments, most indicated they would have preferred additional information on their unborn child's anticipated QOL, short- and long-term treatment outcomes and anticipated parenting challenges. However, based on the findings from this study that indicated parents' preferences varied considerably in relation to the level of detail of diagnostic, prognostic and treatment

information, it is recommended that HCPs initiate their discussion with parents by determining the parents' priorities in terms of the content of information and level of detail preferred, and then tailoring the discussion accordingly.

When considering how to improve the content of health information related to the diagnosis of a fetal anomaly, parents also indicated a strong preference for verbal information to be augmented with written information on the fetal diagnosis and the full range of pregnancy and neonatal treatment options. Interestingly, several parents noted that they received very little written information about the fetal diagnosis from the healthcare team, with many noting HCPs assumed they would look up the information themselves on the Internet. In contrast, the majority of parents noted that they valued written information, especially when HCPs individualized it by highlighting particularly pertinent sections or adding information specific to the fetal diagnosis and/or pregnancy and treatment options. A final recommendation is for HCPs to provide parents with up-todate information about a range of potentially helpful and credible websites, online parent support groups, and other Internet-based resources, with the understanding that these resources are meant to augment, not replace, the individualized information and support provided by the healthcare team. The availability of additional Internet-based health information tailored to parents' informational, emotional, practical and decision-making needs was a common recommendation from both parent and HCP participants.

Accurate and consistent health information was also of paramount importance to parents. An analysis of research findings resulted in several recommendations to facilitate HCPs in providing parents with accurate and up-to-date health information, while limiting the potential for conflicting information and/or misinformation. These recommendations include: (1) regular meetings between parents and the multidisciplinary team, including both MFM and pediatric subspecialists who are knowledgeable about the management of the anticipated antenatal and postnatal course; (2) formalized systems of sharing information related to the fetal/newborn diagnosis, pregnancy and/or treatment plan, and parents' priorities and concerns among the multiple specialist teams, community providers and parents; and (3) identification of a specific HCP(s) for each parent/family who can act as an advocate, liaison, and consistent support person(s) to assist parents in navigating the multiple healthcare teams and systems they interface with during their antenatal and early post-pregnancy journey. Although this role could be performed by a medical specialist, social worker or other qualified antenatal HCP, I believe advanced practice nurses in antenatal care would be ideally positioned to address the multiple emotional, informational, and practical challenges parents face following the diagnosis of a fetal anomaly, as well as to promote equity in antenatal communication and decision-making support.

HCPs also need to present prognostic information in a manner that respects the tenuous balance between hope and dread/despair that was inherent in parents' antenatal experiences. In particular, parents emphasized their strong recommendations for a balanced approach characterized by a presentation of the full range of fetal outcomes, both positive and negative, and the need for HCPs to demonstrate an appreciation that potential positive outcomes extend beyond the narrow medically-defined definitions of success focusing on fetal/neonatal survival and/or surgical repair of congenital anomalies (or on TOP, with the hope of a "fresh start" with a "healthy" fetus), to include the love and joy of parenting a child, including one with health concerns or disabilities, and the personal growth and resilience that comes from facing life's challenges.

Parents also emphasized the need for HCPs to demonstrate an understanding of and respect for the hope they derived from their faith, religion, and/or other personal perspectives and worldviews. Consistent with the need for the promotion of critical and reflective analysis of antenatal communication and support at a system-wide level, recommendations also call for individual HCPs to be reflexive about the organizational structures that push and pull them away from their priority of providing relational, individualized and holistic care; discursive structures that can lead HCPs to directly or indirectly influence parents toward health-constructed norms without an appreciation of parents' viewpoints or experiences. HCPs also need to prioritize understanding parents' unique perspectives, priorities and decisional-support needs as they relate to the pregnancy, including their viewpoints on TOP and childhood disabilities, as part of a *discussion* (i.e. not a "one-way speech") of pregnancy and treatment options. Ideally, these proposed changes will foster respectful and trusting interactions, during which topics such as the option of continuing or terminating the pregnancy can be discussed fully and openly, rather than be treated like the "elephant in the room." Undoubtedly, this is not a proposal for a simple change in practice, as both HCPs and parents will need to feel comfortable that information is exchanged in a manner that allows for parents to make informed decisions. Nevertheless, an HCP approach that foregrounds a balanced presentation of prognostic information contextualized to include an understanding of parents' unique perspectives and priorities, and which demonstrates respect for how individual parents derive hope from their experience, has the potential to considerably improve HCP-parent antenatal communication and decision-making support.

Implications for HCP Education

Study findings reinforce that there are no quick fixes to the complex and interrelated factors influencing antenatal health communication and decision-making support. Educational strategies that focus on "how to communicate bad news" or utilize decision-support tools or algorithms may be helpful in and of themselves; however, they tend not to consider the broader contextual, personal and organizational structures influencing and shaping HCP-parent interactions. Research results emphasize that rather than prioritizing specific communication skills or patient scenarios in isolation, health educators must understand and provide guidelines and practical strategies on how HCPs can come to understand the political, discursive and economic contexts within which they work, and learn to challenge and disrupt the dominant discourses and power relations not aligned with optimal antenatal health communication and patient/family outcomes. As a first step, there is a need for a greater emphasis in healthcare curricula on the use of a relational practice lens that encourages reflexivity on not only how we interact with patients and families, but also on the multiple, dynamic and interacting historical, economic, socio-political, physical and linguistic contexts that shape and influence how we communicate with patients and families and how we provide healthcare services (Hartrick Doane & Varcoe, 2015).

Addressing health inequities requires a collective understanding that HCPs' practices are contextualized within organizational structures and practices as well as within matrices of power (Varcoe, Browne, & Cender, 2015). Rankin (2009) offers several strategies to accomplish consciousness-raising about the powerful discursive practices that can have deleterious consequences for both nursing practice and patient outcomes. Specifically, she provides specific strategies for nursing education that I propose are also

applicable to HCP education more generally, including curricula that support both undergraduate and graduate students to: (1) engage in a critical analysis about their professional work; (2) develop analytical skills to understand and critique the dominant discourses and power relations underpinning practice; and (3) gain insight into how HCPs participate in and reinforce social and ruling relations within health organizations. Further, Reimer Kirkham and Browne (2006) encourage fostering a critical analysis of social injustices in nursing education that allows for an understanding of the "unequal relations of power and opportunity that result in privileges for some and disadvantages for others" (p. 332). Moreover, they caution nurses to avoid simply fostering *adaptation* to current unjust social structures; rather, they emphasize the need to integrate a critical perspective into our social justice discourses in order to effectively *address* issues such as poverty, health disparities, and systemic diminishment of individuals' participation in life as full citizens (Kirkham Reimer & Browne, 2006, p. 332).

Educators in all health disciplines also need to formulate comprehensive programs that facilitate the learning of both the theoretical knowledge and practical skills required to individualize health communication and decision-making support to the unique needs of patients and families. The knowledge and practical skills gleaned from comprehensive programs on health communication and decision-making support are applicable to a wide variety of healthcare settings, not only those specific to antenatal care. Just as HCPs are expected to learn the skills and techniques to provide comprehensive physical examinations, education programs must prioritize the need for students in all health disciplines to be equally adept in health communication and decision-making support, including how to collaborate with each other in effective multidisciplinary teams. This will help to avoid clinical scenarios of passing the antenatal counselling role on to those who are assumed to be more qualified, rather than every HCP being responsible and accountable for demonstrating excellence in health communication and decision-making support related to their discipline and/or subspecialty. Furthermore, insights gleaned from the findings of this study can guide training programs for HCPs working in antenatal care by sensitizing them to the issues and challenges parents face, providing insights into supportive and unsupportive health communication strategies, and serving as a starting point for antenatal practitioners to reflect on their own practice and consider additional or alternative strategies aimed at improving HCP-parent communication.

Research Implications

In addition to those already discussed, findings from this study highlighted multiple areas for future research that need to be considered in improving antenatal communication and decision-making support specific to prenatal screening and the diagnosis of a suspected or confirmed fetal anomaly. For example, this research reinforces that parents often enter into PNS naively, without having thought through the implications arising from a result that indicates the presence of a fetal anomaly. Further research is necessary to document potential strategies to facilitate parents' informed decision-making related to PNS, such as the implementation of a Decision Support Aid, as well as the effectiveness of utilizing this tool. Research is also required that further explores the nature of parents' experiences for those who learn of a suspected fetal anomaly that is later ruled out with additional antenatal testing. This is particularly important in light of the findings that this subpopulation of parents can experience significant emotional distress that is largely unacknowledged and unaddressed in the context of subsequent "normal" results, which has significant implications for the shortand long-term health of these parents and their children.

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Future research initiatives are also necessary to build upon the proposed conceptualization of parents' emotional responses to the diagnosis of a fetal anomaly. Specifically, further insight is required that provides greater detail on the emotional responses of parents who pursue TOP, and how this differs from those who continue the pregnancy and pursue neonatal interventions. In addition, additional research is required that explores the effectiveness of specific HCP strategies to assess parents' emotional responses by considering the intersecting emotional continua of dread/despair–hope, powerlessness–control, self-stigma– self-respect (and associated social isolation–social integration) and low PFA–high PFA, as well as evaluates the effectiveness of HCP interventions aimed at supporting parents' emotional progression toward hope, control, self-respect, social integration and high PFA. In particular, clinical practice would benefit from additional research-based initiatives focused on mitigating the emotional distress and potential short- and long-term emotional trauma associated with the diagnosis of a fetal anomaly, for both parents who continue and those who terminate the pregnancy.

Research efforts are also necessary to provide a more in-depth examination of how HCP-parent relationships evolve over time, both within the antenatal and the postnatal/post-pregnancy periods, as well as the multiple personal, contextual and organizational factors that contribute to supportive HCP-parent interactions and relationships. For example, findings from this study indicate that HCPs do not always approach antenatal interactions as relationships; however, what is left unaddressed is whether there are additional factors beyond those identified in this study that contribute to HCPs taking a more guarded approach. Similarly, does the potential for parents to terminate the pregnancy contribute to HCPs' tentativeness in actively engaging in developing relationships with parents until they establish that parents plan to continue the pregnancy? Likewise, are the sonographer actions and behaviours that parents perceived as "robotic" influenced by organizational policies that constrain sonographers' abilities to share diagnostic information with parents and thereby lead them to mask their reactions to the point that they come across as unengaged in HCP-parent interactions?

Finally, results of this study have provided new insights into how dominant discourses and power relations impact and shape parents' antenatal experiences and can lead to inequities in health and healthcare delivery. Building on the organizations' values and intentions as articulated in their mission statements, next steps will need to focus on changing system and institutional structures, policies and processes and advocating for improved HCP-parent communication and decision-making support. This includes research that focuses on documenting the development of specific equity-promoting strategies in antenatal communication and decision-making support, at both the organizational and individual HCP level, as well as careful examination of the associated results to allow for further refinement of future interventions.

Limitations

This study has several limitations. First, data collection was limited to two Canadian health centres with relatively similar antenatal care programs. Parents and/or HCPs from other Canadian locations and/or other countries, especially those with privatized or fee-for-service health programs and/or different abortion laws and guidelines may have significantly different experiences. In particular, parents may have considerably different experiences if they live in a country where medical TOP is not legalized or government funded, and/or if prenatal screening and pregnancy and treatment options are shaped or influenced by parents' abilities to pay for these services. A second limitation is that study findings are based on a sample of English speaking Canadians. Although participant recruitment did involve a relatively diverse sample of parent participants in terms of ethnicity, age, gestational age, gender, and first language, I did not include parents who did not speak English, which may have significantly influenced parents' antenatal experiences. Finally, I was unable to complete any follow-up interviews with parents who chose to terminate their pregnancy, which limited my ability to describe the nature of this subgroup's experience.

Conclusion

I believe the findings of this study contribute to an overall understanding of the multiple intersecting factors and underlying frameworks and power dynamics that constitute, shape and influence HCP-parent communication and parents' decision-making related to prenatal screening and the diagnosis of a fetal anomaly. Through dissemination of the insights gleaned, the subtle refinements in our understanding of parents' antenatal experiences, and the vivid and heartrending descriptions provided, I hope to sensitize HCPs and others to the experiences of parents who receive a diagnosis of a fetal anomaly, including the multiple and intersecting personal, contextual and organizational factors that influence and shape these experiences. Results from this study have the potential to guide clinical training programs, facilitate tangible improvements in antenatal HCP-parent communication and decision-making support, and ultimately, the health outcomes of parents and families. By drawing attention to the existing inequities in antenatal care and the significant and sometimes tragic consequences for parents and families that can result from these health inequities, I hope to challenge HCPs and organizational leaders to carefully consider the organizational structures, processes and power relations that contribute to scenarios in which those with the greatest need receive the least support. By doing this, I aim to disrupt taken-for-granted assumptions about how

antenatal care and communication is enacted, and challenge antenatal care providers and organizational leaders to consider changes to practice that will lead to prioritizing the needs and concerns of parents and families over those of HCPs and the broader health institutions and systems. I believe that this is a necessary first step to real and sustained change in antenatal care and that the findings from this study have the potential to act as a catalyst to initiate multiple changes in practice, education, research and policy development, with the ultimate goal of promoting excellence and equity in antenatal care delivery and HCP-parent communication and decision-making support.

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APPENDIX A: OBSERVATION GUIDE

This observation guide was informed by Emerson, Fretz & Shaw (Emerson et al., 2010), Carspecken (Carspecken, 1996), and Thorne (Thorne, 2008) and was used to guide non-participant and participant observations at both research sites. The following elements were considered as I conducted and reflected on my observations in the field and as I wrote up the field notes.

A. What I Will Observe:

- 1. Setting and Organizational Features:
 - What does the actual building and environment look like and how is it used?
 - Where is the building positioned?
 - What do you see when you enter the building, describe the pictures on the walls, the general cleanliness and age of the furnishings, art etc.?
 - What is the history of the building, has it been renovated?
 - What is the physical layout and how is the space organized?
 - How does the physical layout influence or shape interaction between and amongst parents and HCPs?
 - Exam Rooms and Meeting/Conference Room How is the equipment/examining tables/ultrasound screens/equipment and tables/chairs organized? Consider positions of power (e.g. speaker standing and occupying power position vs. neutral power if all individuals are sitting around a table).
 - How would you describe the ambience/mood of the interactions/meetings and specific individuals involved (e.g. serious/tense/relaxed)? Consider artwork, posters, notice boards, etc. Are there any distracting noises or

disruptions? Consider smells and temperature, and corresponding effects on participants.

2. People:

- How do they behave, interact, dress, and move?
- What are their roles?
- Where and how are the individuals situated in the room? Consider spacing between people and how this impacts interactions/sense of power.
- Consider interactions between individuals including: (1) health care provider to parent; (2) health care provider to health care provider; and (3) interactions between parents and other family members.

3. Dialogue

- Tone of voices
- Type of language used formal/informal
- Simplicity/complexity of language
- What is the focus of the discussion? What is not discussed or focused on less?
- How is dialogue divided? Does one person speak more than others?
- What is the emotional tone of the voice? Does the emotional tone of the dialogue change over time?
- Who initiates dialogue? Who doesn't?
- Consider body language/posture and facial expressions/nonverbal
 expressions. Consider eye contact which person makes/breaks contact.
- How does the dialogue unfold?
- 4. Description of events as they occurred chronologically in the field.

5. Personal and reflective thoughts about entering the field and being there, as well as reflections on my own personal and professional life experiences that could potentially influence the way that I filter what I observe. These reflections will also include how I will present myself in terms of appearance and actions.

B. Recording of Field Notes

- 1. Pre-observation/interview reflections
- 2. Detailed notes taken during observation
- 3. Post observation/interview reflections

APPENDIX B: CONSENT FORMS Combined Information Letter/Consent Form for Parent Participants #1







School of Nursing T201-2211 Wesbrook Mall Vancouver, BC, Canada V6T 2B5 Tel: (604) 822-7417 Fax: (604) 822-7466

INFORMATION LETTER AND CONSENT FORM FOR PARENTS

PROMOTING EQUITY IN PARENTAL ANTENATAL DECISION MAKING SUPPORT

Who is conducting the study?

Principal Investigator:

Dr. Colleen Varcoe Professor, School of Nursing University of British Columbia Telephone (604) 827-3121

Co-investigators:

Laurie Cender Doctoral Student, School of Nursing University of British Columbia Telephone (604) 868-4846 Email: laurie.cender@alumni.ubc.ca

Dr. Sally Thorne, Professor, School of Nursing Dr. Gladys McPherson, Assistant Professor, School of Nursing Dr. George Sandor, Pediatric Cardiologist, BCCH (retired) & Professor, Faculty of Medicine,

This research project is being done as part of Laurie Cender's (a co-investigator) doctoral studies at the University of British Columbia School of Nursing. The study is funded in part by the Canadian Institute of Health Research.

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What is the purpose of this study?

The aim of this study is to improve how doctors, nurses and other health care workers provide support and health information to parents who are taking part in prenatal screening as well as those parents who receive a diagnosis of a fetal anomaly. We want to learn about how health care professionals provide information and support to parents. We also want to learn about how to encourage and promote parent-health care provider interactions that ensure all parents receive the information and support they need.

Why should you take part in this study?

We are inviting you to take part in this study because you (or your partner /significant other) speak English and because you (or your partner/significant other) are having an ultrasound to check for a fetal anomaly. We want to learn more about parents' experiences with prenatal screening and how health care providers and parents talk about and make decisions about a diagnosis of a fetal anomaly. We are asking parents who are taking part in prenatal screening to help us.

What happens if you say, "Yes, I want to be in the study"?

- Laurie will sit in and observe the ultrasound of the fetal heart. Laurie may write down some notes during this time to help her remember the interactions that occurred. No audiotape or videotape equipment will be used.
- Laurie will sit in and listen to your discussions with the care providers following your ultrasound.
- After your appointment, Laurie will talk to you for 5 -10 minutes about the
 possibility of arranging an interview with you to discuss your experience of having
 a fetal ultrasound. If you agree, a face-to-face or telephone interview would be
 set up within the following 2 6 weeks at a time and place that is convenient for
 you. A separate consent form will be reviewed with you if you are interested in
 participating in a follow-up interview.

If you are interested in participating in the study, you can contact Laurie Cender prior to your appointment at 604-868-4846 or email her at <u>laurie.cender@alumni.ubc.ca</u> OR

When you come in to the hospital for your fetal ultrasound, a member of the care team will ask you if you would like to participate in the study.

Your Participation is Voluntary

Your participation in the study is voluntary. You have the right to refuse to take part in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason. If you withdraw from the study, you have the right to request that the information you provided not be used in the analysis of study findings. Not

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taking part in the study will not change the health care and support given to you or your family members, nor your relationship with UBC either now or in the future.

Study Results

Laurie Cender will write a report on the results of this study as part of her doctoral program. Study results may also be presented at conferences and published in journal articles, reports or books.

If you would like to receive a summary of the study results, please provide your contact information on the last page of this form. Laurie will mail or email the summary to you upon completion of the study.

Is there any way being in this study could be bad for you?

We do not think that there is anything related to your involvement in this study that could harm you or cause you any discomfort.

Benefits of the Research and Benefits to You

You may not receive any benefit at all from taking part in this study. However, in the future, others may benefit from what we learn in this study. Study results will be shared with patients and health care providers. Results may also be presented at conferences and published in professional articles, reports or books. It is hoped that sharing the study results will lead to better support for parents who participate in prenatal screening and/or learn about a fetal anomaly during pregnancy. By sharing the study results we aim to improve communication and parental support as well as encourage and promote parent-health care provider interactions that ensure all parents receive the information and support they need.

How will your privacy be maintained?

- Your confidentiality will be respected.
- All documents will be identified only by a code name. Information that reveals who you are will not be released without your consent unless required by law.
- Your name will not be used in any presentations or publications of the study results.
- Any documents that contain confidential information will be stored in a locked filing cabinet. All electronic files and devices that contain confidential information will be password protected and encrypted. Only the research team will have access to this information.
- The researchers may use the data for another related study. In this case, your confidentiality will be respected as described in this consent.

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Will you be paid for taking part in this study?

You will not be paid for allowing Laurie Cender to observe your fetal ultrasound or discussions with members of the health care team. However, if you agree to participate in a follow-up interview, you will be paid \$20 for each interview you participate in as a way of recognizing the time you have taken to support the research project.

Who can you contact if you have questions about the study?

If you have questions or concerns about what we are asking of you, please contact Ms. Laurie Cender. You may also contact Dr. Colleen Varcoe, who is supervising Ms. Cender's doctoral research at UBC School of Nursing. The names and telephone numbers are listed on the first page of this form.

Who can you contact if you have complaints or concerns about the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 604-822-8598 or if long distance email <u>RSIL@ors.ubc.ca</u> or call toll free 1-877-822-8598.

CONSENT

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your access to health/support services or the provision of health care/support services for you or any of your family members.

- · Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature below indicates that you consent to participate in this study.

Participant Signature

Printed Name of the Participant signing above

Interpreter Signature (if applicable)

Interpreter Name (if applicable)

Future Research: Consent to Contact

Please indicate with an X in the box below if the members of the research team can contact you to invite you to participate in future research studies.

Yes, I consent to being contacted about taking part in future research studies.

No, I prefer not to be contacted about future research studies.

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Date

Date

Request for Summary of Study Results

Please provide your mailing or email address if you would like to be sent a summary of the study findings.

lacksquare I would prefer to have a summary of the study findings mailed to me

Mailing Address:

igsquare I would prefer to have a summary of the study findings emailed to me

Email Address: _____

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Combined Information Letter/Consent Form for Parent Participants #2







School of Nursing T201-2211 Wesbrook Mall Vancouver, BC V6T 2B5 Tel: (604) 822-7417 Fax: (604) 822-7466

CONSENT FORM FOR PARENTS (#2)

PROMOTING EQUITY IN PARENTAL ANTENATAL DECISION MAKING SUPPORT:

Who is conducting the study?

Principal Investigator:

Dr. Colleen Varcoe Professor, School of Nursing University of British Columbia Telephone (604) 827-3121

Co-investigators:

Laurie Cender Doctoral Student, School of Nursing University of British Columbia Telephone (604) 868-4846 Email: laurie.cender@alumni.ubc.ca

Dr. Sally Thorne, Professor, School of Nursing Dr. Gladys McPherson, Assistant Professor, School of Nursing Dr. George Sandor, Pediatric Cardiologist, BCCH (retired) & Professor, Faculty of Medicine,

This research project is being done as part of Laurie Cender's (a co-investigator) doctoral studies at the University of British Columbia School of Nursing. The study is funded in part by the Canadian Institute of Health Research.

What is the purpose of this study?

The aim of this study is to improve how doctors, nurses and other health care workers provide support and health information to parents who are taking part in prenatal

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screening as well as those parents who receive a diagnosis of a fetal anomaly. We want to learn more about how health care professionals provide information and support to parents. We also want to learn more about how to encourage and promote parent-health care provider interactions that ensure all parents receive the information and support they need.

Why should you take part in this study?

We are inviting you to take part in this study because you (or your partner/significant other) speak English and because you (or your partner/significant other) have had an ultrasound to check for a fetal anomaly. We want to learn more about parents' experiences with prenatal screening and how health care providers and parents talk about and make decisions about a diagnosis of a fetal anomaly. We are asking parents who are taking part in prenatal screening to help us.

What happens if you say, "Yes, I want to be in the study"?

You will be asked to consent to participate in one to two interviews with Laurie Cender, a nurse researcher within the next one to three months. You can choose to participate in as many interviews as you would like.

- Each interview will be set up at a time and place that is convenient for you (either face to face or by telephone).
- Each interview will be recorded and transcribed.
- · Each interview will last approximately one hour.
- During the interview you will be asked to share your story about your experience
 of prenatal screening. If the prenatal screening indicated the presence of a fetal
 anomaly, you will be asked to share what this experience and any subsequent
 interactions with health care providers were like for you, what you found
 supportive or not supportive about your interactions with health care providers
 and about how you made the decisions you made.
- A separate consent form will be reviewed with you if you are interested in participating in an additional third follow-up interview in 3-9 months.

If you are interested in participating in an interview, please let Laurie Cender know in person or by contacting her at the phone number or email listed on the first page of this form.

Your Participation is Voluntary

Your participation in the study is voluntary. You have the right to refuse to take part in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason. If you withdraw from the study, you have the right to request that the information you provided not be used in the analysis of the findings. Not taking part in the study will not change the health care and support given to you or your family members, nor your relationship with UBC either now or in the future.

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Study Results

Laurie Cender will write a report on the results of this study as part of her doctoral program. Study results may also be presented at conferences and published in journal articles, reports or books.

If you would like to receive a summary of the study results please provide your contact information on the last page of this form. Laurie will mail or email this to you at the completion of the study.

Is there any way being in this study could be bad for you?

We do not think that there is anything related to your involvement in this study that could harm you or cause you any discomfort. However, for some people the interview process may trigger some sensitive feelings and emotions as you share your experience. If this happens, you may choose to stop the interview. You will also be offered a list of resources that can provide you and your family with support related to any sad or worrisome feelings you experience during or following the interview.

Benefits of the Research and Benefits to You

You may not receive any benefit at all from taking part in this study. However, you may benefit from being able to share your feelings and thoughts about your experience and your decision making process. In the future others may benefit from what we learn in this study. Study results will be shared with patients and health care providers. Results may also be presented at conferences and published in professional articles, reports or books. It is hoped that sharing the study results will lead to better support for parents who take part in prenatal screening and/or learn about a fetal anomaly during pregnancy. By sharing the study results we aim to improve communication and parental support as well as promote fair practices in parent-health care provider interactions.

How will your privacy be maintained?

- Your confidentiality will be respected.
- All documents will be identified only by a code name. Information that reveals who you are will not be released without your consent unless required by law.
- Your name will not be used in any presentations or publications of the study results.
- Quotes from your interview(s) may be used in the presentations of findings, however these quotes will be edited as necessary to ensure your anonymity.
- For the duration of the study, any documents and audiotapes that contain confidential information will be stored in a locked filing cabinet. All electronic files

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and devices that contain confidential information will be password protected and encrypted. Only the research team will have access to this information.

- All study data, including audiotapes, interview transcripts, and fieldnotes will be kept for at least a 5-year period as per UBC policy. Data may be kept for a longer period of time depending on the outcomes of the study and the plans for future research. Once the data is no longer required, study materials will be destroyed in a way that your confidentiality will be maintained (ie. audiotapes will be demagnetized and paper documents will be shredded).
- Any hired transcriptionists and translators will be informed about privacy and confidentiality procedures and will be required to sign a confidentiality agreement.
- The researchers may use the data for another related study. In this case, your confidentiality will be respected as described in this consent.

Will you be paid for taking part in this study?

You will receive \$20 for every interview that you participate in as a way of recognizing the time and effort you have taken to support the research project.

Who can you contact if you have questions about the study?

If you have questions or concerns about what we are asking of you, please contact Ms. Laurie Cender. You may also contact Dr. Colleen Varcoe, who is supervising Ms. Cender's doctoral research at UBC School of Nursing. The names and telephone numbers are listed on the first page of this form.

Who can you contact if you have complaints or concerns about the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 604-822-8598 or if long distance email <u>RSIL@ors.ubc.ca</u> or call toll free 1-877-822-8598.

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CONSENT

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your access to health/support services or the provision of health care/support services for you or any of your family members.

- Your signature below indicates that you have received a copy of this consent from for your own records.
- Your signature below indicates that you consent to participate in this study.

Participant Signature	Date	
Printed Name of the Participant signing above		
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interpreter Signature (if applicable)	Date	
Interpreter Name (if applicable)		
Future Research: Consent to Contact		
Please indicate with an X in the box below if the members of the research team can contact you to invite you to participate in future research studies.		
Yes, I consent to be contacted about taking part in future research studies.		
No, I prefer not to be contacted about future research studies.		

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Request for Summary of Study Results

Please provide your mailing or email address if you would like to be sent a summary of the study results.

I would prefer to have a summary of the study results mailed to me

Mailing Address:

 $\hfill \Box$ I would prefer to have a summary of the study emailed to me

Email Address: _____

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Combined Information Letter/Consent Form for Parent Participants #3







School of Nursing T201-2211 Wesbrook Mall Vancouver, BC V6T 2B5 Tel: (604) 822-7417 Fax: (604) 822-7466

CONSENT FORM FOR PARENTS (#3)

PROMOTING EQUITY IN PARENTAL ANTENATAL DECISION MAKING SUPPORT:

Who is conducting the study?

Principal Investigator:

Dr. Colleen Varcoe Professor, School of Nursing University of British Columbia Telephone (604) 827-3121

Co-investigators:

Laurie Cender Doctoral Student, School of Nursing University of British Columbia Telephone (604) 868-4846 Email: laurie.cender@alumni.ubc.ca

Dr. Sally Thorne, Professor, School of Nursing Dr. Gladys McPherson, Assistant Professor, School of Nursing Dr. George Sandor, Pediatric Cardiologist, BCCH (retired) & Professor, Faculty of Medicine,

This research project is being done as part of Laurie Cender's (a co-investigator) doctoral studies at the University of British Columbia School of Nursing. The study is funded in part by the Canadian Institute of Health Research.

What is the purpose of this study?

The aim of this study is to improve how doctors, nurses and other health care workers provide support and health information to parents who are taking part in prenatal

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screening as well as those parents who receive a diagnosis of a fetal anomaly. We want to learn more about how health care professionals provide information and support to parents. We also want to learn more about how to encourage and promote parent-health care provider interactions that ensure all parents receive the information and support they need.

Why should you take part in this study?

We are inviting you to take part in this study because you (or your partner/significant other) speak English and because you (or your partner/significant other) have had an ultrasound to check for a fetal anomaly. We want to learn more about parents' experiences with prenatal screening and how health care providers and parents talk about and make decisions about a diagnosis of a fetal anomaly. We are asking parents who are taking part in prenatal screening to help us.

What happens if you say, "Yes, I want to be in the study"?

You will be asked to consent to participate in a follow-up interview with Laurie Cender, a nurse researcher within the next one to six months. You can choose to participate in as many interviews as you would like.

- The interview will be set up at a time and place that is convenient for you (either face to face or by telephone).
- The interview will be recorded and transcribed.
- The interview will last approximately one hour.
- During the interview you will be asked to share your story about your experience since the time of prenatal screening. If the prenatal screening indicated the presence of a fetal anomaly, you will be asked to share your thoughts and reflections about what this experience and any subsequent interactions with health care providers were like for you, what you found supportive or not supportive about your interactions with health care providers and about how you made the decisions you made.

If you are interested in participating in an interview, please let Laurie Cender know in person or by contacting her at the phone number or email listed on the first page of this form.

Your Participation is Voluntary

Your participation in the study is voluntary. You have the right to refuse to take part in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason. If you withdraw from the study, you have the right to request that the information you provided not be used in the analysis of the findings. Not taking part in the study will not change the health care and support given to you or your family members, nor your relationship with UBC either now or in the future.

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Study Results

Laurie Cender will write a report on the results of this study as part of her doctoral program. Study results may also be presented at conferences and published in journal articles, reports or books.

If you would like to receive a summary of the study results please provide your contact information on the last page of this form. Laurie will mail or email this to you at the completion of the study.

Is there any way being in this study could be bad for you?

We do not think that there is anything related to your involvement in this study that could harm you or cause you any discomfort. However, for some people the interview process may trigger some sensitive feelings and emotions as you share your experience. If this happens, you may choose to stop the interview. You will also be offered a list of resources that can provide you and your family with support related to any sad or worrisome feelings you experience during or following the interview.

Benefits of the Research and Benefits to You

You may not receive any benefit at all from taking part in this study. However, you may benefit from being able to share your feelings and thoughts about your experience and your decision making process. In the future others may benefit from what we learn in this study. Study results will be shared with patients and health care providers. Results may also be presented at conferences and published in professional articles, reports or books. It is hoped that sharing the study results will lead to better support for parents who take part in prenatal screening and/or learn about a fetal anomaly during pregnancy. By sharing the study results we aim to improve communication and parental support as well as promote fair practices in parent-health care provider interactions.

How will your privacy be maintained?

Version 1: January 9, 2015

- · Your confidentiality will be respected.
- All documents will be identified only by a code name. Information that reveals
 who you are will not be released without your consent unless required by law.
- Your name will not be used in any presentations or publications of the study results.
- Quotes from your interview(s) may be used in the presentations of findings, however these quotes will be edited as necessary to ensure your anonymity.
- For the duration of the study, any documents and audiotapes that contain confidential information will be stored in a locked filing cabinet. All electronic files and devices that contain confidential information will be password protected and encrypted. Only the research team will have access to this information.

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- All study data, including audiotapes, interview transcripts, and fieldnotes will be kept for at least a 5-year period as per UBC policy. Data may be kept for a longer period of time depending on the outcomes of the study and the plans for future research. Once the data is no longer required, study materials will be destroyed in a way that your confidentiality will be maintained (ie. audiotapes will be demagnetized and paper documents will be shredded).
- Any hired transcriptionists and translators will be informed about privacy and confidentiality procedures and will be required to sign a confidentiality agreement.
- The researchers may use the data for another related study. In this case, your confidentiality will be respected as described in this consent.

Will you be paid for taking part in this study?

You will receive \$20 for every interview that you participate in as a way of recognizing the time and effort you have taken to support the research project.

Who can you contact if you have questions about the study?

If you have questions or concerns about what we are asking of you, please contact Ms. Laurie Cender. You may also contact Dr. Colleen Varcoe, who is supervising Ms. Cender's doctoral research at UBC School of Nursing. The names and telephone numbers are listed on the first page of this form.

Who can you contact if you have complaints or concerns about the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 604-822-8598 or if long distance email <u>RSIL@ors.ubc.ca</u> or call toll free 1-877-822-8598.

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CONSENT

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your access to health/support services or the provision of health care/support services for you or any of your family members.

- Your signature below indicates that you have received a copy of this consent from for your own records.
- Your signature below indicates that you consent to participate in this study.

Participant Signature	Date	
Printed Name of the Participant signing above		
Internetter Signature (if applicable)	Data	
interpreter Signature (ir applicable)	Date	
Interpreter Name (if applicable)		
Future Research: Consent to Contact		
Please indicate with an X in the box below if the members of the research team can contact you to invite you to participate in future research studies.		
Yes, I consent to be contacted about taking part in future research studies.		
No, I prefer not to be contacted about future research studies.		

Version 1: January 9, 2015

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Request for Summary of Study Results

Please provide your mailing or email address if you would like to be sent a summary of the study results.

I would prefer to have a summary of the study results mailed to me

Mailing Address:

 $\hfill \Box$ I would prefer to have a summary of the study emailed to me

Email Address:

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Combined Information Letter/Consent Form for HCP Participants







School of Nursing T201-2211 Wesbrook Mall Vancouver, BC V6T 2B5 Tel: (604) 822-7417 Fax: (604) 822-7466

INFORMATION LETTER AND CONSENT FORM FOR HEALTH CARE PROVIDERS

PROMOTING EQUITY IN ANTENATAL DECISION MAKING SUPPORT

Who is conducting the study?

Principal Investigator: Dr. Colleen Varcoe Professor, School of Nursing University of British Columbia Telephone (604) 827-3121

Co-investigators:

Laurie Cender Doctoral Student, School of Nursing University of British Columbia Telephone (604) 868-4846 Email: laurie.cender@alumni.ubc.ca

Dr. Sally Thorne, Professor, School of Nursing Dr. Gladys McPherson, Assistant Professor, School of Nursing Dr. George Sandor, Pediatric Cardiologist, BCCH (retired) & Professor, Faculty of Medicine,

This research project is being conducted as part of Laurie Cender's (a co-investigator) doctoral studies at the UBC School of Nursing. It is funded in part by the Canadian Institute of Health Research.

What is the purpose of this study?

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This study aims to understand the complex communication and decision making dynamics involved when parents receive an antenatal diagnosis of a fetal abnormality and to explore how health care providers (HCPs) can better support parental decision making, ease parents' distress, and foster equity in HCP-parent interactions and parental decision making support.

Why should you take part in this study?

You are being invited to participate in this research project because you speak English and you have experience in providing care to parents and families who participate in prenatal screening and/or receive an antenatal diagnosis of a structural or chromosomal fetal abnormality. We would like to understand your perspectives on parent-HCP communication and decision making related to prenatal screening and antenatal diagnosis of a fetal abnormality. This includes your perspective on how best to provide information to prospective parents and support their decision-making, existing or potential supports and resources available to both parents and/or HCPs, and specific challenges faced in parent-HCP interactions and decision making related to an antenatal diagnosis of a fetal abnormality.

What are you being asked to do?

You are being asked to participate in an interview with Laurie Cender.

- Laurie Cender will set up a face-to-face or telephone interview with you at a time and place that is convenient for you.
- The interview will take approximately one hour and will be recorded and transcribed.
- During the interview you will be asked to share your story about your experience
 of providing care to parents who participate in prenatal screening and/or receive
 an antenatal diagnosis of a fetal abnormality, what factors guide your approach
 with parents/families, and your perspective on the decision making process
 related to pregnancy and fetal/neonatal diagnostic and treatment options.

Your Participation is Voluntary

Your participation in the study is completely voluntary. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw from the study at any time without giving a reason and without any negative impact on your employment or your relationship with UBC, either now or in the future. If you withdraw from the study, you have the right to request that the information you provided not be used in the analysis of the findings.

Study Results

Version 1: November 27, 2014

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Laurie Cender will write a report on the results of this study as part of her doctoral program. Study results may also be presented at conferences and published in journal articles, reports or books.

If you would like to receive a summary of the study results, please provide your contact information on the last page of this form. Laurie will mail or email this to you at the completion of the study.

What are the Risks of Taking Part in this Research?

We do not anticipate any risks or discomfort from your participation in the research, however the interview process may trigger some sensitive feelings and emotions as you share your experience. If this happens, you may choose to stop the interview. You can also request a list of resources and supports related to any upsetting feelings you may experience during or following the interview.

Benefits of the Research and Benefits to You

You may not receive any benefit from taking part in this study. However, it may be helpful to you to be able to share your feelings and thoughts about your experiences. In the future, others may benefit from what we learn in this study. We will share the results of this study through published articles, reports, and presentations to health care professionals and relevant organizations with the aim of delivering better care to women and their partners who participate in prenatal screening and/or receive an antenatal diagnosis of a fetal abnormality.

How will your privacy be maintained?

- · Your confidentiality will be respected.
- All documents will be identified only by a code name. Information that reveals who you are will not be released without your consent unless required by law.
- Your name will not be used in any presentations or publications of the study results.
- Quotes from the interview with you may be used in the presentations of findings, however these quotes will be edited as necessary to ensure your anonymity.
- For the duration of the study, any documents or audiotapes that contain confidential information will be stored in a locked filing cabinet. All electronic files and devices that contain confidential information will be password protected and encrypted. Only the research team will have access to this information.
- All study data, including audiotapes, interview transcripts, and fieldnotes will be kept for at least a 5-year period as per UBC policy. Data may be kept for a longer period of time depending on the outcomes of the study and the plans for future

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research. Once the data is no longer required, study materials will be destroyed in a way that your confidentiality will be maintained (ie. audiotapes will be demagnetized and paper documents will be shredded).

- Any hired transcriptionists and translators will be informed about privacy and confidentiality procedures and will be required to sign a confidentiality agreement.
- The researchers may use the data for another related study. In this case, your confidentiality will be respected as described in this consent.

Will you be paid for taking part in this study?

You will not be paid for your participation in this study.

Who can you contact if you have questions about the study?

If you have questions or concerns about what we are asking of you, please contact Ms. Laurie Cender. You may also contact Dr. Colleen Varcoe, who is supervising Ms. Cender's doctoral research at UBC School of Nursing. The names and telephone numbers are listed on the first page of this form.

Who can you contact if you have complaints or concerns about the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 604-822-8598 or if long distance email <u>RSIL@ors.ubc.ca</u> or call toll free 1-877-822-8598.

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CONSENT

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your access to health/support services or the provision of health care/support services for you or any of your family members.

- Your signature below indicates that you have received a copy of this consent from for your own records.
- Your signature below indicates that you consent to participate in this study.

Participant Signature

Date

Printed Name of the Participant signing above

Future Research: Consent to Contact

Please indicate with an X in the box below if the members of the research team can contact you to invite you to participate in future research studies.

Yes, I consent to be contacted about taking part in future research studies.

No, I prefer not to be contacted about future research studies.

Request for Summary of Study Results

Please provide your mailing or email address if you would like to be sent a summary of the study results.

lacksquare I would prefer to have a summary of the study results mailed to me

Mailing Address:

 $\hfill\square$ I would prefer to have a summary of the study emailed to me

Email Address:

Version 1: November 27, 2014

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APPENDIX C: PARTICIPANT INTERVIEW GUIDES

Interview Guide — Parent Participants

Interview Plan: My plan for the parent interviews is to start with a preamble that encompasses what I am interested in understanding and then to allow the participant(s) to speak to the area of interest with minimal need for multiple trigger or probing questions.

Sample Preamble: I am very interested in learning more about interactions between health care providers and parents. I am particularly interested in understanding the interactions between parents and health care providers when prenatal screening results in the diagnosis of a fetal abnormality. I am especially interested in understanding your thoughts and ideas about factors that shaped your interactions with health care providers and how this may have influenced your decisions about pregnancy options and/or your child's future health/healthcare. I would like to understand many things about this process, including: what this process was like for you, what guided your decision-making process, what you found supportive during this process, as well as the challenges and obstacles you faced. In addition, I would appreciate if you could share your point of view on ways you think HCPs can better support parents' decision making, ease parents' distress, and help to ensure that all parents are provided with the information and support they require.

Possible Trigger Questions/Probes (if needed):

1) Please start by telling me a bit about how you came to know about the fetal diagnosis of heart disease (or diagnosis of a fetal abnormality). Tell me about how you came to have an ultrasound of the fetal heart. What happened on the day of the ultrasound?

2) Please share your story about how the health care team shared the fetal diagnosis with you? Was there anything about their approach that you found particularly helpful? Was there anything you wish would have been done differently?

3) What has it been like for you (and your partner/family) since the day of the fetal ultrasound? Can you tell me about how you came to your decisions about further diagnostic testing (such as amniocentesis), pregnancy and/or postnatal treatment options for your baby? Who did you involve in these decisions? What was this process like for you?

4) During your meeting with the health care team, did you feel encouraged to share your points of view, beliefs and values? Did you feel comfortable asking questions? If yes, was there anything that encouraged or supported you to do this? On the other hand, was there anything that discouraged or prevented you from asking questions or sharing your point of view?

5) What decisions needed to be made after you were told about the fetal diagnosis? Who was involved in making these decisions? Was there anyone else you would have liked to involve in this process? Was there anyone you did not want involved? What helped you to make these decisions? What did not help?
6) How did the factors you shared in common (or did not share in common) with the health care providers shape your interactions? Consider gender, education, income, ethnic background and other things you shared or did not share in common. Do you think these similarities and/or differences influenced the decisions made following the fetal diagnosis? Please explain/provide examples.

7) Were there any more general factors that shaped your interactions with the health care team? Think about things like the amount of time available, the layout of the meeting rooms, and the health care team's points of view on health, the delivery of health care and health decision-making. Please explain.

8) What interventions/approaches/ decision support aids introduced or utilized by the health care team or others did you find most supportive/valuable? Least supportive?

9) What do you think might have made the experience and/or decision-making process less stressful (easier)?

10) What were some of the barriers/obstacles/constraints that you encountered in your decision making related to further diagnostic testing, and pregnancy and/or neonatal treatment options? What do you think would have made this an easier/smoother process?

11) Do you think your experience was different than others? If yes, please explain.

12) What advice would you give other parents about prenatal screening? What advice would you give health care providers about prenatal screening? Explain.

13) What advice would you give other parents who faced a similar antenatal experience? Explain.

14) If you could change something about your antenatal experience, what would it be?

Interview Guide — Health Care Provider (HCP) Participants

Interview Plan: Similar to my plan for interviews with the parent participants, my plan for interviews with individual HCPs is to start with a preamble that encompasses what I am interested in understanding and then allow participants to speak to the area of interest, hopefully limiting the need for multiple trigger or probing questions.

Sample Preamble: I am very interested in learning about parent and health care provider (HCP) interactions and the decision-making dynamics involved when parents receive an antenatal diagnosis of a chromosomal/congenital fetal abnormality. I am especially interested in learning your thoughts and perspectives on what factors shape your interactions with parents, as well as your ideas on how the nature of HCP-parent interactions may shape/influence how parents and/or HCPs approach decisions about prenatal diagnostic tests and pregnancy and/or neonatal treatment options. I am curious about what this process is like for you, what guides your approach with families, what supportive interventions you think are important, and any challenges or obstacles you face in your practice. In addition, I would appreciate if you could share your perspective on the health care team's role in general, and yours specifically, concerning strategies and approaches to support parental decision making, ease parents' distress and foster equity in HCP-parent interactions and decision making related to the diagnosis of a fetal abnormality.

Possible Trigger Questions/Probes (if needed):

1) Please tell me about your role in providing care and support to women and their partners who receive an antenatal diagnosis of a chromosomal/structural fetal abnormality/fetal heart defect.

2) Please share your perspective as to what you think is the best approach to take in providing information and decision-making support to parents who receive an antenatal diagnosis of a fetal abnormality. What do you view as the strengths of this approach? Are there any limitations/shortcomings that you have experienced in enacting this approach? Is there anything (patient/contextual /other factors) that might cause you to change this approach? If yes, please explain.

3) What factors do you think are important for parents to take into consideration when making decisions related to further diagnostic testing, pregnancy options, and/or neonatal treatment options? Who do you think should be involved in these decisions and what role do you think they should play? What is your vision of the "ideal" antenatal decision-making process?

4) When you meet with parents about pregnancy and neonatal treatment options for their fetus (baby), what information do you think is important/essential for you to understand about their personal and life circumstances? How do you /others obtain/discuss this information?

5) What do you think is the best approach for parents (and/or HCPs) to use when making decisions about further diagnostic testing and pregnancy and/or neonatal treatment

options following the antenatal diagnosis of a fetal abnormality? Who do you see as being involved in these decisions? (E.g. parent/health care providers/shared decision-making process/other). Please provide some specific examples of strategies that you find particularly helpful/not helpful.

6) Do you think socioeconomic, ethnic, gender and other differences between you and the patients and families you interact with might influence and shape your interactions and the associated HCP/parental decision-making? If yes, please explain/provide examples. If no, why not?

7) Are there any broader/more general factors that influence your interactions with parents related to antenatal diagnosis of a fetal abnormality and pregnancy/neonatal treatment decisions? (e.g. available time, factors associated with the hospital environment/philosophy of care/perspectives related to health and the delivery of health care etc.). Please explain.

8) What approaches to decision making do you encourage parents to take? Are there any decision support aids you or other members of the team recommend? If so, which do you think are the most supportive/valuable? Least supportive/helpful?

9) What personal/contextual/other factors do you think make the decision-making process less stressful/easier for parents/health care providers?

10) If someone in your personal family received a diagnosis of a fetal anomaly, what advice would you give to them (about coping with the experience/HCP-parent interactions /decision-making)?