Exploring parental experiences of continuing pregnancy in the presence of a life-limiting fetal condition: A qualitative meta-synthesis

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A thesis submitted in partial fulfillment of the requirements for the
Master of Science in Nursing Program

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Dedication

This thesis is dedicated to all the families I have worked with who have navigated this experience. Thank you for showing me that meaning and beauty can exist alongside loss and for inspiring me to do better.

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Abstract

Background: The field of perinatal palliative care aims to support the unique needs of parents who choose to continue pregnancy following the diagnosis of a life-limiting fetal condition (LLFC). As parents navigate this challenging trajectory, the support they receive from healthcare providers is crucial in shaping parental experiences.

Objective: to critically reflect on existing literature and to reveal a deeper understanding of the experience of continuing pregnancy in the presence of a LLFC

Design: Qualitative meta-synthesis

Methods: The primary search strategy consisted of multiple searches within four electronic databases. The analysis was guided by thematic analysis.

Results: This meta-synthesis included 29 qualitative studies. Three main themes were identified; time, uncertainty and relationships. These concepts exist concurrently within this trajectory and continuously influence each other as well as the overall experiences of parents.

Conclusion: Nurses are encouraged to acknowledge the significance of the interconnectedness between these key concepts and to critically reflect on how their everyday interactions become part of parents' lived experiences.

Acknowledgements

Dr David Wright: To my thesis supervisor, thank you for your ongoing encouragement and mentorship over the past four years. Completing this program has been challenging for me in many ways, but your continuous support enabled me to succeed. Throughout this journey, you have taught me many invaluable lessons and I am forever grateful to have shared this experience with you.

Dr Julie Chartrand & Dr Wendy Peterson: To my thesis committee advisors, thank you for sharing your knowledge and expertise with me. I have truly appreciated your ongoing encouragement, support and guidance throughout this process.

My family: To my husband, whose love and support made it possible to achieve this goal, thank you for always believing in me. To my children, thank you for your ongoing patience, I know it wasn't always easy. Mommy loves you. To my parents, thank you for always being so proud of me, no matter what.

Chapter 1: Introduction

For expecting parents, pregnancy is presumed to be an occasion marked by excitement, joy and hope for the future (Côté-Arsenault & Denney-Koelsch, 2016). However, receiving an unexpected diagnosis of a life-limiting fetal condition (LLFC) suddenly propels parents down a path inundated with complex medical decisions that yield far-reaching consequences (Luz et al., 2017; Wool, 2012). When a LLFC is identified for which no curative treatment options exist, it is anticipated that the baby will die either in utero or shortly after birth (Limbo et al., 2017; Wool et al., 2016). In these circumstances, some parents choose to continue their pregnancy with the hope of creating valuable memories and cherishing the limited time they have together. The growing field of perinatal palliative care (PPC) aims to support the unique needs of parents who choose to continue their pregnancy in the presence of a LLFC (Limbo et al., 2017; Wool et al., 2018). Support begins at the time of diagnosis, continues throughout the pregnancy and birth and extends into the bereavement period following death (Limbo et al., 2017). Within this model of care, several overarching goals are emphasised: validating the life of the infant, promoting bonding between parent(s) and child, pain and symptom management for the baby, creating valuable memories, as well as enhancing the quality of life of the child and family (Hasegawa & Fry, 2017; Limbo et al., 2017).

As parents navigate this complex and challenging trajectory, the support they receive from healthcare providers (HCP) plays a key role in shaping how parents experience and remember their pregnancy, as well as the life and death of their baby for years to come (Horning & Braun, 2006; Limbo & Kobler, 2010; Limbo et al., 2017; O'Connell et al., 2019; Quinn & Gephant, 2016; Wool, 2011). Relationship has been identified as a central component in the delivery of quality PPC and emphasis is placed on the importance of developing supportive and

therapeutic relationships that promote trust, foster hope, and provide comfort to parents throughout this difficult situation (Limbo & Kobler, 2010; O'Connell et al., 2019). Yet, the relatively new introduction of palliative care principles in the perinatal setting has revealed numerous ethical challenges encountered by HCP such as: a lack of familiarity supporting this population, a lack of clarity on best practices to guide care, as well as a lack of comfort in navigating the death of infants and parental grief (Mendez et al., 2017; Tosello et al., 2017; Wool, 2012). These challenges can ultimately hinder the development of meaningful relationships and adversely impact the care provided to this population (Atienza-Carrasco et al., 2018; Wool, 2012; Wool, 2015). Nurses are ideally situated to support the unique needs of parents who continue pregnancy in the presence of a LLFC as well as expand literature and enhance clinical practice in this area (Kratovil & Julion, 2017; Shorey et al., 2017). Within the field of PPC, nurses play a crucial role in supporting evolving healthcare needs, collaborating with key disciplines (such as obstetrics, neonatology and social work), coordinating specialized approaches to care, advancing health policy and research as well as improving program development and service delivery (Limbo et al., 2017).

The aim of this study is to review and analyze qualitative literature exploring the experiences of parents who choose to continue pregnancy in the presence of a LLFC. Since literature within this area has been relatively well established, a meta-synthesis of this literature can enable a deeper interpretation of previous research findings on this topic as well as expose new ways of understanding this experience that may not have been previously considered. This thesis will respond to existing literature gaps by enabling the critical analysis of key themes that occur throughout this experience. The insights gained from this study can inform clinical practice in this area, improve the supports families receive as well as enhance the therapeutic

relationships formed between HCP and parents navigating these situations. It is my intent with this thesis to inspire HCP working within this context to critically reflect on their everyday interactions with parents throughout this trajectory and to acknowledge the significant impact that these interactions have on the lived experiences of families.

To address my research aim, a qualitative design underpinned by the constructivist paradigm was used. Constructivism represents a naturalistic methodology for nursing research, in which a hermeneutic approach guides inquiry on a particular phenomenon of interest (Appleton & King, 1997). Within this paradigm, the researchers' clinical experience and knowledge inspires and guides the research process (Appleton & King, 1997). Guided by a constructivist approach, this thesis will enhance the readers' overall understanding regarding the experience of continuing pregnancy in the presence of a LLFC by exploring the narratives of participants who have lived it (Creswell, 2009; Weaver & Olsen, 2006). Critically analyzing the qualitative body of literature that has explored this topic from the perspective of parents will illustrate the many intricacies that exist within this trajectory and reveal valuable insights into this complex experience. The knowledge gained from a constructivist approach can help address some of the prevalent gaps that exist within this field as well as enhance our ability as HCP to support the unique and holistic needs of this population.

This thesis is guided by a relational ethics framework. Relational ethics asserts that ethical issues exist within everyday clinical practice across a variety of settings and that these ethical issues are situated within a relational context (Pollard, 2015). The concepts of relationship and experience are central within this framework and emphasis is placed on the development of ethical relationships that foster health, healing and personal growth (Pollard, 2015). It is in fostering intimate and reciprocal relationships with patients that HCP can enhance

their understanding of individual patients' needs as well as gain an appreciation for what patients identify as the most important aspects of their care. Relational ethics draws attention to the inherent value that exists within the experiences of others, the level of complexity within each individual situation and the impact relationships have on the overall experiences of patients (Austin et al., 2003; Pollard, 2015).

Organization of this thesis

Following this introduction, the first chapter of this thesis will describe the significance of this topic as well as inspiration for this research project. Chapter one will also provide a descriptive review surrounding the prenatal detection of life-limiting conditions as well as the field of perinatal palliative care. Chapter two will summarize existing literature surrounding the topic of continuing pregnancy following the diagnosis of a LLFC, which is presented as a narrative review of the lived experiences of families who have navigated this phenomenon. The third chapter of this thesis outlines the philosophical orientation, theoretical framework, proposed methodology, quality appraisal and analytic process for this research project. Chapter four presents the findings revealed from the data analysis according to the following three overarching themes; time, uncertainty and relationship. The fifth chapter of this thesis contains the discussion, which includes a summary of the overall findings as well as situates these findings within supporting literature from similar contexts such as perinatal loss and pediatric life-limiting illness. Chapter five also explores the interconnectedness that exists between the central themes of time, uncertainty and relationship and the significance of this connection. The fifth chapter of this thesis also contains implications of these findings on clinical practice, the study strengths and limitations, implications for future nursing research and education as well as concluding remarks.

Inspiration

The inspiration for this thesis was derived from my direct clinical practice within this area. Since graduating in 2008, my nursing practice has primarily focused on supporting the perinatal population across a variety of diverse contexts. Throughout my career thus far, I have gained experience and knowledge surrounding perinatal nursing throughout multiple clinical areas along this continuum of care: pregnancy, labour and birth, postpartum and neonatal intensive care. I have always appreciated having such a diverse clinical background and feel it has enhanced my ability to support the perinatal population within a variety of clinical settings. Professional growth and development represents a core value that underpins my nursing practice and I have continuously pursued opportunities that would challenge my level of expertise and expand my existing knowledge base and skill-set. This passion for ongoing learning has not only enabled me to better support the evolving needs of this population but has also created opportunities for me to share my knowledge and expertise with novice nurses entering this field.

A few years ago, my career journey brought me to a pediatric palliative care facility in Ottawa, where I was formally introduced to palliative care nursing. Given my past clinical experience, I quickly found myself drawn towards the organization's perinatal hospice program, where I subsequently became a nurse coordinator. This opportunity allowed me to combine my past clinical experience in perinatal nursing with my newly acquired palliative care skills and support the unique needs of a vulnerable population. I began to appreciate how much the hospice setting differed from an acute hospital environment when caring for infants and children with life-limiting conditions. The most notable difference was the overall goals and approach to care; instead of an intensive, task-based approach, the hospice focused primarily on enhancing comfort and quality through a holistic model of care. As I gained clinical experience within the perinatal

hospice program, my desire to provide exceptional care to families navigating these situations grew. My clinical involvement within this field also enabled me to observe several gaps in the care and services that existed for this population. The following case exemplars are drawn from my clinical practice and describe the experiences of two families within the perinatal hospice program. These stories, along with many others, are what inspired the focus of this research inquiry. All names used within the case exemplars are pseudonyms.

Mary and her husband John arrived at the hospital in labour following a healthy first pregnancy. There were unexpected complications during the delivery of their daughter Lily. Shortly after her birth, Lily was transferred to the neonatal intensive care nursery, placed on a mechanical ventilator for breathing support, started on intravenous hydration and received multiple medications for sedation as well as management of seizures. After conducting several diagnostic tests, Mary and John were told that their daughter Lily had a very poor prognosis and that she would not survive long after withdrawing life-prolonging interventions. Mary and John suddenly faced an unanticipated new reality where they were experiencing parenthood for the first time while simultaneously preparing to say goodbye to the future life they had envisioned with their daughter. After a few days, Mary and John made the difficult decision to discontinue Lily's mechanical ventilation and to transition from intensive care towards the more comfort-based approach of palliative care. Lily's mechanical ventilation was stopped and Mary, John and Lily transferred to the nearby pediatric hospice to spend additional quality time together as a family. At the hospice, the family received on-going support from the PPC team. Mary, John and Lily were able to create many valuable memories together in the short time they had. Through the entire experience, there were so many unknowns encountered by Mary and John: what caused Lily's lethal prognosis, how long would she survive without life-prolonging

interventions, what symptoms would she experience, would she feel any pain, would she experience hunger and what does end of life look like for a newborn? During the several weeks the family spent at the hospice, their journey was a rollercoaster of emotions and uncertainties, which became increasingly challenging, not only for Mary and John, but also for the staff caring for Lily. Throughout this experience, I began to appreciate the importance of every action and interaction with the family and how it could influence their experience surrounding the life and death of their child. It also became evident that for parents navigating such a vulnerable situation, the guidance received from HCP as well as the therapeutic relationships formed throughout these experiences could have a profound impact on parental decision-making, coping and levels of distress. Following my involvement with this family, I began to question the extent to which our interactions as HCP shape the overall lived experiences of the families we care for.

Within the hospice, I cared for another family, Anna, Bryan and their newborn son Henry. Henry had been diagnosed with a life-limiting cardiac condition during a routine ultrasound at 20 weeks gestation. The cardiac condition that Henry had was severe and it was not expected that Henry would live long following birth. Anna and Bryan were informed that they could terminate the pregnancy or continue until its natural end and meet their son. They were also advised that if they chose to continue the pregnancy, heart surgery could be performed on Henry following birth, which could potentially give Anna and Bryan more time with their son. There were significant risks associated with the operation and Henry would undergo multiple medical procedures soon after he was born, with no guarantee of success. Anna and Bryan chose to continue the pregnancy and decided on a comfort-based approach to care instead of the surgical option, which would not change Henry's underlying prognosis. They were referred to the PPC team for support throughout the remainder of the pregnancy. A specialized birth plan

was created in collaboration with the team, in which Anna and Bryan articulated their desire to transfer to the hospice as soon as possible after delivery, so that they could spend quality time with Henry. I was the nurse assigned to care for them. I settled Anna into the king size bed of one of the palliative suites, where she held Henry skin to skin. I remember sitting next to her with Henry in her arms and we began talking about his birth. Anna shared with me a video that Bryan had taken from Henry's delivery. Anna, like many other mothers, was so proud to share details from this special occasion with me and to talk about the birth of her son. This experience was the first time that I had ever cared for a family who received the diagnosis of a LLFC during pregnancy. I listened as Anna reflected back on her pregnancy experience and on the final weeks leading up to Henry's birth. Anna made a comment that stuck out to me; she said that she was so grateful that Henry survived pregnancy and birth, and that she felt so blessed that they were able to meet him alive. I empathized with how difficult continuing pregnancy in the presence of a LLFC must have been for Anna and her family. In most developed countries, we assume that pregnancy will end with the birth of a "healthy" child, however in Anna's case, her greatest hope was transformed into a desire to meet her baby alive, even if only for a moment. For Anna, this desire to meet Henry alive was threatened daily by the reality that, as with many LLFCs, there was an increased risk of death occurring in utero or during delivery. As I continued to reflect on this family's story, I was inspired to gain a deeper understanding of the lived experiences of families such as Anna and Brian, who choose to continue their pregnancy in the presence of a LLFC.

Background

Prenatal screening is now considered a standard prenatal practice that can reveal important information to HCP (Carlsson et al., 2017; Lou et al., 2017; Sullivan & Faoite, 2017;

Wright & Perry Black, 2013). In Ontario, prenatal screening is done between 11 to 14 weeks gestation to determine the viability of a fetus, estimate the gestational age as well as identify chromosomal abnormalities (Born Ontario, 2019). In addition, a second ultrasound is offered in pregnancy between 18-20 weeks gestation to assess the growth and anatomical structures of the fetus (Born Ontario, 2019; Carlsson et al., 2017).

Over the past several decades, advances in the field of fetal diagnostics have enabled an increase in the detection and accuracy of fetal anomalies during routine ultrasounds (Hasegawa & Fry, 2017; Kidszun et al., 2016; Lou et al., 2017; Sullivan & Faoite, 2017). Additional testing such as maternal blood draws, amniocentesis, as well as chorionic villus sampling have also increased the identification and specificity of fetal conditions in utero (Hasegawa & Fry, 2017; Marty & Carter, 2018). These advances provide opportunity to positively influence perinatal management through the early detection, prevention or treatment of certain illnesses and conditions (Chevalier McKechnie et al., 2015; De Jong et al., 2015; Kermorvant-Duchemi & Ville, 2017). For example, early detection through prenatal testing has improved infant mortality for anomalies such as congenital diaphragmatic hernia or transposition of the great arteries, which require immediate postnatal intervention or surgery for survival (Kermorvant-Duchemi & Ville, 2017). For some babies diagnosed with fetal anomalies in utero, various types of medical therapies and treatments may be available and appropriate (Wool, 2011). However, some anomalies detected during pregnancy are so severe that it is anticipated the baby is unlikely to survive, a condition commonly described within the literature as life-limiting (American College of Obstetrics and Gynecologists [ACOG], 2019; Limbo et al., 2017; Wool et al., 2016).

Life-limiting fetal conditions (LLFC) refer to circumstances where no curative treatment options exist, life expectancy is severely shortened and death is anticipated to occur as a result of

the condition (ACOG, 2019; Côté-Arsenault & Denney-Koelsch, 2016; Limbo et al., 2017; Wool et al., 2016). These conditions are typically associated with poor quality of life for which treatments are deemed burdensome and the effectiveness of medical interventions is uncertain (ACOG, 2019). Related terms used to describe these types of conditions within the literature include: lethal, fatal, incompatible with life and viability-limited. However, several authors have recommended that the term life-limiting condition be used as the alternative since it conveys compassion and sensitivity towards the parents, demonstrates respect for the child's life as well as acknowledges the reality that due to ongoing medical advances, conditions previously deemed as fatal now have increased rates of survival (Kidszun et al., 2016; Mendez et al., 2017; Wilkinson et al., 2014).

The diagnosis of a LLFC results in a perinatal death, which is defined as the loss of a fetus at any point during the pregnancy or the death of an infant in the first 28 days of life (Hendson & Davies, 2018; Wool et al., 2016; World Health Organization [WHO], 2016). Despite on-going technological advances, the rate of perinatal death within Canada has remained relatively stable (Statistics Canada, 2019). In Canada and the United States, congenital fetal anomalies represent the leading cause of perinatal mortality and account for more than 20% of all perinatal deaths (ACOG, 2019; Blakeley et al., 2019a; Kamrath et al., 2019; Statistics Canada, 2017; Tosello et al., 2017; WHO, 2016). These conditions occur in approximately 3% of all pregnancies and refer to either structural or functional malformations in fetal development that exist prior to birth (Chevalier McKechnie et al., 2015; DiMiceli-Zsigmond et al., 2015; WHO, 2016). Although it is often difficult to identify the exact cause of all anomalies, they are typically the result of one or more genetic, infectious, nutritional or environmental factors (WHO, 2016). Various types of life-limiting conditions exist, such as brain anomalies, genetic

disorders, cardiac malformations and renal tract anomalies (Blakeley et al., 2019a). Congenital fetal anomalies most commonly described as being life-limiting include anencephaly, renal agenesis, trisomy 13, trisomy 18 and hypoplastic left heart syndrome (Lotto et al., 2018; Rocha Catania et al., 2017; Tosello et al., 2017; Wilkinson et al., 2014).

Following the diagnosis of a LLFC, two approaches to care exist for parents; they can elect to terminate the pregnancy relatively soon after the diagnosis is confirmed, or they can choose to continue the pregnancy irrespective of the diagnosis (ACOG, 2019; Lefkowits & Solomon, 2016; Marty & Carter, 2017; Parravicini, 2017). The dominant choice of parents in these circumstances has been termination of pregnancy following such a diagnosis (Blakeley et al., 2019a; Côté-Arsenault & Denney-Koelsch, 2018; Lefkowits & Solomon, 2016; Marty & Carter, 2017). However, more recent literature within this field has revealed that the option to continue the pregnancy while receiving support from a specialized interdisciplinary team is becoming an increasingly popular alternative to termination for some families (Limbo et al., 2017; Wool et al., 2018).

Perinatal Palliative Care

Perinatal palliative care (PPC), also referred to as perinatal hospice, represents a developing speciality that supports the unique needs of families who choose to continue pregnancy following the diagnosis of a LLFC (Hasegawa & Fry, 2017; Limbo et al., 2017; Wool et al., 2018). PPC emerged from the adult hospice model, focusing initially on comfort and pain management of the newborn, however has evolved over the years to also emphasise the importance of providing holistic and family-centered support as well as advocating for bonding and attachment between the parent(s) and baby (Hasegawa & Fry, 2017; Marty & Carter, 2017). The overarching goals of PPC align closely with those of adult palliative care; to alleviate

suffering and improve the quality of life of individuals with life-limiting diagnoses and their families (Canadian Hospice and Palliative Care Association [CHPAC], 2013; Hasegawa & Fry, 2017; Kenner et al., 2015; Lefkowits & Solomon, 2016; Limbo et al., 2017; WHO, 2018). PPC represents a subspecialty of pediatric palliative care, which is defined as an active, family-centered process that aims to address the holistic needs of children with life-limiting illness and their families (Kiman & Doumic, 2014; WHO, 2018). Within the pediatric and perinatal contexts, the notion of palliative care extends beyond simply focusing on end-of-life, to provide on-going, compassionate and comprehensive support to families beginning at the time of diagnosis, continuing throughout the remainder of the illness trajectory and extending into the bereavement period (CHPCA, 2013; Cole et al., 2017; Kiman & Doumic, 2014; Limbo et al., 2017; Mendez et al., 2017; Wool, 2013). This model of care supports families in making informed decisions regarding complex medical issues as well as ensures that the individual values and wishes of each family are honoured (ACOG, 2019; Hasegawa & Fry, 2017). Emphasis is placed on validating the life of the child and on enhancing the quality of time the family has together, no matter how brief (Hasegawa & Fry, 2017; Quinn & Gephart, 2016; Sumner et al., 2006; Wool, 2013).

Regardless of the type and severity of the life-limiting condition, PPC represents an appropriate option to support the unique needs of parents who are expecting or caring for an infant diagnosed with an uncertain prognosis (ACOG, 2019; Kiman & Doumic, 2014). PPC consists of several essential elements that aim to provide the best possible supports to families navigating these situations (Kiman & Doumic, 2014). The following paragraphs will outline some of the key elements embedded within this approach.

Interdisciplinary team

PPC is delivered by a specialized interdisciplinary team comprised of nurses, physicians, social workers, child life specialists and spiritual care workers (Bennett et al., 2010; Cole et al., 2017; Coleman, 2015; McNamara et al., 2013; Rocha Catania et al., 2017). The interdisciplinary support provided to families aims to address the holistic needs of the parents, offer a sense of security, improve the continuity of care and reduce feelings of isolation or abandonment (Áskelsdótti et al., 2008; Cole et al., 2017; Rocha Catania et al., 2017). Due to the sensitive nature of the topics discussed with parents as well as the complexity and magnitude of decisions that occur throughout this trajectory, it is essential that therapeutic relationships fostering trust and respect are developed between HCP and families early on (Côté-Arsenault & Denney-Koelsch, 2016; Wool, 2012). Within this interdisciplinary team, nurses play an essential role in the delivery of PPC and are ideally situated to form intimate relationships with parents navigating these situations. Nurses are able to draw on various areas of expertise such as family-centered care, service coordination, interprofessional collaboration and bereavement care, to enhance the supports provided to this population.

Care Coordination

In many PPC programs, nurses are engaged as care coordinators (Cole et al., 2017; Limbo et al., 2017; Wool & Catlin, 2018; Wool, 2013). Care coordination has been identified as essential in ensuring continuity of care, consistent communication between all members of the healthcare team, enhancing parental satisfaction, facilitating access to services as well as monitoring the quality of care and services provided (Cole et al., 2017; Limbo et al., 2017; Wool, 2013). Nurse coordinators serve as a consistent point of contact for parents, possess advanced knowledge in birth planning and bereavement care as well as play a key role in providing ongoing support and minimizing exposure to fragmented care (Cole et al., 2017; English &

Hessler, 2013; Limbo et al., 2017; Wool & Catlin, 2018). Care coordination ensures that parents have access to more frequent medical visits with the healthcare team, ensures adequate time is available to address questions, shares clinical information with families so it can be absorbed gradually over time and supports the multitude of diverse emotions that parents experience throughout this trajectory (Kamrath et al., 2019; McNamara et al., 2013).

Specialized birth planning

Specialized birth planning represents another essential component of PPC (ACOG, 2019; Cole et al., 2017; English & Hessler, 2013; Limbo et al., 2017; Roush et al., 2007; Wool, 2013). Within the literature, the term advanced care planning is commonly used interchangeably with birth planning (Marty & Carter, 2018; Wool & Catlin, 2018). A birth plan, which is co-designed between HCP and parents, represents a document that outlines parental wishes surrounding the care desired throughout the pregnancy, birth, post-partum, and end-of-life periods (Kamrath et al., 2019; Kenner et al., 2015; Marty & Carter, 2017; Mendez et al., 2017). The birth planning process helps families to explore what is most meaningful to them as well as their personal values and beliefs, thus each plan is individualized and tailored to the family's unique needs (Cole et al., 2017; Wool, 2013; Wool & Catlin, 2018). These specialized plans evolve over time and must be flexible in order to accommodate changes to parental decisions and wishes (Kamrath et al., 2019; Wool & Catlin, 2018). The plan addresses topics such as: desired support people at the time of delivery, spiritual and cultural preferences, memory making opportunities, management of pain and symptoms (for both mom and baby), the plan for the baby immediately after birth (postnatal interventions desired) as well as any end-of-life considerations that are important to the family (Gomes Guimaraes et al., 2019; English & Hessler, 2013; Wool & Catlin, 2018). Birth planning also provides parents and HCP an opportunity to discuss the many

possible outcomes that can occur during pregnancy and following birth. These outcomes may include a variety of post-natal symptoms, the possibility that baby may be stillborn and estimates for length of time baby is anticipated to survive (English & Hessler, 2013; Marty & Carter, 2017; Roush et al., 2007; Wool & Catlin, 2018). Acknowledging the different potential outcomes that can occur helps parents anticipate what to expect next, yet also encourages them to "hope for the best while preparing for the worst" (Cole et al., 2017, p. 906). The birth plan also serves as an important communication tool for all members within the circle of care, which helps to minimize the amount of onerous or repetitive discussions that families engage in and provides a clear outline of parental wishes, limiting assumptions or misconceptions regarding the plan of care (Gomes Guimaraes et al., 2019; Kamrath et al., 2019; Marty & Carter, 2017). In addition, when done effectively, the birth plan has been shown to increase parental satisfaction, decrease feelings of fear and anxiety, assist parents in developing resiliency while also providing them with a sense of control (Cole et al., 2017; Côté-Arsenault et al., 2015; Lou et al., 2017; Marty & Carter, 2017; Roush et al., 2007; Wool & Catlin, 2018).

Memory making and legacy building

Memory making and legacy building are also key elements within PPC (Kamrath et al, 2019; LeDuff et al., 2017; Miller et al., 2014; Ryan et al., 2015). Memory making refers to the creation of meaningful experiences together as a family as well as the creation of tangible mementos that the family can cherish for years following the death of their child (Kamrath et al., 2019; Lou et al., 2017; Miller et al., 2014; Ryan et al., 2015). Due to the limited amount of time available to many parents within this context, "an entire lifetime of memories must often be compressed into days, hours, or even minutes" (Miller et al., 2014, p.103). Nurses and other HCP caring for parents navigating these situations are encouraged to be creative while promoting

memory making opportunities and to think beyond routine protocols to accommodate families' requests (Kamrath et al., 2019). Memory making opportunities can include photographs, ink prints and molding of hands and feet. The collection of various newborn mementos can be initiated at any point along this trajectory and has been shown to positively impact the parental grieving process (Coleman, 2015; Kamrath et al., 2019; Kenner et al., 2015; LeDuff et al., 2017; Miller et al., 2014; Rocha Cantania et al., 2017; Wool & Catlin, 2018). Legacy formation refers to the memories and lasting impression someone leaves behind once they have died (Kamrath et al., 2019). Many parents have discovered a profound sense of meaning within legacy building activities such as organ donation, breastmilk donation and participating in research studies, fundraisers or awareness campaigns (Kamrath et al., 2019).

Attachment and bonding

Promoting opportunities for parents to bond with their baby is essential within PPC (Cole et al., 2017; Kenner et al., 2015; Marty & Carter, 2017; Wool & Catlin, 2018). As with any pregnancy, attachment between a mother and their baby can begin to form early on, often within the first trimester (Wool & Catlin, 2018). Since many LLFC are confirmed in the second trimester of pregnancy, bonding between parent(s) and baby has often already started by the time the condition is identified. Given the short life expectancy associated with many LLFC, parents within this context have limited opportunities to bond and spend time with their baby. Thus, promoting and advocating for bonding opportunities during pregnancy (such as more frequent ultrasounds, reading stories and taking prenatal photographs) as well as after the birth (such as newborn photography, holding, feeding, diapering and bathing) can enhance and maximize the time parents have with their child (Cole et al., 2017). Several publications in this area now recognize the importance of routine bonding activities such as cuddling, bathing and dressing

baby after death if parents desire (Cole et al., 2017; Kamrath et al., 2019; Ryan et al., 2015; Wool & Catlin, 2018). These acts of bonding have been described as being very therapeutic and can positively influence the grieving process (Van Dinter & Graves, 2012). Encouraging parents to participate in traditional parenting activities despite the diagnosis and prognosis can promote a sense of normalcy during pregnancy and after birth as well as assist parents in celebrating life rather than solely focusing on the anticipated loss (Cole et al., 2017; Kamrath et al., 2019).

Grief and bereavement support

Grief and bereavement support is considered an essential component within PPC (Bennett et al., 2010; Kiman & Doumic, 2014; LeDuff et al., 2017; Wool & Catlin, 2018). Due to the many difficult and complex emotions that parents may encounter throughout this experience, it is essential that they have access to professional support and counselling beginning at the time of diagnosis, throughout the pregnancy and following death (Bennett et al., 2010; Kenner et al., 2015; Kiman & Doumic, 2014; Wool & Catlin, 2018). The supports offered to families must be individualized as well as reflect the unique and complex bereavement needs of each family member (Bennett et al., 2010; Miller et al., 2014; Wool & Catlin, 2018). Within PPC, peer support either during the pregnancy or following death enables parents to connect with others who have navigated similar experiences and can enhance the supports available to parents throughout this trajectory as well as decrease feelings of isolation (Rocha Catania et al., 2017; Ryan et al., 2015). Within many PPC programs, bereavement services are available to other family members such as siblings and grandparents, who are also grieving a loss, yet may require different supports and resources (Cole et al., 2017; Roush et al., 2007). Follow-up contact with the family is considered a standard practice in bereavement care and can be in the form of phone-

calls, cards or invitations to special memorial ceremonies (McNamara et al., 2013; Wool & Catlin, 2018).

Ethical considerations surrounding Perinatal Palliative Care

Over the past two decades, the importance of offering palliative care to families who receive the diagnosis of a LLFC in pregnancy or the newborn period has been increasingly recognized (Hasegawa & Fry, 2017; Sumner et al., 2006; Wool et al., 2018). Prior to the emergence of PPC in the late 1990's, the options and supports offered to families within this context were limited and arguably lacked the same dignity and respect provided within a traditional model of palliative care (Hoeldtke & Calhoun, 2001; Sumner et al., 2006; Wool et al., 2018). Dignity and respect, which represent ethical principles that guide clinical practice, emphasise that the intrinsic worth of every human being be recognized, and that all patients receive high quality care that respects and honours life (Wool & Dudek, 2013). It has been widely acknowledged that many parents who choose to continue pregnancy following the diagnosis of a LLFC assign an identity to their unborn child (fetus), thus within the context of this thesis the unborn child (fetus) will be referred to as a unique person. This framing reflects the parental perspectives described throughout the literature exploring this topic; it should not be read as a broader normative stance regarding the legal status of a fetus or the ethics of pregnancy termination. Despite the personhood assigned to an unborn child (fetus) by parents, several practices previously implemented while caring for families navigating a perinatal death demonstrated a lack of dignity and respect for the unborn child (fetus) and for the wishes of the parents. Historically, the experience of perinatal loss was often regarded as a "non-event" or a "professional blind-spot" which ultimately failed to acknowledge the personhood of the unborn child (fetus) as well as the significance of the death on the family (Hoeldtke & Calhoun, 2001,

p.526; Limbo & Kobler, 2010). For instance, the importance of promoting parental bonding within this context has only been recognized within the last few decades. Prior to this, practices such as seeing or holding a deceased infant were discouraged and were even thought to have a negative impact on parents' psychological well-being (Limbo & Kobler, 2010). This previous protective approach was believed to shelter parents from undue hardships, however it ultimately denied them the opportunity to bond, create memories and say goodbye to their baby (Limbo & Kobler, 2010; Wool, 2012). Yet, in the adult model of palliative care, acts that promote bonding and permit time to say goodbye to loved ones are considered routine practices that are widely supported following death (Registered Nurses Association of Ontario [RNAO], 2011).

Despite PPC becoming increasingly recognized as an alternative approach to care, many families continue to voice that this option was not presented to them following the diagnosis of a LLFC (Marty & Carter, 2017; Wool, 2013; Wool & Dudek, 2013). When all management options are not presented equally, families are not adequately prepared to make informed decisions regarding how to proceed in the pregnancy and following birth. It has been suggested that "without a perinatal palliative care plan in place, the default treatment for infants with prenatally diagnosed life-limiting conditions is likely to be invasive" (Kamrath et al., 2019, p.313). An intensive approach to care for these babies can result in an increased number of painful procedures which are unlikely to result in long-term survival, an increased level of parental stress and anxiety as well as limited opportunities for bonding due to the physical and emotional separation parents experience when newborns are admitted to the intensive care unit (Kamrath et al., 2019; Wool & Catlin, 2018). To uphold ethical standards of practice, HCP have an obligation to disclose all information regarding medical conditions to families, including all available treatment options, which will ensure the choices made by families are truly informed

(Kamrath et al., 2019; Wool et al., 2018). However, literature within this area has revealed significant gaps in how management options following the diagnosis of a LLFC are presented to parents, demonstrating both a lack of respect and dignity for the life of the unborn child (fetus) and for parental decision-making. It is also important to note that in some countries around the world, termination of pregnancy beyond a certain gestational age is considered illegal, regardless of the fetal condition, which fails to offer certain parents a choice at all (Blakeley et al., 2019a; Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsch, 2011; McNamara et al., 2013).

Many families have articulated that when the option to continue the pregnancy was presented, it was often accompanied by dismissive language as well as personal assumptions and bias from HCP (Marty & Carter, 2017; Wool, 2013). For example, the notion of a child's anticipated quality of life is often discussed with parents in conversations pertaining to management options, yet several studies in this field have identified that clinicians typically projected the quality of life of these babies to be particularly negative, in comparison to parental perspectives (Guon et al., 2014; Hasegawa & Fry, 2017; Kukora et al., 2017). The use of biased language and personal assumptions within dialogue surrounding management options can devalue the life and personhood of the unborn child (fetus), adversely impact parental decision-making and create breakdown within the therapeutic relationship between HCP and parents (Guon et al., 2014; Hasegawa & Fry, 2017; Kukora et al., 2017).

Several studies have also revealed that following the diagnosis of a LLFC, many parents articulated feeling pressured to terminate their pregnancy by the healthcare team (Côté-Arsenault & Denney-Koelsch, 2011; Denney-Koelsch et al., 2018; Hasegawa & Fry, 2017; Wool, 2012; Wool, 2013; Wool & Dudek, 2013). It has been proposed that the preference for termination could be the result of a lack of comfort and understanding regarding the alternative management

option of continuing the pregnancy (Wool, 2012). Literature in this field has also suggested that by placing emphasis on pregnancy termination, clinicians intended to minimize additional suffering and prevent parents from experiencing any undue emotional burdens that were thought to accompany continuing pregnancy in the presence of a LLFC (Coleman, 2015; Fleming et al., 2016; Hasegawa & Fry, 2017). Yet literature that has explored the experiences of parents who terminate the pregnancy within this context has demonstrated the contrary; following termination, some parents experienced difficulty coping, self-blame, isolation and stigmatization as well as negative psychological consequences such as distress, guilt, anxiety, depression and post-traumatic stress (Blakeley et al., 2019b; Lafarge et al., 2013; McCoyd, 2009; Wool, 2011).

Deciding whether to continue or terminate the pregnancy is a devastating and difficult choice that yields far-reaching consequences regardless of which option parents choose (Wool, 2011). Although ethical principles are fundamentally rooted within nursing practice, supporting families in their decision-making within this context can be complex and challenging (Wool, 2012). The College of Nurses of Ontario (CNO) has outlined a code of ethics in addition to several professional practice standards that are in place to guide daily nursing practice (CNO, 2019). Ethical values identified by the CNO include: client well-being, client choice, confidentiality, respect for life, truthfulness and fairness. (CNO, 2019). It is through the enactment of these values within clinical practice that nurses can ensure the provision of high quality, safe, and ethical care (CNO, 2019). However, when parents are pressured by HCP, including nurses, to choose one option over the other, it fails to demonstrate respect for parental choices and the life of the unborn child (fetus) as well as fails to uphold these professional standards that guide clinical practice.

In addition to the above-mentioned inconsistencies that exist in counselling families on various management options, the lack of access to PPC services has also been identified as a barrier for many families. Although PPC continues to develop as a distinct subspecialty within pediatric palliative care and there continues to be increasing awareness surrounding this approach, not all families have access to these specialty services (Sumner et al., 2006; Côté-Arsenault & Denney-Koelsch, 2016). Within Canada, there are currently less than ten PPC programs (Perinatal Hospice & Palliative Care, 2018). The limited number of established programs reinforces the reality that many families who could benefit from these services may not be presented with this option due to lack of accessibility and geographical considerations. Thus, many families who feel that this model of care closely aligns with their values and beliefs may be deprived of this opportunity due to this lack of access. This represents another significant gap in services available to this population. In contrast, there are many more established palliative care programs available to support the adult population in Canada (Canadian Hospice and Palliative Care Association, 2020).

Although the model of PPC is a relatively new addition to the perinatal field, HCP have an obligation to provide competent and compassionate care as well as on-going support to parents navigating these situations (Wool, 2012). Due to the innate sadness and complexity surrounding the experience of continuing pregnancy in the presence of a LLFC, it has been suggested that HCP who are inadequately trained to care for this population are at risk of experiencing moral distress, which can have a negative impact on their psychological health (Wool, 2012). For parents navigating this experience, the lack of understanding and support from HCP can perpetuate feelings of isolation and abandonment within the healthcare system (Hasegawa & Fry, 2017; Wool, 2013). The principles of PPC can be enacted by any healthcare

team or organization, yet a lack of knowledge, comfort or confidence in providing PPC can result in HCP disengaging from patients and negatively impact the development of meaningful therapeutic relationships (Pollard, 2015; Wool, 2012). In addition, the lack of awareness surrounding the principles of PPC can result in clinicians promoting termination as the preferable choice when LLFC are detected prenatally, resulting in fewer referrals to established PPC programs and unjustly limiting the supports offered to families navigating pregnancies where a LLFC is identified (Wool, 2012). Limited funding dedicated to expanding PPC services also continues to hinder the accessibility and implementation of such programs across the country (Limbo et al., 2017; Wool & Catlin, 2018).

Research objective

The aim of this study is to conduct a meta-synthesis of qualitative literature exploring the experiences of parents who choose to continue pregnancy in the presence of a LLFC. The existing body of literature exploring this topic has generated a wealth of knowledge surrounding this experience. Despite this, there remains both research and practice gaps in this area. In reflecting on how best to approach these gaps, rather than conducting an individual qualitative study, it is my belief that drawing on the collective wisdom from previous researchers will offer a deeper understanding of this experience and avoid duplicating previous findings. Although a recent qualitative meta-synthesis on this topic has been published (Blakeley et al., 2019b), the focus of that study was on the *decision-making process* of parents following the diagnosis of a LLFC, whereas this study will explore parental experiences throughout this entire phenomenon, from diagnosis into the bereavement period. In addition to exploring parental narratives, I will also analyse the ways in which these experiences have been constructed and interpreted by the various authors. Guided by a relational ethics framework, it is my intent to illustrate the intrinsic

value for nursing knowledge that exists within participant narratives, as well as the significant impact that everyday interactions have on the overall lived experiences of parents within this context. Critically analysing the overarching themes that characterize this experience across multiple qualitative studies will reveal insights that can inform clinical practice, improve the supports parents receive while navigating this experience as well as enhance the therapeutic relationships formed between parents and HCP throughout this trajectory.

Chapter 2: Literature Review

Although a meta-synthesis is itself a form of reviewing the literature, this chapter of the thesis will provide a descriptive overview of the experience of continuing pregnancy in the presence of a LLFC, situating the research study within the current literary context as well as revealing pertinent gaps that exist within both research and clinical practice. This literature review will enhance the reader's understanding of this experience and serve as a foundation for engaging with my meta-synthesis that is presented in subsequent chapters. It was developed through an ongoing process of thoughtful engagement with the literature, enabling the purposeful selection of publications that would enhance the reader's understanding of continuing pregnancy in the presence of a LLFC. The primary strategy for this literature review consisted of multiple searches within various electronic databases. Initially, key terms such as PPC, LLFC and pregnancy, were searched for in the titles, major headings and abstracts to develop a foundation of publications that would be incorporated into the literature review. Over time, as my familiarity with the literature increased, the search strategy evolved into a more dynamic and iterative process. Additional publications were also identified by reviewing reference lists. The search was limited to scholarly journals that were written in English and were peer reviewed. To demonstrate relevance within our current healthcare context, studies published prior to the year 2000 were not included in this review. For a publication to be included, it needed to explore the experience of continuing a pregnancy in the presence of a life-limiting condition at any point throughout this trajectory. The search for this literature review is distinct from the search conducted for the meta-synthesis, which will be described in Chapter 3.

The experience of continuing a pregnancy in the presence of a LLFC

The body of literature exploring this topic continues to grow. Among this research, several studies across diverse fields and methodologies have sought to describe the experience of continuing pregnancy in the presence of a LLFC, from diagnosis to bereavement. As I became increasingly familiar with the literature surrounding this topic and continued to reflect on my own clinical involvement with this population, I noticed that the narratives of parents emphasized distinct periods of time that occurred throughout this experience. I began to reflect on the significance of these distinct periods of time, which appeared to resemble unique milestones that occur throughout this trajectory. Milestones within this context represent important life events that stimulate change and signify the start of a new chapter. In exploring qualitative literature that seeks to understand human experience, the narratives shared by participants represent their unique story surrounding a significant time in their lives. Thus, in organizing this section of the thesis, I conceptualized the phenomenon of continuing pregnancy in the presence of a LLFC as a *story* containing four distinct chapters. Conceptualizing this experience as a story, and organizing it according to various chapters enabled me to highlight the key milestones that parents encounter throughout the duration of this experience, from receiving the diagnosis to the period of time following the death of their child. The next section will explore the story of continuing a pregnancy in the presence of a LLFC, which has been organized into the following four chapters: receiving the diagnosis of a LLFC, making a decision about how to proceed in pregnancy, continuing the pregnancy and perinatal death and parental grief.

One- Receiving the diagnosis of a LLFC

The phenomenon of continuing a pregnancy in the presence of a LLFC begins the moment parents receive the diagnosis, which typically occurs during a routine prenatal

ultrasound (Áskelsdótti et al., 2008; Blakeley et al., 2019b). For most expectant parents, fetal ultrasounds are eagerly anticipated since the information obtained provides reassurance about the pregnancy as well as confirms normal growth and development of the baby (Áskelsdótti et al., 2008; Lou et al., 2017). Although prenatal ultrasounds are noninvasive procedures that result in many health benefits, several publications have articulated that parents are not always fully informed of the purpose, potential risks and limitations associated with this testing (Áskelsdótti et al., 2008; Grenier & Conklin, 2015; Lou et al., 2017; Wool, 2013). Within our current healthcare context, prenatal ultrasounds have developed a strong social meaning that enables expectant parents to see their baby, affirms their child's existence as well as helps establish early bonding and attachment (Côté-Arsenault & Denney-Koelsch, 2018; DiMiceli-Zsigmond et al., 2015; Kratovil & Julion, 2017; Luz et al., 2017). However, the social meaning commonly attributed to ultrasounds may overshadow the reality that prenatal screening ultimately aims to identify fetal abnormalities (Lalor et al., 2009). Several studies have noted that the divergent perspectives that exist between HCP and parents surrounding the purpose of prenatal ultrasounds renders most parents completely unprepared to receive any type of adverse fetal diagnoses prenatally (DiMiceli-Zsigmond et al., 2015; Grenier & Conklin, 2015; Kratovil & Julion, 2017; Lalor et al., 2009; Lou et al., 2017; Luz et al., 2017; O'Connell et al., 2019; Wool, 2011; Wool, 2013). In a grounded theory study exploring the experiences of women (n=41) who received a diagnosis of a LLFC during a prenatal ultrasound, the authors described how the traditional societal assumptions surrounding pregnancy and the normalization of ultrasounds as routine antenatal care rendered most participants unprepared to receive the news of an adverse fetal anomaly (Lalor et al., 2009). In addition, many fetal anomalies are detected in women with no pre-existing risk factors, thus when anomalies are identified in low-risk pregnancies, expectant

parents were often shocked when they received the news (Grenier & Conklin, 2015; Lalor et al., 2009; O'Connell et al., 2019). In a literature review (n=32) conducted by Luz and colleagues (2017) exploring the experiences of both parents and physicians regarding the detection of a LLFC in pregnancy, the findings suggest that after receiving the diagnosis, parents were unexpectantly propelled into a very difficult and challenging situation inundated with varying levels of uncertainty (Luz, George, Spitz & Vieux, 2017).

Life-limiting fetal conditions represent one of the most common forms of "bad news" communicated to parents in the perinatal period (Atienza-Carrasco et al., 2018; Luz, George, Spitz & Vieux, 2017). The notion of delivering bad news has received much attention within healthcare literature (Bumb et al., 2017; Oikonomidou et al., 2017; Machado et al., 2020; Matthews et al., 2019). Bad news is defined as "any health-related information that adversely alters a person's view of his or her future" (Oikonomidou et al., 2017, p.657). Receiving bad news, such as adverse diagnosis, prognosis or changes to the treatment plan, often results in both emotional and cognitive responses for patients and their families that can persist for some time following the disclosure of the news (Matthews et al., 2019). The perception of bad news has been described as personal, thus making it difficult to predict the individual responses and consequences of the information on the patient and their family (Bumb et al., 2017). Literature exploring this topic suggests that how bad news is conveyed to patients can influence: their understanding of their medical condition, their psychological adjustment to illness, their decision-making, their adherence to medical treatments and their overall level of satisfaction with the care they receive (Matthews et al., 2019; Oikonomidou et al., 2017). Moreover, it has been identified that ineffective communication surrounding the delivery of bad news can result in negative long-term effects on patients, family members and HCP (Bumb et al., 2017).

Although bad news is commonly defined as a single event, within the context of LLFCs, it has been suggested that for some parents, receiving bad news is an on-going process that occurs throughout multiple interactions during this trajectory (Atienza-Carrasco et al., 2018).

In a scoping review conducted by Machado and colleagues (2020) on communicating bad news to parents of newborns admitted to Neonatal Intensive Care Units (n=17), the authors acknowledged the additional challenges associated with delivering bad news to a such a vulnerable population and the added emotional burden the news created in the lives of the parents (Machado et al., 2020). The findings also revealed divergent perspectives on what is considered bad news according to those who receive it (parents) and those who deliver it (HCP) (Machado et al., 2020). HCP primarily defined bad news in terms of the imminent death of a newborn, whereas parents within this context felt that any news relating to changes in their newborn's care routine or clinical condition was perceived as "bad" and stressful (Machado et al., 2020). These findings illustrate the divergent perspectives that may exist between receiving and disclosing bad news within the perinatal period as well as how parents' values and priorities regarding their newborn's medical condition and care can differ from that of the healthcare team.

Within the literature, many parents who received the diagnosis of a LLFC in pregnancy have described it as a traumatic event (Aite et al., 2011, Áskelsdótti et al., 2008; Black & Sandelowski, 2010; Fleming et al., 2016; Hasegawa & Fry, 2017; Lalor et al., 2009; Luz et al., 2017). A traumatic event refers to an unanticipated life stressor that disrupts one's beliefs and assumptions as well as impacts an individual's physical, emotional and psychosocial well-being (Aite et al., 2011). Such events have commonly been associated with feelings of distress, anger, anxiety and depression (Black & Sandelowski, 2010). In a qualitative study conducted over a six-year period, Aite and colleagues (2011) interviewed 165 prospective mothers and 91

prospective fathers one month after the diagnosis of an antenatal congenital anomaly and found that the majority of parents described the diagnosis as sudden and unexpected (Aite et al., 2011). Over 80% of participants voiced that receiving the diagnosis was a traumatic event and that the diagnosis of a LLFC placed a burden of uncertainty on their family (Aite et al., 2011). Similarly, Hasegawa and Fry (2017) explored parental experiences following the diagnosis of LLFC by reviewing literature on infants born with Trisomy 13 and Trisomy 18. The findings also acknowledge the diagnosis of a LLFC during pregnancy as an unexpected, traumatic and life altering experience for prospective parents (Hasegawa and Fry, 2017).

In the literature review conducted by Luz and colleagues (2017), the authors identified several parental responses following the disclosure of LLFC in pregnancy including shock, distress, anxiety, fear, guilt, grief, denial, disbelief, anger, sadness, isolation and hopelessness (Luz et al., 2017). Similarly, Marokakis and colleagues (2017) interviewed 42 parents regarding their experiences with counselling in pregnancy following the detection of a congenital anomaly and identified that parental responses following the diagnosis of a LLFC included; shock, distress, uncertainty, guilt and self-blame (Marokakis et al., 2017). These same parental reactions have also been identified by Wool (2011) in her systematic review exploring parental outcomes in the presence of a LLFC. Wool's study identified that for women experiencing these situations, a grief response often accompanied the diagnosis of a LLFC regardless of whether parents chose to continue or terminate the pregnancy (Wool, 2011). The notion of grief accompanying the diagnosis of a LLFC in pregnancy has been cited in several publications within this context (Áskelsdótti et al., 2008; Hasegawa and Fry, 2017; Lou et al., 2017; Luz et al., 2017; Marokakis et al., 2017). Additional psychological reactions such as depression and post-traumatic stress have also been described within the literature as a potential response following the diagnosis of a

LLFC (Coleman, 2015; Luz et al., 2017; Marokakis et al., 2017; Wool, 2011). It has also been identified that factors such as prognostic uncertainty, parental ability to process clinical information as well as the time sensitive nature of decision-making often placed additional cognitive and emotional demands on parents (Hasegawa and Fry, 2017).

Hasegawa and Fry's (2017) publication found that receiving the diagnosis of a LLFC during pregnancy could impact the development of parental self-identify as well as the transition into parenthood and traditional process of becoming a parent (Hasegawa & Fry, 2017). This finding has also been acknowledged by several qualitative studies within this context (Côté-Arsenault & Denney-Koelsch, 2011; Côté-Arsenault & Denney-Koelsch, 2016; Lotto et al., 2018; O'Connell et al., 2019). Some parents have voiced experiencing a sudden halt within their journey of becoming a parent, which is traditionally characterized by a particular set of assumptions and expectations. However, receiving the diagnosis of a LLFC often results in a multitude of diverse emotions, challenges and decisions that most parents do not anticipate. It has also been suggested that the detection of an adverse fetal diagnosis in pregnancy can significantly affect parental attachment and bonding with their unborn child (Áskelsdótti et al., 2008; Marokakis et al., 2017).

Several studies have identified that receiving the diagnosis of a LLFC can have a profound impact on parents' social interactions with others (Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsh, 2011; Côté-Arsenault et al., 2018; de-Vitry Smith et al., 2013; Hasegawa & Fry, 2017; Meaney et al., 2017). Some parents have voiced experiencing a lack of understanding and empathy regarding their situation as well as a generalized lack of support (Hasegawa & Fry, 2017). Since their experiences did not resemble that of a traditional pregnancy, parents within this context often expressed feeling a sense of social and emotional disconnect from those around

them, which resulted in feelings of isolation (Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsh, 2011; Hasegawa & Fry, 2017; Meaney et al., 2017).

Several publications exploring this topic have referred to the multiple losses that parents experience following the diagnosis of a LLFC, beyond the physical loss of the baby (Aite et al., 2011; Blakeley et al., 2019a; Hasegawa & Fry, 2017; Lou et al., 2017). In a systematic review of qualitative literature (n=28) exploring parental responses following the diagnosis of a LLFC in pregnancy, the overarching theme identified by parents was surrounding the various types of losses they experienced after they received the diagnosis (Lou et al., 2017). Parents voiced that receiving a prenatal diagnosis of a LLFC shattered their dreams of having a healthy child as well as their hopes for the future they had envisioned, regardless if they decided to continue or terminate the pregnancy (Lou et al., 2017). Additional losses described by parents within this context include: the loss of a normal pregnancy, the loss of previous beliefs and expectations, the loss of participating in traditional pregnancy rituals and the loss of future parenthood (Aite et al., 2011; Hasegawa & Fry, 2017; Lou et al., 2017).

Kermorvant-Duchemin and Ville (2017) conducted a literature review exploring the impact of the prenatal detection of fetal anomalies on neonatal outcomes and parental psychological well-being. The findings suggest that the prenatal detection of fetal anomalies can positively influence prenatal and postnatal management, promote informed parental decision-making and enhance parents' psychological preparation and adaptation to the diagnosis (Kermorvant-Duchemin & Ville, 2017). Despite this, some studies included in this review argued that prenatal diagnosis of fetal anomalies may inadvertently contribute to increased levels of parental stress and anxiety earlier in the trajectory (Kermorvant-Duchemin & Ville, 2017). The overall findings also suggest that the impact of prenatal detection on neonatal outcomes and

psychological well-being are highly variable and dependent on the type of fetal anomaly present (Kermorvant-Duchemin & Ville, 2017). Thus, there may not be much benefit to the prenatal detection of fetal anomalies compared to postnatal detection, in alleviating the psychological responses of parents (Kermorvant-Duchemin & Ville, 2017).

The perceptions of HCP regarding the disclosure of bad news in the perinatal period have been explored within the literature (Aite et al., 2011; Atienza-Carrasco et al., 2018; DiMiceli-Zsigmond et al., 2015; Greiner & Conklin, 2015; Hasegawa & Fry, 2017; Luz et al., 2017). It has been articulated that the detection and disclosure of LLFC has created many challenges for HCP (DiMiceli-Zsigmond et al., 2015; Luz et al., 2017). Healthcare providers have reported that breaking bad news within the perinatal context is often a stressful event that causes great discomfort (DiMiceli-Zsigmond et al., 2015; Gomes Guimaraes et al., 2019; Luz et al., 2017; McNamara et al., 2013). Within this body of literature, high-quality communication has been identified as essential during these discussions and has also been associated with increased levels of parental satisfaction (Áskelsdótti et al., 2008; Atienza-Carrasco et al., 2018; Kratovil & Julion, 2017; Luz et al., 2017). Despite this, HCP have reported that training specific to disclosing bad news to patients and their families is often limited and inadequate (Bumb et al., 2017; Luz et al., 2017). In a discussion paper written by a well-cited author in this field, it was suggested that the lack of physician preparedness has contributed to a decreased sense of comfort and confidence surrounding the delivery of bad news in the perinatal period (Wool, 2012). Although the diagnosis of a LLFC can be distressing for both parents and HCP, how the diagnosis is communicated can further impact parental experiences. When not done well, it can intensify feelings of distress and trauma, create feelings of isolation and negatively impact the therapeutic relationships formed (Hasegawa & Fry, 2017; Luz et al., 2017; O'Connell et al., 2019). In an

integrative review (n=33) conducted by Kratovil & Julion (2017) which explored the impact HCP have on parental experiences of receiving an adverse prenatal diagnosis, it was identified that the information communicated to parents and how it was communicated greatly influenced parental coping. When communicated effectively, parents voiced feeling an increased level of confidence with the care they received as well as feeling a sense of empowerment which better prepared them to develop the necessary resources to cope with the diagnosis (Kratovil & Julion, 2017). The effective communication of information by HCP also enabled the development of more positive therapeutic relationships (Kratovil & Julion, 2017).

It has been acknowledged that the language and terminology used when communicating the diagnosis of a LLFC are vividly remembered by parents' years after the death of their child (Áskelsdótti et al., 2008; Kratovil & Julion, 2017; Lou et al., 2017). Kratovil and Julion (2017) suggest that the meanings parents attribute to language can vary and that attention should be paid to the choice of words used when communicating adverse diagnosis within this context. For example, the use of overly optimistic language in the presence of a potentially lethal defect can be perceived as disingenuous or the use of language beyond the parent's ability to comprehend could be viewed as insensitive (Kratovil & Julion, 2017). Several studies identified that when communication surrounding the diagnosis of a LLFC is accompanied by misleading, directive or biased language, it can unduly influence parental decision-making on how to proceed next in the pregnancy, a choice that can have far reaching consequences (Atienza-Carrasco et al., 2018; Hasegawa & Fry, 2017; Marty & Carter, 2017; O'Connell et al., 2019; Wool, 2013).

Atienza-Carrasco and colleagues (2018) conducted a qualitative study using non-participant observation and semi-structured interviews to analyze the approach of physicians, nurses and midwives (n=37) when communicating adverse prenatal diagnoses to patients. The

study sought to improve clinical practice in this field and identified three key areas of focus; the delivery of bad news, the communication style and skills of HCP and the interactions between HCP and patients (Atienza-Carrasco et al., 2018). The authors emphasized the need for enhanced communication when disclosing adverse prenatal diagnoses and that increased attention should be placed on conveying empathy and authenticity within these conversations (Atienza-Carrasco et al., 2018). These findings are similar to those identified in a systematic review conducted by Lou and colleagues (2017), which explored parental experiences of receiving a LLFC. Participants voiced that given the inherent complexity and vulnerability of these situations, they greatly appreciated when HCP were kind, genuine and empathetic when communicating the news of a LLFC (Lou et al., 2017). The review also revealed that the amount, quality and timing of information presented to parents when disclosing the diagnosis greatly influenced parental understanding (Lou et al., 2017).

Two- Making a decision about how to proceed in pregnancy

When LLFCs are detected prenatally, parents are suddenly compelled to make a difficult and life-altering decision regarding how to proceed, often relying on limited information and support (Wool, 2011). After the initial diagnosis is made, parents are often sent for additional testing as well as referred to various specialists for counselling specific to the diagnosis, for example a cardiologist (Betremieux et al., 2016; Hodgson et al., 2016; Marokakis et al., 2017). Hodgson and colleagues (2016) conducted a qualitative study exploring parental experiences (n=102) of receiving a prenatal diagnosis and the decision-making process about whether or not to continue the pregnancy (Hodgson et al., 2016). The findings revealed that both additional testing and specialist referrals prolonged the diagnostic timeframe, and thus delayed parental decision-making regarding how to proceed in pregnancy (Hodgson et al., 2016). Many parents

across several qualitative studies have described the period of waiting for test results and a confirmation of the diagnosis as extremely challenging and distressing (Carlsson et al., 2017; Côté-Arsenault & Denney-Koelsch, 2016; Côté-Arsenault et al., 2018; Denney-Koelsch et al., 2016; de-Vitry Smith et al., 2012; Lotto et al., 2017).

During the period between receiving the diagnosis and making a decision, parents often seek additional information from various sources, such as literature or the internet, to help them better understand their baby's condition, prepare mentally and emotionally for what to expect and determine how to proceed (Áskelsdótti et al., 2008; Côté-Arsenault & Denney-Koelsch, 2016; Flemming et al., 2016; Lotto et al., 2018; Marokakis et al., 2017). However, some parents found that the information obtained on the internet emphasised the poor outcomes or provided inaccurate descriptions of the conditions, which often increased their level of anxiety (Marokakis et al., 2017). Connecting with other families who received a similar diagnosis during pregnancy was described as a valuable source of information and support for some parents throughout the decision-making process as well as helped to decrease feelings of isolation (Áskelsdótti et al., 2008; Marokakis et al., 2017; Tan et al., 2012). It has also been suggested that visible confirmation of the anomaly was important for some parents and helped them to accept the reality of the diagnosis (Gomes Guimaraes et al., 2019; Lotto et al., 2018).

Within the literature, the informational needs of parents have been described as individualized, with some parents preferring minimal information, while others required a significant amount of detail to understand and process the situation (Côté-Arsenault & Denney-Koelsch, 2016; Kratovil & Julion, 2017; Marokakis et al., 2017; McNamara et al., 2013). Lalor and colleagues (2008) conducted a grounded theory study exploring the information preferences and coping styles of parents following the antenatal diagnosis of fetal abnormality (n=41). The

sample included both women who continued and terminated their pregnancies and described a process of regulating the information they received in order to cope with the situation (Lalor et al., 2008). Information seeking represented a key coping strategy for parents and was also described as essential in supporting informed decision-making (Lalor et al., 2008). Two distinct information-seeking styles were described by participants; 'Getting my head around it' was an information-seeking style where in order to regain a sense of control, participants displayed high informational needs. 'I'll cross that bridge when I come to it' was another information-seeking style in which participants preferred to focus more on normalcy and the positive aspects of the situation, thus parents tended to avoid seeking out information, particularly if it was negative (Lalor et al., 2008). Women who adopted high information-seeking preferences tended to experience distress when insufficient information was provided whereas women who displayed low information-seeking behaviours tended to become distressed when the amount of information provided was overwhelming (Lalor et al., 2008). Participants in this study also noted the added challenges and tensions that existed when a discrepancy existed between their information-seeking preferences and those of their partners (Lalor et al., 2008). In a subsequent study conducted by these same authors using the same sample (n=41), Lalor and colleagues (2009) noted that in situations where there was uncertainty surrounding either the diagnosis or prognosis, the information-seeking behaviours of some women represented a way to regain control, reduce levels of uncertainty or find meaning within their experience (Lalor et al., 2009). It has been suggested that failing to adequately meet the informational needs of parents within this context can result in decreased levels of confidence and trust with the healthcare team (Kratovil & Julion, 2017; Lalor et al., 2008).

Parental decision-making on how to proceed following the diagnosis of a LLFC is influenced by several factors such as legal guidelines surrounding abortion, cultural beliefs, religious and spiritual considerations, availability of external resources to support the family, parental attachment to the pregnancy and personal values of the parents (Betremieux et al., 2016; Blakeley et al., 2019b; Guon et al., 2014; Luz et al., 2017; Kermorvant-Duchemi & Ville, 2017; Rocha Cantania et al., 2017). In a systematic review exploring this influence (n=24), the dominant factors identified included: the importance parents placed on the life of their unborn child (fetus), hope that the outcome of their child would be more positive than predicted and considerations surrounding the quality of life they anticipated their child to have (Blakeley et al., 2019b). Parents' described making choices that were impacted by their attachment and connection to baby during pregnancy, which grew with the length of gestation. Seeing their child's face during an ultrasound further personified their child to them (Blakeley et al., 2019b). Alternatively, some parents attempted to avoid creating further attachment with their baby during pregnancy in an effort to prevent this from influencing their decision-making (Blakeley et al., 2019b). Knowledge gained from other people who had similar experiences was also identified as extremely valuable to parents throughout the decision-making process (Blakeley et al., 2019b). Some parents appreciated learning that there could be value in the child's life regardless of disability, while others valued honesty regarding the challenges experienced after giving birth to a baby diagnosed with a LLFC (Blakeley et al., 2019b).

Within the literature, parents describe many reasons for the decisions they make following a diagnosis of LLFC. Some of these are explicitly focused around respecting the needs of the baby, such as considering whether the baby would suffer if carried to term, and the value placed on the baby's life (Blakeley et al., 2019b; Carlsson et al., 2017; Guon et al., 2014;

Hasegawa & Fry, 2017). Others are more focused on parents' own hopes, fears, and experiences such as: previous challenges conceiving, the desire to meet and parent their baby, personal health considerations and ability to cope with the chosen outcome, the impact the decision would have on the larger family's quality of life, experiential knowledge of disability and the desire to avoid feelings of guilt or regret regarding their decision (Betremieux et al., 2016; Blakeley et al., 2019b; Guon et al., 2014; Hasegawa & Fry, 2017). The diagnosis of a LLFC later in the pregnancy was also found to impact parental decisions due to challenges associated with late pregnancy terminations (Coleman, 2015). In one retrospective chart review following 20 pregnancies in the presence of a LLFC, the authors identified that being pregnant with twins influenced whether parents decided to continue the pregnancy or not, primarily due to the implications their decision had for the other baby (Betremieux et al., 2016).

Parents have reported that deciding whether to continue or terminate the pregnancy was the hardest part of the whole experience (Hodgson et al., 2016). Two qualitative studies in this area have emphasized the inherent challenges that exist for parents in making this decision (Lotto et al., 2018; Wool et al., 2018). Wool's (2011) systematic review, exploring parental outcomes in the presence of a LLFC, described how some parents experience conflicting emotions throughout the decision-making process, where they struggled between wanting to protect themselves and their unborn child with the desire to avoid placing unnecessary burdens on themselves or their family (Wool, 2011). The period of time it took parents to make this decision varied within the literature (Betremieux et al., 2016; Breeze et al., 2007). For some parents, making a decision about how to proceed in the pregnancy was a gradual process that evolved over time and required multiple meetings with the healthcare team (Betremieux et al., 2016). However, in a retrospective chart review of 20 pregnancies where a LLFC was detected, participants made a

decision about how to proceed in pregnancy within 1-2 days following the diagnosis (Breeze et al., 2007).

Benute and colleagues (2012) conducted a qualitative study exploring the decision-making process of women who chose to terminate pregnancy following the detection of LLFC (n=249) and found that at the time of the diagnosis, participants had difficulty fully understanding the information provided to them (Benute et al., 2012). As a result, the authors recommended that families should be given time after the initial shock of the diagnosis to reflect, prior to making a decision about how to proceed in pregnancy so that parental decisions would be well informed (Benute et al., 2012). In a qualitative study conducted by Fleming and colleagues (2016) exploring the experiences of parents (n=32) and HCP (n=29) surrounding LLFCs detected in pregnancy, parents voiced feeling rushed into making a decision soon after receiving the diagnosis, with some of the participants presenting for pregnancy termination within 24 hours of receiving the diagnosis (Fleming et al., 2016). In contrast to the parental perspective, the HCP in this study expressed that there was no urgency in making a decision about how to proceed and that parents could take all the time they needed (Fleming et al., 2016). It is important to note that this study was conducted in Switzerland, and although families can access pregnancy terminations at any time, termination became harder to obtain further along in the pregnancy (Fleming et al., 2016). The authors also identify a significant gap in the care provided to this population surrounding the apparent lack of informed decision-making amongst study participants (Fleming et al., 2016).

Throughout the decision-making process, many parents have voiced feeling pressured by HCP to terminate the pregnancy or that their decision to continue was not well respected (Côté-Arsenault & Denney-Koelsch, 2011; Coleman, 2015; Guon et al., 2014; Hasegawa & Fry, 2017;

Lotto et al., 2018; Wilkinson et al., 2015). Parents have articulated that feeling unsupported by HCP often created conflicts within the therapeutic relationship, increased feelings of isolation as well as resulted in parents feeling like they would receive suboptimal care because their choices were not well understood by HCP (Côté-Arsenault & Denney-Koelsch, 2011; Hodgson et al., 2016; Horning & Braun, 2006). Parents have also expressed valuing reassurance from close family and friends and have stated that when their decisions were not supported or were challenged by loved ones, it often perpetuated feelings of isolation and distress (Côté-Arsenault & Denney-Koelsch, 2011). For these reasons, having their decisions validated and respected by family, friends and the healthcare team has been described as important to many parents (Chevalier McKechnie et al., 2015; Guon et al., 2014; Hodgson et al., 2016; O'Connell et al., 2019).

Three- Continuing the pregnancy

Although termination of pregnancy continues to be cited within the literature as the predominant choice of parents following the diagnosis of a LLFC (Hodgson et al., 2016; Lotto et al., 2018; Sullivan & de faoite, 2017), the option of continuing pregnancy has become an increasingly recognized alternative (Limbo et al., 2017; Hasegawa & Fry, 2017; O'Connell et al., 2019). In a meta-analysis of empirical studies (n=20) exploring PPC published between 1995 and 2012, it was estimated that between 37-85% of parents who receive a diagnosis of a LLFC opt to continue the pregnancy (Wool, 2013). This statistic illustrates that a relatively large number of this population are choosing to continue pregnancy irrespective of the dominant discourse that most parents within these situations opt to terminate.

Numerous qualitative studies have identified that choosing to continue pregnancy in the presence of a LLFC was largely regarded by parents as a positive experience (Breeze et al.,

2007; Coleman, 2015; Côté-Arsenault & Denney-Koelsch, 2016; Guon et al., 2014; Wool, 2013; Wool et al., 2018). Wool and colleagues (2018) conducted a mixed-methods study using an online survey (n=405) to examine the concept of decisional regret in parents who opted to continue a pregnancy affected by a LLFC (Wool et al., 2018). The authors found that for many parents, their attachment to their unborn baby, and their motivation to nurture, protect, and socialize their child contributed to their choice as being regarded as a positive one (Wool et al., 2018).

After deciding to continue the pregnancy, coping with their decision remained an on-going process for many parents (Carlsson et al., 2017; Lalor et al., 2009; Redlinger-Grosse et al., 2002). Parents have reported using various coping strategies throughout this experience such as maintaining hope, reprioritizing goals, turning to spirituality, preparing for the worst, focusing on typical pregnancy tasks and accepting the diagnosis (Carlsson et al., 2017; Chevalier McKechnie et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016; Redlinger-Grosse et al., 2002). The idea of preserving normalcy throughout pregnancy has been identified within the literature as an important coping strategy, where parents described efforts to maintain everyday routines, find distractions and resume other common activities within their day to day lives (Chevalier McKechnie et al., 2015; Côté-Arsenault & Denney-Koelsch, 2018; Fleming et al., 2016). Parents also voiced seeking support from others to help them cope throughout the remainder of pregnancy. Carlsson and colleagues (2017) conducted a cross-sectional qualitative study involving messages in online discussion boards to explore the emotional process of parents following the diagnosis of a congenital anomaly, from diagnosis to birth (Carlsson et al., 2017). Analysis of over 850 online messages revealed that expectant parents relied heavily on informational, emotional, and practical support from family, friends, and HCP in order to cope

with their situation (Carlsson et al., 2017). The study also found that for some parents, receiving the diagnosis prenatally enabled them time to emotionally prepare for the birth of their baby and to develop early coping strategies (Carlsson et al., 2017).

Although it has been acknowledged that this population has unique physical and emotional needs compared to women with low-risk pregnancies, many women have voiced a desire to receive routine prenatal care and that this sense of normalization enhanced their enjoyment of the pregnancy (Côté-Arsenault & Denney-Koelsch, 2011; Fleming et al., 2016; Guon et al., 2014; Thiele, 2011; Welch, 2018). Fleming and colleagues (2016) conducted a qualitative study exploring the experiences and trajectories of parents (n=32) and HCP (n=29) surrounding the management of pregnancies in the presence of a LLFC. These authors noted that routine antenatal care throughout pregnancy made parents feel a sense of acceptance rather than avoidance and positively impacted their overall experience and level of satisfaction (Fleming et al., 2016).

Throughout the experience of continuing pregnancy in the presence of a LLFC, parents often expressed the notion of transforming previous beliefs, hopes and assumptions into new ones that reflected the new reality of the LLFC (Cortezzo et al., 2019; Currin-McCulloch; 2018; Guon et al., 2014; Hasegawa & Fry, 2017; Horning & Braun, 2006; Lalor et al., 2009; Lou et al., 2017; Wool, 2013). A grounded theory study conducted by Lalor and colleagues (2009), described the adaptive process of women (n=41) following the diagnosis of a LLFC in pregnancy. Participants voiced experiencing a period of "rebuilding", which represented a process of reconstructing previous beliefs and assumptions surrounding pregnancy and rebuilding their futures within the new reality of the diagnosis (Lalor et al., 2009). Similarly, given the poor prognosis associated with the majority of LLFCs, many parents have also

expressed the ability to gradually transform previous hopes they had for their life with baby into new hopes that reflected the severity of the diagnosis such as being able to meet their baby alive and hold them (Hasegawa & Fry, 2017; Lou et al., 2017; Wool, 2013; Guon et al., 2014). Reflecting the reality that baby's life was expected to be brief, many parents expressed a strong desire to bond with their newborn and to create meaningful memories together as a family (Hasegawa & Fry, 2017; Lou et al., 2017; Wool, 2013). Additional hopes described within the literature include: that baby would survive longer than predicted, that baby would not suffer or feel pain, and that baby would know they were loved (Guon et al., 2014). As pregnancy progressed, parents voiced that reconstructing previous hopes and beliefs enabled them to focus on cherishing the limited time they had with their baby (Côté-Arsenault & Denney-Koelsch, 2016; Wool et al., 2018). The important role of HCP in supporting families in transforming previous hopes and expectations to reflect the new reality and limitations of the diagnosis has been acknowledged by several authors (Currin-McCulloch; 2018; Kamrath et al., 2019; Lou et al., 2017; Wool, 2013). The concept of transforming hopes has also been explored within similar clinical contexts. Hill and colleagues conducted a mixed-methods study exploring the hopes of parents (n=200) whose children were diagnosed with severe medical conditions (Hill et al., 2018). The study found that for the majority of parents, their initial hopes for their child changed throughout the illness trajectory and over time, parental hopes began to focus on their child's quality of life, physical health, future well-being and medical care (Hill et al., 2018).

For some parents navigating the presence of a LLFC, coping with the reality of their unborn baby's diagnosis was more challenging. A few qualitative studies have identified that disengagement and avoidance helped some parents cope emotionally and cognitively with the reality of their baby's diagnosis (Blakeley et al., 2019a; Cole et al., 2019; Côté-Arsenault &

Denney-Koelsch, 2018; Lotto et al., 2017). Parents voiced how avoiding talking or thinking about their situation helped them cope, but also made them feel even more alone (Cole et al., 2019; Lotto et al., 2017). Other parents voiced how they attempted to avoid creating an emotional connection with their baby during pregnancy as a way of protecting themselves from experiencing even more pain after the baby died (Blakeley et al., 2019a). In one longitudinal phenomenological study of parent's (n=30) experiences continuing pregnancy in the presence of a LLFC, the authors identified the term "arrested parenting", which describes an abrupt cessation of rituals commonly associated with pregnancy, such as decorating the nursery, and an end to feelings of excitement and anticipation (Côté-Arsenault & Denney-Koelsch, 2011). That some parents choose to continue their pregnancy despite the LLFC, while simultaneously disengaging from certain elements traditionally associated with pregnancy and parenthood, illustrates the complexity, and contradictions, that characterize this experience.

Within the literature, many parents have described experiencing an emotional rollercoaster, often fluctuating between feelings of hope or fear and optimism or pessimism, as they continued to navigate everyday life in the face of an uncertain future (Bennett et al., 2011; Carlsson et al., 2017; Côté-Arsenault et al., 2015). Given the severity of many LLFCs, there is an increased risk of miscarriage and intrauterine fetal death for women in these situations (Guon et al., 2014; Kuchemba-Hunter, 2019; McNamara et al., 2013). This increased level of risk can result in additional feelings of fear, anxiety and uncertainty for some parents throughout the remainder of the pregnancy (Guon et al., 2014; McNamara et al., 2013). Due to the increased risk of death in utero, one qualitative study identified that parents often felt a sense of reassurance when feeling their baby move or kick during pregnancy and that prenatal ultrasounds became even more meaningful in confirming their baby's health (Côté-Arsenault et al., 2015). It

has also been identified that there is an increased risk of preterm labor for this population, which can add an additional level of uncertainty to the pregnancy trajectory and potentially initiate the birthing process sooner than expected for some parents (Côté-Arsenault et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016).

The notion of anticipatory grief has also been identified within the literature as being experienced by parents who continued pregnancy in the presence of a LLFC (Côté-Arsenault & Denney-Koelsch, 2011; Côté-Arsenault & Denney-Koelsch, 2016; Gomes Guimaraes et al., 2019; Kenner et al., 2015; Miles, 2015; Wool et al., 2018). Anticipatory grief refers to feelings of grief before the loss occurs and is considered to be a normal process of coping with an impending loss (Toyama & Honda, 2016). Within the context of LLFCs, anticipatory grieving often begins when parents receive the initial diagnosis and continues throughout the pregnancy as parents grieve the eventual physical loss of their baby that is expected to occur either before or shortly following birth (Kenner et al., 2015; Miles, 2015; Schonfeld, 2012; Titus & de Souza, 2011). The process of anticipatory grief has been described as nonlinear and unpredictable (Schonfeld, 2012). It remains an individual experience and there is no finite timeframe in which families move through it (Schonfeld, 2012). Often times, parents who continue pregnancy in the presence of a LLFC must balance the anticipation of their child's birth and life, with the anticipation of their child's death. It has been suggested that anticipatory grief enables parents to practice grieving as a gradual process while their baby is still alive and to create a special connection with their child while also acknowledging the eventual loss (Schonfeld, 2012).

Although feelings of grief can persist throughout the experience of continuing pregnancy in the presence of a LLFC, for some parents the intensity of grief can subside as they gradually begin to look forward to the birth of their baby (Carlsson et al., 2017). In one grounded theory

study involving 20 families following the detection of a LLFC, the overarching theme identified was “preparing heart and mind for becoming a parent” (Chevalier McKechnie et al., 2015). Preparing heart and mind refers to the dynamic process that parents navigate during the pregnancy trajectory and to the various turning points that they encounter throughout this experience (Chevalier McKechnie et al., 2015). Preparing heart and mind enabled parents to develop strategies that equipped them, both emotionally and cognitively, for parenthood within this context (Chevalier McKechnie et al., 2015).

Several studies have described the bond and relationship formed between parent(s) and baby throughout this experience (Côté-Arsenault et al., 2015; Fleming, et al., 2016; Guon et al., 2014; Wool, 2013; Wool et al., 2018). Parenting literature tends to focus on the assumption that parenting begins after birth, however the parenting role that develops throughout pregnancy has been increasingly acknowledged (Côté-Arsenault et al., 2015). In a qualitative research study exploring the experiences of parents who continued pregnancy in the presence of a LLFC, authors identified the concept of “prenatal parenting”, which described the active and evolving process of parenting during pregnancy and after birth as well as the creation of emotional space for the baby in their lives of parents (Côté-Arsenault et al., 2015, p.172). Moreover, the term “emergency bonding” has also been used within the literature to describe the maternal desire to bond with their unborn baby, recognizing that the amount of time women have to spend with their child following birth is limited (Wool, 2013, p. 379). These findings reflect parental desire to form relationships with their unborn baby, while also acknowledging that their baby’s life will be brief. Moreover, parents have described how interacting with their baby through physical, visual or audio contact during pregnancy represented important quality time together as a family that enhanced bonding (Côté-Arsenault et al., 2015). Participating in various memory making

activities during pregnancy such as photography and reading nightly stories was another way that parents cherished the limited time they had to bond and connect with their child (Côté-Arsenault & Denney-Koelsch, 2016; Miller et al., 2014).

In a longitudinal phenomenological study conducted by Côté-Arsenault and colleagues (2015), exploring the experiences of couples (n=30) who chose to continue their pregnancy after receiving the diagnosis of a LLFC, the authors described how some parents chose a name for their child as a way to validate the life of their baby and to promote their baby's personhood (Côté-Arsenault et al., 2015). Parents voiced that they greatly appreciated when HCP referred to their baby by their name, since this provided further validation of their child's life (Côté-Arsenault et al., 2015). Some parents also attributed characteristics (such as 'fighter' or 'mischievous') to their babies and would adjust their actions according to the child's mood, which represented another way that parents promoted the personhood of their unborn baby (Côté-Arsenault et al., 2015). The importance of validating baby's personhood has been described by many parents across several qualitative studies (Côté-Arsenault & Denney-Koelsch, 2016; Côté-Arsenault et al., 2015; Guon et al., 2014; Kuchemba-Hunter, 2019; Lathrop & VandeVusse, 2011b; O'Connell et al., 2019; Redlinger-Gross et al., 2002; Thiele, 2011; Wool et al., 2018). For parents, having their baby's life validated by others provided acknowledgement of the unique place the child held within the hearts and lives of parents, irrespective of the length of time they were anticipated to live. Validating the life and personhood of the baby also recognized the difficulty associated with navigating the death of a child.

Parents have identified that navigating the social aspects of an obvious pregnancy in the presence of a nonapparent LLFC was often challenging (Côté-Arsenault & Denney-Koelsch, 2018). As pregnancy progressed, parents were required to think about how they would address

their baby's diagnosis with others socially (Côté-Arsenault & Denney-Koelsch, 2016; de-Vitry Smith et al., 2013). Since it is widely assumed that pregnancy ends with the birth of a healthy baby, parents within this context have identified that communicating the diagnosis of a LLFC with others was a particularly difficult task (Chevalier McKechnie et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016; de-Vitry Smith et al., 2013; O'Connell et al., 2019). Parents often remained strategic about whom they disclosed the diagnosis to as well as how much information they shared, for fear there would be a lack of understanding or acceptance (Chevalier McKechnie et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016; Côté-Arsenault et al., 2018; de-Vitry Smith et al., 2013). Some women avoided telling anyone outside their immediate social circle about the diagnosis and felt it protected them from insensitive comments (Côté-Arsenault & Denney-Koelsch, 2016). In a qualitative study (n=31) exploring the experiences of couples following the diagnosis of a LLFC, women reported feeling like public property during their pregnancy, which often resulted in negative psychological consequences (de-Vitry Smith et al., 2013). Women found that at times, well-intended comments by others increased feelings of guilt about not producing a healthy baby, perpetuated feelings of isolation, pressured women into sharing intimate details regarding their pregnancy and resulted in unsolicited advice that was uninformed (de-Vitry Smith et al., 2013). Participants also voiced that questions regarding the baby often felt invasive and were a recurrent reminder of hopes and dreams that no longer existed (de-Vitry Smith et al., 2013). Due to the challenges associated with sharing the news of a LLFC, parents appreciated support from HCP regarding how best to share information about the diagnosis with others (Côté-Arsenault et al., 2018).

As pregnancy progressed, parents' focus often shifted towards planning for the birth of their child (Côté-Arsenault & Denney-Koelsch, 2016). It has been articulated within the

literature that parents valued opportunities to actively participate in birth planning as it provides them with a sense of control throughout this uncertain experience (Carlsson et al., 2017; Cortezzo et al., 2019; Côté-Arsenault et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016). Cortezzo and colleagues (2019) conducted a mixed-methods study exploring the perspectives of both parents (n=20) and HCP (n=116) surrounding birth planning in the presence of a LLFC (Cortezzo et al., 2019). Parents identified that the process of birth planning represented a valuable therapeutic activity, enabled them to plan memory making opportunities, ensured effective communication across the medical team as well as helped them to better prepare for what to expect (Cortezzo et al., 2019). Whereas HCP described focusing more on the medical management of mom and baby following birth rather than the psychosocial aspects of care throughout the birth planning process (Cortezzo et al., 2019).

Parents have voiced experiencing a multitude of feelings as they anticipated the birth of a child diagnosed with a LLFC. Some parents expressed feeling excited to meet their baby, yet at the same time dreading the birth since it brought them closer to their child's death (Carlsson et al., 2017). Parents also voiced experiencing increased levels of anxiety regarding the birth as well as uncertainty surrounding the type of delivery (vaginal or caesarian) and the postnatal health of their child (Carlsson et al., 2017; Carlsson & Mattson, 2018).

The experience surrounding the birth and immediate postpartum period varies between families. Regardless of whether the baby was born alive or stillborn, many parents verbalized experiencing tremendous joy and excitement towards meeting their baby (Côté-Arsenault et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016). Findings from one phenomenological study suggest that following the birth of a child diagnosed prenatally with a LLFC, parents felt unconditional love for their baby, irrespective of the anomaly or condition (Côté-Arsenault et al.,

2015). Many parents expressed a desire to interact with baby following birth in ways they could not in utero such as through touch and eye contact, and that they greatly valued physical closeness to their child (Côté-Arsenault et al., 2015). These moments allowed parents the opportunity to experience the joy of life, despite the grief associated with death (Côté-Arsenault et al., 2015). While most parents expressed feeling a profound sense of love after meeting their baby, some parents experienced more ambivalent feelings and felt torn between wanting to enjoy the limited time they had with their child, but at the same time feared becoming even more attached (Côté-Arsenault et al., 2015). In Wool and colleagues' (2018) study exploring this topic, over 97% of the participants (n=405) expressed confidence in their decision, stating that they had no regrets and did not second guess their choice, regardless of the length of time their baby lived (Wool et al., 2018). Many parents expressed having positive long-term memories following their choice to continue pregnancy in presence of a LLFC, despite the devastation they experienced following the death of their child (Wool et al., 2018).

The importance of creating additional memory making opportunities after birth, such as additional photographs, and ink prints or moldings of hands and feet has also been identified within the literature (Côté-Arsenault & Denney-Koelsch, 2016; Kenner et al., 2015). It has also been articulated that parents greatly valued when HCP encouraged them to participate in routine parenting tasks such as bathing and dressing their child, regardless of if their baby was born alive or died in utero (Kenner et al., 2015). In a scoping review of qualitative and mixed methods studies (n=25) exploring bereavement care following the death of a newborn, memory making was identified by parents as a significant part of care they received following the death of their newborn (Thornton et al., 2019). Important elements of memory making described by parents within this review included: physical contact with baby, taking photographs, the collection of

special mementos and opportunities to participate in parenting acts (Thornton et al., 2019). In a qualitative study exploring the narratives of women who continued pregnancy in the presence of a LLFC, participants identified the unique context of caregiving surrounding end of life and how these acts represented their final role as direct caregivers for their child (Limbo & Lathrop, 2014). The final acts described by participants involved nurturing, protecting and socializing baby up until and even after death had occurred (Limbo & Lathrop, 2014). The narratives of participants demonstrated that for them, caregiving did not end when the baby died, but rather continued throughout the rest of their lives (Limbo & Lathrop, 2014).

Four- Perinatal death and parental grief

When continuing a pregnancy in the presence of a LLFC, the outcome of perinatal death is anticipated from the time of the diagnosis (Wool et al., 2016). Within the literature, many parents have described the challenges of coping with the physical loss of their child (Côté-Arsenault & Denney-Koelsch, 2016; Lathrop & VandeVusse, 2011a; Stevenson et al., 2017; Welch, 2018). In a longitudinal qualitative study exploring parental experiences within this context, parents expressed feeling a sense of "empty arms" following the death of their baby (Côté-Arsenault & Denney-Koelsch, 2016, p.107). This refers to the experiences of parents leaving the hospital without their baby and feeling like something was missing (Côté-Arsenault & Denney-Koelsch, 2016). Similarly, in a grounded theory study exploring this same topic, parents also describe the notion of empty arms and the challenges in navigating the physical separation from their baby as well as the difficulty associated with leaving the hospital alone (Welch, 2018). Parents often described a wavering experience of wanting to process their grief and move forward while also trying to maintain a connection to their child after death (Côté-Arsenault & Denney-Koelsch, 2016; Lathrop & VandeVusse, 2011a; Stevenson et al., 2017).

After the death of their infant, parents have described the various ways they integrated the memory of their baby into their lives as a way to maintain an ongoing connection and to honour their baby's life (Côté-Arsenault & Denney-Koelsch, 2016; Davies, 2004; Stevenson et al., 2017). Some women choose to donate their breastmilk so that other newborns could benefit from it (Côté-Arsenault et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016; Stevenson et al., 2017). Donating breastmilk enabled women to honour their baby's life in a special way, find meaning in their child's death as well as preserve their child's memory (Côté-Arsenault et al., 2015; Côté-Arsenault & Denney-Koelsch, 2016; Stevenson et al., 2017). Other parents participated in meaningful rituals such as visiting burial sites or creating trust funds in their child's name as a way to preserve their child's legacy (Stevenson et al., 2017). Parents also voiced maintaining a connection to their baby by talking about their experience and the life of their child with others who knew them (Stevenson et al., 2017; Welch, 2018). Although it often triggered feelings of both pain and joy, sharing the story of their child's life and death represented an important way to validate their experience and the personhood of their child (Welch, 2018). Other parents identified that reminiscing about the life of their child was an important aspect of their bereavement and that reflecting on the care they received was an important factor in decreasing feelings of guilt or distress (Tan et al., 2012). Parents have also described how helping other families in similar situations allowed them to find some positive meaning within their grief experience as well as gave their child's life an additional sense of meaning and purpose (Tan et al., 2012; Welch, 2018).

In addition to the death of their baby, this period is also characterized by maternal postpartum recovery, funeral/memorial services and for some parents, preoccupations about returning to work (Côté-Arsenault & Denney-Koelsch, 2016; Dias et al., 2017; Fleming et al.,

2016; Malacrida, 1999; Welch, 2018). In the qualitative study conducted by Fleming and colleagues (2016), parents voiced the importance of receiving routine postnatal care, regardless of the fact their baby was no longer living as well as having the birth acknowledged by others (Fleming et al., 2016). This study also identified several postnatal challenges experienced by this population including limited access to adequate counselling services and inadequate maternity/bereavement leave depending on the parents' insurance coverage (Fleming et al., 2016). These findings are similar to those identified in another qualitative study, where parents voiced their disappointment surrounding the lack of paid bereavement leave available and how it devalued their loss and left them feeling even more alone (Malacrida, 1999).

Perinatal death (commonly referred to as perinatal loss) was only formally recognized as a "grief-producing phenomenon" within the literature in the late 1960's (McNamara et al., 2013; O'Leary & Warland, 2013). Prior to this, the impact a perinatal death on parents as well as the significance of this loss in their lives was largely underestimated (McNamara et al., 2013). Within the context of continuing a pregnancy in the presence of a LLFC, parents start grieving at time of the diagnosis and continue throughout the remainder of the pregnancy (Côté-Arsenault & Denney-Koelsh, 2011; de-Vitry Smith et al., 2012; Horning & Braun, 2006; Limbo & Lathrop, 2014; Locock & Alexander, 2005). Perinatal grief has been described as an individualized and multidimensional experience, with many diverse ways to grieve and varying timeframes for how long grief will last (Côté-Arsenault & Denney-Koelsch, 2016). Perinatal grief is a unique form of grieving in many ways: families must navigate experiencing the joy of birth while also preparing for death, and parents often get very little time to spend with their baby which often results in limited memories built together as a family (Hoeldtke & Calhoun, 2001; Miller et al., 2014). In

addition, a perinatal death is often not acknowledged by others within society the same way the death of an older child or adult would be (Hoeldtke & Calhoun, 2001; Miller et al., 2014).

The death of an infant has been described as both a psychological and sociocultural event in the lives of parents (Wool & Catlin, 2018). Such a death is devastating and represents an unparalleled and enduring experience (Davies, 2004; Henson & Davies, 2018; Stevenson et al., 2017). Regardless of the cause of death, the number of years since the death has occurred or the child's age at the time of death, parental grief is profound (O'Leary & Warland, 2013). Several publications have articulated the transformational nature of grief within this context in that it creates change within the lives of parents and can influence their personal identities, relationships, roles, finances and social supports (Dias et al., 2017; Miles, 2015; Price & Jones, 2015; Ripley et al., 2007; Stevenson et al., 2017; Titus & de Souza, 2011; Wright & Perry Black, 2013). For some families, the death of an infant can negatively impact family functioning and adjustment as well as parental coping, physical health and psychological well-being (Blakeley et al., 2019a; Michael & Cooper, 2013; Miles, 2015; Ripley et al., 2007; Schonfeld, 2012).

There exists a large body of literature exploring the bereavement experiences of parents following the death of a child. Titus and de Souza (2011) conducted a qualitative analysis of narrative stories exploring the grief experienced by parents (n=10) following the death of a child due to a terminal illness (Titus & de Souza, 2011). The findings revealed similarities in the parental grief experiences between parents who had lost an infant and parents who had lost an older child (Titus & de Souza, 2011). Regardless of the age of the child, their death was found to significantly impact all areas of the parent's lives (Titus & de Souza, 2011). Participant narratives also highlighted the social aspects of grieving the death of a child and that in addition

to managing their own personal grief, parents were often required to address the grief of their partners, other children and family members (Titus & de Souza, 2011).

In a qualitative study conducted by Dias and colleagues (2017), the authors explored the bereavement challenges experienced by parents (n=10) following the death of a child (< 2 years old) diagnosed with a life-threatening condition. The findings revealed the complexity of parental grief following the death of a child as well as various coping strategies developed by parents (Dias et al., 2017). In the period following the death, many parents described living one day at a time, facing uncertainty surrounding their ability to cope and their emotional responses on any given day (Dias et al., 2017). Parents within this study voiced the difficulties in navigating life without the physical presence of their child and also the dilemmas they experienced between wanting to move forward while at the same time, not forgetting valuable memories of their child (Dias et al., 2017). Parents were often required to find a "new normal" as they attempted to get back to their routine daily activities and found that keeping busy was a key coping strategy following the loss (Dias et al., 2017).

Tan and colleagues (2012) conducted a qualitative study exploring the bereavement needs of parents (n=14) whose infants died from a chronic life-threatening condition such as extreme prematurity and congenital heart disease (Tan et al., 2012). The findings revealed that parental needs following death remained complex and were influenced by multiple factors that occur throughout the entire trajectory, beginning at the time of diagnosis (Tan et al., 2012). Parents described how receiving all possible treatment options at the time of diagnosis and being actively involved in all care decisions helped to reduce levels of distress in the bereavement period (Tan et al., 2012). For some parents, discovering the LLFC prenatally enabled them to be better prepared for the death of their infant and also helped to minimize some of the negative

consequences that accompany grief (Tan et al., 2012). An overarching theme voiced by participants within the study was the importance they placed on memory making (Tan et al., 2012). Memories and tangible mementos were cherished by parents and inspired feelings of comfort, love and support within the bereavement period (Tan et al., 2012).

Within the literature, differences in the grief experience of parents following the death of a child have also been identified (Côté-Arsenault & Denney-Koelsch, 2018; Dias et al., 2017; Lang et al., 2011; Locock & Alexander, 2005; Stevenson et al., 2017). Dias and colleagues' qualitative study (2017) acknowledged the challenges of grieving as a couple, where each parent needs to grieve the death of their child individually and thus may not be able to emotionally support their partner (Dias et al., 2017). In the study conducted by Stevenson and colleagues (2017), the authors noted differences between couples' communication surrounding grief, where mothers tended to want to talk about the loss and fathers were more reluctant to discuss it (Stevenson et al., 2017). This study also found that fathers tended to return to work sooner as a way to cope with the death of their child, whereas mothers did not find returning to work as helpful (Stevenson et al., 2017). It has been acknowledged that for some couples, differences in grieving between parents can contribute to increased levels of frustration, tension and conflict as well as place additional strains on the relationship (Côté-Arsenault & Denney-Koelsch, 2018; Dias et al., 2017; Stevenson et al., 2017; Titus & de Souza, 2011). One descriptive study suggests that bereaved parents experience heightened levels of conflict and higher rates of separation and divorce (Ryan et al., 2015). However, in a qualitative study exploring the experiences of parents (n=30) who continued pregnancy following the diagnosis of a LLFC, many parents voiced that after the death of their baby, their relationship was strengthened, they were able to provide each other with mutual support and they developed enhanced coping

abilities as a couple (Côté-Arsenault & Denney-Koelsch, 2018). Similarly, in other qualitative studies, parents did not always find the differences in coping to be an issue, and voiced an ability to respect each other's unique grief process and found that the experience brought them closer together as a couple (Stevenson et al., 2017; Titus & de Souza, 2011).

Throughout the literature, many parents have commented on the importance of relationships throughout this experience and how feeling unsupported by friends, family and HCP had a negative impact on their grief (Blakeley et al., 2019a; Côté-Arsenault & Denney-Koelsch, 2011; Côté-Arsenault et al., 2018; Denney-Koelsch et al., 2016; Stevenson et al., 2017; Titus & de Souza, 2011). A qualitative study exploring the coping process of parents (n=21) following the death of their child due to a life-limiting illness, found that parental coping was greatly influenced by social relationships (Stevenson et al., 2017). Parents found it helpful when their existing social circles provided them with a safe space to grieve that was free from judgement (Stevenson et al., 2017). However, relationships became problematic and parents experienced increased levels of distress when they felt they were not well understood or supported throughout their grieving (Stevenson et al., 2017). Parents have articulated that insensitive comments, uncomfortable interactions and a lack of acknowledgement of their infant's death often intensified feelings of isolation and distress as well as resulted in families feeling like the death of their infant was not validated by others (Côté-Arsenault & Denney-Koelsch, 2011; Titus & de Souza, 2011; Stevenson et al., 2017). The findings of a qualitative study exploring the experiences of parents (n=22) surrounding perinatal death (between 20 weeks gestation and 7 days of life), revealed that the lack of support offered to parents by family, friends and the healthcare team resulted in parents feeling alone and not validated in their loss (Malacrida, 1999). The overall lack of acknowledgement surrounding the significance of a

perinatal death within the lives of parents, particularly by those who knew a death had occurred, was found to contribute to more complicated grieving (Malacrida, 1999). The concept of complicated grief has been identified within literature surrounding perinatal loss and is characterized by distress, prolonged disbelief, and preoccupied thoughts (Miles, 2015; Ripley et al., 2007; Stevenson et al., 2017). Complicated grief can result in ineffective coping, social isolation, depressive symptoms as well as strain within the parental relationship (Miles, 2015; Ripley et al., 2007; Stevenson et al., 2017).

The concept of disenfranchised grief has also been described within literature surrounding perinatal death (Lang et al., 2011; Van Dinter & Graves, 2012). Disenfranchised grief refers to grief that is further complicated by a lack of societal acceptance, understanding and support from the surrounding community (Lang et al., 2011; Van Dinter & Graves, 2012). In a qualitative study conducted by Lang and colleagues (2011) exploring the experiences of bereaved couples following a perinatal loss, the overarching theme revealed from the narratives of participants was the ambiguity that existed throughout the grieving process and how their grief went unrecognized by others (Lang et al., 2011). Within this context, parents referred to ambiguity as situations or issues that were unclear, indefinite, or uncertain to them or others supporting them (Lang et al., 2011). Parents acknowledged the challenges associated with the varying levels of ambiguity throughout the experience of perinatal loss, including surrounding the viability of the baby, what to expect throughout the remainder of the pregnancy, what it would be like to lose a baby as well as additional levels of ambiguity within the grief process after death (Lang et al., 2011).

Although the death of a child can result in negative psychological and physical outcomes, many parents have described experiencing positive change and have expressed feeling a sense of

healing and personal growth following the death of a child (Côté-Arsenault & Denney-Koelsch, 2016; Coleman, 2015; Ripley et al., 2007; Stevenson et al., 2017; Titus & de Souza, 2011; Wright & Perry Black, 2013). In a retrospective cross-sectional study involving over 400 participants who received a prenatal diagnosis of a LLFC, it was identified that the majority of parents experienced positive self-transformations as a result of continuing the pregnancy (Wool et al., 2018). Positive self-growth was described by participants as opportunities for personal learning, healing, and positive self-change (Titus & de Souza, 2011; Wool et al., 2018). Additional examples of positive growth that have been voiced by parents following the death of a child include: an increased sense of compassion and empathy, improved interpersonal relationships, enhanced spirituality, increased appreciation for life, and re-evaluating priorities (Coleman, 2015; O'Connell et al., 2019; Ripley et al., 2007; Stevenson et al., 2017; Wright & Perry Black, 2013). Similarly, the concept of post-traumatic growth has also been identified within the literature as a potential consequence of perinatal death (Côté-Arsenault & Denney-Koelsch, 2016; Dias et al., 2017; O'Connell et al., 2019; Wool et al., 2018). Post-traumatic growth has been defined as a transformation or positive change that occurs as a result of the struggle to overcome and cope with a traumatic life event or form of adversity (Michael & Cooper, 2013; O'Connell et al., 2019). Michael and Cooper (2013) conducted a systematic review of both qualitative and quantitative studies (n=15) examining post-traumatic growth within the bereavement period following the death of a child. The authors found that all studies included in the sample described a positive self-transformation among participants such as an increased sense of compassion, appreciation, empathy, patience and courage (Michael & Cooper, 2013). Across the included studies, another common theme revealed was the reappraisal of life priorities which lead to discovering new talents, trying new experiences and living in the

moment as opposed to holding off on certain things (Michael & Cooper, 2013). The study also found that experiencing post-traumatic growth strengthened the participants' communication, connections and social relationships with others (Michael & Cooper, 2013).

Finally, although the detection of a LLFC is anticipated to end in a perinatal death (either in pregnancy or relatively soon after birth), some newborns survive longer than predicted (Nageswaran et al., 2018; Parravicini & Lorenz, 2014). This also has implications for parental grief. Families in these situations encounter additional challenges associated with caring for a newborn who is anticipated to die, yet not knowing how long their child will survive or how to best manage their care. In a retrospective database review of postnatal outcomes following the diagnosis of prenatal LLFC (n=45), the findings illustrated the difficulty in estimating the time to death after birth and the importance of communicating to parents that longer survival is possible (Parravicini & Lorenz, 2014). Moreover, in a retrospective cohort study exploring the postnatal courses of neonates (n=192) diagnosed with congenital anomalies classified as lethal, it was revealed that parents often encountered additional challenges associated with the uncertainty surrounding how long their baby would live (Courtwright et al., 2011). Within this context, several studies have described the complex medical needs of infants who survived longer than predicted (Bijma et al., 2005; Janvier et al., 2016; Nageswaran et al., 2018; Pal et al., 2015). Regardless of the type of LLFC or length of time the child survives, this experience is undoubtedly complex, difficult and forever changes the lives of parents who have navigated it.

Summary

The literature presented in this chapter illustrates the drastic and unexpected shift that occurs throughout the experience of continuing pregnancy following the diagnosis of a LLFC as well as the complexity that exists within these situations for both parents and HCP. For parents

within this context, the pregnancy experience is forever changed and is characterized by distinct challenges that are not encountered in typical low-risk pregnancies. As such, parents navigating these experiences often face additional emotional, physical and psychosocial demands and have individualized needs. The importance of providing optimal and holistic care to this population has been widely acknowledged within the literature as well as the key role HCP have in shaping the overall experiences of parents. However, the literature continues to describe a lack of familiarity and comfort surrounding the experience of continuing pregnancy in the presence of a LLFC as well as a lack of guidelines to direct clinical practice in this area. These represent both knowledge and practice gaps within this field and limit our ability as HCP to adequately respond to the unique needs of this population, which can have an adverse impact on the therapeutic relationships developed between HCP and parents. The care and supports offered to families throughout this trajectory are situated within a relational context, and each interaction that occurs has the potential to influence parental experiences in either a positive or negative way. Within these situations, parents have voiced how positive interactions with HCP enhanced their coping abilities, decreased their feelings of isolation and increased their level of satisfaction, whereas negative interactions resulted in feelings of distress, frustration, abandonment, and fear. Given the additional emotional, ethical and cognitive challenges that exist within this trajectory, families rely heavily on the care, services and supports provided by HCP in order to navigate this uncertain journey.

There exists a growing body of qualitative literature surrounding the narrative experiences of parents who have continued pregnancy following the diagnosis of a LLFC. Although summarizing existing literature provides a descriptive overview of parental experiences, it does not illustrate the cumulative and in-depth knowledge that could be gained

from analysing key themes across a sample of studies exploring this topic. Conducting a meta-synthesis of qualitative literature in this area will reveal the central themes that characterize this experience from the perspectives of individuals who have lived it and can ultimately enhance the level of comfort and understanding of HCP working in perinatal settings.

Chapter 3: Methodology

Philosophical paradigm: Constructivism

Nursing research is conducted and interpreted through various paradigmatic approaches, depending on the underlying philosophical beliefs of the researcher (Creswell, 2009; Weaver & Olsen, 2005). As researchers, we hold a set of assumptions and a way of thinking about the world that influences the types of questions we ask as well as guides the way we approach a particular research question (Kelly et al., 2018). For this thesis, a qualitative design approach from the constructivist paradigm was used.

Constructivism represents a research paradigm that focuses on understanding the experiences of people as well as understanding how we know what we know and the meanings that we attribute to that knowledge (Kelly et al., 2018). Despite a past emphasis on quantitative designs within health research, the constructivist paradigm challenges these empirical assumptions by seeking to contribute powerful insights into health inquiry and emphasising the contextual importance that exists surrounding a particular research question (Weaver & Olsen, 2005). Through a constructivist approach, researchers can enhance their overall understanding of complex human phenomena by exploring the narratives of participants who have experienced them firsthand (Creswell, 2009; Weaver & Olsen, 2006). Within this thesis, I intend to illustrate the experience of continuing a pregnancy in the presence of a LLFC by synthesizing qualitative literature that explores parental perspectives surrounding this topic. Due to the inherent complexity that exists surrounding this topic, approaching this meta-synthesis from the constructivist paradigm will enable a deeper interpretation of the overall findings as well as the critical analysis of the central themes revealed throughout this process.

Constructivism acknowledges how personal experiences and beliefs can shape the interpretation of the data as well as how pre-existing knowledge surrounding the topic of interest guides the investigation and enhances the richness of the data (Appleton & King, 1997; Creswell, 2009). My academic involvement surrounding PPC as well as my clinical experience supporting parents who have continued pregnancy following the diagnosis of a LLFC will serve as a vital guide throughout the entire research process. My intimate involvement with families who have navigated this experience is what inspired this research project and also motivates me to critically reflect on this body of literature and synthesize it in a way that reflects the unique experiences of this population. Since my thesis aims to review and analyze existing qualitative literature surrounding the lived experiences of this population, my rationale for utilizing a constructivist approach is evident. Analyzing key themes that occur throughout this trajectory will provide valuable insights into the intricacies that exist within this experience, respond to existing gaps within both clinical practice and research as well as enhance our ability as HCP to support parents navigating these situations.

Theoretical Framework: Relational Ethics

The use of theory within research provides a lens through which researchers can make sense of complex phenomena and frame research problems (Connelly, 2014). When incorporating theory into research, a clear connection between the theory and the phenomenon of interest must be evident (Connelly, 2014). Relational ethics is a theoretical framework that asserts all ethical issues and decisions are situated within a relational context and emphasises the need for a critical appraisal of nurses' everyday actions within clinical practice (Pollard, 2015). Guided by this framework, I intend to demonstrate how the relationships formed between parents and HCP throughout the experience of continuing pregnancy in the presence of a LLFC, are

ethically significant, insofar as they influence the quality of care and support provided to this population. I also plan to illustrate the ethical impact that relationships have on the experiences and lasting memories of parents, even years following the death of their child (Luz et al., 2017; Tosello et al., 2017).

Since the concepts of ethics and relationships are relevant features within the phenomenon of continuing a pregnancy in the presence of a LLFC, this framework serves as a valuable guide to approach this inquiry. Ethics is concerned with what is morally right or wrong and is viewed as an integral part of everyday nursing practice within any healthcare context (Moore et al., 2014). As previously discussed, obstetrics represents an area that is predominantly viewed from a wellness perspective, within which it is anticipated that most pregnancies end with the uncomplicated birth of a child in good health. Yet, despite the on-going advances in this field, there remains a number of ethical challenges within this context. Our ability to detect and manage adverse fetal and maternal outcomes has outpaced our ability to respond to the complex needs of families within clinical situations where various levels of uncertainty can create multiple ethical dilemmas for both parents and HCP. Yet as HCP caring for this population, we must recognize how influential each relationship and interaction can be on parents' overall lived experience. Relational ethics draws attention to the critical role of relationships within clinical practice, particularly in ethically complex settings such as PPC.

The relational ethics framework is underpinned by the following central tenets: engagement, mutual respect, embodied knowledge, environment and uncertainty; all of which will be explored more in depth in the following paragraphs (Austin et al., 2013: Pollard, 2015). Caring for families during complex situations represents a fundamental challenge and nurses may attempt to disconnect themselves from the suffering experienced by patients in an effort to

manage these challenging situations (Austin et al., 2013). However, the engagement of nurses throughout therapeutic interactions is necessary so patients and families can be authentically supported in their health experience (Austin et al., 2013; Pollard 2015). Engagement with patients requires a deeper subjective responsiveness to the needs and capacities of others, and it is through this connectedness that nurses understand what is important to the patient and what is in their best interest (Moore et al., 2014; Pollard, 2015). Being fully engaged enables nurses to better understand the complexity that exists within individual situations as well as fosters meaningful therapeutic relationships, which subsequently enables nurses to meet the holistic needs of their patients (Pollard, 2015). Within the experience of continuing pregnancy in the presence of a LLFC, literature has revealed that when HCP fail to engage with parents or fail to acknowledge their emotions, this can result in parents feeling isolated and abandoned within the healthcare system (Wool, 2013). Nurses are ideally situated to create meaningful therapeutic relationships with families navigating these situations and to provide them with holistic support throughout this difficult and complex health trajectory (Shorey et al., 2017).

Mutual respect represents a critical element within both communication and therapeutic relationships (Austin et al., 2013). This concept refers to a genuine respect for both self and others that is reciprocal in nature (Austin et al., 2013). This entails shifting any existing power imbalances between nurses and patients towards a relationship that recognizes how the inherent strengths of individuals can compliment each other (Pollard, 2015). For mutual respect to be developed, interactions must comprise equally of dialogue and active listening, which helps to avoid judgement when divergent perspectives arise (Austin et al., 2013). Supporting a climate of mutual respect can positively influence everyday interactions within clinical practice that are continuously challenged by ethical dilemmas (Austin et al., 2013). Within the field of PPC,

promoting dignity and respect for an unborn child (fetus) as well as supporting parental decision-making throughout this experience is essential. However, divergent perspectives surrounding the lethality of certain fetal conditions and the ideal management approach within this context has been identified as being particularly challenging for both parents and HCP. These challenges can be further complicated by the increasing level of uncertainty that exists within the field of fetal diagnostics. Thus, HCP working with this population must critically reflect on their interactions with parents who choose to continue their pregnancy following the diagnosis of a LLFC and acknowledge the difficulty and complexity that exists surrounding these situations, while attempting to foster relationships that promote mutual trust and respect.

Embodied knowledge represents another important aspect of relational ethics, asserting that knowledge is derived from a combination of physical, cognitive, emotional and past experiences (Pollard, 2015). Embodied knowledge is a multidimensional process that occurs without any conscious thought and is situated in the relational space between self and others (Pollard, 2015). From this perspective, individuals draw upon all aspects from their personal lives and embrace both objective and subjective thoughts or feelings while also acknowledging both empirical knowledge and human compassion as equally important and valuable (Austin et al., 2013). As HCP, our clinical practice is influenced by many factors such as experiential knowledge, regulatory bodies and evidence-based practice guidelines, however providing patient and family centered care that is based on individual needs, hopes and desires is equally as important. This is especially vital in the context of perinatal death, where parents have identified how, even years after the death of their baby, they still remembered the care they received from HCP.

Human existence entails an inherent degree of uncertainty which is acknowledged as well as embraced within this relational framework (Austin et al., 2013). Since knowledge is influenced by the relational context and uncertainty is an innate human characteristic, the knowledge we have is therefore considered incomplete, however it is through this uncertainty that possibilities are created (Austin et al., 2013; Pollard, 2015). To respond to the uncertainty that exists within ethical dilemmas, nurses bring a combination of humility and understanding to their relationships with patients and families (Pollard, 2015).

The above-mentioned values identified within the relational ethics framework are all situated within an environmental context (Pollard, 2015). Relational ethics asserts that individuals are socially constructed and cannot be separated from the environment that surrounds them (Pollard, 2015). Mutuality exists between agents and their environment, where people are a product of their social context and this connectedness significantly influences personal identities, values and beliefs (Pollard, 2015). The healthcare environment within which nursing practice is situated, represents a moral space that can either support or impede the enactment of ethical practice and the development of supportive relationships (Austin et al., 2013). As previously demonstrated, societal factors (such as social norms, expectation and reactions) can significantly impact the experiences of parents who continue pregnancy in the presence of a LLFC. Thus, it is important to acknowledge the environmental and social factors that will influence the relationships formed with families throughout this trajectory.

It is through the enactment of these values within clinical practice that nurses can promote optimal health and healing, attend to individual grief and bereavement needs as well as enhance the overall experiences of patients (Pollard, 2015). Underpinning nursing practice with a relational ethics lens can improve our ability to navigate the complex and multifaceted ethical

situations that are frequently encountered within clinical practice (Doane & Varcoe, 2007). Although balancing one's professional responsibilities to provide efficient, competent and compassionate care with the development of meaningful therapeutic relationships is continuously challenging, we cannot overlook the enduring influence that everyday interactions have on the experiences of parents as they continue pregnancy in the presence of a LLFC (Quinn & Gephant, 2016). A relational ethics framework will enable nurses to develop meaningful therapeutic relationships with families while also upholding ethical standards of nursing practice (Doane & Varcoe, 2007). By exploring this research topic through a relational ethics lens, I aim to draw much needed attention to the many factors that shape and influence interactions between nurses and parents, in order to optimize the level of support provided to families within this context (Doane & Varcoe, 2007). To fully appreciate what is morally at stake for everyone involved throughout these situations, the focus must shift from attempting to 'solve' ethical dilemmas, to instead critically reflect on how the experiences and values of people are being realized or thwarted through their relationships with nurses and with the wider healthcare system (Hunt & Carnevale, 2011).

Methods

Design: Qualitative Meta-synthesis

A variety of methodological approaches exist for synthesizing qualitative research. Qualitative meta-synthesis, which was recognized as a viable methodology for reviewing qualitative health literature in the 1990's, aims to identify, organize, and synthesize existing qualitative research on complex human phenomena (Finlayson & Dixon, 2008; Thorne, 2017; Sandelowski, Barroso & Voils, 2007). Inspired by a particular research inquiry, this approach draws on existing qualitative research conducted by multiple scholars across various disciplines, settings, methodologies and interpretive styles (Thorne, 2017). Qualitative meta-synthesis moves

beyond simply identifying common themes and conclusions generated by previous studies, towards developing an appreciation for the subtle nuances within the included studies to achieve a deeper conceptualization of a phenomenon (Thorne, 2017). Within qualitative meta-synthesis, an emphasis is placed on the interpretation of findings from a sample of purposively selected research studies (Finlayson & Dixon, 2008). The inductive and interpretive approach to analysis achieved within qualitative meta-synthesis can reveal rich insights into a particular experience that are derived from the narratives of participants who have lived it (Thorne, 2017). In addition, the cumulative knowledge gained from qualitative meta-synthesis can be used to enhance evidence-based clinical practice and policy development within this field (Finlayson & Dixon, 2008). Since the overall goal of this thesis is to critically reflect on existing literature and to reveal a deeper understanding of the experience of continuing pregnancy in the presence of a LLFC, a qualitative meta-synthesis represents an ideal methodology to approach this topic. In addition to reflecting the inspiration and objective of this research project, a qualitative meta-synthesis is also consistent with my philosophical underpinnings in constructivism.

Search methods

The primary search strategy for this meta-synthesis consisted of multiple searches within the following electronic databases; CINAHL, PubMed, Psych Info and Google Scholar. Key terms were searched for in study titles, major headings and abstracts. Various combinations of search terms were used and targeted the population of interest (perinatal), the condition (life-limiting fetal diagnosis), the experience (continuing pregnancy) as well as the desired perspective (parent); these terms are identified in Table 1 (see below). In addition to the database searches, I also performed citation tracing as well as searched the reference lists of relevant publications. To be included, studies needed to have been either qualitative in design or include

qualitative data analysis within a mixed methods study. They needed to have explored the parental experiences of continuing a pregnancy in the presence of a LLFC at any point between the receiving the diagnosis and the bereavement period following death. In addition, papers needed to be a peer-reviewed research paper and written in English. Studies were excluded for various reasons: if the fetal condition identified was not considered life-limiting as previously defined within the background section of this thesis, if the study did not describe the parental perspective or if the study focused exclusively on pregnancy termination. Several studies examined data from mixed participant populations (e.g., parents and HCP) or diverse experiences (the experiences of parents who chose to continue pregnancy and others who terminated). From these sources, only data pertaining to the parental experiences of continuing a pregnancy were extracted and studies were excluded if authors did not clearly situate findings within the sample from which they were derived. To demonstrate contextual relevance, the search was limited to papers published in 2000 or later. The search for this meta-synthesis was conducted in September 2020 and was updated in February 2021.

Table 1

Search terms

Population	Condition	Experience	Desired perspective
prenatal* or perinatal* or antenatal* or pregnan* or obstetric* or fetus* or fetal* or in-utero	life-limit* or life limit or lethal* or terminal* or fatal* or incompatible or palliative or poor prognos* AND condition* or diagnos* or detect* or prognosis or illness	qualitative or experience* or narrative* or lived or explor* or interview* or perception*	Parent* or mother* or father* or couple*

Search outcome

The detailed screening process is outlined in a PRISMA diagram (see Appendix A). A total of 2128 articles were identified through the electronic database search and an additional 58 records were identified through additional sources such as Google Scholar and reference list checks. A total of 42 duplicate studies were removed, leaving 2186 studies to be screened. Following an initial screening of the titles and abstracts, 2136 studies failed to meet the inclusion criteria and were excluded, leaving 50 studies remaining. The secondary screening consisted of reviewing the full texts of each article to determine eligibility; this process eliminated an additional 21 studies from the sample, leaving a total of 29 qualitative articles included in the final sample for the meta-synthesis. This screening process was completed independently by myself. The final sample of papers (n = 29) was subsequently screened by an additional independent reviewer (from my advisory committee) to confirm eligibility of the final sample against the inclusion criteria. Any discrepancy between reviewers throughout this process was discussed and a consensus was reached. Although some studies included in the final sample also appear in the literature review section of my thesis (Chapter 2), the criteria for inclusion in the meta-synthesis differs from that of the literature review, thus the final sample is a different collection of papers.

Quality appraisal

The Critical Appraisal Skills Programme (CASP) tool (see Appendix B) was used to appraise the over-all quality of the studies included in this meta-synthesis and to describe each study's methodological strengths. Although there remains little consensus on how best to assess the methodological quality of qualitative research, completing a quality appraisal provided me an opportunity to enhance familiarity with the content from individual studies as well as assess the overall validity of the research findings, in order to avoid presenting unreliable conclusions

(Thorne, 2008). Despite these benefits, relying solely on a quality appraisal tool to determine inclusion risks excluding papers that might contain important participant perspectives, published within a wider paper that are deemed "imperfect" or lacking in quality based on a systematic checklist approach (Thorne, 2017). In addition, eliminating studies that fail to meet a particular set of quality standards also poses the risk of overlooking the collective wisdom that exists within the body of qualitative literature surrounding this topic (Thorne, 2017). Since determining the quality of qualitative literature is both a fraught and subjective process, the CASP tool was not used to determine inclusion or exclusion of studies in this meta-synthesis, but instead was used as a reflective guide to interpret and describe the overall quality and strengths of the individual studies (Thorne, 2017).

The CASP tool is a 10-item standardized checklist designed to assess the quality of qualitative research according to the following categories; validity, results and utility (Chenail, 2011). An overview of the findings from the CASP tool as well as the methodological strengths for each article is captured in a summary table of included studies (see Appendix C). The extent to which each individual study satisfied the 10 areas of methodological quality within the CASP tool was represented numerically, with an average score of 9/10. All 29 studies met the majority of criteria outlined within the CASP tool, thus demonstrating that the aim, design, data collection and analysis were appropriate to address the objective of this thesis. The area of the CASP tool that several studies failed to satisfy concerned reflexivity, however this shortcoming could be attributed to text limitations in publishing. Although no studies were excluded from this sample based on the CASP tool, it is important to note that not all studies contributed to the overall findings with the same richness and depth. The data from some studies within this sample informed the findings in a more meaningful way and as such, were relied on more heavily

throughout the analytic process. These studies are identified by an asterisk within the first column in the summary table of included studies (Appendix C).

Analysis

The analytic process for this meta-synthesis was guided by thematic analysis as described by Clarke and Braun (2006). Thematic analysis is a method used to identify, analyze and interpret patterns of meaning or themes within qualitative data (Clarke & Braun, 2017). This approach can be used to identify patterns that occur across papers exploring a particular area of interest, such as the lived experiences of participants and captures both explicit and implicit meanings within the data (Clarke & Braun, 2017). Thematic analysis emphasises the more organic approach to theme development as well as the importance of active engagement from the researcher throughout the analytic process (Clarke & Braun, 2006). Although various methods exist for analysing qualitative data, thematic analysis can be applied across a variety of theoretical frameworks and research paradigms (Clarke & Braun, 2017). It represents an ideal approach given the research aim and philosophical underpinnings of this thesis. Clarke and Braun (2006) outline the following 6 phases in conducting thematic analysis: 1) familiarising oneself with the data, 2) generating initial codes, 3) searching for common themes, 4) reviewing the themes, 5) defining the themes and 6) producing the final report (Clarke & Braun, 2006).

The data analysis for this qualitative meta-synthesis occurred concurrently with the data collection and evolved as an organic and iterative process. Papers were manually reviewed in their entirety to increase familiarity with the individual studies as well as the narrative data within them. Following this, a more in-depth review was completed, focusing on the results and discussion sections of each paper. This process involved critically reflecting on the narrative data from participant quotes as well as the authors' interpretations of these findings to identify key

themes. Both explicit and implicit themes within each individual study were coded and summarized into a table. These themes were further reviewed across all studies which generated a variety of new codes. This process involved ongoing and intimate engagement between the analytic summaries and the individual research papers to ensure accurate interpretations of the themes and meanings associated to them.

As previously stated, the objective of this research inquiry was to critically reflect on existing literature and to reveal a deeper understanding of the experience of continuing pregnancy in the presence of a LLFC. Thus, in addition to analyzing the overarching themes that emerged from the studies, several analytic questions were created in consultation with my committee and were used to guide this analysis. These questions include: what key concepts emerge from the article, what is the relational context of the concepts identified, how are these concepts influenced by the relationships formed throughout this experience, what is most important to these families and what are the consequences on the overall experiences of parents? The analytic process also included ongoing discussions as a committee to ensure all members were in agreement and to deepen the analytic insights revealed.

Chapter 4: Results

The comprehensive search for this meta-synthesis resulted in 29 qualitative studies that explored the experiences of parents who continued pregnancy in the presence of a LLFC. Characteristics of the studies included in the analysis are outlined in a summary table (see Appendix B). Dates of publication ranged from 2002 to 2019 and studies were conducted in a number of countries including; Italy, the UK, Sweden, Ireland, the United States and Australia. The included studies were from a variety of disciplines: nursing, medicine, midwifery, psychology and sociology. The final sample is comprised of the following study designs; descriptive (11), ethnography (1), phenomenology (9), narrative (2), "naturalistic" (2), mixed methods (qualitative component) (3) and grounded theory (1). The combined samples included 930 participants total, of which 292 were female, 140 were male, 45 were 'couples' and 408 were identified as 'parents'. Of the 29 papers included in this meta-synthesis, some studies focused on the period of time during pregnancy and prior to birth (n=6), others focused on the bereavement period following death (n=9) and some studies explored the experiences of parents across multiple points of time throughout this trajectory (n= 14). The 14 studies that interviewed parents across multiple points of time captured the experiences of parents before and after the birth of their child as well as before and after their child's death. The LLFCs described across this sample of papers consisted of a variety of neurologic, genetic and cardiac conditions including anencephaly, hypoplastic left heart syndrome, trisomy 18 and bilateral renal agenesis. Although navigating pregnancy in the presence of a LLFC remains an individualized experience, the findings from this meta-synthesis revealed the following three themes that characterize this trajectory; time, uncertainty and relationship. This chapter presents a detailed description of these overarching themes.

Time

The concept of time has been both explicitly and implicitly identified by authors as a prevalent feature within the lived experiences of parents across the majority of studies in the sample. Many authors made reference to the disruption of time that occurred for parents during pregnancy after receiving the diagnosis of a LLFC. Parental narratives described their contrasting experiences between the period of time before learning about the LLFC, where they were "living in innocence" and the period of time after receiving the diagnosis which propelled them into a "new reality" (Welch, 2018). Parents who continued pregnancy in the presence of a LLFC acknowledged how their expectations and hopes for pregnancy were profoundly altered in comparison to a "normal pregnancy" experience. Within this new reality, the chronology of time was disrupted and parents were required to cope with the changes and temporal limitations imposed by the LLFC. Participant narratives across this sample also described how parents' individual appraisal of time throughout the remainder of the pregnancy shaped their overall experiences and memories of their child. In this first theme, I explore the ways in which time and temporality manifest throughout the included papers, both explicitly and implicitly, according to the following two sub-themes: cherishing limited time and the distortion of time.

Cherishing limited time

Many parents acknowledged the gradual process of coping with the new reality of continuing pregnancy in the presence of a LLFC and described how they transformed previous hopes, beliefs and expectations into new ones that reflected their child's prognosis. In the study by Black and Sandelowski (2010), one couple described their ability to reframe earlier perspectives surrounding the birth of their child and voiced that rather than "expecting a death, it was nice knowing we were waiting for a baby" (Black & Sandelowski, 2010). This process of

transforming previous beliefs and expectations enabled parents to reconsider the value of time throughout their individual experience and helped them to cherish their time together while focusing on finding meaning despite the diagnosis. Similarly, in the study by Thiele (2011) which explored the author's personal experience of continuing pregnancy in the presence of a LLFC, she shared; "Our hope was not for a miracle but lay in the smaller things - to hold our child, that Liam would know that he was loved and that he would die peacefully with symptom relief" (Thiele, 2011). The notion of transforming previous expectations and hopes was also identified in the study conducted by Côté-Arsenault and colleagues (2015) where one parent revealed:

> Our pastor baptized him right away in that first minute. That right there was like our primary goal with Tyler once we found out, you know, what he was diagnosed with [trisomy 18], was just to have that live birth and have him baptized (Côté-Arsenault et al., 2015).

Although the experience of transforming previous beliefs, hopes and expectations was not explicitly associated with temporality in these papers, these participant narratives illustrate how parents' reappraisal of time following the diagnosis of a LLFC enabled them to create new pregnancy goals and expectations that reflected their current reality. Parents acknowledged the limitations of the time available to them and chose to embrace the time they had together in a meaningful way.

The diagnosis of a LLFC is anticipated to end in a perinatal death, therefore the time parents have to be with their child is significantly shorter than they had expected. Across these studies, many authors described how parents' realization of this limited time prompted them to focus on "living in the moment" and served as a daily reminder of how precious any amount of

time together was (Black & Sandelowski, 2010). In the study conducted by O'Connell and colleagues (2019), parents described their evolving relationship with their baby that developed throughout the pregnancy irrespective of the diagnosis of a LLFC. Participants voiced how they "started to appreciate every single day" with their child and since time was limited, they knew "that would be it" (O'Connell et al., 2019). de-Vitry Smith and colleagues (2012) found similar findings in their study about appreciating limited time, as illustrated in the following narrative; "I made a promise to myself that I was going to enjoy the rest of my pregnancy…this is all I have, this time". Parents within this context recognized that the diagnosis of a LLFC meant their time with their baby would not last forever, prompting many parents to cherish whatever time was available to them (de-Vitry Smith et al., 2012).

In the study conducted by Welch (2018) exploring the experiences of parents anticipating the birth of a child with a LLFC, parents acknowledged how it is unknown exactly how much time they will have with their child and the reality of the future without their baby. Within the study, parents described the notion of "squeezing a lifetime into a moment" and emphasized the importance of embracing every opportunity to be with their child and creating valuable memories (Welch, 2018). Parents in this study also shared that no matter how much time they had with their baby, it felt as though it was "never enough time" (Welch, 2018). Across these papers, many parents described the time with their child as "too short" and expressed a desire to have "more time" or wished that their time together was "a little longer" (Côté-Arsenault & Denney-Koelsch, 2011; Lathrop & VandeVusse, 2011b). In the study conducted by Côté-Arsenault and colleagues (2015), one mother shared her efforts of trying to maximize the time she had with her daughter; "Right now, keeping myself healthy to keep her healthy, protecting her, doing my part and giving her the longest time" (Côté-Arsenault et al., 2015). Parents within

this context acknowledged how the chronology of time was altered in comparison to a "normal" pregnancy and began to develop a deeper appreciation of the time they had with their child.

Across these papers, parents labelled the time spent with their child as "precious" and described how they "cherished every moment" they had together (Côté-Arsenault et al., 2015; de-Vitry Smith et al., 2012). In the study conducted by Côté-Arsenault and Denney-Koelsch (2016), parents described making a conscious decision to value the time they had with their child, both during pregnancy or after birth. These findings were also reflected in a study conducted by Côté-Arsenault and colleagues (2015) where participants shared narratives such as; "I just would rather her have whatever time she has here and make it the best" and "we both decided to take this attitude that we are going to cherish every day, every moment that we have with her" (Côté-Arsenault et al., 2015). de-Vitry Smith and colleagues (2012) identified similar parental perspectives about valuing limited time in their study; "As a family…we've stressed how important it is to just enjoy this. Let's not focus on how long we're going to have him…let's focus on what we've got now, and right now we've got him" (de-Vitry Smith et al., 2012). Wool and colleagues' (2018) conducted a study exploring the experiences of over 400 parents who continued pregnancy in the presence of a LLFC and the overarching theme revealed from participant narratives was "cherishing time". Parents described how they would not trade the time they had with their child "for anything in the world" and how they would "always cherish the time" they had with their child (Wool et al., 2018). These narratives illustrate parents' conscious decision to transform previous hopes and expectations about the amount and type of time they had with their child, ultimately enabling them to focus on the quality of their time together rather than the quantity. This reappraisal of time was found to empower parents to

create valuable memories and a lasting legacy for their child, despite their limited life expectancy.

Several authors refer to the valuable time parents spent interacting with their baby during medical appointments, such as ultrasounds. Although it was not presented as a key feature within the authors' own analysis of these experiences, several papers implicitly acknowledged the value of time during ultrasound appointments and how this time enhanced bonding between parent and child as well as provided parents with an additional opportunity to connect with their baby. In the study by Côté-Arsenault and Denney-Koelsch (2016), one parent shared the following narrative regarding her ultrasound; "I think it's really wonderful. This may be the only opportunity that we actually have to meet her in all her life" (Côté-Arsenault & Denney-Koelsch, 2016). Across these papers, parents also described how prenatal ultrasounds provided them with reassurance regarding their child's overall health. The following participant narrative illustrates the reassurance and affirmation gained from having tangible confirmation of their child's life; "I've heard her heart beating - many times now. I've seen her squirming. I've felt her kicking and I know she's very much alive" (Côté-Arsenault et al., 2015). Being able to "see baby on the screen" or "listen to the heartbeat" during appointments became even more meaningful to parents who continued pregnancy in the presence of a LLFC as it confirmed that baby was still alive and that parents had more time with their child (Blakeley et al., 2019a). The time during prenatal ultrasounds was also described as valuable by the non-pregnant parent. In the study conducted by Côté-Arsenault and Denney-Koelsch (2016), one father shared; "It is nice especially for me because I don't get to feel her everyday. I don't have that same bond and so to see her is huge for me because I need that" (Côté-Arsenault & Denney-Koelsch, 2016). Within this context, ultrasounds developed a special significance and many parents expressed a

profound sense of appreciation towards HCP when more frequent or longer appointments were offered. In the study conducted by Guon and colleagues (2014), one mother shared her appreciation for being offered more time with her baby; “He allowed us to have longer ultrasound appointments so we could spend time with Jordan, seeing him alive” (Guon et al., 2014). Given the limited amount of time parents are expected to have with their child, all opportunities to interact with their baby, including during prenatal appointments, represented extra time that was cherished by parents.

Across these papers, parents described placing an urgency on the creation of lasting memories in the short time they had and viewed all time during pregnancy and after birth as valuable time in which to create memories and collect mementos. In the study conducted by Côté-Arsenault and Denney-Koelsh (2011), parents recognized the personhood of their child despite the LLFC and expressed a strong desire to remember the life of their baby; “I really do want a memory of my baby. Regardless if he’s alive…he’s still my baby”. Similarly, in the study conducted by Kamrath and colleagues (2019) exploring the experiences of women navigating pregnancy in the presence of a LLFC, one of the key themes revealed from participant narratives was the importance of creating lasting memories in the limited time available (Kamrath et al., 2019). One mother shared how meaningful it was to have mementos that symbolized her daughter’s life; “They made me a plaster mold in the shape of a heart that’s got her hands and feet on it. That is my most cherished possession in the entire world” (Kamrath et al., 2019). Within this context, parents described how all mementos created throughout this experience were cherished and how they preserved their child’s memory as well as enabled parents to maintain a connection with their child, even after death.

The distortion of time

After receiving the diagnosis of a LLFC, many parents made reference to how their perception of time changed throughout the remainder of the pregnancy. Across this sample of papers, parents described how their sense of time was altered and how time appeared to pass by at different speeds, either slowly or quickly. In de-Vitry Smith and colleagues' (2012) qualitative study, time distortion was explicitly identified as a central theme experienced by parents who continued pregnancy following the diagnosis of a LLFC (de-Vitry Smith et al., 2012). The notion of time distortion is apparent in the following narrative:

> I look back from when we first found out…and although that was what 3 months ago, I feel like it was just ages ago…boy, it seems like just yesterday that I thought everything was just fine and dandy and…to where we are now, it just seems like sooo long ago, it's almost like time has flown but time has gone by so slowly at the [same] time (de-Vitry Smith et al., 2012).

Similarly, in the study conducted by Carlsson and colleagues (2017), parents described challenges associated with waiting for diagnostic information and feeling as though time was passing by slowly; "We have another appointment, but it's about three weeks away and it feels like several years!" (Carlsson et al., 2017). These narratives demonstrate the disruption that occurs in the chronology of time when a LLFC is detected. They also illustrate how parents are required to adapt to this distortion of time following the diagnosis of a LLFC. In addition, parents also used language such as being "in a daze", "seems like a lifetime ago" or feeling as if they were "in limbo" to describe their experiences with time distortion throughout the remainder of pregnancy (Côté-Arsenault & Denney-Koelsh, 2011; de-Vitry Smith et al., 2012; O'Connell et al., 2019). Many parents acknowledged that receiving a diagnosis of a LLFC was a disorienting experience and that following the diagnosis, their perceptions of time were forever altered. The

distortion of time that occurs within this context illustrates how temporality becomes a more subjective experience for parents and requires parents to renegotiate their relationship with time in order to make the most of every moment available to them.

While navigating time throughout the remainder of pregnancy, parents found a balance between cherishing time and living in the present moment while also coping with the anticipated death of their baby. In the study conducted by Côté-Arsenault and Denney-Koelsch (2018), one participant described her ability to accept the time limitations associated with the diagnosis and how it helped her to embrace the time she had with her son; "When you hear that your child has a deadly disease you have 2 choices: ignore it or embrace it. We chose to embrace it...our goal was to let Blake know that we loved him more than life itself" (Côté-Arsenault & Denney-Koelsch, 2018). de-Vitry Smith and colleagues (2012) revealed similar findings in their study as illustrated in the following narrative:

> You can't afford to look forward, I mean, there's just too much that could happen and you miss out on what is happening when you do that…You just live kind of a day-to-day, and just take care of the now instead of what could happen (de-Vitry Smith et al., 2012).

In this same study, another mother voiced:

> The biggest thing that I've learned so far…is the importance of living right now, just taking every day, one day at a time…Not looking too far ahead because sometimes what's most important is what's in front of you right now at this very moment and we have him (de-Vitry Smith et al., 2012).

These narratives illustrate how parents' reappraisal of time following the diagnosis enabled them to appreciate the significance of the time they had and assisted them in focusing on living in the moment.

Several papers make frequent reference to the contrasting experiences of women navigating a “normal pregnancy” and those who are navigating a pregnancy in the presence of a LLFC. The social discourse of a traditional “healthy pregnancy” which lasts 9 months and ends with the birth of a “healthy” baby gets disrupted when a LLFC is detected, since the baby is anticipated to die either in utero or shortly after birth. This unexpected shift in expectations between a “normal pregnancy” and the new reality of perinatal death further distorts parents’ perceptions of time leading up to birth. In the study conducted by de-Vitry Smith and colleagues’ (2012), parents described their challenges in navigating time when their experiences differed greatly from that of a “normal pregnancy”. One mother shared the following; “I struggle most with that understanding — that death, in my case, is so incredibly close to life. I used to think a baby is as far away from death as you can possibly get. Now death's at my side every day” (de-Vitry Smith et al., 2012). Similarly, another mother in this study voiced; “I know once I do have him, it’s like the clock just starts ticking and I almost just want to keep him inside me where he’s safe and sometimes that’s just overwhelming” (de-Vitry Smith et al., 2012). Although birth traditionally represents the natural end of a pregnancy, within this context parents described a desire to slow down the progression of pregnancy since birth also signified baby’s journey towards death. One parent described her desire to hold onto the pregnancy for as long as possible so she could have more time with her child; “I kind of wanted him to stay inside forever…because I knew when I had him inside, he was safe but as soon as he came out it was going to be bad” (de-Vitry Smith et al., 2012). For parents in these situations, the notion of prolonging pregnancy meant that they could hold onto time with their child, and that this extra time could be used to create valuable memories.

Although not explicitly acknowledged in these papers, parents also described the distortion of time that occurred after the death of their child. Several parents acknowledged the conflicting emotions that existed between preparing to say their final goodbyes to baby and their desire to hold onto baby for as long as possible so they could continue cherishing their time together, even after death. In the study conducted by Côté-Arsenault and Denney-Koelsch (2016), a participant shared:

> Tomorrow, I will see my little girl once last time, attend a service in her honor, and bury her. In some ways, I just want the day to be over. But in so many other ways, I don't want tomorrow to come at all (Côté-Arsenault & Denney-Koelsch, 2016).

The realization of the finality of this time altered parent's perceptions regarding temporality and even after death, parents desired as much time as possible with their baby.

Uncertainty

Across the majority of the papers included in this meta-synthesis, I identified the concept of uncertainty as a prominent feature in the lived experiences of parents. Although a level of uncertainty is inherent in any pregnancy, the findings from this meta-synthesis suggest that uncertainty is more pronounced for parents who continue pregnancy in the presence of a LLFC. Many authors made reference to the varying levels of uncertainty that exist after continuing pregnancy in the presence of a LLFC as well as the challenges encountered by parents while negotiating these multiple uncertainties. For parents in these situations, the onset of uncertainty throughout this trajectory has been primarily associated with the time the LLFC was initially detected. Many parents voiced feeling unsure of what to expect after receiving the diagnosis and described how their pregnancy experience suddenly transformed into "uncharted territory" (Horning & Braun, 2006). Several studies also acknowledged how the uncertainty that parents

encountered was often perpetuated by the lack of experience and comfort surrounding the management of LLFCs among HCP. The following section will further explore the ways in which uncertainty manifests throughout this experience according to the following four subthemes: prognostic uncertainty, uncertainty navigating social norms, uncertainty as a catalyst for hope and living within an uncertain reality.

Prognostic uncertainty

Across these studies, the majority of authors made reference to the level of diagnostic and prognostic uncertainty that exists for parents after receiving the diagnosis of a LLFC prenatally. Although there have been significant advances in the field of fetal diagnostics, the ability to fully predict the severity of illness or life expectancy of a child diagnosed with a LLFC prenatally remains limited. In the study conducted by Blakeley and colleagues (2019), parents described the challenges associated with navigating "the unknown" regarding their child's prognosis and the difficulty of "not having any concrete answers" (Blakeley et al., 2019a). Similarly, Guon and colleagues (2014) noted that for parents, the diagnostic uncertainty and the "unknown outcome" for the baby as a result of the LLFC influenced parental decision-making on how to proceed in the pregnancy (Guon et al., 2014). Although decision-making in this context is inherently complex given the far-reaching consequences, parents reported that not knowing the full extent of their child's condition or medical needs after birth made choosing between continuing or terminating the pregnancy particularly challenging. These findings were also reflected in Blakeley and colleagues' study (2019), where parents expressed that since they "didn't really know" what would happen, it was hard to know whether or not they were "making the right choice" (Blakeley et al., 2019a). Several authors also acknowledged that making a decision of this magnitude based on inadequate diagnostic information often created a sense of decisional

uncertainty for parents about how to proceed and resulted in a wavering decision-making process.

Several papers made reference to the challenges that parents experienced as they navigated prognostic uncertainty and the impact that this uncertainty had on their overall experience. In the study lead by Côté-Arsenault and Denney-Koelsch (2016), one mother described how her son's uncertain prognosis left her feeling "lost" throughout the remainder of her pregnancy:

> I'm uncertain of what's going to happen because my medical professionals are uncertain…I'm not coming up with that feeling. I'm simply mirroring theirs…They don't know what's going on. They don't know how it's going to be. That's kind of where my position is (Côté-Arsenault & Denney-Koelsch, 2016).

This narrative illustrates not only the prognostic uncertainty that exists within this context, but also the impact of the uncertainty felt by HCP on the parental experience. Parents who continued pregnancy following the diagnosis of a LLFC also described not knowing how long their child would survive if born alive. One parent expressed this uncertainty in the following narrative; "We didn't know how close hello and goodbye would really be" (Kamrath et al., 2019). In this study, although the uncertainty parents experienced regarding their child's life expectancy enabled some to focus on appreciating the limited time they had together, other parents described the challenges associated with not knowing whether the time with their baby would end abruptly. Similar findings were revealed in the study conducted by Blakeley and colleagues (2019), where one parent voiced; "We don't know how long this will go on for…our baby could survive another two weeks…they could survive another six weeks" (Blakeley et al., 2019a). This quote

demonstrates that although death is anticipated to occur shortly after birth, some babies live longer than predicted, creating an additional level of uncertainty for parents to contend with.

Uncertainty navigating social norms

As previously mentioned, several authors have acknowledged the divergence that exists between the "normal pregnancy" experience and the experience of continuing pregnancy in the presence of a LLFC. This sudden and drastic shift resulted in many parents feeling unsure of how their experience fit into the traditional social norms typically associated with pregnancy and generated much uncertainty surrounding how best to navigate these social aspects when the baby was not anticipated to live. In the study conducted by Carlsson and colleagues (2017), one parent described the dilemma she experienced regarding sharing her baby's diagnosis with others; "How do you deal with other people? What on earth do you say when you get comments about when the baby comes? Should you just keep silent, or tell them? I think it's terribly difficult" (Carlsson et al., 2017). Many parents within this context expressed fears about how others would react or worried about the judgements others may have towards their decision to continue the pregnancy despite the diagnosis of a LLFC. Similar findings were identified in the study by Côté-Arsenault and Denney-Koelsch (2011), where participants described the awkward and painful feelings they experienced while navigating social situations and how they "picked up on the discomfort and uncertainty of others" throughout the remainder of the pregnancy. Although parents are required to adapt and cope with the uncertainty that exists when continuing pregnancy in the presence of a LLFC, parents voiced that managing the uncertainty felt by others within their immediate social circle created additional challenges. Several parents acknowledged that uncertainty surrounding the socialization of pregnancy left them feeling unsure of how their

experience fit in with existing social norms, which often perpetuated the feelings of isolation that were already experienced by many parents who continued pregnancy in the presence of a LLFC.

Uncertainty as a catalyst for hope

Although many parents acknowledged the additional challenges associated with uncertainty, uncertainty was not always perceived as a negative experience and for some, the uncertain prognosis inspired feelings of hope. In the study conducted by Côté-Arsenault and Denney-Koelsch (2011), one family shared how despite the prognosis, they chose to embrace uncertainty and remain hopeful; ‘‘I need to have hope. I know what the reality is, but I still need the little bit of hope’’ (Côté-Arsenault & Denney-Koelsch, 2011). These findings were also reflected in Carlsson and colleagues (2017) study, where one mother voiced; “I hope the doctors are wrong. They have been before, not especially often, but sometimes. And maybe, maybe we can be in that 1 percent that turns out well” (Carlsson et al., 2017). In this same study, another parent shared; “The doctors think our son won’t make it…they’re 99 percent certain. After a lot of thought, we’ve decided we want to try and fight, and hope, and believe it might work. It's hard, but it feels completely right” (Carlsson et al., 2017). Many parents expressed that the lack of certainty surrounding their child’s diagnosis and prognosis provided them with a sense of hope and optimism throughout their experience. These narratives illustrate how parents transformed the uncertainty they faced into hope that their outcome might be different than predicted. Several papers acknowledged how maintaining hope represented an important coping mechanism for parents as they navigated the uncertain reality of continuing pregnancy in the presence of a LLFC.

Living within an uncertain reality

Several participant narratives within the selected papers implicitly described the challenges of living with perpetual uncertainty and the impact it had on their overall experience. In the study conducted by Denney-Koelsch and colleagues (2016), parents described coping with the "uncertain nature of what was ahead" as difficult, stressful and overwhelming (Denney-Koelsch et al., 2016). Similarly, in the study conducted by de-Vitry Smith and colleagues (2012), parents identified how coping with the "unknown future" of their child's condition was "extremely stressful" and created feelings of fear and anxiety throughout the remainder of the pregnancy (de-Vitry Smith et al., 2012). Multiple studies described the diverse and fluctuating emotions that parents experienced throughout this trajectory and how the presence of uncertainty often influenced parents' overall mood as they navigated their day-to-day lives. In the study conducted by Carlsson and colleagues (2017), the authors noted that the lack of information available to parents resulted in feelings of worry, confusion and frustration (Carlsson et al., 2017). One participant shared the following narrative; "I don't feel like we've gotten very much information at all and they haven't really been able to tell us what's actually going to happen" (Carlsson et al., 2017). Within this context, parents continuously sought information that would help them prepare for what to expect next, however, the reality of the uncertainty that surrounds many LLFCs and the rarity of most conditions often prevented parents from accessing concrete answers to guide them throughout the remainder of pregnancy.

Across these papers, parents described various coping strategies used to navigate the uncertainty that existed within this experience. Black and Sandelowski (2010) identified how some parents coped with the uncertainty of the pregnancy and eventual birth of their child by "living one day at a time" (Black & Sandelowski, 2010). This adaptive process enabled parents to focus on the present moment and helped them to avoid worrying about things that were out of

their control. In the study by Lotto and colleagues (2018) exploring parental decision-making following the diagnosis of a LLFC, the overarching theme revealed was "negotiating uncertainty" (Lotto et al., 2018). The findings described the multiple uncertainties that exist surrounding the diagnosis and prognosis of children with LLFCs and that parental decision-making on how to proceed was greatly influenced by parents' ability to navigate uncertainty. Parents in this study identified information seeking as a key strategy that enabled them to decrease feelings of uncertainty and helped them to accept and cope with the uncertain future (Lotto et al., 2018).

Relationship

The concept of relationality was explicitly identified as a predominant feature within the experience of continuing pregnancy in the presence of a LLFC across all papers included in this meta-synthesis. Pregnancy is largely regarded as a social experience, however several studies acknowledged the changing nature of all relationships developed throughout the trajectory. Many authors described the significance of the relational trajectories and connections formed throughout this experience and the lasting impact they had on parents' years after the death of their child. All interactions, no matter how brief, remained part of parents lived experiences and had a meaningful impact on parental perceptions regarding the level of support and care they received throughout this trajectory. The subsequent paragraphs will explore the ways in which relationality manifests throughout the experience of continuing pregnancy in the presence of a LLFC according to the following five subthemes: the unique relationship developed between parent and child, finding a new sense of self, the relational impact of pregnancy loss on parents as a couple, the lasting impact of interactions with HCP and the social implications of carrying a baby that is not anticipated to survive.

The unique relationship developed between parent and child

The unique relationship formed between parent and child has been explicitly acknowledged by all studies included in this meta-synthesis. All authors across this sample of papers described the intricate process of parenting during pregnancy in the presence of a LLFC, irrespective of the diagnosis, and the strong desire of parents to love, protect and nurture their child. The majority of participants across contributing papers identified themselves as "parents" and referred to their unborn child as "son" or "daughter." In addition, several narratives revealed language that affirms the parent-child relationship such as "I am a parent" or "this is our child" and described their "parental role" or "parental responsibility" throughout the remainder of the pregnancy and following birth (Blakeley et al., 2019a; Chevalier McKechnie et al., 2015; Côté-Arsenault & Denney-Koelsch, 2011). The use of such vocabulary within the narratives of parents readily illustrates the development of the parent-child relationship in early pregnancy, irrespective of the LLFC. In the study conducted by Côté-Arsenault and colleagues (2015), one mother acknowledged her role as a parent in the following narrative; "We need to do what we can and just be her parents and let her know that we are here with her" (Côté-Arsenault et al., 2015). These findings are also reflected in Côté-Arsenault and Denney-Koelsch's (2011) study, where one woman shared; "I'm going to be a mom, then I have to do what's best for my child and me" (Côté-Arsenault & Denney-Koelsch, 2011).

Although parenting literature traditionally focuses on the role of parents following birth, the term "prenatal parenting" was identified within the study by Côté-Arsenault and colleagues (2015) and describes the attachment and distinct parenting behaviours developed in pregnancy in the context of a LLFC (Côté-Arsenault et al., 2015). These authors found that parenting, in light of the LLFC, was more deliberate, accelerated and compressed given the limited life expectancy

of the child (Côté-Arsenault et al., 2015). In this study, the findings revealed the different parenting behaviours displayed by participants during pregnancy, including: making decisions based on the best interest of baby, promoting baby's personhood, interacting and spending time with baby and loving baby (Côté-Arsenault et al., 2015). Due to the relationship and strong emotional connection that formed in pregnancy, the majority of parents across the selected papers assumed a parental identity early on and displayed a variety of parenting behaviours that acknowledged the value of their unborn child's life and the innate love they shared, despite the diagnosis of a LLFC. Carlsson and colleagues (2017) explored the emotional process of expectant parents within this context and found that the special parent-child bond that developed prenatally enhanced parents' ability to accept their child's adverse diagnosis, to become advocates for the rights and personhood of their child and to find meaning and joy within their experience (Carlsson et al., 2017).

A love that is unconditional

The intimate bond and connection formed between parent and child has been characterized as a "deep" and "unconditional" love (Côté-Arsenault et al., 2015). Within this sample of papers, several authors explicitly described the love that parents have for their child despite the diagnosis of a LLFC. The following narrative illustrates the unconditional love felt by one mother during her pregnancy; "Even though she does have the problems that she does…I love her so much…And it's crazy because I haven't even met her yet.…She's just my angel, my blessing. She changed my life" (Chevalier McKechnie et al., 2015). In the study conducted by Carlsson and colleagues (2017) exploring written posts in online discussion boards, several participants voiced having a "deep maternal love", being "so in love" with their child, loving their child "to pieces" and how their child held a "special place in their heart" (Carlsson et al.,

2017). A study conducted by Côté-Arsenault and Denney-Koelsch (2011), revealed that although receiving the diagnosis of a LLFC often initiated a grief response, the "intense love" parents had for their child enabled them to cope with the challenges of continuing pregnancy and had an overall positive impact on their lived experience (Côté-Arsenault & Denney-Koelsch, 2011). In the study conducted by Côté-Arsenault and colleagues (2015), one mother shared the happiness and love she experienced following her son's birth; "He was my miracle, my joy, my greatest accomplishment…I loved him the minute he was born and every day since" (Côté-Arsenault et al., 2015). Several studies acknowledged how the deep meaningful connections formed between parent and child within this context enabled parents to love their child without condition, irrespective of their prognosis and limited life expectancy.

The desire of parents to express and demonstrate their unconditional love as well as the importance parents place on their child knowing or feeling love was also revealed in several studies across this sample of papers. In the study conducted by Côté-Arsenault and Denney-Koelsch (2018), the findings described parents' active choice to love their child despite the diagnosis, which represented a key theme that the authors highlighted in the study's title; "Love is a choice". Within this study, one mother voiced; "I know he hears my voice…I tell him every single day that I love him" (Côté-Arsenault & Denney-Koelsch, 2018). Similar findings were identified in the study conducted by de-Vitry Smith and colleagues (2012), where participants frequently described feelings of love and the importance of sharing those feelings with their child during pregnancy. Another mother shared:

> I wanted to spend every moment thinking about her and letting her know that she was loved and so when I wasn't thinking about her I felt like, Oh my gosh, I've just wasted 10 minutes not telling her I loved her (de-Vitry Smith et al., 2012).

Within this context, parents acknowledged their limited time with baby and made a conscious decision to actively love their child without condition. Parental narratives across these papers attest to a profound desire to feel like a "good parent", to do "what is best for baby" and above all, that their child "know they are loved" (Denney-Koelsch et al., 2018).

The love and connection formed between parent and child within this context was also described by several authors as being an influential factor in parental decision-making surrounding how to proceed in pregnancy following the diagnosis of a LLFC. One mother shared how the love she felt for her child early in the pregnancy contributed to her decision-making; "In reality I knew that most people terminated such babies but for me it was not an option because this child was already loved" (Thiele, 2011). Despite the dominant discourse that many families in this situation terminate following such a diagnosis, this mother illustrates how her love and attachment prompted her to continue. Similarly, in the study conducted by Guon and colleagues (2014), several participants described how the love they felt and the value they placed on their child's life inspired them to continue the pregnancy following the diagnosis of a LLFC. One parent within this study shared the following narrative; "We loved her as we love our other children. Our children have value. We do not love our kids because of their accomplishments. We love them because they are our kids" (Guon et al., 2014). Several other participants in this study also expressed the love they felt for their children: "the diagnosis made no difference to the fact that I loved him", "she was our baby and we loved her", "she was already a member of the family and was loved" (Guon et al., 2014).

An enduring connection

Many papers within this meta-synthesis implicitly acknowledged how the relationship developed between parent and child endured despite the passage of time and how even following

death, parents continued to maintain a connection with their deceased child. In the study conducted by Lathrop and VandeVusse (2011a), one of the overarching themes identified by parents was the ongoing connection and love that continued after their child's death and how their child maintained a special place in their lives, even years after the physical loss (Lathrop & VandeVusse, 2011a). One mother illustrated this enduring connection in the following narrative; "It's been nine years, but we still think of him every day and every time we say a prayer, we always say 'Give [baby] a hug and a kiss.' Every day" (Lathrop & VandeVusse, 2011a). Parents within this study also described how they continued to think about their child daily and how when they reflected back on their child's life years later, they still felt a sense of pride and love (Lathrop & VandeVusse, 2011a). The lasting connection that exists between parent and child within this context was also apparent in the study conducted by Wool and colleagues (2018), where one participant expressed "I will love her until the day I die" (Wool et al., 2018). Across this sample of papers, parents voiced how they continued to identify themselves as parents even after the death of their child and described the importance of maintaining a connection to their deceased child that "lasts beyond the final heartbeat" (Kamrath et al., 2019). In the study conducted by Kamrath and colleagues (2019) exploring the maternal experiences of receiving PPC following the diagnosis of LLFC, the authors described the enduring connection that exists between parent and child and the importance role of memory making in maintaining these connections after death (Kamrath et al., 2019). Parental narratives across this sample of papers identified how displaying tangible mementos such as photographs, organizing special memorial events and sharing their child's story with others enabled them to maintain a connection and share their cherished memories with others. Several authors recognized the importance parents placed on maintaining a connection to their deceased child and the significance of this

relationship even following death. Parents voiced how feelings of love and connection often extended into the bereavement period and how over time, the pain of grief lessened, but their child's life and memories stayed with them.

Advocating for the personhood of an unborn child

Several papers in this sample made reference to the distinction that exists between parenting behaviours in a traditional pregnancy and those adopted by parents who continued pregnancy in the presence of a LLFC. The notion of advocating for the personhood of baby as well as acknowledging the intrinsic value of the child's life represents a prevalent feature within the narratives of many parents across this sample of papers. Although advocacy is an assumed responsibility of parenthood in general, several authors suggested that the prognosis associated with a LLFC and the complexity surrounding medical decision-making throughout this period made advocacy more pronounced. After receiving the diagnosis of a LLFC, parents accept both the complex medical needs of their child as well as their child's limited life expectancy and therefore assume a strong advocacy role during pregnancy and after birth. Across these studies, parents frequently described their role as advocates for their children and voiced that "no one else loves them as much" as they do, thus it was their responsibility as parents to "fight for their child" (de-Vitry Smith et al., 2012; Carlsson et al., 2017). Many authors identified how parents continuously advocated for the personhood of their child, made difficult decisions that reflected their child's best interest and validated the life of their child. In the study conducted by Côté-Arsenault and Denney-Koelsh (2011) entitled "My baby is a person", the overarching theme describes participants strong desire to have the personhood of their baby acknowledged by others and for people to recognize the intrinsic worth of their child within their lives. All parents in this study gave their child a name and expressed appreciation for when others addressed their child

by their name, since this gesture further legitimized the unique life of their baby (Côté-Arsenault & Denney-Koelsh, 2011). Similarly, Denney-Koelsch and colleagues (2018) described parents desire for their child to be treated like a "normal baby" and to not frame the value on their child's life around the diagnosis they were given (Denney-Koelsch et al., 2018). Parents within this context described the active process of advocating for the personhood of their child and ensuring that their child was treated with compassion, honor, dignity and respect, regardless of their prognosis and life expectancy. In the study conducted by Limbo and Lathrop (2014), one parent shared "We were very adamant about them treating him with dignity and respect" (Limbo & Lathrop, 2014). Similarly, another participant in this study voiced; "We upheld her dignity…we just did our jobs as parents" (Limbo & Lathrop, 2014). Parents in this study also described protective parenting behaviours intended to shield their child from any "unpleasant experience" such as pain, cold, hunger or thirst (Limbo & Lathrop, 2014). Within this context, parents acknowledged the identity of their child as a distinct person and advocated for them to ensure their needs were met.

Finding a new sense of self

Many studies included in this meta-synthesis speak to the impact that continuing a pregnancy in the presence of a LLFC has on the self-identity of parents. Although these insights are sometimes only implicitly apparent, parental narratives across this sample of papers have described how this experience forever changed who they are and how they view the world. For example, some papers identified how parents developed a sense of personal strength in the face of adversity and how despite the numerous challenges, this experience made them a "better person" (O'Connell et al., 2019). Many authors noted that continuing pregnancy in the presence of a LLFC enabled parents to find an increased sense of compassion, empathy, gratitude and

spirituality. In addition, the narratives of several parents voiced how this experience inspired them to find a new appreciation for life and has helped them to reprioritize previous life goals. In other cases, the impact on sense of self was more explicit. For example, in the study conducted by Côté-Arsenault and Denney-Koelsch (2011), the authors identified how the experience of continuing pregnancy in the presence of a LLFC and the associated grief "led to significant changes in parents' sense of self" (Côté-Arsenault & Denney-Koelsch, 2011). In the study conducted by Black and Sandelowski (2010), the overarching theme revealed from the findings was the positive change and personal growth of parents after receiving the diagnosis of a LLFC in pregnancy. Participants in this study expressed feeling more self-reliant and discovering an inner strength that helped them to cope with their experience, as evident in the following narrative; "I learned I can handle a lot more than I thought I could" (Black & Sandelowski, 2010). Similar findings about the positive impact on parental self-identify were revealed in the study conducted by Wool and colleagues (2018) exploring the experiences of over 400 participants who continued pregnancy following a LLFC. In this study, one parent shared; "The experience has helped form who I am today, who my husband is today. We learned and grew from the experience" (Wool et al., 2018). In the study conducted by Lathrop and VandeVusse (2011a), participants described the impact that continuing pregnancy in the presence of a LLFC had on their personal identity: "I just knew we would get through. A lot of people in this kind of situation or any kind of a terminal illness realize strength that they didn't know they had" and "I'll never be the same…it really made me a lot more compassionate person" (Lathrop & VandeVusse, 2011a). Although parents voiced slightly different trajectories and supports throughout this experience, many of them described a sense of personal growth and lasting change on their identity as a result of the challenges they overcame.

Although some parents identified positive changes following their experiences, other parents described struggling with ambiguous feeling surrounding their self-identity. In the study conducted by Blakeley and colleagues (2019), some parents voiced feeling unsure about their identity following the diagnosis of a LLFC, particularly as it related to parenthood and how although pregnancy is traditionally filled with parenting tasks, the diagnosis left them feeling unsure of how to parent (Blakeley et al., 2019a). Similarly, O'Connell and colleagues (2019) found that parents struggled with their own self-identify after continuing pregnancy in the presence of a LLFC as evident in the following participant narrative; "I didn't know who I was anymore or if I was ever coming back" (O'Connell et al., 2019). Parenting is very much an individualised process and influenced by many elements throughout a lifetime. The complexity and challenges associated with continuing pregnancy in the presence of a LLFC have been widely acknowledged within this body of literature and the impact on parental roles and self-identify is not surprising. Within this context, the majority of parents embraced their role as parents early in pregnancy, however when their experience deviated from a "normal" pregnancy experience, their self-identity was impacted.

The relational impact of pregnancy loss on parents as a couple

Several of the papers included in this meta-synthesis implicitly allude to the dynamic nature of parents' relationship as a couple throughout the experience of continuing pregnancy in the presence of a LLFC. Although the majority of participants across this sample of papers are women, a small portion of papers explored the perspectives of men within this context. Many authors described the divergent experiences that occurred in pregnancy between women and men, primarily attributing the contrasting experiences to the physical connection pregnant women have to the baby. Côté-Arsenault and Denney-Koelsch's (2016) study found that several

couples voiced “being stronger” following this experience and how they developed an “increased sensitivity to each others’ needs” (Côté-Arsenault & Denney-Koelsch, 2016). In a subsequent paper by these same authors, the narratives of participants described how their experience enabled them to overcome such a challenging life event and as a result, they felt “closer and stronger” as a couple (Côté-Arsenault & Denney-Koelsch, 2018). The following participant narrative further illustrates the positive impact this experience had on the relationship of one couple:

> I feel that I have a stronger connection with him more now than ever…like we’re on the same page. I feel like he respects the way I feel and I respect the way he feels...He said he has a lot more respect for me, I guess, as a mother (Côté-Arsenault & Denney-Koelsch, 2018).

In the study conducted by Black and Sandelowski (2010), women described an increase in emotional closeness to their partners and men reported feeling a heightened sense of protectiveness over their partner. One woman shared; “I feel like it has made us stronger. I feel like I appreciate him more, and he appreciates me more. I think if anything it has helped us when before we would take a lot for granted” (Black & Sandelowski, 2010). In this same study, one male participant described his desire to protect his wife; “A part of me was so sad to see [my wife] so distraught and so upset about this. That’s a part of what I was crying about. I mean I, it’s my job to take care of her. I couldn’t take this away, and just to see that despair, just broke my heart” (Black & Sandelowski, 2010). Similar protective behaviours were also described in the study conducted by Cole and colleagues (2019) as well as in the study conducted by Carlsson and Mattson (2018). Within these papers, men voiced a “paternal instinct” to protect their pregnant partner from emotional distress and how they often set aside their own needs to be able

to support the needs of their partner (Carlsson & Mattson, 2018; Cole et al., 2019). One father shared the following narrative; “It was important to me to be good at taking care of my wife” (Cole et al., 2019). Similarly, another male participant voiced; “My primary interest during the planning period was high quality, coordinated support for my wife and unborn son. Knowing that they were being taken care of with minimal drama was the most important thing to me” (Cole et al., 2019). Although relational challenges were identified across this sample of papers, the majority of narratives describing the relationship of the couple were positive and supportive. Parents described how the shared experience of continuing pregnancy in the presence of a LLFC enabled them to develop a deeper connection together as well as fostered a new level of mutual trust, love, understanding and respect.

The lasting impact of interactions with HCP

The essential role of HCP and the therapeutic relationships formed throughout the trajectory of continuing pregnancy in the presence of a LLFC has been explicitly acknowledged across the majority of papers included in this meta-synthesis. Receiving the diagnosis of a LLFC initiates a series of medical appointments accompanied by ongoing interactions with HCP throughout the remainder of this experience. Parents described how they rely heavily on the support and guidance of HCP and how each interaction influenced their overall lived experiences as they navigated pregnancy in the presence of a LLFC. In the study conducted by Horning and Braun (2006), these authors identified that participants vividly recalled their encounters with HCP and how each interaction could “make or break” their experience (Horning & Braun, 2006). In the study conducted by Denney-Koelsch and colleagues (2018), entitled “Feeling cared for versus experiencing added burden”, parental narratives described contrasting interactions with HCP, where they either felt well understood and supported or where they felt the treatment they

received lacked empathy and respect. Within this study, the theme "feeling cared for" represented care that validated the personhood of baby, supported the needs and values of parents, fostered hope and enabled parents to cherish the limited time they had with their child. However, the theme "experiencing added burden" described interactions that lacked continuity, demonstrated emotional indifference or displayed judgement towards the decisions and wishes of parents (Denney-Koelsch et al., 2018). Similar findings were explicitly identified within several studies included in this sample of papers, where parents described interactions that were either positive, supportive and helpful or negative, unsupportive and hurtful.

Interactions that were helpful

Many authors within this sample described interactions between HCP and parents that positively impacted the experience of continuing pregnancy in the presence of LLFC and that helped parents navigate such a difficult life event. For example, in the study conducted by Denney-Koelsch and colleagues (2018), one participant shared; "The doctors that I've met, um, I would be lost without them... I would have no idea what to do…they were my rock through this whole thing" (Denney-Koelsch et al., 2018). Similar findings were also reported by Côté-Arsenault and Denney-Koelsch (2011), where one study participant voiced her appreciation for the care her child received:

> They made me feel like they would take care of her like I would take care of her as a parent, not as they would take care of her as a doctor [crying], that was the most important part to me (Côté-Arsenault & Denney-Koelsch, 2011).

In the study conducted by Horning and Braun (2006), one mother expressed her gratitude towards the compassionate care she received:

> So we went in and the nurse met us at the desk, "I am yours for the day. You're my only patient, I am here for you." She was unbelievable. She said, "I am gonna cry," and I said, "That is just fine, we'll all be crying." You know, she had that personal touch, she really cared (Horning & Braun, 2006).

Numerous parental narratives across this sample of papers have described feeling well supported by their healthcare team and how the compassion and dedication displayed by HCP positively influenced such a challenging life event. In the study conducted by Kamrath and colleagues (2019), parental satisfaction with the care received was revealed in several participant narratives. One mother shared:

> I had the same pediatrician for all four of my kids. She said, "I'm going to be that baby's doctor", so she was there. She wasn't on call or anything, but she was there for my daughter, and just knowing that because over the years we've built a relationship and that that doctor wanted that baby for a patient, that meant a lot (Kamrath et al., 2019).

In this same study, another parent voiced; "We never felt rushed, we never felt we were putting someone out. We felt so cared for, cared about" (Kamrath et al., 2019). Parents within this context described the lasting impact of receiving compassionate, empathetic and genuine care. Although HCP support multiple patients every day and often within fast-paced clinical settings, for parents who continued pregnancy in the presence of a LLFC, these interactions became increasingly meaningful since they contributed to their child's life and legacy. In the auto-biographical study by Kuchemba-Hunter (2019), she articulated the significant impact of feeling cared for and supported throughout her experience of continuing pregnancy in the presence of a LLFC:

> Our care embodied the fullness of community….my primary OB sacrificed his day off to attend to my care. My nurse was with me the entire time, both monitoring my medical needs and engaging in the relationship of my son with my husband and me. From the moment of his birth, everyone in the care team called him by his name. My husband, myself, and most importantly, our tiny, still son, were treated with dignity, as a family. There is no way to accurately describe the pain of losing my son but it was a life-altering event that I feel more than 3 years later. Yet the devastation of that time is tempered by the fullness of care I received during that time, and even afterwards (Kuchemba-Hunter, 2019).

Interactions that were hurtful

In contrast, several papers in this sample also acknowledged interactions between parents and HCP that negatively affected parental experiences. Studies frequently described parents' interactions with ultrasound technicians, as often times this represented the initial exposure to the diagnosis of a LLFC for many parents. Within this context, parents voiced the importance of prenatal ultrasounds as valuable time to see and connect with baby, thus interactions with HCP during these appointments were a prevalent topic within participant narratives. In the study conducted by Denney-Koelsch and colleagues (2016) exploring parents' experience with ultrasound technicians during pregnancy following the diagnosis of a LLFC, the authors described how these interactions had a "profound impact" on parents (Denney-Koelsch et al., 2016). The following narrative illustrates how routine interactions that occur throughout pregnancy such as prenatal ultrasounds, can significantly alter parental experiences:

> From being up right there [held hand up to show high emotions] to all of a sudden her demeanor changing and realizing something is wrong, that drop in emotion. It's

> something I never ever want to go through again in my life…you can immediately tell—it became heavy in the room. I knew something was wrong (Denney-Koelsch et al., 2016).

In the study conducted by Côté-Arsenault and Denney-Koelsh (2011), one mother shared how her excitement towards her appointment changed in response to the interaction she had with an ultrasound technician:

> The person who did the ultrasound didn't talk very much. And I was a little confused, [the] lady before us came out with pictures. And then we went in and she said the ultrasound machine was broken for pictures and so I thought something was wrong then. And then she didn't really say much. She just took some measurements (Côté-Arsenault & Denney-Koelsh, 2011).

Similarly, in the study conducted by Denney-Koelsch and colleagues (2018) one participant voiced:

> I was already a mess just because this was all still so new and I was just scared to death about what was going to happen... She came in and... started the ultrasound. And after a few minutes…I realized that she didn't know anything (Denney-Koelsch et al., 2018).

Receiving the diagnosis of the LLFC places parents in a vulnerable situation and parents often experienced contrasting emotions during prenatal ultrasounds, balancing their excitement about seeing baby with their fears of hearing adverse findings. Many authors noted that these contrasting feelings and the experiences of parents could be enhanced by receiving supportive care during all medical appointments.

Guon and colleagues (2014) described parents' interactions with HCP after choosing to continue pregnancy despite the LLFC and acknowledged the negative interactions that occurred

when their choices were not supported by the healthcare team. One participant shared; “Our first OB refused to continue seeing us if we would not abort, so we found a new OB” (Guon et al., 2014). In this same study, another parent voiced; “The obstetrician encouraged abortion, saying that we would never find any doctors to treat her and that we would be doing her a favor by saving her from suffering” (Guon et al., 2014). The authors noted that these types of interactions negatively affected the experiences of parents and resulted in parents feeling additional levels of distress and isolation. Similar findings were also identified in the study conducted by Côté-Arsenault and Denney-Koelsch (2011), where participants described the care they received as fragmented or lacking understanding and how interactions with HCP were often accompanied by avoidance or judgement (Côté-Arsenault & Denney-Koelsch, 2011). In the study by Denney-Koelsch and colleagues (2018), one participant shared how her providers’ lack of preparedness and familiarity with her child’s condition left her feeling unsupported; “The doctor really couldn’t answer any questions. That really frustrated me and I felt like nobody really cared” (Denney-Koelsch et al., 2018). Across this sample of papers, parents described the challenges associated with feeling unsupported by the team responsible for caring for them and how each interaction represented a significant part of their child’s story, an experience they remembered forever.

Social implications of carrying a baby that is not anticipated to survive

Pregnancy is very much a social event for parents and the social interactions of parents who continued pregnancy in the presence of a LLFC have been explicitly addressed by several studies in this sample of papers. In a “normal” pregnancy, many social interactions relating to pregnancy are typically welcomed, supportive and positive. However, when a LLFC is identified prenatally, parental experiences are altered and the lack of familiarity or understanding by others

has been found to significantly impact the socialization of pregnancy when the baby is not anticipated to survive. The following narrative illustrates the contrasting social experiences some parents encounter when continuing pregnancy in the presence of a LLFC:

> People are so excited when they see a pregnant woman and they know there's going to be a new little baby. And then you tell them 'well, there's a little defect' and you kinda feel bad…more for them because their expression changes and they don't know how to react (de-Vitry Smith et al., 2013).

Across this sample of papers, similar to the interactions described with HCP, parents within this context described social interactions with others as being either positive or negative. In the study conducted by Chevalier McKechnie and colleagues (2015), authors explored the process of parenting after receiving a diagnosis of a LLFC and identified how the social interactions of parents with family, friends and peers changed as a result. The authors acknowledged that within this context, the circumstances and expectations surrounding pregnancy no longer adhered to traditional social norms and thus were no longer "socially understood" (Chevalier McKechnie et al., 2015). As a result, the social interactions parents encountered during pregnancy were inconsistent, unpredictable and ultimately influenced their overall pregnancy experience (Chevalier McKechnie et al., 2015). In the study conducted by Blakeley and colleagues (2019), one of the overarching themes revealed by participants was that there is "a fine line between supportive and unhelpful" in terms of the comments and interactions offered by others (Blakeley et al., 2019a). Participants described various social relationships throughout pregnancy and how they experienced both compassionate and supportive interactions as well as others that are unsolicited and unhelpful.

Positive social interactions

Across these papers, many parents spoke with appreciation towards family, friends and peers for being supportive and caring, which had an overall positive impact on their experience of continuing pregnancy in the presence of a LLFC. Many parents readily described how this experience brought them "closer together" or "strengthened their relationship" with those in their immediate social circles and how these positive interactions with close friends, family and peers made them feel "loved", "understood" and "supported" (Black & Sandelowski, 2010; Blakeley et al., 2019a; Carlsson et al., 2017). In addition to positive social interactions, several parents implicitly acknowledged the supportive and helpful relationships developed with strangers through online forums. In the study conducted by Black and Sandelowski (2010), participants described the intimate connections developed virtually with complete strangers who navigated similar experiences and how sharing their stories with others who truly understood their situation helped them cope. Interactions with individuals from virtual communities was also noted in the study conducted by Carlsson and colleagues (2017), where parents described the therapeutic benefits of finding and communicating with others in similar situations (Carlsson et al., 2017). Kuchemba-Hunter (2019) shared the following narrative in her paper regarding connecting virtually with other parents; "Coming home with empty arms, I found comfort in an online grief group for parents of children—mostly babies—who were diagnosed with Trisomy disorders and had died" (Kuchemba-Hunter, 2019). These interactions helped parents to grow through their shared experiences and to decrease feeling of isolation, as they were able to connect with someone who navigated a similar trajectory. Many studies also noted that for parents, sharing their stories and experiences with others positively impacted their grieving process, for example one participant in Black and Sandelowski (2010) study shared; "She said that what I was telling her was helping, and that felt really good to be an encourager to someone else, to have something

positive come out of these feelings and this experience" (Black & Sandelowski, 2010). Although parents acknowledged that many people often lacked familiarity surrounding the experience of continuing pregnancy in the presence of a LLFC, these studies illustrate that it remains possible to develop and maintain meaningful social relationships that convey compassion, understanding and support.

Negative social interactions

Across this sample of papers, several authors have identified that the social landscape surrounding pregnancy in the presence of a LLFC resulted in some uncomfortable, hurtful and unsupportive interactions with others. Some parents described the difficulty they experienced at times when family, friends and peers failed to "truly understand" their situation or decision-making and how interactions with others left them feeling "utterly alone", "deserted" or "heart-broken" (Côté-Arsenault & Denney-Koelsh, 2011; de-Vitry Smith et al., 2013). Côté-Arsenault and Denney-Koelsh (2011) identified how at times, even well-intended comments could be negatively received by parents, resulting in additional feelings of distress or isolation (Côté-Arsenault & Denney-Koelsh, 2011). One mother reflected on the social challenges she experienced while navigating a poorly understood pregnancy; "It's not like you go around telling everybody 'Hey, I'm pregnant, baby is not going to live'…you're not going to offer that up….so during the pregnancy I kind of closed myself off from all social situations" (de-Vitry Smith et al., 2013). In the study lead by Côté-Arsenault and Denney-Koelsh (2016), the authors identifed how the lack of understanding towards this situation prompted many participants to communicate news about their unborn baby's condition electronically or over social media as a way of limiting social exchanges and managing the reactions of others (Côté-Arsenault & Denney-Koelsh, 2016). Within this context, parents fail to fit into the social norms of a "normal" pregnancy and

instead of experiencing many of the positive interactions that traditionally accompany pregnancy, parents often felt alienated from those within their immediate social circles.

Many studies within this sample identified how some social relationships became strained as a result of continuing the pregnancy following the diagnosis of a LLFC. In the study conducted by Black and Sadelowski (2010), one parent shared; “I lost some friends because I decided to keep the baby” (Black & Sandelowski, 2010). Similarly, participants in Côté-Arsenault and Denney-Koelsh’s (2016) study also described the loss of social relationships that occurred throughout this experience; “I only have two people, and I don’t consider them friends anymore, that when I first told them…they had a negative reaction…you go your way and I’ll go mine and we’ll just leave it like that” (Côté-Arsenault & Denney-Koelsh, 2016). de-Vitry and colleagues’ (2013), by contrast, described other situations of relational strain, where for example one mother voiced:

> I’ve actually even had friends who felt our relationship has been jeopardised because I haven’t shared as much with them. And I’ve tried to explain to them that emotionally, it’s not helpful for me to go through the details…even with close people (de-Vitry Smith et al., 2013).

Another participant in this same study shared the following narrative;

> I really thought she would sympathise but she said to me…in a somewhat judgemental way “Whatever’s best for the baby” and…I felt defensive…who loves this baby more than I do?...but they just don’t understand…what the options mean and the risks involved…you do feel like you have to defend your decisions (de-Vitry Smith et al., 2013).

Across this sample of papers, parental narratives acknowledged how feeling unsupported, misunderstood or judged by those around them created an additional level of vulnerability throughout such an uncertain and challenging experience.

Chapter 5: Discussion

The aim of this study was to critically reflect on existing literature and to reveal a deeper understanding of the experience of continuing pregnancy in the presence of a LLFC. Qualitative literature in this area has been relatively well-developed, thus conducting a meta-synthesis was an ideal approach to address this aim. My meta-synthesis expands on existing qualitative findings from individual research studies as well as provides a cumulative and in depth understanding of this lived experience. Although continuing pregnancy in the presence of a LLFC remains an individualized experience, this meta-synthesis has revealed several common themes that characterize this trajectory and has illustrated the significant interplay that exists between these themes as well as the impact it has on the overall lived experiences of parents within this context.

Summary of findings

Parents acknowledged the diagnosis of a LLFC as a significant milestone that forever altered their parenting experience. Various studies described the dynamic nature of time that exists within this context and how the traditional chronology of time throughout pregnancy and following death was disrupted. In order to cope with the changes and limitations of time imposed by the diagnosis, parents were required to reframe previous hopes and expectations, a process that enabled them to focus on the quality of time rather than the quantity. Parents described a strong desire to cherish the limited time they had with their child, create valuable memories together and validate and honour the personhood of their child.

Receiving the diagnosis of a LLFC also initiated various forms of unanticipated uncertainties that persisted throughout the remainder of this trajectory. For parents within this context, the overall lack of understanding and recognition regarding their distinct experience

created numerous social challenges as well as perpetuated additional levels of uncertainty surrounding how to navigate the social norms of pregnancy. Although studies in this meta-synthesis described the challenges associated with navigating multiple uncertainties, some parents demonstrated an ability to transform these feelings of uncertainty into feelings of hope and optimism. Despite the diagnosis of a LLFC and the uncertain future it entailed, parents described the development of a unique relationship between parent and child that is characterized by a deep unconditional love. The enduring love and connection shared between parent(s) and child strengthened despite the diagnosis and persisted despite the passage of time.

Continuing pregnancy in the presence of a LLFC poses many challenges and the lack of awareness and understanding towards these situations increases the vulnerability of this population. Although pregnancy is largely a social event, parents within this context described how failing to fit into existing social norms and expectations surrounding pregnancy influenced the relationships they formed throughout this experience. Parents navigating these situations relied heavily on the compassion and support received from family, friends, peers and HCP, however interactions that occur throughout this trajectory are described as leaving a lasting impression, either positive or negative.

Supporting literature

The findings reported in this study reflect similar findings identified throughout the literature describing parental experiences surrounding pediatric life-limiting illness and perinatal loss. Although the context is slightly different, the focus of these topics remains on the experiences of parents who have navigated the journey before or after the death of a child. Across all of these contexts, the parent-child relationship that develops and persists despite the age of the child or length of time the child lives, represents a central aspect within the narratives

of parents. Since there exists limited published studies that have synthesized qualitative literature on the topic of continuing pregnancy in the presence of a LLFC, drawing on the findings identified within similar contexts will substantiate the findings from this study as well as situate them within the existing body of literature.

In a meta-synthesis conducted by Bally and colleagues (2018) exploring the experiences of parents caring for a child diagnosed with a life-limiting or life-threatening illness, these authors identified similar findings across the 23 studies included in their sample (Bally et al., 2018). The authors described how after receiving the shocking diagnosis, parents experienced a "profound and unremitting uncertainty" as they navigated the remainder of their child's illness trajectory (Bally et al., 2018). Following the diagnosis, parents were required to reconstruct life and find a new normal that reflected their child's diagnosis, reframe their previous assumptions, hopes and expectations to reflect the reality of the diagnosis as well as cherish their time together as a family (Bally et al., 2018). Parents struggled with the shifting nature of time and expressed the belief that their child's quality of life was not defined by the amount of time they live (Bally et al., 2018). Relationality was also described as a central feature within this study, where parents voiced the ability to form deeper and more meaningful relationships with their child as a result of the diagnosis as well as the importance of redefining and restoring existing relationships with family and friends to promote positive and supportive environments for their child. These findings are also reflected in other qualitative studies exploring the experiences of parenting within the context of pediatric life-limiting illness. Supporting literature in this area has demonstrated the presence of time, uncertainty and relationship as dominant features within the narratives of parents caring for a child diagnosed with a life-limiting or life-threatening illness

(Buzgova & Palenikova, 2015; Collins et al., 2016; Dias et al., 2017; Kerr & Haas, 2014; Price & Jones, 2015; Tan et al., 2015; Titus & de Souza, 2011).

Berry and colleagues (2021) conducted a meta-synthesis of qualitative literature (n=5) surrounding the parental experiences of navigating perinatal loss (due to of life-limiting congenital anomalies, stillbirth and intrauterine fetal death) and these authors reported similar findings (Berry et al., 2021). Three of the five studies included by Berry and colleagues were also captured in this meta-synthesis. The findings described "the paradox of perinatal loss" and highlighted parents' ability to demonstrate positive growth and resilience despite the devastation of navigating the death of a desired child (Berry et al., 2021). The authors recognized the connection and relationship that develops between parent and child as well as the strong desire for the personhood of the child to be respected and acknowledged by others. The interactions that occur between parents and HCP were also reported as a prominent feature across their sample of papers and parental narratives described how these interactions could significantly impact their overall experience in either a positive of negative way (Berry et al., 2021). The final theme identified within their synthesis was the notion of "traversing the social sphere" which described the changing nature of social interactions and social networks as a result of the perinatal loss (Berry et al., 2021). Several other studies exploring the perspective of parents who experienced a perinatal loss have also identified the ambiguity associated with perinatal death, the lack of societal recognition and understanding surrounding pregnancy loss as well as the significant impact of all relationships formed throughout this experience on parents (Cacciatore et al., 2008; Lang et al., 2011; Mills et al., 2014; Nuzum et al., 2018). The context of perinatal loss closely resembles the experience of continuing pregnancy in the presence of a LLFC and qualitative literature in this area further validates findings of time, uncertainty and relationship as

characterizing the experience of losing a child during pregnancy or shortly after birth (Abdel Razeq & Al-Gamal, 2018; Berry et al., 2021; Cacciatore et al., 2008; Currie et al., 2016; Lang et al., 2011; Malacrida, 1999; Mills et al., 2014; Nuzum et al., 2018).

Interplay between time, uncertainty and relationship

Existing qualitative literature on the topic of continuing pregnancy in the presence of a LLFC as well as literature from similar contexts, including parenting a child with a life-limiting illness or the experience of perinatal loss, all describe comparable findings and contribute valuable insights into the parental perspectives of navigating these experiences. However, these central themes are typically presented as distinct findings without much acknowledgement of the extent to which these themes influence each other and ultimately impact the lived experiences of parents. Although identifying central themes that occur within this trajectory can enhance our understanding of this experience, critically reflecting on the interplay that exists between these themes and the significance of this connection is essential in appreciating the overall impact on parental experiences, which I suggest is a key contribution of my meta-synthesis. Moreover, in reflecting on the interconnectedness that exists between central themes throughout the experience of continuing pregnancy in the presence of a LLFC, it has been valuable to look at the perspectives of parents from various points along this trajectory (e.g., during pregnancy, after birth and following death). Analysing parental narratives across multiple points of time throughout this experience demonstrates that these themes and the interplay that exists between them, remain constant over time, which represents another valuable contribution of this meta-synthesis.

As illustrated within my analysis, the concepts of temporality, uncertainty and relationality exist concurrently within this experience and continuously influence each other as

well as the overall experiences of parents throughout this trajectory. The uncertainty that accompanies the diagnosis of a LLFC challenges the traditional discourse surrounding the amount of time an expectant parent will have with their child. In a "normal" pregnancy, time with baby is not considered finite, however the diagnosis of a LLFC drastically alters these assumptions and the uncertainty of time available to parents influences the value and quality they attribute to the time they have with baby, since within this context, time is finite. The reality that time is limited significantly influences the quality and nature of the relationships formed throughout this trajectory. The shortened life expectancy inevitably reduces the number of interactions parents will engage in during their child's lifetime, yet despite these limited opportunities, parents demonstrate an ability to develop and maintain meaningful connections with their child as well as others socially. Parental narratives illustrate that the intimacy and love formed within these relationships is not impeded by a lack of time and that it is parents' acknowledgement of the limited time available to them that enhances the quality and significance of many interactions throughout this trajectory. Although the notion of cherishing limited time had a positive impact on some relationships, the presence of uncertainty, particularly in relation to navigating social norms following the diagnosis of a LLFC, can adversely affect relationships throughout this experience. Within this context, the traditional social norms and expectations of pregnancy are abruptly altered and the lack of understanding and familiarity with this experience changes the dialogue that is traditionally characteristic of conversations surrounding pregnancy. As a result, interactions that convey a lack of understanding, sensitivity or respect for parental beliefs, values and decisions negatively influenced the quality or status of certain relationships within this experience. Despite pregnancy being regarded as a social phenomenon, the deviation from traditional expectations as well as the

societal discomfort that exists surrounding perinatal death can hinder the development of supportive relationships or result in the loss of some relationships all together. Irrespective of the adverse prognosis, uncertain pregnancy trajectory and limited time with their child, parents within this context describe the importance of forming meaningful connections throughout this experience and how the individuals in their life play a key role in creating supportive relational spaces where they can positively experience the life and death of their child.

The interconnectedness that exists between time, uncertainty and relationships throughout this trajectory significantly contributes to the individual experiences of each parent as they continue pregnancy in the presence of a LLFC. Given the innate challenges that exist within these situations, the support and guidance received from HCP plays a key role in shaping their overall experiences and memories for years to come. Across this pregnancy trajectory, the presence of numerous ethical dilemmas and far-reaching consequences creates both hesitations and challenges in caring for this vulnerable population. Although the growing field of PPC aims to support the unique needs of parents who choose to continue pregnancy following the diagnosis of a LLFC, not all HCP engaging with this population are familiar with this model of care. Irrespective of limited theoretical and clinical expertise surrounding PPC, nurses remain ideally situated to provide holistic support to parents across several points of care throughout this trajectory. Understanding the interconnectedness of central themes that exist within this experience can help nurses to truly appreciate the magnitude of this experience as well as what is morally at-stake for parents navigating the life and death of their child. Equipped with this knowledge and insight, nurses can guide other HCP in promoting and preserving positive relational spaces where parents feel cared for and cared about, as they journey towards the birth and death of a beloved child. Although HCP cannot change the diagnosis or outcome, their

support and compassion can help to lessen some of the avoidable adverse consequences encountered by parents as well as positively impact parental experiences of navigating a pregnancy where the child is not anticipated to survive.

Relational Ethics as a framework to guide nursing practice

Supporting parents in choosing to continue pregnancy in the presence of a LLFC is undoubtingly complex given the numerous ethical dilemmas and challenges that exist within the context. Furthermore, factors such as increased workloads, high-acuity patients, competing clinical priorities, staffing shortages and time constraints all represent prevalent barriers within clinical practice that can impede the development of meaningful therapeutic relationships with patients. Despite these ongoing challenges, the development of intimate relationships within healthcare remains essential in understanding the unique needs of patients across various clinical contexts and in gaining an appreciation for what patients identify as the most important aspects of their care. Relational ethics represents an ideal framework that can support nurses in overcoming barriers that adversely impact therapeutic relationships, in critically reflecting on the significance of everyday experiences and interactions within clinical practice and in fostering relationships that will enhance parents' overall experiences.

Relational ethics acknowledges the ethical dilemmas that exist within everyday clinical practice across a variety of settings and asserts that all actions and decisions are situated within a relational context (Pollard, 2015). Within this framework, emphasis is placed on the significance of our interactions with others and the morality that exists within these relational spaces. The central tenets of relational ethics, which were previously discussed in chapter 3, include mutual respect, engagement, embodied knowledge, environment and uncertainty (Moore et al., 2014; Pollard, 2015). It is the interconnectedness that exists between these tenets that influences the

development of ethical relationships within clinical practice (Moore et al., 2014; Pollard, 2015). Moreover, the interdependence that exists between the interactions of HCP and patients can have both a direct or indirect impact on the quality of the relationships formed and subsequently the patients' overall experience (Moore et al., 2014). Ethical relationships extend beyond superficial interactions to recognize the inherent value that exists within the experiences of others as well as appreciate the complexity within the unique situations, perspectives and vulnerabilities of each patient (Pollard, 2015). Relational ethics acknowledges the time and conscious effort required to connect with patients in a meaningful and reciprocal way as well as the challenges encountered by nurses within clinical practice regarding the development of ethical relationships. Relational ethics encourages the critical reflection of everyday nursing actions and urges nurses to prioritize the quality of the time spent with patients, above the provision of task-based care. Although nurses are required to balance the ongoing tensions that exist between task-focused and person-centered care within clinical practice, person-centered care ensures that individual patient needs, values and preferences are what guide clinical decision-making (Doane & Varcoe, 2007; Pollard, 2015).

Similar to the framework of relational ethics, the field of PPC also emphasises the significance of the relational space that exists between parents and HCP and the impact of individual relationships on the experiences and memories of parents who choose to continue pregnancy in the presence of a LLFC. Relationships have been identified as an essential component within the provision of quality PPC and the critical role of HCP throughout this trajectory has been widely acknowledged in multiple publications in this field (Limbo & Kobler, 2010; Limbo et al., 2017). Parents within these situations experience increased levels of vulnerability and require ongoing holistic support to address the complex and evolving needs

that exist throughout this experience. Continuing a pregnancy in the presence of a LLFC does not solely reflect a pregnancy, but also encompasses the life, death and legacy of a child as well as the parental grief associated with perinatal death. Parents within this context are unexpectantly navigating the experience of birth and death simultaneously, and irrespective of the inherent challenges, this experience leaves a lasting imprint within the lives of all parents.

Implications for clinical practice

The results from this meta-synthesis contribute important perspectives that can inform nursing practice within a variety of settings including obstetrics and neonatology. Combining knowledge surrounding the tenets of relational ethics together with our new appreciation for how time, uncertainty, and relationship impact parental experiences can support nurses in answering: *How should we approach our practice with this population?* Adopting a relational ethics approach within this context will enable nurses to prioritize the development of meaningful relationships, acknowledge the inherent value that exists within parental narratives and engage with parents in a more responsive and reciprocal way. Given the interconnectedness that exists between central themes throughout this experience, nurses must continuously reflect on their everyday actions within clinical practice and on the extent to which their presence throughout this trajectory significantly impacts the lived experiences of parents. These findings also illustrate that it is through the development of intimate and reciprocal relationships that nurses can truly appreciate what is most "at-stake" for parents navigating these situations. Understanding what is most important to parents represents invaluable information that should be used to guide clinical practice in this area.

Despite the desire of nurses to engage fully and ethically with patients, ongoing issues surrounding increasing task-oriented demands, competing priorities and time constrains within

clinical practice pose significant barriers that need to be addressed at an organizational level. In addition to informing direct clinical practice, the findings generated from my thesis can be used by hospital administrators and policy makers to inspire a cultural change within the organization that will prioritize the quality over the quantity of nursing care. As revealed across numerous parental narratives, quality care is described as care that demonstrates compassion, empathy and respect, validates the personhood of baby, supports the individual needs and values of parents, and enables parents to cherish the limited time they have with their child. By critically examining organizational barriers as well as various strategies to address these barriers, hospital administrators and managers can foster clinical environments that ensure nurses have adequate time to engage with patients in meaningful ways, thus directly impacting the level of care provided to this population.

Study strengths and limitations

Several study strengths were identified. To my knowledge, this is the first study that has sought to conduct a qualitative meta-synthesis exploring the experience of continuing a pregnancy in the presence of a LLFC**.** My thesis also describes the experiences of parents over a longer period of time, the papers included contained interviews with parents during pregnancy, following birth and even years after the death of their child. Therefore demonstrating that the findings and key themes remained constant over time. In addition, I was able to identify a large number of papers that met the inclusion criteria for this meta-synthesis and had a large sample of papers to analyze (n=29). Lastly, another strength of this thesis is that it kept parental voices at the forefront and resurfaced the narratives of parents from past studies that continue to be relevant and contain meaningful insights regarding the experience of continuing pregnancy in the presence of a LLFC.

Limitation for this thesis are related to both the individual studies included in the final sample as well as the study design. Participants across the studies included in this meta-synthesis were predominantly heterosexual couples, English speaking and from Caucasian, North American cultures, thus findings from this study may not reflect the experiences of parents from diverse backgrounds and cultures. Moreover, Canadian studies were largely missing from this meta-synthesis, thus findings may not reflect the experiences of parents within the Canadian healthcare system, as medical care and programs within the field of PPC may differ between countries. This study also excluded the experiences of parents who choose to terminate following the diagnosis of a LLFC, which represents a distinct phenomenon and therefore the results presented in this thesis do not reflect the experiences of those parents. An additional limitation is related the study design. In a meta-synthesis, you do not have access to direct participant interviews and there is no opportunity to deepen your understanding or elaborate on a participant's response since you can only analyse what was written within the published paper. Thus, you do not have access to the "person" or to the particular nuances that can be revealed through experiencing these narrative stories first-hand and this design limits your ability to seek out additional knowledge or clarifications from participants and to observe them as they share their story.

Implications for nursing education and research

Although this study explored the parental experiences of continuing pregnancy in the pregnancy of a LLFC, the experiences of nurses throughout this trajectory are an important consideration as well. Nurses working with the perinatal population may experience varying levels of moral distress or compassion fatigue while supporting parents navigating the birth and death of a child who is not anticipated to survive. Future research and education should focus on

equipping nurses working in these settings with the knowledge and skills required to manage their own psychological well-being as they support families who are navigating such a challenging situation. In addition, Canadian studies are relatively absent within the literature and given that healthcare systems can differ greatly between countries, Canadian literature published on this topic would provide better insight into the needs and experiences of parents within the Canadian healthcare context. Moreover, future research and education should focus on the implementation of PPC practices and programs into more organizations across Canada as well as strategies to engage key stakeholders throughout this process. Advancing research and education surrounding program implementation across Canada would increase access to these services and supports as well as enhance clinical comfort in providing palliative care within perinatal settings.

Conclusion

Although continuing pregnancy following the diagnosis of a LLFC represents a complex and individualized experience, the findings from this meta-synthesis reveal that time, uncertainty and relationship are prevalent features throughout the narratives of parents across multiple time points throughout this trajectory. Moreover, the findings demonstrate the interconnectedness that exists between these central themes as well as the overall impact this interconnectedness has on the overall experiences of parents navigating these situations. Throughout this trajectory, the relationships formed and support received can significantly influence how parents experience and remember the life and death of their child for years to come, for better or worse. Nurses working within perinatal settings are encouraged to critically reflect on how their everyday interactions influence parental experiences and to acknowledge the significance of the relationships formed on parents' overall lived experience.

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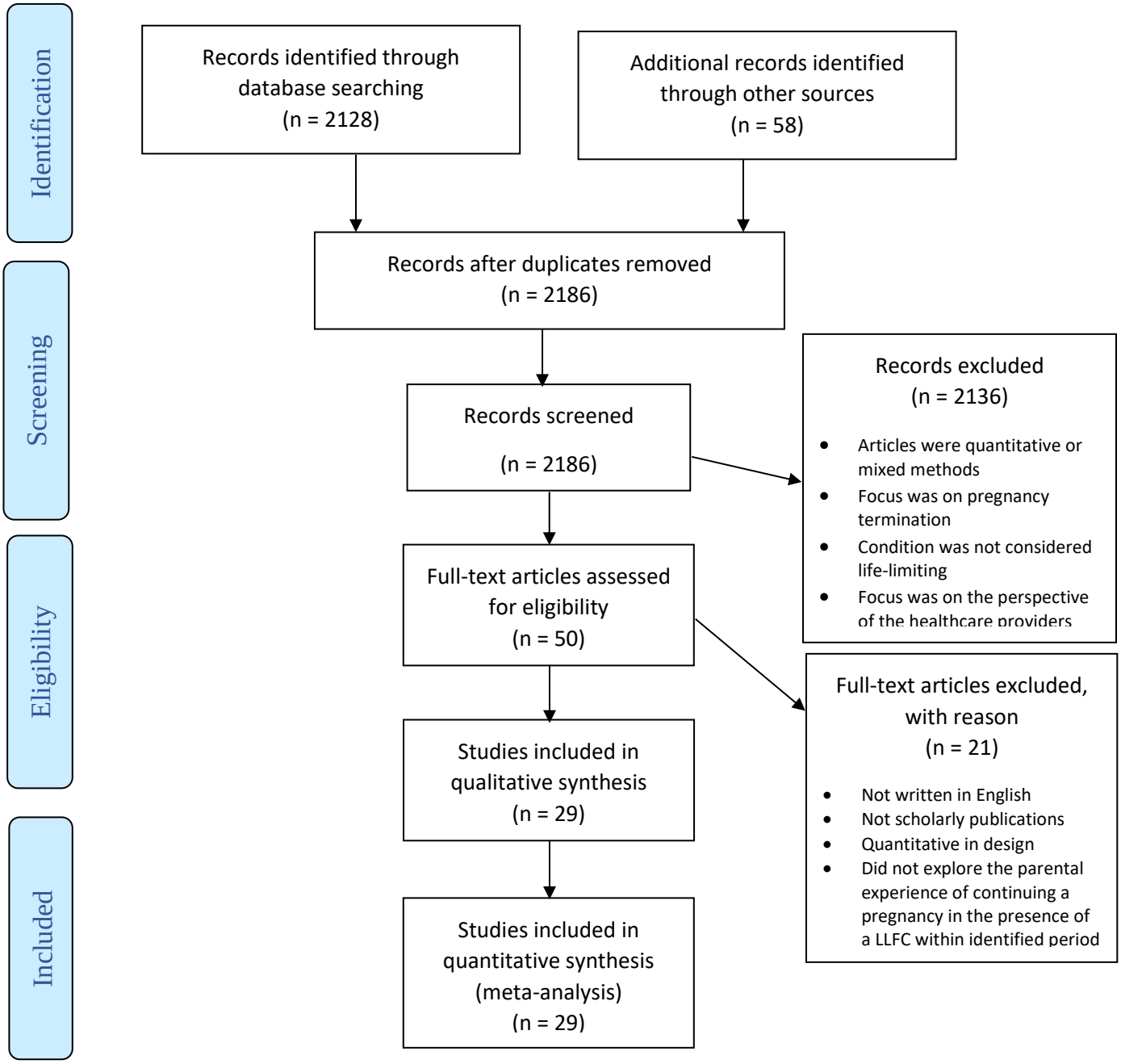
Appendix A

Figure 1: PRISMA Flow Diagram



Appendix B

Critical Appraisal Skills Programme (CASP): Qualitative Studies Checklist

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

2. Is a qualitative methodology appropriate?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

3. Was the research design appropriate to address the aims of the research?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

4. Was the recruitment strategy appropriate to the aims of the research?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

5. Was the data collected in a way that addressed the research issue?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

6. Has the relationship between researcher and participants been adequately considered?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

8. Was the data analysis sufficiently rigorous?
   Yes ☐ Can't tell ☐ No ☐
   Comments:

9. Is there a clear statement of findings?

Yes ☐ Can't tell ☐ No ☐
Comments:

Section C: Will the results help locally?

10. How valuable is the research?

Yes ☐ Can't tell ☐ No ☐
Comments:

Appendix C

Characteristics and quality appraisal of studies included in meta-synthesis (n=29)

Authors Country	Title and Objective	Methodology (Methods)	Participants	Quality appraisal (CASP) and study characteristics (1-10)	Methodological strengths identified
*Black & Sandelowski (2010) United States	**Title:** Women's lived experiences of a prenatal diagnosis of fetal growth restriction the limits of viability: An Interpretative phenomenological study **Objective:** To compare the experiences of parents who received a severe fetal diagnosis, including those who terminated, continued pregnancy with intervention and resuscitation, or who continued with PPC	Qualitative study (Ethnographic interviews)	15 women and 10 male participants following the detection of a severe fetal diagnosis.4 interviews total over trajectory (post diagnosis to 1-year after death) n= 25	**CASP- 8/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rich and comprehensive data collection (combination of interviews, clinical observations, chart reviews and use of tangible meaningful to parents. • Validity: rigorous sampling to achieve maximum variation and use of purposive sampling optimized data sources
*Blakeley, Smith, Johnstone & Wittkowski (2019a) United Kingdom	**Title:** Women's lived experiences of a prenatal diagnosis of fetal growth restriction at the limits of viability: An interpretative phenomenological study **Objective:** To understand women's lived experiences during pregnancies with poor prognosis following prenatal detection of Fetal Growth	Interpretive Phenomenology (Qualitative interviews)	6 women who had continued pregnancy following the diagnosis of FGRLV and experienced the loss of a fetus/child within the past 6 to 48 months	**CASP-10/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection ✓ Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings	• Validity: Transparency about authors subjective valued and how it influences the interpretation of the data. • Results: rigorous analysis (use of interpretative phenomenological) with sufficient data to support findings • Utility: study meaningfully integrates relevant literature and interprets findings in a

	Restriction at the limits of viability (FGRLV).		n= 6	Utility ✓ Value of research	way that can support clinical practice
*Carlsson, Starke, & Mattson (2017) Sweden	**Title:** The emotional process from diagnosis to birth following a prenatal diagnosis of fetal anomaly: A qualitative study of messages in online discussion boards **Objective:** To explore narratives found in online discussion boards where parents currently expecting, or with previous experience of expecting, a child with a prenatally diagnosed congenital anomaly	Cross-sectional qualitative study (Written statements found in online discussion boards)	10 pregnant women and 8 partners currently expecting or had previous experience expecting a child with a prenatally diagnosed congenital anomaly n= 18 (total of 852 messages)	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: innovative data collection- use of messages in public online discussion boards (written anonymously) • Results: rigorous and transparent analytical process • Utility: findings provide new conceptual understanding of expectant parents' emotional process from diagnosis to birth
Carlsson & Mattson (2018) Sweden	**Title:** Emotional and cognitive experiences during the time of diagnosis and decision-making following a prenatal diagnosis: a qualitative study of males presented with congenital heart defect in the fetus carried by their pregnant partner **Objective:** To explore the emotional and cognitive experiences, during the time of diagnosis and decision-making, among males presented with congenital heart defect in the fetus carried by their pregnant partner.	Qualitative descriptive study (Interviews)	12 expectant fathers whose partner was pregnant with a fetus that had a congenital heart defect. Interviews took place 5-15 weeks post-diagnosis. n= 12	**CASP-9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection ✓ Considered reflexivity Results Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rigorous sampling and data collection • Results: rigorous and transparent analytical process • Utility: worthy topic addressed as findings provide valuable insight into lived experiences of fathers

Cole, MacDonald & Qamar (2019) United States	To understand how men cope with the anticipated loss of their child when a life-limiting fetal diagnosis is confirmed in pregnancy	Qualitative (Online questionnaire with 28 open ended questions)	25 fathers whose partners gave birth to a baby with a life-limiting fetal diagnosis confirmed in pregnancy. Interviews occurs 0-6 months after death n=25	**CASP-8/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: authors demonstrate transparency in adapting data collection methods and consider situation ethics surrounding participants as it related to data collection • Utility: Worthy and timely topics, findings provide valuable insights into the bereavement experiences of men in the context of pregnancy loss following the diagnosis of a LLFC
*Côté-Arsenault, & Denney-Koelsch (2011) United States	**Title:** ‘‘My Baby Is a Person’’: Parents’ Experiences with Life-Threatening Fetal Diagnosis **Objective:** To clarify the experiences and needs of families who continue pregnancy following diagnosis with a lethal fetal anomaly in order to design responsive perinatal palliative care services	Qualitative descriptive design (Semi-structured interviews)	2 women and 3 couples who continued pregnancy following diagnosis with a lethal fetal anomaly. Interviews occurred during pregnancy n= 8	**CASP-9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Results: rigorous data analysis, clear and detailed analytic process • Utility: use of engaging narrative quotes throughout are sufficient to support the findings and provide rich descriptive insight into the lived experience of parents
*Côté-Arsenault, Krowchuk, Hall & Denney-Koelsch (2015)	**Title:** We want what’s best for our baby: Prenatal parenting of babies with lethal conditions **Objective:** To report on the experience of couples who chose to continue their	Longitudinal interpretive phenomenology (Qualitative interviews)	16 mothers and 14 partners (13 male and 1 female) who continued pregnancy following diagnosis with a	**CASP-10/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection ✓ Considered reflexivity	• Validity: rigorous data collection data through a series of in person, phone or video interviews (longitudinal) • Results: analysis enriched by used of multi-disciplinary research team which brought

United States	pregnancies after receiving a lethal fetal diagnosis		lethal fetal. Multiple interviews (average of 4) after diagnosis, through birth, and postpartum n= 30	Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	multiple perspectives during analysis and increased dependability and confirmability of findings
*Côté-Arsenault, & Denney-Koelsch (2016) United States	**Title:** Having no regrets: parental experiences and developmental tasks in pregnancy with lethal fetal diagnosis **Objective:** To learn the experiences and developmental needs of parents who continue pregnancy despite a lethal fetal diagnosis	Longitudinal phenomenological study (Qualitative interviews)	16 mothers & 14 partners who continued pregnancy despite the diagnosis of a lethal fetal anomaly. Multiple interviews (average of 4) after diagnosis, through birth, and postpartum n= 30	**CASP-9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Results: rigorous analysis, clear and detailed analytic process. • Utility: study credibility and dependability enhanced through use of a single interviewer and prolonged engagement with participants. Confirmability of findings achieved by providing numerous narrative quotes • Utility: study provides framework for understanding experiences of parents who continue pregnancy with LLFC
*Côté-Arsenault, Krowchuk, Hall & Denney-Koelsch (2018) United States	**Title:** Feeling Cared for Versus Experiencing Added Burden: Parents' Interactions with Health-Care Providers in Pregnancy with a Lethal Fetal Diagnosis **Objective:** To report on parental responses to and needs from health-care providers during	Longitudinal phenomenological study (Qualitative interviews)	16 mothers & 14 partners who continued pregnancy despite the diagnosis of a lethal fetal anomaly. Multiple interviews (average of 4)	**CASP-10/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection ✓ Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis	• Validity: rigorous sampling (multistate recruitment, high retention rate). Rich data collection- multiple interviews over time • Results: transparent and detailed analysis. Trustworthiness demonstrated by repeated member checks and comparison of results with the existing literature

	pregnancy with a lethal fetal diagnosis		after diagnosis, through birth, and postpartum n= 30	✓ Clear statement of findings Utility ✓ Value of research	• Utility: findings well supported with many in-depth narrative quotes. Findings used to generate recommendations for clinical practice.
Côté-Arsenault & Denney-Koelsch (2018) United States	**Title:** "Love Is a Choice": Couple Responses to Continuing Pregnancy with a Lethal Fetal Diagnosis **Objective:** To describe pregnant couples' responses and relationships in continued pregnancy with lethal fetal	Longitudinal naturalistic study (Qualitative interviews)	16 mothers & 14 partners who continued pregnancy despite the diagnosis of a lethal fetal anomaly. Multiple interviews (average of 4) after diagnosis, through birth, and postpartum n= 30	**CASP-9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rigorous sampling (purposive) optimized data sources • Validity: rich data collected through in-depth interviews, field notes, participant blogs. • Validity: trustworthiness demonstrated through member checking • Utility: longitudinal research design with multiple participant interviews provided prolonged engagement, and thus increased credibility of findings
Denney-Koelsch, Côté-Arsenault & Lemcke-Berno (2016) United States	**Title:** Parents' Experiences with Ultrasound During Pregnancy with a Lethal Fetal Diagnosis **Objective:** To describe parent experiences of ultrasounds during pregnancies with lethal fetal diagnoses (LFDs)	Longitudinal naturalistic study (Qualitative interviews)	16 mothers & 14 partners who continued pregnancy despite the diagnosis of a lethal fetal anomaly. Multiple interviews (average of 4) after diagnosis, through birth, and postpartum	**CASP-10/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection ✓ Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rigorous sampling with high retention rate • Results: rigorous and detailed analytical process. Trustworthiness enhanced by single interviewer, analysis conducted by research team and clarification of interpretations with participants • Utility: longitudinal research design long-term engagement. Findings well supported with many in-depth narrative

			n= 30		quotes and meaningful integration of relevant literature.
*de-Vitry Smith, Dietsch & Bonner (2012) Australia	**Title:** Parents' Experience of Time Distortion Following Diagnosis of a Serious or Lethal Fetal Anomaly **Objective:** To explore the experience of couples who continued pregnancy following a diagnosis of serious or lethal fetal anomaly.	Interpretative phenomenology	20 women and 11 male partners who continued pregnancy following a diagnosis of serious or lethal fetal anomaly. Interviews occurred during pregnancy and after birth. n= 31	**CASP-10/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection ✓ Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Results: rigorous and transparent analytic process • Utility: findings substantiated by numerous engaging quotations and integration of supporting literature
de-Vitry Smith, Dietsch & Bonner (2013) Australia	**Title:** Pregnancy as public property: The experience of couples following diagnosis of a foetal anomaly **Objective:** To explore the experience of couples who continue pregnancy following the diagnosis of a fetal anomaly	Interpretative phenomenology (Qualitative interviews)	20 women and 11 male partners who continued pregnancy following a diagnosis of serious or lethal fetal anomaly. Interviews occurred during pregnancy and after birth. n= 31	**CASP-9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Results: rigour enhanced by use of direct quotes in the findings section which allows reader to assess depth of interpretation • Utility: findings well supported with many in-depth narrative quotes. Findings used to generate recommendations for clinical practice
*Guon, Wilfond, Farlow, Brazg & Janvier (2014)	**Title:** Our children are not a diagnosis: The experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18	Mixed methods (Self-completed online questionnaires	98 mothers and 30 fathers who received a prenatal diagnosis of	**CASP-9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design	• Validity: rigorous sampling and data collection. Mixed methods- questionaries carefully designed using

Worldwide	**Objective:** To gain a better understanding of parents who decide to continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18	including open-ended questions)	trisomy 13 or 18 and who continued pregnancy. Questionnaires were completed after birth of the child. n= 128	✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	expert opinion and significant parent input • Results: rigorous and transparent analytical process • Utility: use of numerous engaging quotes and incorporation of photographs of child submitted by participants affects readers through evocative representation
Hodgson, Pitt, Metcalfe, Halliday, Menezes, Fisher, Hickerton, Petersen & McClaren (2016) Australia	**Title:** Experiences of prenatal diagnosis and decision-making about termination of pregnancy: A qualitative study **Objective:** To describe parental experiences and examine how best to provide support after a prenatal diagnosis	Qualitative (Telephone interviews)	27 couples & 9 women who received a diagnosis of fetal abnormality (including those who terminated and who continued). Interviews occurred 6 weeks post-diagnosis n= 102	**CASP-9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rigorous sampling • Results: Thematic analysis involved rigorous process of qualitative coding, enabled iterative development and validation of emergent themes • Utility: findings substantiated by ample quotation, • Utility: significance of contribution- this study has interviewed women and their male partners; ensuring the male perspective captured
*Horning & Braun (2006) Unites States	**Title:** The Lived Experience of Families who are Told Their Child will Die at or Shortly after Birth **Objective:** To discover a fuller understanding of the lived experience of families who are told their child will die at or	Qualitative phenomenology (Semi-structured interviews)	5 families who were told at some point in pregnancy that their child would die at or shortly after birth. Some families were	**CASP-8/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results	• Results: rigorous and transparent analytical process • Utility: findings substantiated by engaging narratives and the meaningful integration of literature.

	shortly after birth and their journey through the remainder of the pregnancy, loss, and grief		interviewed after birth with child still alive and others after death n=10	Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	
*Kamrath, Osterholm, Stover-Haney, George, O'Connor-Von & Needle (2019) Unites States	**Title:** Lasting Legacy: Maternal Perspectives of Perinatal Palliative Care **Objective:** To describe infant interaction with the health care system and by gaining deeper understanding of the maternal experience after being offered perinatal palliative care	Mixed methods (Retrospective chart review and focus group with interviews)	Phase 1: 27 mother–infant pairs offered PPC) Phase 2: 7 mothers. Interviewed during pregnancy. n=34	**CASP-10/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection ✓ Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rigorous data collection consisting of retrospective chart review, focus groups and individual interviews • Results: rigorous and transparent analysis • Utility: key findings substantiated by integration of participant narratives, recommendations for clinical practice offered
Kuchemba-Hunter (2019) Unites States	**Title:** Compassion and Community in Perinatal Palliative Care: Understanding the Necessity of the Patient Perspective Through Narrative Illustration **Objective:** to describe personal journey of continuing pregnancy with diagnosis of Trisomy 18	Qualitative descriptive (Narrative)	1 mother who was pregnant with child diagnosed with Trisomy 18 who died in utero-delivered stillborn. Narrative captures time during pregnancy and after death.	**CASP- 7/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design n/a Appropriate recruitment strategy n/a Appropriate data collection ✓ Considered reflexivity Results ✓ Ethical considerations addressed n/a Rigorous data analysis ✓ Clear statement of findings Utility	• Validity: use of narrative illustration design provided several detailed quotes and in-depth insight into this lived experience

			n=1	✓ Value of research	
*Lathrop & VandeVusse (2011a) United States	**Title:** Continuity and Change in Mothers' Narratives of Perinatal Hospice **Objective:** To explore the experiences of women who chose to continue pregnancies affected by lethal fetal diagnoses and to develop knowledge useful to nurses and other healthcare professionals who provide perinatal hospice (PH) care	Qualitative descriptive study (Interviews)	15 women who learned during their pregnancies of a lethal fetal diagnosis and chose to continue the affected pregnancies. Interviews took place at an interval of 1-12 years after death of baby. n= 15	**CASP- 8/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Results: Analytic rigor was ensured by collecting field notes, maintaining an audit trail, expert checking, and member checking • Utility: use of multi-disciplinary research team increased dependability and confirmability of findings. Findings also substantiated by abundant quotations which supported recommendations for clinical practice
Lathrop & VandeVusse (2011b) Unites States	**Title:** Affirming Motherhood: Validation and Invalidation in Women's Perinatal Hospice Narratives **Objective:** To explore the experiences of perinatal hospice mothers to gather knowledge useful to health professionals	Qualitative study (Interviews)	15 women who continued pregnancies affected by lethal fetal diagnoses. Interviews took place at an interval of 1-12 years after death of baby. n= 15	**CASP- 8/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: recruited participants with an interval of at least 1 year since the birth since short-term perinatal bereavement outcomes are well represented in literature • Results: analytical rigor ensured by maintaining audit trail, expert checking, and member checking
Limbo & Lathrop (2014) Unites States	**Title:** Caregiving in Mothers' Narratives of Perinatal Hospice	Qualitative study	15 women who continued pregnancies affected by	**CASP- 8/10** Validity ✓ Clear Aim ✓ Appropriate methodology	• Validity: theme of "caregiving" identified in previous paper, thus authors

	Objective: to explore experiences of mothers who continued pregnancy after the prenatal detection of LLFC and to identify aspects of caregiving theory that extend the theory beyond what is currently known using data from these mothers.	(Secondary analysis of data from qualitative interviews)	lethal fetal diagnoses. Interviews occurred at an interval of >1 year since the birth. n= 15	✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	used secondary analysis to further explore this topic • Results: authors chose a theory-guided approach to analyze narrative data collected (applied caregiving theory to bereaved population for the first time)
Lotto, Smith & Armstrong (2017) Unites Kingdom	**Title:** Diagnosis of a severe congenital anomaly: A qualitative analysis of parental decision making and the implications for healthcare encounter **Objective:** To explore parental decision-making following diagnosis of a severe congenital anomaly, and implications for healthcare encounters	Qualitative (Semi-structured interviews)	20 mothers & 18 partners whose pregnancy was suspected or diagnosed as being affected by a severe congenital anomaly. Interviews occurred during pregnancy. n= 38	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rigorous sampling and data collection. • Validity: qualitative methodology with triangulation of in-person interviews and audio-recordings of clinical consultations • Utility: study provides important insight into the decision-making process of parents affected by a severe congenital anomaly
Meaney, Corcoran & O'Donohue (2017) Ireland	**Title:** Death of One Twin during the Perinatal Period: An Interpretative Phenomenological Analysis **Objective**: To explore the effect of the loss of one twin diagnosed with a congenital abnormality during pregnancy on parents	Interpretative Phenomenology (Semi-structured interviews)	9 parents who have experienced perinatal loss, all of whom had a prenatal diagnosis of congenital abnormality. n=9	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis	• Results: rigorous and transparent analysis • Utility: valuable insight into lived experience of twin pregnancy with diagnosis of LLFC in one twin

				✓ Clear statement of findings Utility ✓ Value of research	
*McKechnie Chevalier, Pridham & Tluczek (2015) Unites States	**Title:** Preparing Heart and Mind for Becoming a Parent Following a Diagnosis of Fetal Anomaly **Objective:** To address this gap in the theoretical and empirical literature by examining how parenting develops after a major fetal anomaly diagnosis	Cross-sectional (Qualitative interviews)	25 mothers and 12 fathers who received the diagnosis of a fetal anomaly of at one major congenital anomaly (21 singletons and four sets of twins). Interviews occurred during pregnancy. n= 37	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: use of a comprehensive and rigorous methodological approach (grounded dimensional analysis) • Results: use of a rich data set to refine and to relate previous conceptualizations to "preparing heart and mind" theory. Theoretical saturation in data analysis achieved • Utility: findings support the theoretical model of preparing heart and mind for becoming a parent following such a diagnosis.
*O'Connell, Meaney & O'Donoghue (2019) Ireland	**Title:** Anencephaly; the maternal experience of continuing with the pregnancy: Incompatible with life but not with love **Objective:** to increase the understanding of the lived experience of mothers with a prenatal lethal diagnosis who continued their pregnancy and their responses of the care they received	Interpretive phenomenology (Qualitative interviews)	4 mothers who received a prenatal diagnosis anencephaly and continued the pregnancy in a country where termination was not legalized. Interviews were done > 1 year after death of baby. n=4	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Results: rigorous data collection and analysis, used double-hermeneutic approach • Utility: findings substantiated by ample narrative quotations and the integration of supporting literature.

Redlinger-Gross et al. (2002) Unites States	**Title:** The Decision to Continue: The Experiences and Needs of Parents Who Receive a Prenatal Diagnosis of Holoprosencephaly **Objective**: To explore parental experiences in making the decision to continue the pregnancy following a prenatal diagnosis of Holoprosencephaly and to identify informational, emotional, and supportive needs of parents throughout their decision-making process	Qualitative descriptive study (Interviews)	10 parent couples and 4 mothers who continued pregnancy following a prenatal diagnosis of Holoprosencephaly. Interviews took place after birth & after death. n=24	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: Robust recruitment (4 different sources) • Utility: valuable insight into lived experience of parents, authors use findings to generate recommendations for clinical practice.
Thiele (2011) Australia	**Title:** A million little pieces: Parental and physician perspectives on trisomy 18 **Objective:** To explore the experience of the author who chose not to terminate pregnancy following the diagnosis of a 'lethal' abnormality	Qualitative Descriptive (Narrative-ethnography)	1 parent of child with trisomy 18 (nurse) & a physician involved in the care. Narrative captures time during pregnancy and after death. n=2	**CASP- 7/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design n/a Appropriate recruitment strategy n/a Appropriate data collection ✓ Considered reflexivity Results ✓ Ethical considerations addressed n/a Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: use of personal narrative design provided several detailed quotes and in-depth insight into this lived experience • Utility: findings substantiated by ample narrative quotations
*Welch (2018) Unites States	**Title:** Navigating Infant Death from Life-Limiting Congenital Anomaly: A Classic Grounded Theory Study **Objective**: To explore how parents experience the expected	Grounded theory (Non-structured interviews)	11 mothers and 1 father of infants diagnosed with a life-limiting congenital anomaly.	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy	• Validity: use of classic grounded theory represents powerful method to understand this experience • Utility: Findings substantiated by ample narrative quotations and the integration of

	death of an infant from a life-limiting congenital anomaly		Interviews occurred after death. n= 12	✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	supporting literature. Findings from this study also generated theory "Negotiating Infant Death", which could be used as a conceptual framework to guide clinical practice
Wool, Limbo & Denney-Koelsch (2018) Worldwide	**Title:** "I Would Do It All Over Again": Cherishing Time and the Absence of Regret in Continuing a Pregnancy after a Life-Limiting Diagnosis **Objective:** To examine the concept of decision regret in parents who opted to continue a pregnancy affected by an LLFC	Mixed-methods Cross-sectional study (Online survey with open ended questions)	402 parents who experienced a life-limiting prenatal diagnosis and opted to continue their pregnancy (at any point of time between the diagnosis and period after death) n=402	**CASP- 9/10** Validity ✓ Clear Aim ✓ Appropriate methodology ✓ Appropriate research design ✓ Appropriate recruitment strategy ✓ Appropriate data collection Considered reflexivity Results ✓ Ethical considerations addressed ✓ Rigorous data analysis ✓ Clear statement of findings Utility ✓ Value of research	• Validity: rigorous sample, large sample from around the world • Results: authors used Dimensional analysis which represents an "natural analysis" that is effective in describing common, everyday experiences and can be used for theory development • Utility: Findings substantiated by participant narratives, integration of supporting literature and recommendations for clinical practice