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Processes of Care for Medically Fragile Infants on an Inpatient Pediatric Unit: A Grounded Theory Study

by

Lyndsay Jerusha MacKay

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
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Abstract

Today, increasing numbers of Medically Fragile Infants (MFI) born with severe, life-threatening illnesses are surviving the neonatal period due to medical and technological advancements in care. Such infants require long-term hospitalization and remain dependent on technology for survival. MFI are defined as preterm or full-term infants who (a) have a life-threatening chronic medical illness that require technology for survival, (b) remain hospitalized for several weeks to months, and (c) are expected to be discharged with a chronic health problem. Parenting MFI is typified by frequent health setbacks and uncertainty, which adds complexity, impediments, and complications to becoming a parent. Also, parents of MFI have higher than average rates of anxiety, depression, chronic stress, and post-traumatic stress disorder. The literature reflects that outcomes for MFI and their parents are poor.

The aim of this grounded theory study was to create a deeper understanding of the processes of care provided to MFI from the perspectives of parents and Health Care Professionals (HCP). Specifically, I explored what it was like for parents to provide care to hospitalized MFI, and why some struggled. Also, I explored why caring for MFI was stressful for HCP, and why frustrating encounters often transpired between parents and HCP. I used Charmaz' approach to grounded theory to gain this understanding. The findings suggest that parents and HCP have different yet interconnected experiences of caring for MFI within the inpatient pediatric unit. Parents experienced grief and multiple stressors, and they utilized internal and external coping mechanism to manage their grief and stressors. When they were unable to cope with grief and stressors, they experienced difficulty in their parental role and mental health difficulties. HCP experienced stress and burnout due to the complexity of MFI and the complex parental experience of today. HCP aimed at developing trust with parents so they could establish a supportive relationship. The relationship was a means to educate and empower parents to care for their hospitalized infant and work collaboratively with parents in the planning and delivery of care. However, HCP encountered multiple frustrating encounters with parents that were barriers to the development of a therapeutic relationship because of the complexity and high demands of MFI' care needs and parental ability, or lack thereof, to cope with their grief and stressors.

The parent and HCP' experiences were compared and contrasted; areas where concepts and themes overlapped were identified and the grounded theory emerged: "*Journeying Along Side One Another*". The space where parental and HCP' different, yet interconnected, experiences came together was in the liminal space between their experiences, where parents and HCP interacted with one another. When key factors were present beneficial interactions transpired between HCP and parents, and supportive relationships built on trust were established; experiences and interactions became shared and interconnected, and parents and HCP journeyed together. When the key factors were absent, parents and HCP did not engage in mutually beneficial interactions, and supportive relationships built on trust were not established; difficult interactions transpired between parents and HCP, and they did not journey together. Parental and HCP' characteristics impacted beneficial interactions in conjunction with key factors.

Keywords: medically fragile infant, parenting, hospitalized infant, parental mental health, health care provider

Acknowledgements

First and foremost, it is my honor to acknowledge my exceptional supervisor Dr. Karen Benzies. You believed in me and supported my ideas. I would not have been able to complete this study without your hard work and dedication. I admire your expertise, knowledge, and wisdom that guided my dissertation studies. I will be forever thankful to you for the positive impact you have had on my life, both personally and professionally.

I have been blessed to have a supportive mentorship team. Dr. Shelley Raffin-Bouchal, you were willing and open to accept me back into the program after my extended leave to care for my prematurely born sons. You provided exceptional guidance in data analysis and the grounded theory theorizing process. Dr. Chantelle Barnard, it has been a pleasure to work with you, both clinically and academically. Your exceptional passion to help this population has been an encouragement, and I am very grateful for your expertise and experience that has been an invaluable asset to this study.

I would like to acknowledge the research staff in the Benzies' lab. Pilar Zanoni, your amazing ability to keep this study organized and running smoothly has been a corner stone. John Wong, your help with organizing, conducting, and transcribing focus groups has been beneficial, as well as, organizing all the documentation for the study.

Finally, thank you to my husband for supporting me and encouraging me along the way. This dissertation is the result of your hard work and sweat, managing our home life and children so I could spend countless hours working. And my mom, for encouraging me and cheering me on along the way.

Dedication

I would like to dedicate my dissertation to my two young boys, Benjamin MacKay and William MacKay. I am thankful for your patience while mommy had to work on her studies. Thank you for enduring your premature births, because those experiences helped me to understand the experiences of parents with hospitalized sick babies. I love you for always, and this degree is for you my sons, I hope I make you each very proud and encourage you to one day follow your dreams too.

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Chapter 1: Introduction

Parents of MFI face difficulties and experience high levels stress as they provide complex care to their infants surrounded by medical technology (Aite et al., 2003; Hall, 2005; Sikora & Janusz, 2015). Parents of MFI are not able to easily hold their infant, be physically close to their infant, or provide normal basic infant care (Miles, Burchinal, Holditch-Davis, Brunssen, & Wilson, 2002; Sikora & Janusz, 2015). Parents of MFI experience elevated levels of depression (Hancock et al., 2018), stress (Cantwell-Bartl & Tibballs, 2013), distress (Doherty et al., 2009), worry (Docherty, Miles, & Holditch-Davis, 2002), and Post Traumatic Stress Disorder (PTSD) (Cantwell-Bartl & Tibballs, 2013). Therefore, parents of MFI can struggle to adapt to their parental role when compared to parents of healthy infants (Pridham, Harrison, McKechnie, & Brown, 2017). MFI experience challenges in their cognitive, social, and emotional development (Browne & Talmi, 2017; Holditch-Davis, Cox, Miles, & Belyea, 2003). High levels of mental health difficulties in parents coupled with disorientation of infant cues can negatively impact the development of a parent-infant interactions, which can further impede growth and development of the infant (Browne & Talmi, 2017; Docherty et al., 2002; Kelly, Zuckerman, Sandoval, & Buehlman, 2016).

Definition of MFI

Miles and D'Auria (1994) developed the term Medically Fragile Infants in 1994 to account for the increasing number of infants who were surviving with complex medical problems; previously, these infants would have died shortly after birth. Miles and D'Auria (1994) recognized that the nature of MFI' health problems demanded high levels of complex care and that infants' ability to function optimally in their environment was impaired. At the time, Miles and D'Auria (1994) found that research with this population was limited, and only a handful of studies had been conducted. The limited research available suggested that parenting MFI was stressful and parent-infant dyads experienced problems in caregiving and interactions, which hindered growth and development of MFI and the overall functioning of the child (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Goldberg & Simmons, 1988; Holaday, 1987).

From this foundational research, Miles and Holditch-Davis conducted further studies to better understand this population, and determine how outcomes for MFI and their parents could be improved (Docherty et al., 2002; Holditch-Davis, Docherty, Miles, & Burchinal, 2001; Holditch-Davis, Tesh, Miles, & Burchinal, 1999; Miles, Holditch-Davis, Burchinal, & Nelson, 1999). Currently, the literature regarding MFI remains limited, and much of the research was conducted over a decade ago with questionable relevance given rapid advances in pediatric care. Also, only a few researchers have contributed to this field despite the high cost of hospitalizations for MFI and parental burden of care.

MFI are most comprehensively and inclusively defined as: preterm or full-term infants who (a) have a life-threatening chronic medical illness that requires technology for survival, (b) remain hospitalized for several weeks to months, and (c) are expected to be discharged with a chronic health problem (Catlin, 2008; Cho, Holditch-Davis, & Miles, 2008; Docherty et al., 2002; Gardner, 2014; Holditch-Davis et al., 2001; Holditch-Davis, Miles, Burchinal, & Goldman, 2011; Miles, Holditch-Davis, Burchinal, & Brunssen, 2011; Miles et al., 1999). MFI are a heterogeneous population and carry a variety of diagnoses, such as complications of prematurity and congenital anomalies (Holditch-Davis et al., 2003; Holditch-Davis et al., 1999). Though their diagnoses may vary, MFI share the same serious nature of their diseases; since they make up a small portion of each diagnostic group, they are usually excluded from studies unless grouped together by diagnoses (Holditch-Davis et al., 1999). MFI' diagnoses most often fall within the following categories: chronic lung disease, severe gastrointestinal disorder, congenital airway obstruction, neurologic disorders, complex congenital heart disease and other, including renal, cystic fibrosis, etc. (Docherty et al., 2002).

Aims of this Study

The aim of this study was to better understand processes of caring for hospitalized MFI by exploring parental and HCP' experiences. This research is significant because it will inform the development of relevant measurements for a larger quantitative study. Currently, supports to help parents cope are limited and there is a lack in coordination of cohesive care. HCP experience increased stress while caring for MFI and their parents. Therefore, exploring the experiences of parents and HCP as they care for hospitalized MFI will provide insight into why increased stress and difficulties persist. This understanding will help inform the development and adaptation of interventions aimed at improving care provided to MFI and their parents, offer enhanced supports to parents, and improve parent-HCP interactions.

Summary of Dissertation Format

This dissertation is considered by the Faculty of Graduate Studies, University of Calgary, to be a hybrid dissertation. That is, the document contains a combination of manuscripts and traditional style chapters woven together with short bridging sections. Chapter 1 provides an overview of the study concluding with the aim of the study. Chapter 2 is a scoping review that was formatted as a manuscript for the journal ACTA Paediatrica. The manuscript was revised and resubmitted May 7, 2019. Chapter 3 compares and contrasts theorizing for three grounded theory approaches and was formatted as a manuscript for the International Journal of Qualitative Methods. Following the study purpose and research questions: What is the experience of being a parent of a hospitalized MFI? What is the experience of providing care to MFI and their parents (both mothers and fathers) in the inpatient hospital setting? Chapter 4 describes the methods. Chapter 5 describes themes associated with parental experiences, and Chapter 6 describes the themes associated with HCP' experiences. Chapter 7 is the grounded theory that emerged when themes from parental and HCP experiences were compared and contrasted. Finally, Chapter 8 includes the discussion and recommendations. Information in Chapters 5, 6, and 7 may overlap and be repetitive because the theory emerged from the parental and HCP' experiences. References for all chapters can be found at the end of this document.

Chapter 2: A Scoping Review of Parental Experiences Caring for their Hospitalized Medically Fragile Infants

Authors:
Lyndsay Jerusha MacKay
Dr. Karen Benzies
Dr. Chantelle Barnard
Dr. Alix Hayden

Accepted July 2019, Journal: ACTA Paediatrica

This manuscript provides an in depth understanding of the most up to date literature on parental experiences caring for MFI. Within this dissertation, it acts as a literature review regarding parenting MFI within the hospital setting.

A Scoping Review of Parental Experiences Caring for their Hospitalized Medically Fragile Infants

Background

Medically Fragile Infants (MFI) are a heterogeneous population with a variety of diagnoses, including complications of prematurity and congenital anomalies (Holditch-Davis et al., 2003; Holditch-Davis et al., 1999). MFI diagnoses most often fall within the following categories: chronic lung disease, severe gastrointestinal disorder, congenital airway obstruction, neurologic disorders, complex congenital heart disease, and other including renal, cystic fibrosis, etc. (Docherty et al., 2002). Though their diagnoses may vary, MFI share the same serious nature of their diseases (Holditch-Davis et al., 1999). Since they make up a small portion of each diagnosis group, MFI are usually excluded from studies unless grouped together by diagnoses (Holditch-Davis et al., 1999). MFI are most comprehensively and inclusively defined as preterm or full-term infants who (a) have a life-threatening chronic medical illness that requires technology for survival, (b) remain hospitalized for several weeks to months, and (c) are expected to be discharged with a chronic health problem (Catlin, 2008; Cho et al., 2008; Docherty et al., 2002; Gardner, 2014; Holditch-Davis et al., 2001; Holditch-Davis et al., 2011; Miles et al., 2011; Miles et al., 1999).

Advances in nursing and medical care have increased the survival and improved outcomes of MFI (Browne & Talmi, 2017; Devereaux & Kon, 2017; Holditch-Davis et al., 2003; Tolomeo, Major, Szondy, & Bazzy-Asaad, 2017). MFI require long-term hospitalization and remain dependent on technology for survival (Gardner, 2014; Holditch-Davis et al., 2003; Holditch-Davis et al., 1999; Miles et al., 1999). Due to medical complexity, parents are often unable to be physically close, hold, or provide basic infant care, which results in decreased parental confidence in providing care (Miles et al., 2002; Sikora & Janusz, 2015). The illness trajectory of MFI is often uncertain, and the nature of their diagnoses encompass frequent setbacks (Kosta et al., 2015). Parental care of MFI is time and energy consuming (Hunfeld, Tempels, Passchier, Hazebroek, & Tibboel, 1999). Consequently, parents of MFI experience greater parental stress and difficulties adapting to their parental role than parents of healthy infants (Pridham et al., 2017). MFI experience challenges in their early regulation, as well as challenges in their cognitive, social, and emotional development (Browne & Talmi, 2017; Holditch-Davis et al., 2003). High levels of parental stress coupled with disorganized infant cues can negatively impact the development of a parent-infant relationship, which can further impede growth and development of the infant (Browne & Talmi, 2017; Docherty et al., 2002).

The purpose of this scoping review was to synthesize and summarize evidence from published research articles regarding parental experiences caring for their MFI.

Methods

A scoping review is exploratory and used to map and summarize the literature on a particular topic; it identifies key concepts, sources of evidence, theories, and gaps in research (Canadian Institute of Health Research, 2008; Levac, Colquhoun, & O'Brien, 2010). Scoping reviews differ from systematic reviews because they do not aim to provide answers to specific questions stemming from a narrow range of studies that have been assessed for quality (Arksey & O'Malley, 2005). Rather, scoping reviews address broader topics from studies that used a variety of designs, and do not assess the quality of the studies included (Arksey & O'Malley, 2005).

We followed the recommendations of Levac, Colquhoun, and O’Brien (Levac et al., 2010), which built upon their experiences with Arksey and O’Malley’s (2005) five-stage method.

The five-stage method involved identification of a research question; identification of relevant studies; selection of studies; charting the data; and collating, summarizing, and reporting the results (Arksey & O'Malley, 2005; Levac et al., 2010). Scoping reviews are relevant to disciplines and topics where evidence is sparse and still emerging, and when randomized control trials are slim (Levac et al., 2010), which is a fit for the current literature on MFI. Scoping reviews are rigorous and transparent (Roque, Lasiuk, Radunz, & Hegadoren, 2017), and allow researchers to incorporate a range of study designs and address questions beyond intervention effectiveness (Levac et al., 2010), which is currently needed to better understand the under researched population of MFI and their parents.

In accordance with Levac et al. (2010) and Arksey and O'Malley (2005), the research team formulated a search question and rationale for why the search was completed. The search question was: What are the parental experiences caring for their MFI who are hospitalized for extended periods of time within the infant’s first year of life? The search was completed to inform future research and support development of interventions to improve care provided to MFI and their parents.

Search strategy.

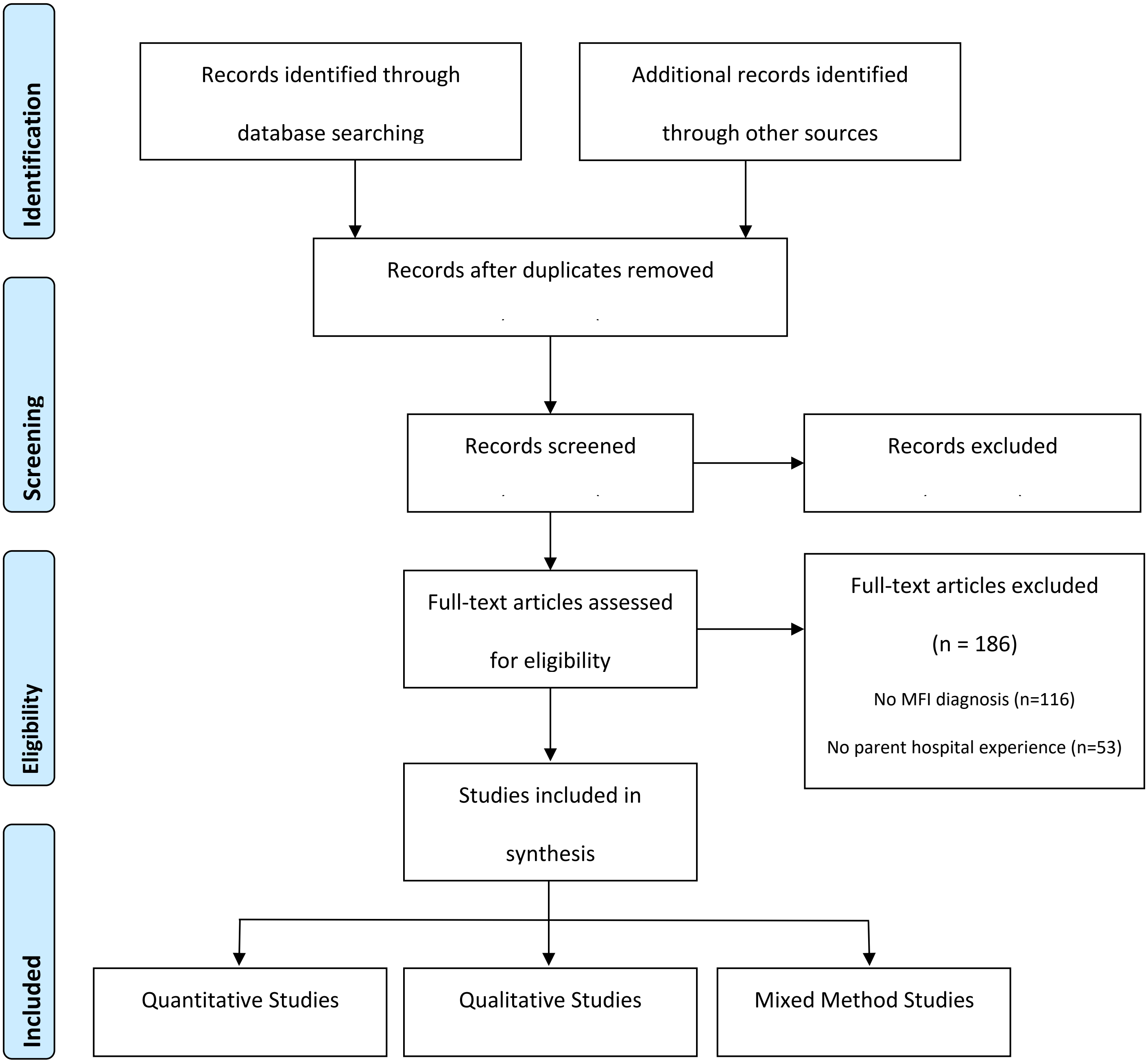
We conducted the search in April 2018 with the assistance of an academic health sciences librarian (KAH). We searched MEDLINE, Embase, PsycINFO, and CINAHL, focusing on three main concepts: infant, medically fragile, parents. Each concept included keywords and relevant subject headings defined by each database (See Appendix A for the exemplar MEDLINE search). Search results were uploaded to Endnote (V.8), duplicates removed, and records exported to Excel for screening.

Data abstraction and synthesis.

LM, CB, and KB screened record titles and abstracts with the following inclusion criteria for MFI: (a) diagnosis of a chronic health condition, (b) dependent on technology for survival, (c) diagnosis that typically resulted in a hospital length of stay $\geq$ 30 days, and (d) $<$ 12 months of age at the time of recruitment in $\geq$ 50% of the sample. Described parental experiences included: (a) lived experiences, (b) qualitative findings of experiences, (c) descriptive quantitative results using various screening tools, and (d) quality of parent-infant interactions. Hospital-based care settings for MFI included: (a) neonatal intensive care units, (b) pediatric intensive care units, and (c) pediatric inpatient care units. We included articles written in English from all countries and healthcare systems, and parents of all sociodemographic, racial, and cultural backgrounds.

LM, KB, CB, and KAH determined article inclusion criteria. To assess inter-rater reliability, LM and KB independently screened 100 titles and abstracts for relevance two times and achieved a high level of agreement (90% and 98%). LM screened the remaining titles and abstracts, resulting in 220 full text articles to be screened. LM and KB reviewed half of the full text articles and LM and CB reviewed the other half. We resolved uncertainties by discussion and consensus. See Figure 1 for PRISMA flow diagram. Aligned with the aims of a scoping review, we did not asses methodological quality of included studies (Arksey & O'Malley, 2005; Levac et al., 2010).

Figure 1. PRISMA Flow Diagram



The PRISMA Group (Moher, Liberati, Tetzlaff, & Altman, 2009)

Analysis.

We extracted data (author, purpose, sample, design, concepts, measures, and main results) and compiled in a table (see Appendix A for Supplementary Table of Study Characteristics). We used thematic analysis to compare data, identify patterns, organize data into themes, map major themes, and describe data in detail (see Table 1) (Braun & Clarke, 2006). See Table 2 for a numerical summary of the studies.

Table 1

Themes

Themes	**# of Studies**	**Studies**
Depression	8 (23%)	(Aite et al., 2003; Bevilacqua et al., 2013; Cho et al., 2008; Hancock et al., 2018; Miles et al., 1999; Sarajuuri, Lonnqvist, Schmitt, Almqvist, & Jokinen, 2012; Solberg et al., 2011a, 2011b)
Stress, Distress, Anxiety	17 (50%)	(Aite et al., 2003; Bevilacqua et al., 2013; Brosig, Whitstone, Frommelt, Frisbee, & Leuthner, 2007; Brunssen & Miles, 1996; De Stasio et al., 2018; Docherty et al., 2002; Doherty et al., 2009; Hancock et al., 2018; Hearps et al., 2014; Hunfeld et al., 1999; Kaul & Lakey, 2003; Kosta et al., 2015; T. Y. Lee, Miles, & Holditch-Davis, 2006; Miles et al., 2002; Miles et al., 2011; Miles et al., 1999; Sarajuuri et al., 2012; Scharer & Brooks, 1994; Sikora & Janusz, 2015; Solberg et al., 2011b; Warschausky, MacKenzie, Roth, & Bartlett, 1995)
Parent-Infant Interaction	10 (29%)	(Cantwell-Bartl & Tibballs, 2013; Cho et al., 2008; Cho, Miles, Holditch-Davis, & Belyea, 2009; Clark & Miles, 1999; Holditch-Davis et al., 2003; Holditch-Davis et al., 1999; T. Y. Lee, Holditch-Davis, & Miles, 2007; Miles et al., 2011; Scharer & Brooks, 1994; Sikora & Janusz, 2015)
Maternal Role Attainment	5 (15%)	(Black, Holditch-Davis, & Miles, 2009; Cantwell-Bartl & Tibballs, 2013; Holditch-Davis et al., 2011; Miles et al., 2011; Sikora & Janusz, 2015)
Health Care Professionals	4 (12%)	(Cantwell-Bartl & Tibballs, 2013; Kosta et al., 2015; Scharer & Brooks, 1994; Sikora & Janusz, 2015)
Supports	7 (21%)	(Black et al., 2009; Docherty, Lowery, & Miles, 2007; Kaul & Lakey, 2003; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2002; Sikora & Janusz, 2015)

Coping	6 (18%)	(Clark & Miles, 1999; Doherty et al., 2009; Graungaard, Andersen, & Skov, 2011; Hancock et al., 2018; Kosta et al., 2015; Sikora & Janusz, 2015)

Table 2

Numerical Analysis of Studies

Key Figures	**# of Studies**	**Studies**
Country		
United States	21 (62%)	(Black et al., 2009; Brosig et al., 2007; Browne & Talmi, 2017; Brunssen & Miles, 1996; Cho et al., 2008; Cho et al., 2009; Clark & Miles, 1999; Docherty et al., 2007; Docherty et al., 2002; Hancock et al., 2018; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; Holditch-Davis et al., 1999; Kaul & Lakey, 2003; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2002; Miles et al., 2011; Miles et al., 1999; Scharer & Brooks, 1994; Warschausky et al., 1995)
Australia	3 (9%)	(Cantwell-Bartl & Tibballs, 2013; Hearps et al., 2014; Kosta et al., 2015)
Italy	3 (9%)	(Aite et al., 2003; Bevilacqua et al., 2013; De Stasio et al., 2018)
Norway	2 (6%)	(Solberg et al., 2011a, 2011b)
United Kingdom	1 (3%)	(Doherty et al., 2009)
Finland	1 (3%)	(Sarajuuri et al., 2012)
Poland	1 (3%)	(Sikora & Janusz, 2015)
Netherlands	1 (3%)	(Hunfeld et al., 1999)
Denmark	1 (3%)	(Graungaard et al., 2011)
Ethnicity		
Caucasian	13 (33%)	(Bevilacqua et al., 2013; Black et al., 2009; Cho et al., 2009; Clark & Miles, 1999; Docherty et al., 2002; Hancock et al., 2018; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006;

		Miles et al., 2002; Miles et al., 2011; Scharer & Brooks, 1994)
African American	11 (32%)	(Black et al., 2009; Cho et al., 2009; Clark & Miles, 1999; Docherty et al., 2002; Hancock et al., 2018; Holditch-Davis et al., 2011; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2002; Miles et al., 2011; Scharer & Brooks, 1994)
Hispanic	7 (20%)	(Docherty et al., 2002; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2011; Scharer & Brooks, 1994)
Asian	6 (9%)	(Clark & Miles, 1999; Docherty et al., 2002; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; T. Y. Lee et al., 2006; Miles et al., 2011)
Native American	8 (24%)	(Docherty et al., 2007; Docherty et al., 2002; Hancock et al., 2018; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2011)
Italian	1 (3%)	(Aite et al., 2003)
Not Specified	18 (53%)	(Brosig et al., 2007; Browne & Talmi, 2017; Brunssen & Miles, 1996; Cantwell-Bartl & Tibballs, 2013; Cho et al., 2008; De Stasio et al., 2018; Doherty et al., 2009; Graungaard et al., 2011; Hearps et al., 2014; Holditch-Davis et al., 1999; Hunfeld et al., 1999; Kaul & Lakey, 2003; Kosta et al., 2015; Miles et al., 1999; Sarajuuri et al., 2012; Sikora & Janusz, 2015; Solberg et al., 2011a; Warschausky et al., 1995)
Data Collection		
Survey	24 (71%)	(Aite et al., 2003; Bevilacqua et al., 2013; Brosig et al., 2007; Brunssen & Miles, 1996; Cho et al., 2008; Cho et al., 2009; De Stasio et al., 2018; Docherty et al., 2002; Doherty et al., 2009; Hancock et al., 2018; Hearps et al., 2014;

		Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; Holditch-Davis et al., 1999; Hunfeld et al., 1999; Kaul & Lakey, 2003; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2002; Miles et al., 2011; Miles et al., 1999; Sarajuuri et al., 2012; Solberg et al., 2011a, 2011b; Warschausky et al., 1995)
Observation	8 (24%)	(Cho et al., 2008; Cho et al., 2009; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; Holditch-Davis et al., 1999; T. Y. Lee et al., 2007; Miles et al., 2011; Miles et al., 1999)
Qualitative Interviews	7 (21%)	(Black et al., 2009; Clark & Miles, 1999; Docherty et al., 2007; Graungaard et al., 2011; Kosta et al., 2015; Scharer & Brooks, 1994; Sikora & Janusz, 2015)
Mixed	1 (3%)	(Cantwell-Bartl & Tibballs, 2013)
Case Study	2 (6%)	(Browne & Talmi, 2017; Docherty et al., 2007)
Randomized Trial	1 (6%)	(Aite et al., 2003; Hancock et al., 2018)
Infant Age at Recruitment		
Prenatal	3 (9%)	(Hancock et al., 2018; Solberg et al., 2011a, 2011b)
0-6 months	9 (26%)	(Aite et al., 2003; Bevilacqua et al., 2013; Brosig et al., 2007; Cho et al., 2009; Holditch-Davis et al., 2011; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2011; Miles et al., 1999)
6-12 months	4 (12%)	(Cho et al., 2008; De Stasio et al., 2018; Holditch-Davis et al., 2003; Kosta et al., 2015)
Between 1-12 months, age not specified	15 (44%)	(Black et al., 2009; Brunssen & Miles, 1996; Clark & Miles, 1999; Docherty et al., 2007; Docherty et al., 2002; Doherty et al., 2009; Graungaard et al., 2011; Hearps et al., 2014; Holditch-Davis et al., 1999; Hunfeld et al., 1999; Kaul & Lakey, 2003; Miles et al., 2002; Scharer & Brooks, 1994; Sikora & Janusz, 2015; Warschausky et al., 1995)
Retrospective 1+	2 (6%)	(Cantwell-Bartl & Tibballs, 2013; Sarajuuri et al., 2012)
Setting		

NICU	9 (26%)	(Aite et al., 2003; Bevilacqua et al., 2013; Clark & Miles, 1999; De Stasio et al., 2018; Docherty et al., 2007; Graungaard et al., 2011; Miles et al., 2002; Scharer & Brooks, 1994; Warschausky et al., 1995)
Inpatient Unit	2 (6%)	(Clark & Miles, 1999; Hunfeld et al., 1999)
Cardiology Unit	3 (9%)	(Bevilacqua et al., 2013; Hancock et al., 2018; Sikora & Janusz, 2015)
PICU	4 (12%)	(Cantwell-Bartl & Tibballs, 2013; Clark & Miles, 1999; Docherty et al., 2007; Miles et al., 2002)
Hospital, unit not specified	20 (59%)	(Black et al., 2009; Brosig et al., 2007; Brunssen & Miles, 1996; Cho et al., 2008; Cho et al., 2009; Docherty et al., 2002; Doherty et al., 2009; Hearps et al., 2014; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; Holditch-Davis et al., 1999; Kaul & Lakey, 2003; Kosta et al., 2015; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2011; Miles et al., 1999; Sarajuuri et al., 2012; Solberg et al., 2011a, 2011b)
Diagnosis		
Non-cardiac anomaly	3 (9%)	(Aite et al., 2003; Brosig et al., 2007; Hunfeld et al., 1999)
Cardiac anomaly	13 (38%)	(Bevilacqua et al., 2013; Cantwell-Bartl & Tibballs, 2013; Clark & Miles, 1999; De Stasio et al., 2018; Doherty et al., 2009; Hancock et al., 2018; Hearps et al., 2014; Kaul & Lakey, 2003; Kosta et al., 2015; Sarajuuri et al., 2012; Sikora & Janusz, 2015; Solberg et al., 2011a, 2011b)
Classified as MFI	16 (47%)	(Black et al., 2009; Browne & Talmi, 2017; Brunssen & Miles, 1996; Cho et al., 2008; Cho et al., 2009; Docherty et al., 2007; Docherty et al., 2002; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; Holditch-Davis et al., 1999; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2002; Miles et al., 2011; Miles et al., 1999; Scharer & Brooks, 1994)
Pulmonary Hypertension on ECHMO	1 (3%)	(Warschausky et al., 1995)
Severely disabled	1 (3%)	(Graungaard et al., 2011)

Parents		
Mothers	23 (68%)	(Aite et al., 2003; Black et al., 2009; Browne & Talmi, 2017; Brunssen & Miles, 1996; Cho et al., 2008; Cho et al., 2009; De Stasio et al., 2018; Docherty et al., 2007; Docherty et al., 2002; Hancock et al., 2018; Holditch-Davis et al., 2003; Holditch-Davis et al., 2011; Holditch-Davis et al., 1999; Kaul & Lakey, 2003; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2002; Miles et al., 2011; Miles et al., 1999; Scharer & Brooks, 1994; Sikora & Janusz, 2015; Solberg et al., 2011a, 2011b; Warschausky et al., 1995)
Fathers	1 (2%)	(Clark & Miles, 1999)
Mothers and Fathers	9 (26%)	(Bevilacqua et al., 2013; Brosig et al., 2007; Cantwell-Bartl & Tibballs, 2013; Doherty et al., 2009; Graungaard et al., 2011; Hearps et al., 2014; Hunfeld et al., 1999; Kosta et al., 2015; Sarajuuri et al., 2012)
Point of Data Collection		
0-6 months	5 (15%)	(Aite et al., 2003; Bevilacqua et al., 2013; Holditch-Davis et al., 2003; Kosta et al., 2015; Solberg et al., 2011a)
6-12 months	1 (3%)	(De Stasio et al., 2018)
Varied: 1-12 months	12 (35%)	(Browne & Talmi, 2017; Brunssen & Miles, 1996; Docherty et al., 2007; Docherty et al., 2002; Doherty et al., 2009; Hearps et al., 2014; Hunfeld et al., 1999; Kaul & Lakey, 2003; Miles et al., 2002; Scharer & Brooks, 1994; Sikora & Janusz, 2015; Warschausky et al., 1995)
Multiple Time Points: 1-18 months	14 (41%)	(Black et al., 2009; Brosig et al., 2007; Cantwell-Bartl & Tibballs, 2013; Cho et al., 2008; Cho et al., 2009; Clark & Miles, 1999; Holditch-Davis et al., 2011; Holditch-Davis et al., 1999; T. Y. Lee et al., 2007; T. Y. Lee et al., 2006; Miles et al., 2011; Miles et al., 1999; Sarajuuri et al., 2012; Solberg et al., 2011b)
Multiple Time Points: 1-24 months	1 (3%)	(Graungaard et al., 2011)
Prenatal and then not specified	1 (3%)	(Hancock et al., 2018)

Results

We included 34 studies in the final analysis. Fifty-nine different scales, measures, and questionnaires were used to assess infant development, mother-infant interactions, mental health symptoms of parents, mental health status of parents, infant characteristics, stressors, infant technology dependence, family coping, parental worry, parental support, maternal identity and role attainment, grief, quality of mother-infant relationship, and amount of parental involvement in infant care. Some scales were developed specifically for the study (Docherty et al., 2002; Miles et al., 1999), while some were well-known postpartum, anxiety and coping measures (Aite et al., 2003; Brosig et al., 2007; Brunssen & Miles, 1996; De Stasio et al., 2018; Docherty et al., 2002; Doherty et al., 2009; Hancock et al., 2018; Hearps et al., 2014; Sarajuuri et al., 2012; Solberg et al., 2011b; Warschausky et al., 1995).

Themes.

Parental mental health.

Several studies examined parental mental health, including symptoms of depression, anxiety, stress, distress, and post traumatic stress disorder (PTSD). Parents of MFI commonly experience mental health difficulties related to the extreme nature of parenting a hospitalized infant. See Table 1. for themes.

Depression.

Parents reported increased depression or depressive symptoms in seven studies (Bevilacqua et al., 2013; Cho et al., 2008; Hancock et al., 2018; T. Y. Lee et al., 2007; Miles et al., 1999; Solberg et al., 2011a, 2011b). Rates of depressive symptoms above the clinical cut-off for mothers were 29.5% (22/73) (Solberg et al., 2011a), 39% (26/67) (Cho et al., 2008), and 47%

(18/38) (Hancock et al., 2018). Both mothers and fathers experienced elevated rates of depression; however, in one study rates for mothers were higher than fathers, 45.7% vs. 20%, respectively (Bevilacqua et al., 2013). Similarly, mothers reported higher levels of depressive symptoms (29.5%) than fathers (20%) (Bevilacqua et al., 2013). At six months postpartum, mothers of MFI reported more depressive symptoms than mothers of healthy preterm infants, 39% vs. 12%, respectively (Cho et al., 2008). Parents who received a prenatal diagnosis reported more depression than parents who received a postnatal diagnosis (Bevilacqua et al., 2013). Mothers of infants who had a more severe diagnosis experienced prolonged symptoms of depression (Solberg et al., 2011b) and increased levels of postnatal depression symptoms at six months postpartum (Solberg et al., 2011a). There were no differences in depressive symptoms whether mothers gave birth to a male or female infant (Cho et al., 2008; Sarajuuri et al., 2012).

Stress, Distress, and Anxiety.

Stress was assessed using various qualitative methods and screening tools. Definitions varied across studies and included: stress (Brosig et al., 2007; De Stasio et al., 2018; Docherty et al., 2002; T. Y. Lee et al., 2006; Miles et al., 2002; Miles et al., 2011; Miles et al., 1999; Sarajuuri et al., 2012), distress (Bevilacqua et al., 2013; Brosig et al., 2007; Doherty et al., 2009; Hearps et al., 2014; Kaul & Lakey, 2003; Miles et al., 2011; Miles et al., 1999; Warschausky et al., 1995), anxiety (Aite et al., 2003; Hancock et al., 2018; Solberg et al., 2011b), worry (Brunssen & Miles, 1996; Docherty et al., 2002; Doherty et al., 2009; Miles et al., 2002; Miles et al., 2011; Miles et al., 1999), acute stress disorder (Cantwell-Bartl & Tibballs, 2013), and PTSD (Cantwell-Bartl & Tibballs, 2013). Stress was the most commonly studied and measured concept. The following concepts were associated with stress: parental role alteration, external sights and sound, uncertainty, infant health status, relationships with health care professionals (HCP), and external stressors. The following causes of stress were reported among parents of MFI:

- Parental Role Alteration: alteration of the parental role (Miles et al., 1999), separation from the infant (Aite et al., 2003; Miles et al., 2002), inability to protect the infant from pain (Hancock et al., 2018; Miles et al., 2002), inability to comfort the infant (Miles et al., 2002)
- External Sights and Sounds: appearance and behavior of the infant (Brunssen & Miles, 1996; Cantwell-Bartl & Tibballs, 2013; Hancock et al., 2018; Miles et al., 1999), watching the infant in pain and undergo medical procedures, witnessing the infant having difficulty breathing and being unresponsive (Miles et al., 2002), sights and sounds in the intensive care unit (Cantwell-Bartl & Tibballs, 2013; Miles et al., 1999)
- Uncertainty and Fear for the Future: shock of receiving the infant's diagnosis (Aite et al., 2003; Cantwell-Bartl & Tibballs, 2013), fear the infant would not recover (Cantwell-Bartl & Tibballs, 2013), worry if the infant would be normal (Docherty et al., 2002), worry about when the infant would come home (Docherty et al., 2002), worry if the infant could die (Aite et al., 2003; Docherty et al., 2002; Hancock et al., 2018; Sikora & Janusz, 2015), lack of understanding the infant's diagnosis (Doherty et al., 2009), concerns about the future (Hancock et al., 2018), uncertain nature of infant's diagnosis (Kosta et al., 2015)
- Infant's Health Status: the infant's health status (Cantwell-Bartl & Tibballs, 2013; Docherty et al., 2002; Hancock et al., 2018), surgical complications (Hancock et al., 2018), waiting during the infant's surgery (Kosta et al., 2015)

- Interpersonal Relationships with HCP: relationships with HCP (Cantwell-Bartl & Tibballs, 2013), insensitive and inadequate communication with physicians (Cantwell-Bartl & Tibballs, 2013), poor interpersonal skills of HCP (Cantwell-Bartl & Tibballs, 2013), lack of empathy from HCP (Cantwell-Bartl & Tibballs, 2013), lack of direction navigating the health care system (Kosta et al., 2015), lack of information (Kosta et al., 2015; Sikora & Janusz, 2015)
- External Stressors: disruption of regular family life (Cantwell-Bartl & Tibballs, 2013), strain of travelling to hospital (Cantwell-Bartl & Tibballs, 2013), disruption to work life (Cantwell-Bartl & Tibballs, 2013; Hancock et al., 2018), separation from spouse and other children (Cantwell-Bartl & Tibballs, 2013), physical exhaustion (Cantwell-Bartl & Tibballs, 2013), financial difficulties (Cantwell-Bartl & Tibballs, 2013; Hancock et al., 2018), parental physical health concerns (Hancock et al., 2018), accommodations and housing (Kosta et al., 2015), food availability (Kosta et al., 2015), parking (Kosta et al., 2015), family difficulties (Cantwell-Bartl & Tibballs, 2013).

Stress related to parenting MFI was lower among mothers with higher education (De Stasio et al., 2018; Docherty et al., 2002; Miles et al., 2002). Parents whose infants were born prematurely reported experiencing higher stress (De Stasio et al., 2018). Docherty, Miles, and Holditch-Davis (Docherty et al., 2002) found no significant difference in levels of worry among mothers of MFI with diverse diagnoses, including chronic lung disease, congenital airway anomaly, severe gastrointestinal problems, complex congenital heart disease, neurological diagnosis, and those grouped as other. There were contradictions in findings related to the severity of infants' diagnosis and the relationship to maternal distress. In two studies, severity of MFI symptoms and diagnosis as measured by HCP was not associated with maternal anxiety

(Solberg et al., 2011b) or stress (Brunssen & Miles, 1996). In another study, maternal perceptions of infant's diagnosis severity were marginally related to distress (Kaul & Lakey, 2003). Increased maternal worry, regardless of illness severity, was related to increased stress (Brunssen & Miles, 1996) In contrast, Brosig and colleagues (2007) found that the severity of the infant's diagnosis was related to greater distress. Also, invasiveness of technology to maintain the infant's survival, such as extracorporeal membrane oxygenation (ECMO), was positively related to increased distress among mothers (Warschausky et al., 1995). Therefore, there were mixed findings about the association between MFI illness severity and parental worry and stress.

Parents of MFI experienced clinically significant levels of psychological distress (Doherty et al., 2009) and exceeded clinical cut-offs (Bevilacqua et al., 2013). Mothers experienced less child-related stress and more parent-related stress than fathers (Sarajuuri et al., 2012). Lower maternal distress was predicted by understanding the infant's diagnosis, maternal coping skills, and degree of family cohesive functioning; paternal distress was predicted by coping and level of worry (Doherty et al., 2009). Maternal distress was not predicted by disease factors, surgical factors, presence of multiple diagnoses, socioeconomic status, or social supports. Mothers with greater distress had younger infants with more recent diagnosis (Docherty et al., 2002; Kaul & Lakey, 2003).

Studies regarding degree of distress in parents of MFI with respect to timing of diagnosis were mixed. In one study, higher parental stress was associated with postnatal diagnosis (Bevilacqua et al., 2013). In another study, there was no difference in rates of emotional distress between parents that received a prenatal or postnatal diagnosis (Hearps et al., 2014). In two studies prenatal diagnosis was related to elevated parental distress at 6 months of age (Brosig et al., 2007) and increased burden and stress associated with parenting their infant (Hunfeld et al., 1999). Specifically, mothers reported greater social impact, lower perceived functional health of the infant, greater difficulty coping, and increased despair, while fathers reported greater financial burden (Hunfeld et al., 1999).

Cantwell-Bartl and Tibballs (2013) found that acute stress disorder or PTSD developed in 24/29 parents (83%). There were no significant differences between mothers and fathers, and the main traumatic stressor was that the infant could die. Most of the parents were highly anxious, and mothers tended to speak to their traumatic stress reactions more than fathers. Scharer and Brooks (Scharer & Brooks, 1994) found that mothers of prematurely born MFI enter parenthood after a traumatic event and worry excessively about the survival of their infant, leaving them extremely frightened and vulnerable.

Parent-Infant Interactions.

Ten studies included parent-infant interaction; eight included mothers, one included fathers, and one included both mothers and fathers. Interactions were disrupted due to maternal depression, negative perceptions of the infant, technology dependence, and infant inability to respond. Interactions were enhanced when mothers were married with higher education, had paternal support, increased education and more alert infants. Mothers often felt unprepared to provide complex medical care to their infant while in hospital because it takes time to become comfortable with their infants' needs (Scharer & Brooks, 1994).

Mothers had increased involvement with their MFI when they had lower depressive symptoms (Cho et al., 2008; T. Y. Lee et al., 2007), higher levels of paternal support (T. Y. Lee et al., 2007), increased education (Holditch-Davis et al., 1999), and less technology dependence (Docherty et al., 2002). Mothers reported more negative perceptions of their infant when they also reported more depressive symptoms (Cho et al., 2008) and the infant was more technology dependent (Docherty et al., 2002). Mothers were more competent when they had less role alteration, were married, had higher education, and had infants who were more alert (Miles et al., 2011). Minority mothers had less involvement with their infant (Holditch-Davis et al., 1999). Neurological status did not influence mother-infant interactions (Holditch-Davis et al., 1999). Mothers who were more present with their MFI were better able to read infant cues (Holditch-Davis et al., 2011).

Cantwell-Bartl and Tibballs (2013) found that 50% of mothers (*n* = 16) and 38% of fathers (*n* =13) experienced difficulties creating a parent-infant relationship while their infant was in an intensive care unit. Gender did not affect mother-infant interactions (Cho et al., 2009). One study measured father-infant interactions and found that paternal attachment was threatened by their fears and anxiety about the infant's outcomes (Clark & Miles, 1999). That is, the physical vulnerability of the infant was related to paternal hesitation in holding their infant and becoming attached, as they feared their infant would die (Clark & Miles, 1999).

MFI had lower functional maturity, slept more, and played less with objects when compared to non-chronically ill premature infants (Holditch-Davis et al., 2003). Older MFI were more alert and vocalized more, which resulted in developmental progression of interactive behaviors between mother and infant (Holditch-Davis et al., 1999). MFI social behaviors increased overtime, and mothers of MFI became more attentive to their infant and were less restrictive over time, especially when the mothers had higher education, were married, and older (Cho et al., 2009). MFI born full term exhibited more social behaviors than preterm MFI at six months corrected age; however, by twelve months there was no difference between groups (Cho et al., 2009).

Maternal role attainment.

In response to their infant's diagnosis, parents of MFI experienced loss of parenting a healthy newborn (Black et al., 2009; Cantwell-Bartl & Tibballs, 2013). Mothers had higher levels of maternal identity when they worried less about their infant (Miles et al., 2011). Medical technology, such as ventilators, decreased maternal ability to establish a physical and emotional relationship with their infant (Black et al., 2009; Docherty et al., 2002), as well as a sense of control and competence (Sikora & Janusz, 2015). As the infant's health improved and behavioral cues were recognized, maternal confidence increased, as did her ability to care for the MFI, which in turn increased role identification as the infant's mother (Black et al., 2009). Protecting the infant was a means for mothers to preserve their maternal role (Black et al., 2009).

Holditch-Davis, Miles, Burchinal, and Goldman (Holditch-Davis et al., 2011) found that maternal role attainment included three components: identity, presence, and competence. When mothers felt more competent and had higher education, they provided better quality care to their infants. Mothers, who had lower competence and infants who were more technology dependent, perceived their infant as more vulnerable, with social cues that were more difficult to interpret. Importantly, maternal role attainment influenced parenting quality more than child illness severity, demonstrating the need for interventions to support development of maternal identity during hospitalization (Holditch-Davis et al., 2011).

Health care professionals.

Mothers felt unprepared to parent and care for their MFI when they first received a diagnosis (Scharer & Brooks, 1994). As the infant became more stable and the mother more comfortable, nurses gradually taught mothers and encouraged them to provide more care (Scharer & Brooks, 1994). Relationships with HCP were helpful, specifically providing information and answering questions, providing practical assistance, and providing emotional support (Kosta et al., 2015). Having a supportive, nice, and helpful approach was appreciated by parents (Kosta et al., 2015). However, parents in Kosta et al.'s (Kosta et al., 2015) study identified challenges with HCP including: (a) unhelpful communication styles, (b) lack of HCP availability, (c) inconsistency, (d) exclusion from decision making, (e) lack of multidisciplinary interactions, (f) unawareness of resources, and (g) lack of emotional support. Scharer and Brooks (1994) found common issues may arise between mothers and nurses, such as differing perspectives, variations in skills, and differing expectations. Poor interpersonal skills, lack of empathy, and insensitive and inadequate communication from HCP increased parental stress during hospitalization (Cantwell-Bartl & Tibballs, 2013). Thus, HCP were a source of support for parents, but also a source of frustration that impeded their ability to manage and cope with their multiple stressors.

Support.

Mothers of MFI received high levels of support from the infants' fathers (Kaul & Lakey, 2003; T. Y. Lee et al., 2006; Sikora & Janusz, 2015), and mothers who were in a marriage relationship reported more satisfaction with support provided by fathers than non-married mothers (T. Y. Lee et al., 2006). Mothers found other women, such as their mothers, sisters, or close friends, were supportive (Black et al., 2009; Kaul & Lakey, 2003). Support provided by female family members included caring for siblings, preparing meals, and caring for the infant so parents could go to work (Black et al., 2009). Mothers who were satisfied in their relationships reported more support in caring for their infants and experienced significantly less emotional distress (Kaul & Lakey, 2003). Social networks were reported as parental sources of support, including friends, extended family, church communities, and other parents at the hospital

(Docherty et al., 2007). Parents reported high levels of satisfaction with support provided by HCP, particularly among nursing staff who provided emotional, informational, and esteem support (Miles et al., 2002; Sikora & Janusz, 2015). Limited research has been conducted on specific types of support, formal or informal, from HCP, family, and friends that aids parents of MFI.

Coping.

Coping was vitally important to manage the stressors of parenting their MFI. Parents in Kosta et al.'s (Kosta et al., 2015) study utilized diverse strategies to deal with their experiences such as cognitive strategies and engaging in hobbies. Fathers tried to maintain a sense of control while feeling a loss of control, and accomplished this by continuing to work (Clark & Miles, 1999). At times, parents suppressed their unpleasant feelings as a means to survive their situation by focusing on the infant's medical course, mastering the medical concepts, understanding of their infant's diagnosis, and joking with HCP and other parents (Sikora & Janusz, 2015). Mothers coped with their situation by venting, found instrumental and emotional supports, and utilized more spiritual and religious support; fathers frequently coped by using alcohol (Doherty et al., 2009). In their grounded theory study, Graungaard, Andersen, and Skov (Graungaard et al., 2011) found that parents coped with parenting their MFI by: (a) emotional bonding, (b) identifying supportive social relations, (c) creating mental respite, (d) meaning making, (e) benefit finding, (f) evaluating existential beliefs, (g) taking action, (h) normalizing, and (i) maintaining hope.

Two interventional studies to enhance parental coping were reported. Hancock et al. (Hancock et al., 2018) found implementation of early palliative care with 38 mothers of MFI significantly reduced maternal anxiety when compared to the control group. Mothers in the intervention group also perceived positive change in communication and family relationships, and improved maternal positive reframing. Mothers (*n* = 30) who received weekly meetings with a psychologist and medical team reported significantly lower rates of anxiety upon discharge from the hospital when compared to mothers who received standard care (Aite et al., 2003). Browne and Talmi (2017) presented the benefits of an Infant Mental Health Specialist working with mothers of MFI. The Infant Mental Health Specialist cultivates nurturing, supportive, and safe relationships with parents and HCP. They work along side staff to identify and address stressors and challenges that parents experience. They found that this role was beneficial in dissipating difficult parent-staff interactions, strengthening parental relationships with staff, supporting and enhancing infant-maternal bonding and interactions, supporting complex family dynamics, improving parental well-being, decreasing parental stress, and improving parental coping.

Discussion/Recommendations

The aim of this scoping review was to locate, synthesize, and summarize evidence from published research articles regarding parental experiences caring for their MFI. Increasingly, infants are surviving with complex health problems, and greater awareness is needed about the implications this has on their parents (Doherty et al., 2009). The findings from this scoping review confirm that parents of MFI experience depression, stress, distress, and PTSD. Therefore, parents of MFI suffer emotionally as they parent their infant. Due to difficulty parenting an infant surrounded by technology, parent-infant interactions were disrupted and mothers experienced difficulty attaining their maternal role. HCP were a source of support that enabled parents to care for their MFI, but interpersonal relationships with HCP were sometimes a source of stress. Parents utilized coping mechanism and supports to help manage their stressors.

One purpose of scoping reviews is to identify gaps in the literature (Arksey & O'Malley, 2005). Of the 34 research studies included in this scoping review, only two included psychological interventional research, and both had positive results from the intervention (Aite et al., 2003; Hancock et al., 2018). Also, 15 of the 34 studies recommended the development of interventions that provide supports, including psychological supports, as a means to help parents cope and manage parenting their medically fragile infant (Bevilacqua et al., 2013; Brosig et al., 2007; Cantwell-Bartl & Tibballs, 2013; Cho et al., 2008; Doherty et al., 2009; Graungaard et al., 2011; Hearps et al., 2014; Holditch-Davis et al., 2001; Holditch-Davis et al., 1999; Hunfeld et al., 1999; Kosta et al., 2015; T. Y. Lee et al., 2006; Miles et al., 2002; Sarajuuri et al., 2012; Solberg et al., 2011a). Specifically, supports that (a) help mothers and fathers work together to support each other (T. Y. Lee et al., 2006), (b) reduce parental stress (Cho et al., 2008; Hearps et al., 2014; Kosta et al., 2015; Miles et al., 1999), (c) help parents achieve their parental identity (Miles et al., 2002; Miles et al., 1999), (d) help parents overcome negative thoughts and normalize their lives (Cho et al., 2008), (e) enhance parents' understanding of their infant's diagnosis (Cantwell-Bartl & Tibballs, 2013; Doherty et al., 2009), (f) promote communication between parents and HCP (Cantwell-Bartl & Tibballs, 2013), (g) ensure family needs are met (Doherty et al., 2009), (h) enhance interactions between parents and infants (Holditch-Davis et al., 2011), and (i) increase parents' resource-creation (Graungaard et al., 2011).

According to Aite et al. (Aite et al., 2003) maternal anxiety levels may be significantly reduced as a result of psychological counseling because this role can provide parents with supportive interventions and increase HCP comprehension regarding the particular responses and adaptations of the family to the current crisis. Based on their interventional study involving palliative care as an intervention for MFI, Hancock et al. (Hancock et al., 2018) recommended a multicentre randomized clinical trial to further evaluate whether the supports provided by palliative care should be integrated into MFI standard care. Therefore, continued research and intervention development that includes psychological supports for MFI and their parents is needed. Such interventions should be available to parents immediately following diagnosis, whether antenatally or postnatally (Bevilacqua et al., 2013; Solberg et al., 2011a).

The infants in this scoping review spent 30 ≥ days in hospital. Therefore, HCP and health care systems are well positioned to contribute to supportive interventions for parents through participation in intervention research and implementation, screening and referral of parents, and educating parents (Cho et al., 2008; Graungaard et al., 2011; T. Y. Lee et al., 2007). Increasing HCP education on the complexity of factors that impact parental ability to cope is necessary to enhance quality of care provided to MFI and their parents (Brosig et al., 2007; Docherty et al., 2007; T. Y. Lee et al., 2007). This education should foster awareness and understanding of parental feelings, emotions, inability to understand medical aspects of their infant, and lack of competence to care for their infant (De Stasio et al., 2018).

Parents should be screened and assessed for stress, anxiety, and depressive symptoms that could negatively impact parent-infant interactions (Hearps et al., 2014; T. Y. Lee et al., 2007; Solberg et al., 2011a). Screening and interventions should be targeted toward parents with lower educational levels (Cho et al., 2009; Docherty et al., 2007; Docherty et al., 2002; Miles et al., 1999) because mothers with less education had (a) significantly higher levels of worry about their infant (Docherty et al., 2002; Miles et al., 2002), (b) increased depressive symptoms (Miles et al., 1999), (c) less competence (Holditch-Davis et al., 2011; Miles et al., 2011), (d) less positive involvement and development stimulation (T. Y. Lee et al., 2007), and (e) lower levels of mastery (Miles et al., 1999). Parents identified as at risk need to be referred for further assessment and interventions.

This scoping review supports that parents of MFI have difficulty attaining their parental role and are at risk for problematic interactions with their infants. The establishment of parent-infant relationships is important among MFI because parenting behaviors have been found to predict cognitive and language outcomes of children with disabilities (Innocenti, Roggman, & Cook, 2013). Therefore, HCP education should enhance HCP understanding on the important impact parent-infant interactions has on the development of the MFI, and provide HCP with strategies to help improve such interactions (Kelly et al., 2016).

Relationships with HCP were a source of stress for parents. Therefore, further research is required to determine strategies and tools to improve HCP interpersonal skills to enhance parent-HCP relationships and interactions. Research should specifically focus on communication, continuity of care, partnership, and collaboration.

As presented, limited research has been conducted that investigates interventions aimed at improving parent's ability to cope with parenting MFI. Interventional research should include: (a) screening parental mental health, (c) psychology supports, (d) HCP education on how to support parents, (d) strategies to enhance parent-infant interaction, and (d) improved relational competencies among HCP.

Limited literature exists on the effects parent-infant interactions has on infant's later development. Therefore, further research is needed to determine the effects infant's medical fragility has on later caregiving, the social environment, and parent-infant interactions (Brosig et al., 2007; Holditch-Davis et al., 2003; Holditch-Davis et al., 1999; Solberg et al., 2011b). Surveillance programs with parents of MFI could provide valuable information about longer term parental emotional health and its effect on infant development (Bevilacqua et al., 2013) and parent-infant interactions (Holditch-Davis et al., 2003; Solberg et al., 2011b).

Strengths and limitations.

A strength of this scoping review was that the identified themes were well supported by evidence. Furthermore, the identified a gap in the literature regarding the lack of parental supports and interventional research to understand how to best enhance supportive care for parents caring for MFI in the hospital setting was prevalent across the reviewed literature. This review was limited by the authors' interpretations of study findings during thematic analysis. Articles in this review were not appraised for scientific rigor, which is recommended because scoping reviews aim to examine the extent, nature, and range of research activity (Arksey & O'Malley, 2005).

Conclusion

This scoping review offers in-depth insight into parental experiences caring for MFI. The results demonstrate that parents of MFI must cope with multiple stressors while attaining their role as a parent. Parents experience an increase in depressive symptoms and levels of depression, as well as increased levels of stress, distress, anxiety, worry, acute distress disorder, and PTSD. As a result, parents experience parental role alteration, disrupted parent-infant interactions, and specifically mothers encounter difficulty with maternal role attainment. Limited interventional research has been conducted and implemented among this population, however, the two interventional studies that implemented emotional supportive interventions for parents proved to be effective (Aite et al., 2003; Hancock et al., 2018). Thus, further development of interventional strategies is needed, along with implementation research to determine the effectiveness of such interventions. Also, screening tools and strategies are needed to identify parents who are at greater risk of mental health disparities that could possibly affect their ability to be present and create nurturing relationships with their infants. Such screening is needed immediately upon receiving the infant's diagnosis and throughout the infant's medical journey.

Our findings highlight the need for continued research regarding (a) screening and identifying parents at risk for mental health disparities and difficulty coping with their multiple stressors, (b) intervention development and adaptation, and (c) outcome research of implemented interventional research. It is imperative that parents of MFI receive easy access to comprehensive supports and services throughout their infant's medical trajectory.

Chapter 3: Three Grounded Theory Methodologies: Considering Theorizing Within the Traditions

Authors:
Lyndsay Jerusha MacKay
Dr. Karen Benzies
Dr. Shelley Raffin

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This manuscript provides an in depth understanding on the philosophical underpinnings of three predominant approaches to grounded theory, and how each grounded theorist directs data analysis and defines theory. I used Charmaz' approach to grounded theory to understand the processes of care for parents and HCP caring for MFI on an inpatient pediatric unit. This manuscript provides an understanding of Charmaz' approach to grounded theory and how it was influenced by previous grounded theorist and the philosophies of Pragmatism, Symbolic Interactions, and Social Constructivism. This manuscript was submitted to the Journal of International Qualitative Methods, however, it was rejected. Reviewers stated it did not add new material to existing grounded theory literature, requires improvement in structure, and lacks synthesis on foundational concepts. This manuscript is currently being revised to focus primarily on how the three predominant grounded theorist approach theorizing within their method. Synthesis of data analysis techniques and theory formation unique to each predominant grounded theory approach will be presented. The portion on philosophical underpinnings will be removed to improve structure and clarity. It will be re-submitted to journal Qualitative Health Research summer 2019.

Three Grounded Theory Methodologies: Considering Theorizing Within the Traditions

Every human being has a philosophy. This is the most interesting and important aspect of humans because it determines the perspectives from which they view the universe (James, 1907, 1981). According to William James, a founding philosopher of pragmatism, philosophy "can inspire our souls with courage" (James, 1981, p. 8). That is what the philosophical traditions of pragmatism and the theory of symbolic interactionism (SI) have done in our universe, they have inspired the souls of great sociologists to courageously create and shape Grounded Theory (GT), a method of constructing social scientific theory (Charmaz, 2011; Corbin & Strauss, 2015). This occurred amid an empirically driven society, when Glaser and Strauss (1967) introduced and pursued the idea that theory can be grounded in data from real life experiences, not based on mere notions and speculations. Charmaz, a contemporary expert in GT, took another great leap in shaping and influencing GT through the use of a third philosophical perspective, that of constructivism (Charmaz, 2006).

Grounded theorists echo disagreements about the definition of theory, without recognizing their different epistemological underpinnings (Charmaz, 2014a). If they looked beneath the surface, they would discern that their differences are based on whether their definitions assume an empirical positivist position or an interpretative stance derived from the philosophical and theoretical traditions of pragmatism, SI, and constructivism (Charmaz, 2014a). Thus, in this paper the philosophical and theoretical perspectives of pragmatism, SI, and constructivism will be described, and how they relate to one another will be intertwined throughout the discussion. The limitations of each perspective will be presented, their ontological and epistemological standpoints will be identified, and how they define theory will be discussed. To further the understanding of theory within the GT method, how grounded theorists, including Glaser, Strauss, Corbin, and Charmaz define theory based on the philosophical perspectives of pragmatism, SI, and constructivism will be explored.

Pragmatism

Pragmatism evolved during a time when positivist thought and empirical research dominated the understanding of reality and its application in research (James, 1907, 1981) Within positivism, an apprehendable reality exists and is driven by immutable natural laws; knowledge is viewed as way things are, free of context (Guba & Lincoln, 2004). Pragmatism challenged the dominant empirical positivist thought and way of understanding reality during the late eighteenth and early nineteenth century. According to Stikkers (2009), William James' take on pragmatism had the greatest role in the development of sociology's school of knowledge. However, throughout James' career and writings, he always gave Charles Peirce the credit as being the fore-father of pragmatism. According to James (1907, 1981), Charles Peirce first introduced the idea of pragmatism to philosophy in 1878, when he wrote an article entitled, *How to Make Our Ideas Clear*. In this article, Pierce pointed out that beliefs are just rules for action: to develop an idea one considers the desired consequences that would result from an action (Pierce, 1878). James addressed Pierce's idea of pragmatism before a philosophy union at the University of California 20 years after the formation of Pierce's pragmatic notion, and from there it flourished (James, 1907, 1981). However, Pierce did not accept James' position on pragmatism, because he resented the psychology-focused liberties James utilized with his empiric-focused principles (Crotty, 2003; McCready, 2010). Thus, Pierce worked diligently and wrote much material attempting to present how his take on pragmatism was different than that of James; Pierce termed his philosophy pragmaticism (Crotty, 2003; Whitehead, 2015).

To James, the pragmatic 'method' was primarily a method used to settle "metaphysical disputes that otherwise might be interminable" (James, 1981, p. 25); disputes that involved the nature of reality, such as material or spiritual, fated or free. Usually such arguments had no end point. Therefore, James encouraged the interpretation of each argument to determine the respective practical consequence: if there was no practical difference between either answer being correct, then both answers mean the same thing and all arguments are pointless (James, 1907, 1981). For an argument to be of a more serious nature, then the supporting notions must have practical implications and make a difference in the present world (James, 1907, 1981).

To James, reality does not just call upon individuals to agree with it for no reason; it bothered him to simply claim that reality is unconditional or transcendent (James, 1907, 1981). He discredited the intellectualist's notion that one truth could be discovered, which encompassed the fullness of all knowledge (James, 1907, 1981). Facts and principles were good, but James urged his readers to avoid looking at the world one way. In the world, James saw multiple truths and realities existing at the same time. What made a truth true was its ability to help people deal, either practically or intellectually, with reality. If it did not entangle progress with frustrations, if it fit, then truth becomes a collective name for a verification process (James, 1907, 1981). Truth is made true by its ability to work and make life work for the better (James, 1907, 1981). "Truth happens to an idea," it becomes true and is made true by events (James, 1981, p. 92). Thus, experience makes an idea true (Skilbeck, 1970).

In his lecture entitled *Lecture I,* James identified that the philosophy based on absolute truth by the empiricists is simple, clean, and noble (James, 1907, 1981). However, empiricist's notion of truth was contradictory to the muddy, tangled, painful, and perplexed experiences of everyday life (James, 1907, 1981). The current way of understanding the world did not explain the reality of it; there was a gap between theory and reality. James sought to close that gap by espousing that truths are multiple, and our understanding of them must spring from real life experiences and have practical value.

John Dewey was influenced by James' pragmatic reinterpretation of traditional empiricism, known as 'radical empiricism' (Skilbeck, 1970). Radical empiricism argues that a useful concept must be grounded in human experience, and that truth is found through the fruitful consequences of action (Skilbeck, 1970). To Dewey, all experience is interactive between self and some aspect of the environment, and purposeful and intelligent action is how such interactions are rendered significant (Dewey, 1917, 1970). Dewey added the notion that humans can use their minds (or intellect) to create meaning through interactions, and that such meaning produces subsequent actions.

Pragmatism was a change in psychology; it exploded the philosophy of the eighteenth and nineteenth century (Dewey, 1884, 1972). Such philosophy viewed mental life as originating in sensations, which passively received knowledge by laws of retention and association, to create images, perceptions, and conceptions in the mind. Thus, the senses were regarded as the gateway to knowledge and the mind was passive in knowing (Dewey, 1910, 1972). John Dewey was greatly influenced by Darwinism, which emphasizes that human intelligence has an instrumentality of control (Dewey, 1910, 1970). Darwinism contends that humans have evolved a capacity to control the environment and exercise their intelligence with humanity, compassion, and well-being to solve social problems (Skilbeck, 1970). This understanding of science by Darwin opened up the once closed universe to one with infinite space and time, having no limits (Dewey, 1910, 1970). Humans are able to actively engage in experiences with other humans, rather than being passive agents that are enacted upon and stimulated by the environment through their senses (Dewey, 1917, 1972). The Darwinian principle of natural selection undercut the historical philosophy that espoused the need for a prior casual force to preordain humans. If organic adaptions are due to constant variation and elimination of variations that are harmful, knowledge formation can be a process in which humans attribute meaning to what they do; they keep and build upon ideas that work and disregard those that do not work (Dewey, 1910, 1970). People create beliefs and ideas (knowledge) through their interactions and experiences with each other and the environment (Dewey, 1917, 1970, 1972). That, according to pragmatism, is what forms the mind. Dewey's idea of experience is an important precursor to the constructivist notion of viability, meaning that which is theoretically devised must fit the actual world of experience that individuals act upon (Reich, 2009).

Pragmatism's ontological and epistemological standpoints.

Ontologically speaking, pragmatism does not espouse one truth, but attests that multiple ideas and truths exist among society and make up reality. Reality is fluid and open to multiple interpretations (Charmaz, 2014a). What makes an idea true is the consequence of the idea, the idea becomes true if it proves useful and beneficial (James, 1907, 1981). Thus, meanings emerge through actions that produce fruitful outcomes, actions that solve problems (Charmaz, 2014a). Epistemologically speaking, James and Dewey indicated that to understand the multiple truths that make up reality, one needs to gain insight and understanding into the meanings applied to advantageous actions.

Pragmatism's definition of theory.

Pragmatism evolved from the notion that there is a split between theory and practice, which then causes a dualism between knowledge and action (Reich, 2009). Pragmatism espouses that theory must be closely tied to the reality of human life, to the stream of pure experience, otherwise such ideas would have no function (Lewis & Smith, 1980). All concepts within a theory must be fragments of pure experience, and understanding such experience is accomplished through relations to other individuals' experiences (Lewis & Smith, 1980). Pragmatically speaking, theory is a description of individuals' experiences and an explanation of why they carry out certain actions, which is based upon the meaning and consequences linked to such actions. Thus, theory provides a detailed account of the processes by which individuals make meaning out of their environment, interact with their environment and with others, and how meanings and interactions instigate them to act in ways that produce fruitful and positive outcomes.

Limitations and criticisms.

McCready (2010) noted that a limitation among the pragmatist school of thought is that there is significant diversity among pragmatists in their beliefs, as seen with the division between James and Pierce. Thus, it can be difficult to speak of pragmatism in singular terms and base coherent arguments on an incommensurable school of thought (Crotty, 2003; McCready, 2010). Also, pragmatism is criticized for taking a too relaxed notion of truth, as James himself noted that it was difficult for people to accept a relaxed approach to truth (James, 1907, 1981).

Symbolic Interactionism

Pragmatism is known to have laid the philosophical backdrop of SI, as it was pragmatism that informed much of George Herbert Mead's social psychology, whose ideas created the foundation of SI (Charmaz, 2014a; Charon, 1979; Crotty, 2003; Morris, 1962). Mead taught at the University of Chicago for almost 40 years, where Herbert Blumer was his student (Crotty, 2003; Morris, 1962). Mead wrote very little about his work and ideas on SI. It was Blumer who compiled most of Mead's papers and lecture notes into a posthumous work entitled, *Mind, Self* *and Society*. Thus, Blumer has received most of the credit for the impact Mead's ideas have had on the sociological realm of thought (Charon, 1979; Crotty, 2003; Meltzer, 1972). Blumer (1969) stated Mead, Dewey, and James were a few of the scholars who contributed to the intellectual foundation of SI. However, he noted that he relied chiefly on Mead, who above all else laid the foundation of SI (Blumer, 1969). SI is a theoretical perspective with the assumption that society, self, and reality are constructed by means of interaction, and thus relies on language and communication (Charmaz, 2014a).

Diverse patterns of group life were a clear indication to Mead that cooperative life is not brought about by physiological factors and cannot be explained by the same means as that of lower animals (Meltzer, 1972). Mead rejected the notion that humans have individualistic psychologies, in which social process is the product of the mind. Rather, he viewed the mind as a product of social process, and believed it was developed through communication with the self and with others (Meltzer, 1972). The work of Mead can be viewed as a reaction to the state of science that endorsed human behavior could be measured, and that alone was considered enough to understand individuals and explain human behavior (Charon, 1979).

Mead (1962) believed that social process, or patterns of group life, stemmed from within the person as well as outside the person. He was curious about the science that made use of introspection, observing what is within the experience of the individual, phenomena that only the individual himself has experiential access to. Mead believed that social cooperation is accomplished by some process wherein each individual ascertains the intention of others' actions and is able to act in response on the foundation of that same intention (Mead, 1962; Meltzer, 1972).

Symbols are found within the social process and can alter the response of another. Significant symbols enable individuals to respond in the same way and share one another's experiences, because the symbol holds meaning for individuals (Mead, 1962; Meltzer, 1972). A symbol can be a bodily gesture or a vocal gesture such as communication. To Mead, the symbol is a product of the human's disposition to act rather than an antecedent stimulus that induces an act (Blumer, 1962). Thus, cooperative social life consists of individuals acting and reacting within human interactions, influenced by the meaning of symbols used within the interactions. The meaning of a symbol is established by the reaction of others towards the symbol during interaction, which individuals formulate by way of introspection.

According to Blumer (1969), SI refers to the distinctive and peculiar character of interactions among humans; peculiar in the fact that humans define or interpret one another's reactions rather than merely react to them. The response to an action is based on the meaning attached to the action, not directly to the action itself (Blumer, 1962). This challenged the dominant sociological thought of Blumer's time, where it was believed that humans were organisms that responded to the forces placed upon them: they were not individuals that had a self (Blumer, 1962). To Blumer (1969), human interaction is mediated through the use of symbols, by interpretation of others' actions and symbols, and by giving meaning to the actions of others.

Blumer (1969) stated that SI rests on three simple premises. The first premise states that humans act towards things based on the meaning that such things have for them. Blumer noted that 'things' entail physical objects (chairs or trees), other humans, ideals (independence or honesty), institutions (school or government), and activities of others (requests or commands). The second premise states that humans derive meaning of such things from the social interaction that one has with others. The third premise states that the meaning of things is handled and modified through the human interpretive process, where they understand and deal with things they encounter.

Blumer (1969) postulated that meaning occurs through a process of interpretation in two steps: (a) the actor interacts with himself through communication and points out a thing towards which he is going to act, and (b) by the process of communicating with himself, interpretation becomes a way in which he handles meaning. When communicating with oneself, the individual views himself as a social object, one that he shares with others during interactions. The individual can act towards himself in the same manner he would act towards another object (Charon, 1979). This view of the self enables individuals to identify things to themselves, interpret situations, and communicate with themselves (Charon, 1979). Individuals then become viewed as reflective, active, creative, and social creatures; hence, they are able to consciously think (Charmaz, 2014a). This is the same underlying belief of Dewey, that humans can actively engage in experiences, and are not passive agents that are enacted upon or stimulated by the environment. SI assumes that society precedes the self, and that language and culture shape the self, although, actions might alter language and culture (Charmaz, 2014a).

SI’s ontological and epistemological standpoints.

Both pragmatism and SI resist the positivist notion that one reality exists that ought to be grasped, attained, and understood. Ontology within the SI tradition views the nature of reality as social, humans see the world through perspectives developed by social interactions with others; thus, there are multiple and diverse realities (Charon, 1979). SI operates from an assumption that an objective, physical reality exists independent of the social definitions, that the social definitions respond to something real or physical (Charon, 1979; Lewis & Smith, 1980).

However, this reality is not directly responded to, the majority of human actions are a social definition of that reality (Charon, 1979). Thus, a Truth at Large does not exist, but is a hypothetical construction with the world (Lewis & Smith, 1980). Epistemologically, to understand reality, one needs to gain insight into the perspectives developed during social interaction and understand the meaning attributed to symbols that guide social action and interaction. This is like constructivism, in that to understand reality one must gain insight into the meanings' individuals hold that determine their actions and construct their reality.

SI's definition of theory.

Within SI, meaning is the core element of a phenomenon. There is freedom of choice within human behavior, and such choices are defined by society, personal interpretation, and cultural norms (Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2015). Thus, theory aims to get at the core element - understanding how society, personal interpretations, and cultural norms inform action by formulating meaning for individuals - by understanding the process by which individuals attribute meaning to symbols, and how such meaning informs their actions. SI encourages the researcher to study and create theory that understands how individuals interpret objects and other individuals, and how such processes of interpretation initiate behavior in specific situations (Benzies & Allen, 2001). This is like pragmatism's definition of theory, in that theory is based on an explanation of individuals' actions, getting to the core of that which causes individuals to act in certain ways.

Limitations and criticisms.

An important criticism of SI is that it de-emphasizes structure, which in turn can give a false impression that the human world is always changing (Charon, 1979). Barbalet (2009) noted that SI is frequently criticized for neglecting emotion and is overtly cognitive, the self acts exclusively through the cognitive process. Also, conservative non-reflexive consequences produced during interpretations are drawn upon for the construction of action. Within SI, creativity is left behind in preference for choosing actions with a conservative outcome. However, James' pragmatism can be used to cut through this criticism of a purely cognitive understanding of action, as he attests that action is carried out by creative agents who recognize a possible generative future that is transformative (Barbalet, 2009; Weinberg, 2009).

Constructivism

The basic premise of constructivism is that lived reality is constructed by social actors: it seeks to understand the complex world of lived experience through the point of view of the individuals who live in it (Holstein & Gubrium, 2011; Schwandt, 1994). The mind is not passive, it does not find or discover knowledge. Rather, the mind constructs knowledge, it invents concepts, schemes, and models to make sense of experience (Holstein & Gubrium, 2011; Schwandt, 1994). Knowledge is actively constructed through forms of social action, where individuals continually test and modify such constructions (Holstein & Gubrium, 2011).

Constructivism has drawn a great deal from the tradition of pragmatism, inaugurated by philosophers such as, Pierce, James, Dewey, and Mead (Holstein & Gubrium, 2011; Weinberg, 2009). Constructivism is built on the pragmatist tenets, which emphasize creative agency over structurally determined explanations of social events, and that human experience is mediated by socially inherited meanings that actors infer upon it (Weinberg, 2009). Reich (2009) identified the following similarities between pragmatism and constructivism: both traditions reject the absolutist claims to knowledge and lean towards the idea that individuals construct their realities, and both view culture as a powerful instrument, in that even scientific knowledge and thought are viewed as being culturally constructed and situated. Constructivism and pragmatism do not plead for constructions for the mere sake of constructions, but for the sake of solutions to individuals' problems, with the anticipation of growth and advancement. Both pragmatism and constructivism espouse that only through exploring the environment and communicating their findings do individuals generate the values they share and experience the desirable growth they strive for. Weinberg (2009) pointed out that constructivism built upon SI tenets presented by Blumer in that reality is mediated by socially constructed symbols. Building on a pragmatic and symbolic interactionist foundation, philosophers such as Marx, Mannheim, Berger, Luckman, and Fleck have created what is known today as constructivism.

Karl Marx had the greatest impact on constructivism through his writings on ideology, developing this concept to suggest that individuals can suffer from a false consciousness that leaves them reinforcing their own oppression (Weinberg, 2009). Marx's ideology indicated that individuals' socially constructed beliefs and ideas can determine how they view reality (Mannheim, 1971). Mannheim transformed Marx's critical concept of ideology into a general concept of knowledge, by espousing that all knowledge is socially embedded and constructed (Berger & Luckmann, 1971; Mannheim, 1971; Weinberg, 2009). By expanding the theory of ideology, Mannheim set the foundation for all knowledge of sociology, understanding that no human thought is immune to the influences of its social context (Berger & Luckmann, 1971). To Mannheim (1971), embodied truths do not exist, rather, individuals confront 'reality' with ready-made questions and systems.

In 1929, Mannheim wrote the ground-breaking volume, *Ideology and Utopia* (Gergen, 2009). In it he proposes four tenets: (a) scientific theories spring from the scientist's social groups, not from observation, (b) scientific groups are organized around particular theories, (c) theoretical disagreements are thus issues of group conflict, and (d) what is assumed to be scientific knowledge is actually a by-product of social process (Gergen, 2009; Mannheim, 1936). Thus, Mannheim was paramount in postulating the idea that scientific facts were not facts at all, but social constructions based on the predominant theory of the time. Life, as it is known, is socially constructed within the individual, not floating facts and truths that one tries to grasp and possess.

Berger and Luckman are associated with the burst in popularity of constructivism by way of their 1966 publication, *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* (Holstein & Gubrium, 2011). Berger and Luckman (1971), like Mannheim, also built upon Marx's ideas, specifically his twin concept of 'substructure/superstructure,' which was under raging controversy. Berger and Luckman understood it to mean that human thought was founded in human activity and in the social relations that brought about such activity.

Berger and Luckmann (1971) viewed everyday life as a reality that is interpreted by individuals. Such a reality originates in the individual's thoughts and actions, and is maintained as real by such: reality is shared with others, and is as real to others as it is to the individual (Berger & Luckmann, 1971). An individual's reality cannot exist without continually communicating and interacting with others (Berger & Luckmann, 1971). Every individual has perspectives that differ, and there is an ongoing correspondence between one another's meanings. Therefore, social reality is shaped by such ongoing correspondence (Berger & Luckmann, 1971).

Ontological and epistemological standpoints.

Ontologically, constructivism views reality as multiple, intangible mental constructions that are socially and experientially based (Guba & Lincoln, 2004). Reality is pluralistic and plastic in nature: pluralistic in that it is expressed in a variety of language and symbol systems, and plastic in that it is shaped and stretched to fit purposeful acts by intentional human agents (Schwandt, 1994). Epistemologically, in order to understand reality within the constructivist perspective, one must interpret individuals' multiple meanings and constructions (Charmaz, 2014a; Schwandt, 1994). The inquirer explains the process of meaning that individuals construct, and clarifies how such meanings and constructions are embodied in action and language (Schwandt, 1994).

Limitations, criticisms and strengths.

Constructivism is a term like no other in social theory, because it ignites controversy and yields great criticisms (Weinberg, 2009). Some criticisms have come from outside the social sciences, and much comes from the social scientists themselves (Weinberg, 2009). According to Weinberg (2009), authors of constructivism often neglect epistemological questions, and contribute little to the understanding of knowledge itself. Also, constructivism has been criticized for lacking criteria that warrant subjectively mediated accounts of meaning: without a set of criteria how is one to know if accounts are good or bad, true or false, worthy or unworthy (Schwandt, 1994).

Constructivism has been criticized as being a highly interpreted science, with the power of the interpretation lying in the hands of the one defining the interpretations (Schwandt, 1994). As it is often questioned: if knowledge resides within the mind of the individual and not in the natural world, how can such knowledge be fully and truly shared with the outside world (Schwandt, 1994)? The greatest criticism of constructivism is the fact that it has currently become so popular that it can fit virtually every research approach imaginable: in this sense, constructivism has no credibility (Holstein & Gubrium, 2011).

Reich (2009) stated that a strength of constructivism is that it provides a generous and broad access to the history of thought. It does not exclude certain approaches due to discursive reservations, nor does it prejudice against claims that do not fit its agenda. Rather it tries to understand why certain discourses and constructions have been developed in the history of culture, and identify what leads to their successes and failures. Constructivism has an attitude of tolerance and open-mindedness that seeks understanding rather than judgement (Reich, 2009).

Table 3

Comparison of Pragmatism, Symbolic Interactionism, and Constructivism

	Ontology	Epistemology	Theory
Pragmatism	Multiple truths and ideas exist among society to make up reality. What makes an idea true is if it is useful and beneficial.	To understand multiple truths that make up reality one needs to gain insight and understanding into the meanings that make it useful and beneficial.	Theory must be closely tied to the reality of human experience. Theory is a description of individuals' experiences and an explanation of why they carry out certain actions.
Symbolic Interactionism	Multiple and diverse truths and realities exist that are formed through social interactions among individuals.	To understand reality, one needs to gain insight into the perspectives developed during social interactions and understand the meaning attributed to truths that guide social action.	Theory aims to get to the core of social interaction, understanding how society, personal interpretations, and cultural norms inform actions by formulating meaning for individuals.
Constructivism	Reality is multiple, intangible mental constructions that are socially and experimentally based.	To understand reality, one must interpret individuals' multiple meanings and constructions; explain the process of meaning that individuals construct, and clarify how such meanings and constructions are embodied in action and language.	Theory interprets and conceptualizes the actions and processes of individuals to reveal their implications, it aims at answering the *why* question.

How Pragmatism, SI, and Constructivism have shaped GT

GT is a systematic approach to generating theory that highlights and gains understanding into human behavior and social processes among actors (Aldiabat & Le Navenec, 2011). Disagreements exist among grounded theorists on how to use the GT method and what the completed theory should entail (Charmaz, 2014a). This is mostly likely because GT has evolved since its original conception in 1967, and has been shaped by four distinct social theorists that produced varying styles. The original founders of GT were Barney G. Glaser and Anselm L. Strauss with the writing of their book, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser & Strauss, 1967). Strauss took GT in an interpretive direction with the publication of his book entitled *Qualitative Analysis for Social Scientists* (Strauss, 1987), and later paired with Juliet Corbin in the writing of their book *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (Strauss & Corbin, 1990). Kathy Charmaz took GT in the direction of constructivism in the writing of her book entitled *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (Charmaz, 2006).

The purpose of Glaser and Strauss' (1967) original book was to present a new idea of how theory could be generated and discovered from data that is systematically obtained while conducting social research (Glaser & Strauss, 1967). Glaser and Strauss saw theory as useful if it was grounded in data, and if it could 'fit' and be applicable to the situation at hand. Theory had to be meaningful, relevant, and able to explain and predict the human behavior under study (Glaser & Strauss, 1967). Glaser and Strauss indicated that theory must be brought into relation with data or there was a danger that the theory and empirical world might mismatch. Thus, Glaser and Strauss' original definition of theory had positivist underpinnings. Positivism attests that an apprehendable reality exists, the empirical world, that is sustained by immutable natural laws (Guba & Lincoln, 2004).

According to Glaser and Strauss (1967), theory was a codified set of propositions or a running theoretical discussion that used conceptual categories and their subsequent properties to define and explain the empirical world. The form that theory took did not make it a theory, it was its ability to explain and predict human action. Theory was a momentary product, with assumptions that were still developing, of the reality of social interaction and its structural content (Glaser & Strauss, 1967). Glaser and Strauss' (1967) formulation of theory encompassed conceptual categories and hypotheses that evolved from data, and general relations among each category and their properties. Theory was best when it emerged from the data and was not forced: it was a snapshot of a unified preexisting reality, of the social structure that produced social interaction (Glaser & Strauss, 1967). Such social structure could be used to understand and predict human behavior and interactions.

Glaser (1992) went on to write his own book entitled, *Emergence vs. Forcing: Basics of Grounded Theory Analysis*, sticking extremely close to his and Strauss' first conception of theory in 1967. He contested that theory is generated through the systematic collection and analysis of data to reveal concepts of reality within a substantive area. He emphasized the importance of letting concepts emerge from data, rather than forcing them through the researcher's interpretations. He insisted that one enters the research field with no preconceived notions or previously read literature, as this 'excess baggage' can be forced upon the data rather than allowing for true and natural emergence (Glaser, 2016a). Glaser rejected that any underlying philosophy shapes his GT method or resulting theories (Charmaz, 2017; Glaser, 2005).

Therefore, Glaser's definition of theory remains founded in positivism, seeking to understand and predict human behavior and action.

Strauss (1987) veered from his original work on GT with Glaser, and took a much looser approach. He did not identify GT as a method or technique, but rather a style of doing qualitative research that utilized distinctive features. He recognized pragmatic philosophers, including Dewey, Mead, and Peirce, as contributing streams of work and thought to the development of his GT (Strauss, 1987). Together, Strauss and Corbin (1990) emphasized action and the necessity of using a GT method that focuses on problem solving from the perspective of participants' multiple realities. They defined theory as being inductively derived from the study of phenomena; discovered, developed, and verified through systematic data collection and analysis (Strauss & Corbin, 1990). To Strauss and Corbin (1990) theory is more than a description of an event or phenomenon, it is an interpretation of the actions that take place among individuals. Strauss and Corbin placed an interpretative spin on the original GT method, leaning into the influences of pragmatism and SI.

Strauss and Corbin (1990) focus on understanding relationships between concepts, thus placing interpretations on the data (concepts being similar data that are grouped and given conceptual labels). In contrast, Glaser (1992) emphasizes a concept's ability to predict and explain other concepts within the theory, and that concepts strictly emerge from data. Corbin and Strauss (2015) do not believe that there is one reality waiting to be discovered; however, they do believe that real external events occur in the world. Their theory is built upon the meaning that individuals give to the events, meaning that produces subsequent actions by individuals. Such meaning that is attributed to events is based on the biography of individuals, such as gender, time, and place, and their political, cultural, professional, and religious backgrounds (Corbin & Strauss, 2015). Corbin and Strauss (2015) stated in their most recent book that they agree with the constructivist viewpoint that theories are constructed by the researcher, out of stories that research participants construct as they try to explain and make sense of their lives and experiences.

Strauss and Corbin (1990) allow for the use of previously viewed literature and personal and professional experience as a source of theoretical sensitivity. To Strauss and Corbin this sensitivity is an attribute of having insight, a capacity to understand, an ability to give meaning to the data, and the capability to separate pertinent from that which is not (Strauss & Corbin, 1990). Glaser, however, encourages researchers to enter the field with no preconceived notions, no literature review, or even experience in the field (Glaser, 1978; Glaser & Strauss, 1967). This demonstrates Strauss and Corbin's more interpretative approach to theory formulation, using past experiences to help shape the theory. This is associated with SI, as Blumer (1969) emphasized that individuals use meanings that have been created by past experiences to act towards situations and events. Strauss and Corbin's GT method generates theory by utilizing past experiences, which help understand and interpret the phenomenon at hand.

Strauss and Corbin (1990) viewed process as central to the formation of a theory, in that process gives life to data by looking at action and interaction: examining action helps explain why individuals encounter problems and failure, experience growth and development, and occasionally encounter stagnation in social life. Strauss and Corbin (1990) introduced the Conditional Matrix in their data analysis process because they viewed theory as a transactional system. The Conditional Matrix is used in data analysis to help examine the interactive nature of events, interactions, and actions, thereby formulating a theory that depicts and provides understanding into the processes of the phenomenon under study. To Strauss and Corbin, phenomenon causes and leads to other phenomenon, action and interaction are processual in nature (Strauss & Corbin, 1990). Theory captures the essence of action inherent in process.

Strauss and Corbin's definition of theory is aligned with Dewey's philosophy of pragmatism, as Dewey contended that people create beliefs and ideas through interactions and experiences with each other and the environment, and that such beliefs and ideas are what shape subsequent social action and interaction (Dewey, 1917, 1970). To Mead (1962), social process and cooperative group behavior is founded within the individual, where the individual ascertains the intentions of others' actions and acts in response. Thus, social life is interactional and processual in nature (Mead, 1962). As demonstrated, Strauss and Corbin's definition of theory is laid in the philosophical foundations of pragmatism and SI.

Charmaz has built on Glaser and Strauss' (1967) original inductive, comparative, and emergent method, utilized Strauss and Corbin's interpretive approach to data analysis, and embraced pragmatism's emphasis on action and meaning (Charmaz, 2014a). To Charmaz (2014a), theories attempt to answer questions and offer accounts for what happened; they aim at how it occurred and *why* it happened. Constructivist theory "emphasizes interpretation and gives abstract understanding greater priority than explanation" (Charmaz, 2014a, p. 230). Theoretical insight is gained through understanding meaning and actions, and how people come to construct them. Constructivist GT seeks to understand meanings individuals hold and why those meanings direct their subsequent actions inherent in social process. Therefore, Charmaz's constructivist definition of theory is very similar to Strauss and Corbin's (2015) definition.

Charmaz (2017) stated that her constructivist version of GT places a contemporary spin on Glaser and Strauss's (1967) original approach; it involves epistemology shifts and methodological innovations that enhance GT. Charmaz's constructivist definition of theory includes multiple realities, social life as existing within a continuous and ever changing process, and truth as temporary (Charmaz, 2014a). Constructivist GT has a strong foundation in the philosophy of pragmatism, which informs SI, because it is pragmatism that helps make social actions and processes visible that would normally remain unseen (Charmaz, 2014a). According to Charmaz (2014a), Mead's sophisticated take of action is the starting place for analysis, which implies that researchers create an imagined understanding of their participants role and responses that occur during social interaction. Thus, theory produced by constructivist GT conceptualizes the actions and processes of individuals to reveal their implications, it aims at answering the *why* question.

"Theory depends on the researcher's views; it does not and cannot stand outside of it" (Charmaz, 2014a, p. 239). Charmaz encourages researchers to actively interact with data, using their world-view, standpoint, and situation to make sense of and appraise situations; to draw on language and culture to create meaning and frame actions (Charmaz, 2014a). Charmaz (2009) specifies the importance of turning back to examine ourselves, our research situations, and the research process and product. This is because Charmaz aims at identifying the process in which the researcher and participants construct meaning, and how that meaning is embodied in action: this is directly influenced by constructivism (Schwandt, 1994). Data and the process of analysis is "created from shared experiences and relationships with participants" (Charmaz, 2014a, p. 239). Theory emerges during the interaction between researcher and participants, it is an interpretation and description of what the researcher experiences and identifies while collecting and analyzing data. This aligns Berger and Luckman (1971) take on constructivism, where human thought is initiated within human activity and social interactions; it is within individuals' thoughts and actions that reality exists and is constructed. Thus, to grasp and understand the participant's constructed reality, the researcher must actively engage and interact with the participant.

As discussed above, Strauss and Corbin's (2015) newest version of grounded theory takes a much more co-constructivist position to data analysis, utilizing an interpretive approach. However, slight differences exist in the data analysis process between Strauss and Corbin's method and Charmaz's approach. Strauss and Corbin (2015) continue to utilize the Conditional Matrix, which could be viewed as forcing data into the Matrix in order to analyze the components of the developing theory. Strauss and Corbin are more intentional about how theory is built. Charmaz's (2014a) method is more interpretive in nature, as she contends data are constructed and not discovered; data analyses are interpretive renderings and not objective reports or one view point (Charmaz, 2009). Charmaz's interpretive theorizing entails practically engaging with the world and constructing an abstract understanding about and within it (Charmaz, 2014a). To Charmaz, GT is a "guiding interpretive theoretical practice," it does not provide "a blueprint for theoretical products" (Charmaz, 2014a, p. 233). Importantly, constructivist GT encompasses strategies that are substantially flexible, open guidelines, and can be adapted to fit emergent studies, rather than rigid prescriptions for data to describe phenomenon: it allows the exploration of what the researcher finds along the way (Charmaz, 2000, 2006, 2008b, 2017).

Table 4

Comparison of the Three Main GT Methods

	Philosophical Underpinnings	Approach to Data Analysis	Definition of Theory
Glaser	• Positivism	Concepts of the theory emerge directly from the data with no influence from the researcher (Glaser, 2016b).	A codified set of propositions or a running theoretical discussion that used conceptual categories and their subsequent properties to define and explain the empirical world (Glaser & Strauss, 1967).
Strauss and Corbin	• Pragmatism • Symbolic Interactionism	Interpretive, looking at action and meaning. Aims to fit data into the Matrix to produce a process. Theory is inductively derived through systematic data collection and analysis (Strauss & Corbin, 1990).	Theory is an interpretation of actions that take place among individuals (Strauss & Corbin, 1990).
Charmaz	• Pragmatism • Symbolic Interactionism • Constructivism	Interpretive, open, and flexible. Theory is constructed by the interaction between researcher and participant (Charmaz, 2014a)	"Theories aim to understand meaning and actions and how people construct them" (Charmaz, 2014a, p. 231)

Conclusion

Pragmatism played an important role in shifting the way people view the world during a time when positivist and empirical thought dominated scientific research. It opened the possibility that multiple realties and truths can exist among individuals simultaneously. Ideas were deemed true if they had practical value in everyday experience, and were shaped and verified by their ability to lead to fruitful consequences (James, 1907, 1981). Mead (1962) built on the pragmatic foundation by postulating that individuals can interpret and apply meaning to objects, persons, and situations. Individuals, as Blumer (1962) described it, can use these meanings and interpretations to make conscious decisions about the way in which they will act. The human mind was no longer passive in nature, responding to external forces. Rather, humans could use their intellect and conscious minds to actively act upon the environment. Social constructivism took these ideas one step further by adding that lived reality, our way of interpreting and creating meaning towards objects, is culturally constructed and influenced by society; the mind constructs knowledge through social interaction (Berger & Luckmann, 1971).

This transformed understanding of the nature of knowledge, influenced by pragmatism, SI, and constructivism, has stimulated the evolution of GT. As a result, varying GT approaches exist simultaneously, each with a slightly different epistemological foundation resulting in a slightly different definition of theory and approach to theory formulation. These various versions of GT and their corresponding definitions of theory can inspire researchers to conduct GT studies that get to the core of human processes, the stimulus for action, thus providing understanding and fostering change within society.

However, as Howard-Payne (2015) has stated, it is difficult to select and adhere to a GT approach if the researcher “does not clearly understand what differentiates one from the other” (p. 51). This paper provides an in-depth exploration of the underlying philosophies that drive the three main approaches to GT. This will be useful for novice researchers when deciding on a GT approach to utilize for their research project. This foundational knowledge will ensure that the novice researcher has the ability to choose an approach to GT that appropriately answers their research questions, addresses the problem at hand, and fits with the researcher’s ontological and epistemological standpoint in developing knowledge, useful for the discipline and practice.

Utilizing a thorough understanding of the underlying philosophies is imperative to ensure that the chosen GT approach is implemented to its full potential, utilizing the ideas inherent in the underlying philosophies.

Chapter 4: Methods

Study Design

The grounded theory method as described by Charmaz (2014a) was used to address the research questions. Charmaz has moved grounded theory out of its positivist roots and into the interpretive social sciences by adopting a constructivist agenda (Charmaz & Henwood, 2008). Constructionism espouses that realities are understood through multiple intangible mental constructions that are socially and experientially founded, and are reliant for their form and content on the individual whom holds the construction (Guba & Lincoln, 2004). Within constructionism, the researcher and researched are interactively linked, so that the findings are created as the investigation takes place, and such constructions can only be elicited and refined through the interaction between researcher and researched (Guba & Lincoln, 2004).

Charmaz' constructivist approach to grounded theory is aimed towards an abstract understanding versus an explanation and prediction: the researcher is part of the data, not apart from it, facts and values are connected rather than separate, and the views of the researcher and researched are multiple and interpretative rather than singular and self-evident (Charmaz, 2008b, 2014a; Charmaz & Henwood, 2008). Charmaz rejects the twentieth-century assumptions of Glaser and Strauss (1967), that are generality, truth, discovery, and objectivity. She adopts the view of positionality, relativity, and reflexivity (Charmaz & Henwood, 2008). To Charmaz, our way of knowing is interpretive of a reality, not a mere reproduction of it (Charmaz, 2017).

Within Charmaz' approach to grounded theory, the researchers sought to understand empirical findings as they emerged, rather than mechanically and prescriptively forcing data to describe phenomena (Charmaz, 2008b, 2014a, 2017). In using a constructivist methodology, grounded theory consists of understanding theoretical implications that tackle the 'why' questions (Charmaz, 2008a). Constructivist grounded theory encompasses strategies that are substantially flexible, is open, and can be adapted to fit emergent studies, not rigid prescriptions (Charmaz, 2000, 2006, 2008b). It is a pragmatic approach because the criteria for evaluation of the analysis are applicability and usefulness (Charmaz, 2000), and assumes reality is fluid and undetermined (Charmaz, 2017). Researchers can study empirical worlds without subscribing to positivist or objectivist assumptions: they do not have to suppose a narrow objectivist method and assume the truth of their subsequent analyses (Charmaz, 2000). Charmaz' approach to grounded theory was utilized for this current study because it was flexible and could be adapted to fit multiple samples that encompassed different experiences and perspectives. It provided a guideline to explore why parents and HCP struggle to enter a supportive relationship and to care for hospitalized MFI.

Grounded theory provided the researchers of this study with a set of clear guidelines, not detailed data collection techniques (Charmaz, 2000). Each step of the analytic process was moved towards the development, refinement, and interrelation of concepts (Charmaz, 2000). The strategies of grounded theory that were followed included: (a) simultaneous collection and analysis of data, (b) a two-step data coding process, (c) comparative methods, (d) memo writing aimed at the construction of conceptual analyses, (e) sampling to refine the researcher's emerging theoretical ideas, and (f) integration of the theoretical framework (Charmaz, 2000).

Setting and Participants

This study was conducted at Alberta Children's Hospital (ACH), where tertiary level care is provided by a multidisciplinary health care team including allied health professionals (i.e., dieticians, social workers, pharmacists, physiotherapists, occupational therapists, respiratory therapists, etc.), physicians, and nurses, as well as nursing and medical trainees. The philosophy of care is patient and family centered. Each discipline has their own shift schedule and processes of care. The setting for this study was the three inpatient care units at ACH, however, all parents were recruited from one unit where the focus population is infants. Parents were approached from all units, however, a limited number of infants who met eligibility were located on units other than the one with a population focus of infants. Two families were approached from one of the other inpatient units, one refused participation and another infant was discharged prior to participation.

We purposefully sampled participants from two groups: parents of MFI and HCP (including physicians, nurses, social workers, dieticians, occupational therapists, and physical therapists) who cared for MFI.

Parent participants.

Inclusion criteria for parent participants:

1. Biological mother or father of a medically fragile infant, who spoke English or any language that could be translated using the Language Service App
2. MFI were:
    a. Hospitalized with a long-term health condition for at least 30 days on an inpatient unit at the Alberta Children's Hospital to ensure parents had sufficient experience caring for their infant
    b. Less than 1 year of age from date of delivery
    c. Technology dependent
    d. At risk for a chronic health condition or disability
    e. Born preterm (before 37 weeks gestational age) or full-term (at or after 37 weeks gestational age)

Health care provider participants.

Inclusion criteria for HCP participants:

1. Either a Physician, Registered Nurse, Licensed Practical Nurse, Social Worker, Respiratory Therapist, Occupational Therapist, Pharmacist, Physical Therapist, Registered Dietician or Management personal employed on an inpatient unit at ACH.
2. Employed at ACH for at least 2 years and currently providing care to MFI and their parents to ensure sufficient experience from which to speak.

Ethics and Alberta Health Services Approval

The Conjoint Health Research Ethics Board at the University of Calgary provided ethical approval (EID:17-0858). Alberta Health Services provided operational approval.

Recruitment

Parent participants.

L.M. communicated bi-weekly with charge nurses on the inpatient units to identify potential participants. Also, C.B. identified possible patients. The researchers discussed identified potential participants with their care team to ensure appropriateness for the study. Potential participants were approached by a member of the infant's care team to introduce the study, provide an introductory post card that briefly explained the study, and requested verbal approval for L.M. to approach the parent(s). L.M. explained the study and obtained written informed consent. L.M. scheduled parent interviews at a mutually agreeable time and location at ACH. Parent interviews were occasionally conducted in the MFI' patient room at the parents' request.

HCP participants.

The nursing managers sent out an e-mail and letter of invitation to all nurses working on the inpatient units at ACH to introduce the study and invite participation in the study. Interested HCP were asked to indicate their interest via a brief email response to Benzies' Research Office. Only nurses from the inpatient unit with an infant focus indicated interest in participation. C.B. sent an e-mail and letter of invitation to physician teams. Managers of allied health professionals sent an email and letter of invitation to social workers, respiratory therapists, physiotherapists, occupational therapists, pharmacists, and registered dieticians who were routinely involved in the care of MFI on inpatient units. Posters introducing the study and inviting participant interest were placed on the inpatient unit (i.e., nursing break room). The e-mail address and phone number of Benzies' Research Office was located on the posters and e-mail sent. A study team member directed e-mails and phone calls to L.M. who answered questions. Focus groups were held in a private meeting/conference room. L.M. scheduled individual interviews at a mutually agreeable time and location.

Data Collection

Following written informed consent and prior to the start of each interview or focus group, L. M. collected socio-demographic characteristics from parents (see Appendix B) and HCP (see Appendix C) using a researcher designed survey. L.M. conducted 20 one-on-one interviews with parents. L. M. conducted one focus group interview with each of the following groups: physicians, nurses, social workers, occupational therapists and physical therapists, and dieticians. Given scheduling challenges, L.M. conducted 10 one-on-one interviews with nurses, and two one-on-one interviews with pediatricians.

The interviews were conducted with the aid of a semi-structured interview guide: one created for parents (see Appendix D) and one created for health care professionals (see Appendix E). The guides provided direction for questions and were used to engage participants who were less inclined to speak. L.M. focused questions to invite detailed discussion and encouraged reflection about the topic (Charmaz, 2006). Questions were reshaped according to emerging themes and categories, as data analysis occurred concurrently with data collection. Intensive interviewing permitted in-depth exploration of the participants' experiences caring for hospitalized MFI.

Interviews and focus groups were digitally audio-recorded and transcribed by a professional transcriptionist. The transcripts were reviewed by L.M. on an on-going basis to ensure appropriateness and clarity of guiding interview and focus group questions and to monitor for thematic saturation. L.M. collected rich data that provided explicit material to work with, and went beneath the surface of subjective and social life (Charmaz, 2004, 2006).

Data Analysis

Data analysis involved coding as described by Charmaz (Charmaz, 2014a). At each stage of data analysis, L. M. met with her supervisory committee to review her processes and outputs. L.M. conducted initial line-by-line coding of parental and HCP transcripts by hand (Charmaz, 2004, 2014b). This forces researchers to consider the material in various ways that were different from the participants' interpretations: it helps researchers remain open, see the data in new light, and recognize nuances embedded within the data (Charmaz, 2004, 2006). L.M. conducted line-by-line coding by coding with words that revealed action, extracting the potential process from the data; an eye for action in each segment was used rather than apply pre-existing categories to data (Charmaz, 2014a). A language of action was invoked to prevent tendencies to adopt expectant theories and make conceptual leaps (Charmaz, 2014a). Line-by-line coding was compared across all transcripts, and through line-by-line coding data was broken into categories.

Following line-by-line coding, L.M. engaged in focused coding, which is the second major phase of coding (Charmaz, 2014a). Focused coding refers to assessing initial codes and comparing them to data and other codes to distinguish which ones have analytic power (Charmaz, 2014a). L.M. utilized focused coding to sift through large quantities of data (Charmaz, 2004, 2006). Focused coding was more direct and open-ended, and allowed for the creation of categories (Charmaz, 2014a). L.M. pursued codes with flexibility that were fruitful in developing various categories, and set aside the ones that were not useful (Charmaz, 2014a). L.M. utilized focused-coding to advance the theoretical direction of data by concentrating on the most significant or frequent codes and synthesizing them into larger categories (Charmaz, 2014a). During focused coding, re-occurring categories emerged that demonstrated different, yet interconnected, experiences of parents and HCP (see Chapter 5 and 6).

L.M. utilized memo-writing throughout data collection to capture thoughts, create new ideas, and gain insights. Through memo-writing, analytic notes were constructed, data were compared, and categories and concepts were formed (Charmaz, 2006). L.M. wrote memos using free writing, recording thoughts quickly and clearly, as soon as an interesting ideas emerged (Charmaz, 2004). Memo-writing was completed immediately following each interview and throughout the data collection and data analysis phases of this study. L.M. used memos while conducting focus coding to understand what was happening in the field, and to build codes into categories that could be analyzed conceptually (Charmaz, 2006).

Memo-writing initiated and directed theoretical sampling within this study. Theoretical sampling is “seeking and collecting pertinent data to elaborate and refine categories in your emerging theory” (Charmaz, 2014a, p. 192). When categories appeared thin, L.M. collected additional data by asking probing questions with new participants to build emergent categories; thus, she collected all possible data regarding the emerging categories (Charmaz, 2006).

Theoretical sampling was utilized to check hunches about categories, distinguish between categories, and clarify relationships among categories (Charmaz, 2014a). Theoretical sampling assisted to fill gaps among categories and saturated categories by collecting data that purposefully filled such gaps and spoke to the categories under refinement (Charmaz, 2014a). Theoretical sampling was also used to identify variation within the parental experiences. For example, it was identified during data analysis that consented parents leaned towards a positive experience. Thus, parents who HCP identified as struggling to parent their ill infant were targeted for recruitment. Regardless of efforts to recruit additional families who were perceived to be struggling, L.M. consented only two additional parents who were perceived to be struggling. L.M. utilized theoretical sampling until all categories were saturated and gathering fresh data did not spark new theoretical insights (Charmaz, 2006). Data collection was concluded when no new properties of the established concepts and themes were identified. When L.M. attained data saturation she began to sort memos to see relationships between categories, compared categories, and created diagrams to present an initial analytic frame (Charmaz, 2014a). Focused coding, memo-writing, and theoretical sampling presented how parental and HCP' themes and categories were different yet interconnected. Data were then reduced and synthesized to capture parental experiences (Chapter 5) and HCP' experiences (Chapter 6).

Diagraming parental and HCP' categories enabled the direction, power, and scope of the categories to be visualized, as well as, the connections between them (Charmaz, 2014a). Focused codes and categories that described parental and HCP' experiences were compared and contrasted, and their interrelation was interpreted. L.M. and her supervisory committee analytically raised the level of abstractness from parental and HCP' focused codes to develop a grounded theory (see Chapter 7).

Rigor

Charmaz (2014a) uses four criteria to evaluate rigor: credibility, originality, resonance, and usefulness. L.M. utilized these criteria to guide, direct, and inform data collection and analysis. With regard to credibility, L.M. ensured she achieved an intimate familiarity with the setting, and that she collected sufficient data to merit claims (Charmaz, 2014a). Theoretical sampling was utilized to ensure sufficient data provided data saturation and supportive linkages between concepts and themes. With the support of her supervisory committee, L.M. ensured there were logical links between the data gathered, arguments, and analysis to enable readers to independently assess and agree with claims. Originality was supported by her supervisory committee to ensure that categories offered new insights, and that analysis provided new conceptual rendering of the data. Within originality it is important to consider how the grounded theory extends, challenges, and refines current ideas, practices, and concepts (Charmaz, 2014a). Resonance was ensured by creating categories that portrayed the fullness of the experiences of the parents and HCP. Resonance is also ensured by going back to the participants and determining if the theory makes sense to them and offers insight into their lives and worlds (Charmaz, 2014a). However, due to logistics this step was not initiated. Usefulness of the theory is determined by ensuring it offers interpretations of participants that can be used in everyday life, and if it sparks further research (Charmaz, 2014a). The theory from this study provide HCP with key factors that they can implement into their everyday practice. The description of parental experiences is beneficial for HCP as they interact with parents, it provides insight into the stressors and coping mechanism that HCP can utilize in their care approach, decisions, and actions. The findings from this study provided insight and understanding of parental and HCP’ experiences caring for MFI that will be used in the development and implementation of interventional research. Deliberate identification and discussion of potential biases occurred throughout data analysis. To increase reliability, all research team members contributed to the iterative and consensus driven processes of category, theme, and theory development.

Chapter 5: Parent Findings

In Chapter 5, I will present the demographic and health characteristics of parents and infants, as well as findings from focused coding of parent interviews. The resulting categories capture parental experiences of caring for MFI on an inpatient unit.

Characteristics of Parents and Infants

A total of 21 parents participated in interviews, 15 of them were mothers and six of them were fathers. Eleven of the parents had other children at home. The mean age of the parents was 34 years old and 20 of the parents were in a marital relationship. Five had high school diplomas and 15 had either a college or university degree. Twelve of the parents were Canadian and 9 of the parents were immigrants from either Korea, Philippians, India, Serbia, or Pakistan.

MFI had spent an average of 90 days in hospital at the time of the interview, with a minimum of 26 days and maximum of 225 days. The infant with a stay of 26 days was included because the expected stay was going to be another 7 days, however, this was the only time the mother was available for interview. The average gestational age at birth was 37 weeks, with a minimum of 26 weeks and maximum of 41 weeks. There were nine male MFI and six female MFI. See Table 1 for diagnoses of MFI and Table 2 for a list of the medical technologies required by the MFI. L.M. spoke briefly with the attending nurse to clarify and confirm MFI technology dependence.

Table 5

List of Primary and Secondary Diagnosis for MFI

Primary Diagnosis	**Secondary Diagnosis**
NEC	Hypertrophic Cardiomyopathy
Gastroschisis	Hypertonia
Glass Syndrome	Tachypnea
Joubert Syndrome	Arrythmia
Bacterial Meningitis	Heart Murmur
Pierre Robin	Sleep Apnea
Pompe Disease	Aspiration/Reflux
Sequela of Prematurity	
Osteomyelitis	
SVT	
Tracheo/laryngomalacia	
Waardenburg Syndrome	
Sleep Apnea	
Cleft Palate	

Table 6

List of Technologies Required by MFI

Technology Dependence
Oxygen
Continuous Feeding Pump
CPAP
Gastroenteric Tube
Intravenous Antibiotics
Total Parental Nutrition
Monitor
Nasogastric Feed
Ostomy
Tracheostomy
Gastroenteric-Jejunum Tube
Nasopharyngeal-Jejunum Tube
Vaginostomy
Frequent Suctioning
Normal Saline Nebulizer

Parental Experiences

Parents of MFI were bombarded with multiple stressors as they navigated their uncertain situations. While parents coped with their multiple stressors, they also grieved the loss of not parenting a healthy infant at home. Parents of MFI aimed to survive and get through each individual day, managing new and constant stressors that were placed upon them while coming to terms with shattered dreams.

All parents initially entered a period of crisis from the shock and uncertainty of receiving the infant's medical diagnosis, or when infants who were born healthy experienced distressing medical sign and symptoms. A crisis is an emotionally significant event that coincides with a change in status of a person's life, it is time when one experiences an attack of pain, distress, or disordered function (Webster, 2018). When parents of MFI received a diagnosis, their lives were immediately changed, and they were faced with the uncertainty and stress of parenting MFI with unknown futures.

> When you go through the journey… it happen all of a sudden and you are all in shock "What we can do"… I remember we just went for a regular check up. But then we found out from the doctors and the specialist that the baby's foot is already out and we have no choice. Cuz this way maybe the baby is in danger too and maybe her life in risk too… But going through all the trauma and anxiety, it's not easy. Like it's very shocking… I'm a guy, I'm a father but still when that has happened you know that feeling is very tough. You know your baby's life at risk it's more tough, more tough. (Father-13, p. 1)

Many parents remained in a state of crisis longer if their infant remained medically unstable for an extended period or if they had a more difficult time coping with their stressors. The period of crisis was a time when parents experienced very high levels of stress, immense uncertainty, and fear for the future. Parents could also re-enter a phase of crisis if their infant experienced a medical setback or a code situation.

> A month later it prolapsed so they went in and then they had to do another surgery, then after that it was working for a few days and then it stopped working again. Then she came off of feeds and it was insane. She was off the feeds for like a month and a half because there was an obstruction there. They tried everything and they just couldn't. Then… they put her back together so a 6 hour surgery, it was like 5 to 6 hours it was insane it was like 24 hours for us. (Mother-12, p. 1)

Over time, prematurely born MFI became bigger, stronger, and more medically stable. With gentle direction from nurses, parents gained confidence and skills in caring for their MFI providing both basic care (i.e., diaper changing, feeding, cuddling) and nursing care (i.e., ostomy appliance care, nasogastric tube feeds). Parents also became more comfortable and familiar with the hospital environment and processes of care. This helped parents enter a phase of some stability, as they were no longer in a state of crisis.

> [Initially] we can only… see the baby and like you know and just watch what nurses are doing with her. But then slowly they told us like how to be with the baby, how to handle the baby, to start letting us take her thermometer, check her temperature, changing her diapers and stuff. Cuz I was… scared in dealing with the babies, like especially in that space, but they told me there's nothing to be worried about it's simple just do what we say. We used to do skin to skin, that helped baby a lot. That gave us confidence too, like "Yes, the baby is healing the baby is going towards right direction." (Father-13, p. 4)

The extreme stress and uncertainty experienced by parents of MFI diagnosed after a healthy birth was alleviated when they received the medical diagnosis(es) that accounted for their infant's troublesome signs and symptoms. The diagnosis provided answers for the parents amidst great uncertainty and provided direction on beneficial treatments for the infant.

> So when they did the MRI they found out that she had S. syndrome. Since then, we're still here. She still has fast breathing and lots of suctioning required coughing. Um, we're out of isolation cuz I think whatever is happening is… baseline not the bacteria. (Mother-07 p. 2)

Parental experiences with MFI began when they realized something was wrong with their infant or received their infant's diagnosis. Parents received their infant's diagnosis three different ways: (a) infant diagnosed during pregnancy via ultrasound, (b) infant born prematurely and experienced sequela of prematurity, and (c) infant born full-term and diagnosed as a result of problematic symptoms.

Diagnosis during pregnancy.

Some parents received a diagnosis during pregnancy from abnormalities on their prenatal ultrasound. When the infant was diagnosed during pregnancy, mothers experienced uncertainty and fear, which lasted for the duration of the pregnancy and into the postpartum period. Mothers underwent frequent monitoring. They searched the internet for information on their infant's diagnosis, hoping to learn what to expect. Care and information provided by HCP during pregnancy was contradictory and confusing.

> The doctor who tell me that in that moment she say a lot of information at once. And she say then maybe he have a Down Syndrome, maybe he can't survive with his heart, maybe I have to abort him, maybe, maybe, maybe. This was a big shock for me and I was lost in that moment. (Mother-09, p. 1)

Mothers who received an antenatal diagnosis felt traumatized and frustrated. "So I was going every week and it was traumatic. Every week I was hopeful they would see it [the stomach] and I would just be slammed with like this harsh reality that they still didn't know" (Mother-19, p. 2).

Preterm birth.

Both mothers and fathers spoke to preterm birth as a traumatic event. One father described the birth as so traumatic he lost memory of it: "I don't have any… memory around May. I think that one of the effect of the trauma… I lost lots of memories around May and June for whole time… I don't know what happened to me" (Father-11 p. 2). Parents experienced intense feelings of disappointment and grieved being unable to give birth to a full-term healthy infant. Parental recollections of their preterm birth were often captured amidst sorrowful tears. Some mothers were unable to see their infant for a few days after birth, due to the infant being transferred to a different hospital; this distance was extremely difficult for parents. Parents experienced grief and sadness as they visualized their infant, small and fragile, attached to monitors and medical equipment. Parents were afraid to hold their infant because they were scared they would hurt them. One mother stated, “He was just so tiny, he was just so fragile. I was afraid to touch him, I was afraid he would break into pieces. There was so many connections, his mouth, his nose, his bowel” (Mother-14 p. 2).

Following preterm birth parents experienced moments of deep sadness from witnessing their infant in a vulnerable state and being unable to protect them from harm. For most parents, the immediate time period following the premature birth was a phase where they were unsure if their infant would survive. “In the beginning I still wasn’t sure if he was gonna make it or not. There was probably a solid week or so where I thought for sure he was gonna die” (Father-17, p. 49).

It was during such moments that parents received a medical diagnosis. Thus, it was overwhelming for parents to process the preterm birth coupled with the stress of receiving a medical diagnosis for their infant.

Diagnosis of full-term infants.

Parents who gave birth to a full-term infant who then became medically fragile recognized and observed signs and symptoms that were troublesome and caused them to seek medical attention. They described having to piece together information, with the aid of the HCP, to achieve a diagnosis. One mother described recognizing troublesome symptoms and phoning various doctors’ offices to get her infant assessed. “So then Tuesday she was sleeping all night, I couldn’t wake her up, she was hardly eating. She was jaundiced so I was worried about that… Like I tried calling doctor’s offices and the doctor that delivered her” (Mother-05 p. 2). Similar to parents who received a diagnosis in pregnancy or had a preterm birth, parents of infants born healthy and at term experienced uncertainty, worry, fear, and sadness when they discovered their infant was medically ill.

Grief: The Loss of Parenting a Healthy Infant at Home

All parents envisioned giving birth to healthy infants that they could parent in their home and did not expect to give birth to MFI. Instead, they experienced shock and uncertainty of parenting MFI in the hospital setting. Parents experienced deep, emotional distress at the loss of parenting a healthy infant, which contradicted expectations.

> A first picture comes to your mind when you see regular videos on Facebook or anywhere like YouTube, it's normal babies coming out and everything. You have that picture in your mind, "Yes my baby is going to be like that." But then when you have to deal with this procedure premature birth, that give you totally a shock. It gives me, cuz you keep that picture in mind when your healthy baby is coming out. But when you see this happen, that shocks. (Father-13, p. 2-3)
>
> Yeah the hardest thing for me actually this entire time since J. [wife] went in the hospital was taking her into triage with a bunch of happy parents ready to give birth and we think our child is gonna die… that was for me, sitting there for hours and hours listening to these happy parents. (Father-17, p. 33)

Parents noted that they were sad that they were not able to do typical activities with their infants. One mother had three family members who gave birth the same year, and they were at home engaging in typical parenting behaviors. She indicated that she longed to do the same with her daughter.

> My husband's family had three other babies this year and they're all enjoying their babies and stuff…. You feel confined and like you know you… if I wanna go to the mall I can't take her with me right? That would make it easier… I can do all my errands still and she can go with me. But now it's kind of like I don't wanna leave her inside but I have so many other things to do. I mean the hospital is amazing we're lucky to be in such a good system here. But you know, being a hospital is being a hospital. (Mother-12, p. 17)

Coping with Multiple Stressors

Parental experiences caring for their MFI were characterized by coping with multiple stressors. Each parent articulated a variety of stressors. Some varied because of differing medical trajectories, when they received the infant's diagnosis, amount and severity of setbacks, available supports, financial status, and parental personality. Parental ability to cope with stressors was linked to the stressors they experienced and their unique ability, both internally and externally, to offset those stressors.

In the section below, five parental sources of stress will be described including: (a) infant's fragility and uncertainty of the situation, (b) hospital environment and processes of care, (c) navigating functions of daily living, (d) guilt, and (e) loss of control. Two ways in which the stressors were managed, included: (a) internal coping mechanisms and (b) external coping mechanisms. A description of the mental health difficulties that parents suffered because of struggling to cope is provided.

Table 7

Themes and Sub-Themes from Parent Data

Theme	**Sub-Theme**
Stressors	- Infant's fragility and uncertainty of the situation - Hospital environment and processes of care - Navigating functions of daily living - Guilt - Loss of control
External Coping Mechanisms	- Family supports - Teamwork with partner - Talking to social work and spiritual care - Ronald McDonald

	- Creating trusting relationships with HCP - Qualities of HCP o Coordinating with parents o Involving parents in care o Responsive nurses o Taking time to explain and be approachable o Small things make a bid difference o Positive friendly approach o Truly caring for the infant and parents
Internal Coping Mechanisms	- Personality traits - Taking breaks and doing something parents enjoy - Being involved in infant care - Leaning on faith, religion, or spirituality - Detective and master of coordination
Mental Health Implications	- Physical manifestations of stress in parents - Trauma - Stress and anxiety

Parental sources of stress.

Infant's fragility and uncertainty of the situation.

Parents experienced distress from seeing their infant in an extremely small and fragile state. They viewed their infant as being innocent and helpless, and felt as though they were unable to guard and protect their infant, which left them feeling overwhelmed. Parents could not meet their infant's basic needs for comfort and food because often they were unable to hold or breast feed.

> It was also very hard for me because you know as a mom supposedly our instinct is to breast feed them right away, to cuddle them. But it was just so different with C. [baby] because I couldn't touch him, and he was so small I could actually see his veins through his skin. Like his skin was like translucent. He was just so tiny, he was just so fragile. (Mother-14, p. 2)

Parents experienced overwhelming stress witnessing their MFI in pain. Parents regularly witnessed their infant experiencing painful procedures and tests that they were unable to stop, and consequently felt they could not protect their infant. "Very hard, very, very hard. It's very hard not to cry myself when she's screaming in pain" (Mother-10, p. 22).

Parental experience of stress was related to their infant's health status. When MFI were medically unstable due to setbacks or deterioration in health, parents worried more, experienced increased stress, and struggled with their emotional and mental health. When one mother was asked about how well she was doing emotionally, she described her emotional health as directly dependent on how well her son was doing:

> My mental health is largely tied up in how well he's doing on a daily basis. If B. [infant] is doing well I'm doing well, if B. [infant] is doing crappy if he's back on oxygen whatever, then I feel like we're having a setback, you know. (Mother-16, p. 31)

Some parents went through a time where they did not know if their MFI would survive. Most often this occurred with parents of infants born preterm, among infants that had to undergo multiple surgeries, or infants involved in a code situation. This was a significant source of stress for parents, and at times they described such situations as almost unbearable.

> I came upstairs after emergency to see M. [infant], when… I see this machine and everything. His temperature was 32, cold, white, this became line in the neck, blood everywhere, a lot of nurses looking with the lamps and these cables. I don't know how I survived that. I still don't know how. (Mother-09, p. 8)

Unexpected setbacks in MFI' conditions were extremely hard for parents and caused great uncertainty and stress. As a result, the parents lived in a constant state of uncertainty, never knowing what setbacks or hurdles they would have to endure. Constant uncertainty was a source of continuous stress for parents.

> C. [infant] started to deteriorate because he had this perforation. Like his bowel, there's so many holes… they said that this could be very toxic for him. He started to deteriorate, they gave us 48 hours. Yeah and so as a mom I was so, it was so hard for me. I didn't know what to think and I don't wanna leave him, like even a minute I don't wanna leave him because I don't know what could happen in a minute's time. (Mother-14, p. 2)

At times parents had to leave their infants alone in hospital to attend to other responsibilities; this was more difficult for mothers than fathers. Parents worried that their infant would cry and not be attended to due to nursing workload. Parents also worried that a medical mistake or mishap could occur without them there to monitor care provided. Therefore, leaving their infant alone in hospital increased their uncertainty and stress. For parents, leaving their infant alone in hospital was contrary to their instinct to remain in close proximity to their MFI, protecting and comforting them.

> I feel that I can't leave her alone as a main part of the care, because sometimes she cries I can see her crying. When I'm away from her I feel like maybe she's crying and what is she doing? (Mother-15, p. 2)

Occasionally, HCP were unable to provide clear answers for upsetting symptoms experienced by MFI. It was difficult for parents to watch their infant suffer or have upsetting symptoms that they could not resolve. "Probably just not really having answers for her reflux on like how to fix it. Cuz we've tried so many things and the things that were supposed to work have made it worse" (Mother-05, p. 6).

The long-term outcome was often unknown for the MFI, and parents faced an uncertain future, which was a source of stress and sadness.

> It was really, really, hard to have like two normal kids and to have this one… I felt bad for her cuz when she grows up she'll be a bit different than anybody right? Probably won't be able to play with her sisters and it's hard for the sisters to understand kinda thing. So it was sad. (Mother-07, p. 4)

In summary, parents experienced stress and uncertainty parenting MFI. Due to the infant's fragility, parents were often unable to attain their role as a parent: they were unable to meet their infant's basic needs and often had to witness distressing sights of their infant in pain. Parents experienced inner turmoil when they did not know how to alleviate infants' troublesome symptoms, had to leave infants alone in hospital, and did not have answers. This resulted in extreme stress and uncertainty among parents.

Hospital environment.

Monitor alarms.

Parents viewed their infants as requiring high observation. Waiting for a nurse to come while the monitor alarms rang for extended periods of time resulted in the parents feeling worried and afraid that their infant would experience harm or danger. Parents with infants who regularly choked and required suctioning were especially worried that their infant could die if a nurse did not attend to them in a timely manner. "So she could be like silently choking to death and since they don't come in when her stats are down anyways; how do I know they're gonna do it if I'm not there" (Mother-05, p. 14).

Transfer from Neonatal Intensive Care Unit.

Parents experienced additional stress when they transferred from the Neonatal Intensive Care Unit (NICU) to the inpatient unit. Some parents viewed the transfer as a step towards going home. Parents who were given a tour and were prepared to encounter the differences in care seemed to experience less stress from the transfer. Parents identified three major differences between the NICU and the inpatient unit: (a) nurse to patient ratio, (b) greater expectations for parents to provide infant care, and (c) primary nursing. In the NICU nurses have patient assignments of one to two infants, whereas, on the inpatient unit assignments include two to four infants, which results in fewer nursing observations and assessments, and less time providing care. In the NICU nurses provided most of the direct infant care, whereas, on the inpatient unit, parents were expected to provide most care, including basic and some medical care. Most often these expectations were not communicated to parents.

> So for me it would have been helpful to… come down here or… have someone just talk to me about what it's gonna look like, this is what your room is gonna look like, the nursing it's 3 to 1, just to prepare us for that kind of thing. This is what we're expecting of you, you have to change his diapers, whether you do or don't, but just to let you know what the expectation is of the parent. You have to sleep here… like I know you don't have to sleep here but the expectation is that parents are more hands on. Which is totally fine just so that I'm prepared to know what is expected of me when we come down here. (Father-17, p. 7-8)

In contrast to inpatient units, infants received primary nursing in tertiary level NICUs. HCP on the inpatient unit did not practice primary care. Therefore, lack of primary nursing was a difference in staffing processes that parents had to adjust to. Thus, transfer from the NICU to an inpatient unit was stressful because of different expectations of care that required adjustments for parents.

Uncertainty of going home.

Many parents were overwhelmed and unsure of how they would manage their MFI' care needs at home alone without medical support. Anticipation of going home with their MFI was a source of stress and uncertainty. "I know that the suctioning… its ok, I'm scared of doing the trach change you know, and I'm scared of emergency situations, something happens at home and it’s just me” (Mother-20, p. 18). Some parents did not feel that HCP prepared them to go home with adequate supports in place.

Medical errors and near misses.

Medical errors, near misses, and poor care decisions were traumatic events that increased parental stress. Trust with HCP was broken when a medical error or perceived mishap occurred. This led parents to question HCP’ abilities, increased parental vigilance, and reduced parental breaks. Once trust was broken, it was difficult to re-established and parents carried this mistrust into future encounters with HCP. One father indicated that because of a medical mistake and poor care decision he continually tested HCP’ knowledge to determine if he could trust them with the care of his son.

> Basically, I don’t know you and I don’t trust you so I’m gonna ask you lots of questions… I caught myself doing that, I’ll ask questions that I know the answers to just to sort of judge their base line and what their responses are. It’s probably not appropriate but it’s hard cuz at the end of the day we’re leaving our son here for periods of time unattended. (Father-08, p. 9)

In some situations, parents believed that a cardio-pulmonary resuscitation (CPR) code or an unexpected deterioration in the infant’s medical status occurred because HCP failed to listen to their concerns. One mother witnessed her son in a cardiac deterioration. Prior to the episode she recognized the signs and symptoms leading to the episode; however, the nurse failed to respond to the mother’s concerns:

> And he was started puking and I know when he is puking something has happened so arrhythmia is coming and big one under the 200. I called the nurse and he start to be pale, so this is also another sign. I called the nurse 5 times over there and say M. [baby] is not ok. “No it’s ok, you are paranoid mother you start to worry too much”. Bla, bla, bla. After a few minutes she came to see M. [baby]. I say, “Please can you call the doctor somebody, he is not ok, he is fussy he can’t stop to cry something is coming”. “No, he’s fussy I don’t know because the food maybe a lot of calories is too strong for his tummy.” How she say that? Immediately came the arrhythmia 290, 200, 200 and she

> called the rapid team. Here is stat team, over there is rapid team, right away. (Mother-09, p. 12)

Fighting the system.

Parents experienced roadblocks due to the way the healthcare system was designed. They spoke to fighting ‘the system’ in regard to policies, unit rules, being seen by specialty services, and gaining access to certain programs. One mother spoke about being discharged from hospital and needing a pump to deliver the infant’s nutrition via a naso-gastric tube.

> Then the only issue there was we didn’t have a pump to feed her with and Alberta Children’s refused to give us one. They finally gave in, but it took like a full week to convince them. Like people trying to help us out were told that it wasn’t the hospital’s problem. So that was really frustrating, very stressful… I mean it’s nice that they gave in, but we shouldn’t have had to fight that hard to begin with. (Mother-04, p. 8)

Parents were often unaware of services that were available to them. Navigating the system blindly resulted in increased stress because parents needed to invest their limited time and energy just trying to find services. Two fathers clearly indicated, “You don’t know what you don’t know” (Father-08, p. 32). Parents wanted a consistent HCP who could provide direction and advice about what to expect within the health care system and what services they could utilize.

Navigating functions of daily living.

Being from out of town.

Parents who lived great distances from the hospital experienced stress navigating travel, accommodations, and food. Parents who were from small towns had to cope with the stress of being in a large city because it was overwhelming to them and very different from their home town. Such parents lacked support because their friends and families were back home. “It’s been hard not having them [family] around all the time. Well I work with my family, so I see them every day. I usually do stuff with them on the weekends too" (Mother-04, p. 15).

Parents had to find temporary accommodation, which was most often at Ronald McDonald House if there was available space. One mother described sleeping in a waiting room with the twin to her ill infant because she could not find accommodation near the hospital, nor could she bring the twin infant into the parent room. "Yeah so you know sometimes I would go and sleep on the, in the third floor OR waiting room" (Mother-20, p. 6).

Siblings.

Parents with other children experienced constant stress associated with caring for their MFI in hospital and older siblings at home. Most often one of the older siblings was a toddler, an age that is not conducive to parenting in a hospital environment. As a result, parents had to leave at least one child, either the hospitalized infant or sibling, which was emotionally taxing. "Yeah cuz we come here and then he [toddler] wants to be here an hour and then he wants to do something else. It's hard to keep his attention on one thing" (Mother-04, p. 21). One mother cried when asked about her 2-year-old toddler at home because she had to miss her second birthday. She was unable to parent both of her daughters as she would have liked due to being from out of town and her infant in hospital. She broke down in tears, "Yeah and then not being with my 2-year-old has been really hard. So I had to miss her second birthday" (Mother-05, p. 7).

Some parents were concerned about the effect caring for their hospitalized ill infant could have on their other children. One father spoke about his concerns for his 2-year-old daughter's development because she was confined in a hospital room for extended periods.

> We don’t want K. [daughter] to be here in the hospital for 8-10 hours a day, cause it’s not the right place for her, its great because it’s the children’s hospital and there are lots of things for children to do, but because A. [infant] is on isolation, she can’t go to the play spaces and stuff like that, and so essentially she is in the room playing with all the medical stuff and we are chasing after her. (Father-01, p. 7)

Finances.

Finances were a very common and high source of stress among parents of MFI. All parents except two, a married couple with higher education and established careers, reported high financial costs (e.g., parking, meals, transportation, and accommodations) associated with parenting MFI in hospital. Three fathers lost their jobs and one father was extremely fearful he would lose his job due to his stress-related poor performance at work. One father had two full time jobs, and two fathers took paternity leave to support their wives. One mother was worried about her finances because birthing a preterm infant meant forgoing two months of salary. One mother planned to return to work at four months postpartum because she was from the Philippines and she was not eligible for Canadian maternity benefits. One family moved in with the maternal grandparents, and one family rented out their home while residing in the Ronald McDonald House with their 5-yearold son because neither family could afford to pay for their mortgage.

> The other thing that kind of weighs heavily on you is EI, they take so long to make a claim, to make a decision on their claim… You know that’s fine for you guys cuz you have a pay cheque coming in, we don’t. So it’s kinda hard on us cuz I have to buy her diapers and formula and I’ve got nothing to buy it with. My other half has bills and I have bills… my half’s not getting covered cuz I have no money to do it. (Mother-10, p. 7)

All but two parents mentioned the high price of purchasing food from the hospital cafeteria. “You know for two people to have just two sandwiches… I had a bowl of soup, he had a bag of chips and two pops was over $30” (Mother-20 p. 8). This added stress because most often parents did not have time to buy groceries and prepare food at home.

Guilt.

Some mothers felt guilty and blamed themselves for their infant's condition. They regularly questioned whether their behaviors during pregnancy (e.g., eating badly, working too hard, and not getting enough rest) lead to their infant's diagnosis. This guilt was disabling for some mothers, and some expressed that when they let themselves 'off the hook' they were better able to cope with their situation.

> Is it my fault that she's like it. Some of it was, did I overdo it at work that caused this? Like I had no idea why it happened… there is a certain measure of guilt until someone tells you otherwise. (Mother-10, p. 29)

Loss of control.

At times parents felt infant care was organized by HCP with minimal parental input. Parents felt a loss of control within their parental role when their ideas and opinions were not acknowledged and information provided by HCP was confusing and inconsistent.

Acknowledged as the expert.

Given the context of hospitalization parents were forced to share control for care of their MFI with the health care team. At times this loss of control became a power struggle, where the parents were left feeling helpless and powerless. One father spoke of his belief, based on a previous experience with a member of their family, that a surgery would help his son. The medical specialty team held a different opinion, and he and his wife watched their son continue to have debilitating symptoms.

> We say all the time that we are not doctors, we don't claim to be any sort of medical professional, but… we see A. [infant] day in and day out, we have a family history where we know very similar issues have been solved by a couple surgeries. (Father-01, p. 10)

Some parents were afraid to make requests or challenge HCP decisions. They were afraid to speak up for fear of being labelled a bad or difficult parent, or fear that their child would receive less than optimal care, which could result in infant suffering. This increased their perceptions of loss of control because they were not able to say what they thought and parent their way. “If you say, ‘Hey can you pay attention more,’ or say something they offend and they don’t wanna watch your baby. This is true” (Mother-09, p. 32).

Conflicting pieces of information.

Parents of MFI who needed multiple medical specialties involved in their care noted that it was difficult to have a consistent plan of care. Each specialty provided different information and made different plans that did not align. This was frustrating and confusing for parents because, most often, they did not have medical knowledge nor training. Therefore, parents felt overwhelmed and uncertain, had a decreased sense of control, and felt more stressed. Also, each nurse delivered care and instructed parents differently. This also confused and frustrated parents. “We have one doctor come in and tell us one thing and say the specialist and then a nurse, whatever nurse is working with a specialist they’ll come in and say something different so that’s part is frustrating” (Mother-04, p. 23).

Parental stress increased when HCP did not take time to explain information in terms that parents could understand. This was especially true for parents whose first language was not English. When HCP took time to explain information in lay terms, parents experienced increased understanding. This understanding gave the parents a sense of control and security and helped decrease their stress.

> They might not think it’s a big deal when you hear something but I’m not a doctor so I can completely take it out of context… all I hear it something is failing or something along those lines right? Just talk to me like I’m a journeyman electrician not a doctor. (Father-18, p. 2)

One mother described the power of information in helping her cope and survive her journey. “They are so nice… to explain everything, to give you the, the power that you can survive that, then you can accept the stuff” (Mother-09, p. 8).

Parental Coping: Offsetting and Managing Stressors

Parents utilized two mechanisms to cope with their stressors: (a) external coping mechanisms and (b) internal coping mechanisms.

External mechanisms.

External coping mechanisms, those which existed outside of the parents themselves, were utilized to cope with stressors and grief they experienced. These included: (a) family supports, (b) teamwork with partner, (c) talking to social work and spiritual care, (d) Ronald McDonald House, and (e) creating trusting relationships with HCP.

Family supports.

Family supported parents with childcare, house cleaning, caring for pets, grocery shopping, and cooking, and provided emotional support. One father described how his in-laws, who he and his family were temporarily living with, provided care for their toddler and cooked meals. “Having family help around definitely helps with the stress. A.’s [wife] mom is great about helping out with K. [toddler], she’s really helped us a ton” (Father-01 p. 4). Family supports decreased parental stressors by enabling parents to be in hospital with their MFI while other responsibilities were taken care of. A mother described how her family helped her cope with parenting her hospitalized ill infant. This mother lived with her extended family, who did all the grocery shopping, cleaning, child care, and laundry. Her parents visited her often in the hospital; they encouraged her, supported her, and talked through her troubling thoughts and emotions. This mother had a very good relationship with her husband and family.

> They're [daughters] really close with my family which is really, really good. My oldest one she sleeps with my sister in her room while I'm gone... My little one is really attached to my brother and my dad. So I put her crib upstairs while I'm here and she sleeps in my sister-in-law's room in her crib… they're always there with somebody. My dad, my mom, my sister, my sister-in-law, my brother, I have nieces. I live in my brother's basement, so me and my kids, and then my brother and my sister live upstairs… Like she'll [sister] do laundry and everything. (Mother-07, p. 9)

Teamwork with partner.

Most parents, who were in a marital relationship, described how they worked together as a team to care for their MFI. Each parent had strengths and weaknesses within the relationship, and they worked together.

> Well I think A. [father] said we have different strengths. We definitely have different strengths. I'm down in the weeds, I know exactly how much medication he takes, what the side effects are, what the half-life of them is, like you know, and A.'s [dad] very good at being able to be a bit of like a director. You know he went and spoke to H. [nurse] cuz I was in no state to do that, I was upset and that kind of thing. So we both just have different strengths… I'm really into the day to day and he's kind of able to see the bigger picture. (Mother-16, p. 41-42)

Most often the mother was most involved with hands on care of the infant, including basic and medical care. Mothers were the first point of contact with the medical team and most aware of the infant's medical situation. Fathers took a more supportive role for the family, engaging in duties outside of the hospital such as caring for siblings, preparing meals, and cleaning breast pump supplies. Fathers perceived their role as providing emotional support for the mother of the MFI to enable them to provide direct care for the infants. "The hardest parts are, having to see what A. [mom] is going through, and trying to do everything I can to help her to deal with what needs to be dealt with" (Father-01, p. 6-7). Fathers described how they sought to support their wives emotionally because they recognized they are having a hard time coping with parenting an ill infant. One father indicated that he recognized his wife was suffering emotionally and stepped in to protect her. "I dragged her out of here, the one day got really bad, she was just sitting there almost shaking not wanting to leave the room. I knew that moment that I had to, something had to change" (Father-17, p. 46).

A few mothers, who did not receive support from their partners, experienced increased stress because they felt like they were carrying the burden of care for their MFI alone. One mother described how upsetting it was that her husband did not help her care for their ill infant so she cared for the infant alone, "It's just easier just to do it myself" (Mother-20, p. 42).

Talking to social work and spiritual care

Some parents found it helpful to talk to a social worker about their difficulties and frustrations. For some parents, social workers helped them to navigate financial assistance and other services within the health care system.

> She just asks us if we're ok, how we're feeling, making sure that the two of us aren't really like fighting between each other. Making sure how we're coping when something happens with her and how we feel. So it's nice to have someone to talk to in that sense. (Mother-12, p. 5)

Some parents found spiritual care to be a source of support and encouragement. Parents described how they appreciated when chaplains prayed and sang songs for MFI; it brought them feelings of hope and peace.

> He's [chaplain] really nice and he came by twice and he talks to you and asks you… what your thoughts… He said if I would pray for her, and he like prays the way, like put his hand… on… it's really sweet. The first time we prayed I started crying. It's really, really sweet. And then he came by with one of his coworkers and they played lullabies. Cuz she was sleeping so they played this really, really slow, I recorded it, it was really sweet. (Father-07, p. 20)

Talking to staff from social work and spiritual care was a source of support for parents that helped decrease their stress. Secure housing was also a source of support.

Ronald McDonald House.

Ronald McDonald House was supportive for parents who were from out-of-town. It gave them a place to sleep, eat, and do their laundry, while remaining near their infant. Ronald McDonald House reduced financial costs and allowed them to focus on caring for their MFI. The community of parents at Ronald McDonald House provided some parents of MFI with emotional support and a sense of belonging. Creating relationships with other parents who were experiencing similar situations was a source of strength and hope.

> We're in Ronald McDonald now… I go over around 6 in the morning and I'll grab… our lunch and our breakfast and you know a coffee and milk for L. [twin-daughter] for the day… Then I go back over you know, 5, 5:30 and have dinner… and I'll do laundry and then I'll come back so we're here like 20 hours a day. Just having Ronald McDonald over there is so helpful. (Mother-20, p. 40-41)

Thus, Ronald McDonald House provided parents with housing and emotional supports to help cope with their stressors.

Creating trusting relationships with HCP.

Parents reported that HCP supported them and helped them navigate their stressors. Some parents appeared to more easily establish a relationship with HCP than others, and these relationships became a source of strength for some parents. Building a relationship with HCP made the parents feel they could trust them to take care of their infant.

> I think one thing that was very helpful was the nurses. What I did, I talk to them, I think it's good for me to know them to talk with them. That way I would be able to establish rapport. I would be able to establish a really good connection or relationship with these nurses and then that way I would trust them and would develop a very good trust. I know that they will not, they will not just ignore C. [baby], they will really do best for C. [baby]. (Mother-14, p. 11-12)

Parents appreciated engaging in normal everyday talk with nurses; it brought a sense of normalcy to their chaotic and stressful situation. Parents were often lonely sitting in the hospital room with their infant. Thus, developing relationships with HCP fulfilled their need for human connection, and helped enhance their spirits and feel part of a community. “Even if it’s about nothing in particular, like the other day I was talking about horses and I talked to the nurse for probably about half an hour about it” (Mother-10, p. 35).

Qualities of HCP.

Parents identified that certain qualities of HCP enabled them to better establish a trusting relationship with them. These qualities included: (a) coordinating with parents, (b) involving parents in care, (c) responsive nurses, (d) taking time to explain and be approachable, (e) doing small things made a difference, (f) taking a positive, friendly approach, and (g) truly caring for the infant and parents.

Coordinating with parents.

When nurses took a flexible and open approach to care, parents felt more included, respected, and cared for. Parents appreciated nurses who asked them how to provide care to their infant and allowed them to determine the daily schedule. “She asked me beforehand ‘If you’re both asleep do you want me to do that?’ And I said, ‘Yes.’ So she asked me questions like that.” (Mother-16, p. 14).

Also, when physicians were flexible in scheduling procedures around parental wishes and schedules, parents felt validated. It gave them a sense that they were in control and that the physician cared for and considered the parent, which made them feel more at ease and decreased their stress. One mother described in great deal her specific request to a physician to not implant a peripherally inserted central catheter into her son’s left arm because she wanted to save that site for his upcoming cardiac surgeries. Also, she requested a certain day for the procedure to be done because it worked better for her schedule. She expressed her gratitude for the doctor accommodating her requests and how it helped to decrease her worry.

> If you are worried because it is Wednesday I can do this on Friday… Was somebody who care. I start to cry and I say "Thank you, thank God that somebody understand"… He [doctor] fixed this working perfectly he come back and everything was ok. A PICC line [peripherally inserted central catheter] that he just move a little bit and fixed, everything is working, they can take the blood they can put the medicine, everything was ok, and I save the hand for the surgery. (Mother-09, p. 40)

Involving parents in care.

Parents appreciated when nurses took time to teach them how to care for their MFI. Some were first time parents, and it was overwhelming to provide basic care for their infant surrounded by technology. Being involved and included in care of the infant was a mechanism to decrease parental stress.

> They [nurses] encouraged us. Cuz you know when you first have, well at least for us a first child… your kid at first is like this wonderful object and you're so afraid that they're gonna break. That's not the case we know that's normal. But it was nice for them, "Here come change the diaper, touch your child" and make you – like he's not gonna break. (Father-16, p.11)

Responsive nurses.

When nurses responded immediately to the needs of the infant, parental stress decreased. This included responding to the infant's cry, alarms, vomiting, diaper changes, choking, status change, and so on. One mother described how she appreciated having a nurse who was quick to respond to her daughter's choking. "But when we rang the bell she [nurse] heard C. [infant] coughing and she would come in and check and make sure everything was good" (Mother-05, p. 18).

Taking time to explain and being approachable.

Parents were thankful when HCP took time to explain information using terminology they could understand. They felt acknowledged and included in the care team when HCP had an attitude that made parents feel they could ask questions and approach them.

> I mean they make you want to go to them to talk to them, so I've never felt like, oh I don't want to push that button because I really don't want them in here, they're always good, if they don't know that answer they'll go find it, they don't just give us a pad answer like I've had in other hospitals before… so that's been good, I've appreciated that, because it makes you want to talk to them, it makes you want to ask questions, it makes me feel comfortable to say how I feel." (Mother-02, p. 9)

Small things make a big difference.

When HCP did small simple things, such as get parents water, it decreased parental stress and made them feel recognized. A father provided an example a small action that made a difference for parents.

> We had a nurse at the [tertiary hospital] ask if we could transfer over our parking pass from there to here, she didn't have to do that. But she was proactive in trying to help us because she knew that was the last thing we should worry about. (Father-17, p. 28)

Positive and friendly approach.

When HCP took a positive and friendly approach it was easier for parents to interact with them. They heavily relied on HCP for the survival and care of their infant and interacting with someone who was positive and friendly decreased their stress and lightened their spirits. "I mean having a positive attitude, really helps… generally everybody smiles and asks how things are going… I think, people, hear us, whether they can actually do something about it or not" (Father-01, p. 10)

Truly caring for the infant and parents.

Parents recognized and appreciated when HCP truly cared for their infant, when HCP took time to engage and get to know the infant individually. This made the parents feel comfortable trusting HCP to care for their MFI.

> They just take care of your baby like it's their own right? Like they actually care, you need a lot of patience to be a nurse in general but like in NICU, a nurse in pediatrics it's really… I'm amazed by how much patience and how much love they have. Yeah you feel comfortable, you watch them take care of your baby and that makes you feel comfortable. (Mother-12, p. 17)

Parents appreciated when HCP cared for their wellbeing, as well as their infants. They appreciated HCP taking time to check and see how they were coping and managing their situation.

> They proactively try and make you, it's not just about him, it's about trying to facilitate our wellbeing. Because I think there's a correlation between if you feel relaxed the baby feels relaxed, the baby is gonna pick up on your feeling anxious. (Father-17, p. 14)

Establishing a relationship with HCP was a source of support that helped parents manage and cope with their stressors and grief. As presented, specific HCP qualities enabled parents to more readily and easily enter a relationship with HCP.

Internal coping mechanisms.

Some parents utilized internal coping mechanisms to cope with their stressors. Internal mechanisms included: (a) positive personality traits, (b) taking breaks, (c) being involved in infant care, (d) leaning on faith, religion, and spirituality, and (e) becoming a detective and master of coordination.

Personality traits.

Personality was foundational to how parents coped with stressors. Parents with personalities that were more easy-going and able to give control to HCP had a more positive view of their situation. Such parents were able to identify and focus on positive aspects. Their experiences were challenging but involved fewer frustrating encounters with HCP. Parents with an ability to keep looking ahead with hope and positive anticipation were less emotionally and mentally distressed. One mother had a positive outlook.

> So you gotta think positive. Cuz I, at the end of the day, my mom's like, she told me if stuff gets better from crying everybody would cry. But if you cry and stuff stays the same then why are you wasting energy? (Mother-07, p. 14)

Parents who sought perfection were often disappointed because parenting MFI was accompanied by setbacks and uncertainty. Such parents preferred care to be provided in particular ways and wanted to be prepared for what the future held. Parents who sought perfection tended to focus on the negative aspects of care and frequently overlooked the good. One mother compared her son's progress relative to perfection.

> He's ok, he's fine he don't need oxygen nothing he's **perfect** [emphasis added] but for in case something happened here they have a team here to help him…. He's getting the weight and everything was **perfect** [emphasis added]…. Oh M. [infant] is ok, numbers are **perfect** [emphasis added]… And he's open eyes, thank God the brain is ok, the kidneys the organs is **perfect** [emphasis added] so I was happy because of that. (Mother-09, p. 10)

Because of parenting MFI, some parents reported that they either developed strength within themselves or identified a strength had not been previously recognized.

> Through the breast feeding, pumping, I think that I'm stronger than I thought. I used to quit everything really quickly for example, like studying, I gave up math because it's getting difficult… I just never kept doing… anything like this long, I just thought about myself, if I could do this this long, almost 6 months pumping no one expected me to do this. (Mother-03, p. 14)

Recognizing strengths enhanced parental ability to parent their MFI.

Taking breaks and doing something parents enjoyed.

It was hard for parents to take a break because they worried their infant would be sad and lonely without them, and they feared a medical error could occur. However, parents recognized that taking a break was important to maintain their mental health. Often, parents went to the nearby shopping mall, Ronald McDonald House if they were residing there, or went home to play with other children. Also, some parents engaged in hobbies such as reading, doing crafts, or watching movies. "Yeah, at night I'll watch something. I love Christmas movies, they're so much fun" (Mother-07, p. 12). It was difficult, both emotionally and physically, for parents to sit at the infant's bedside all day, however, taking breaks and doing something they enjoyed was refreshing.

Parents expressed that physical activity combated their stress and anxiety. One mother described that yoga helped her to calm down and relax; however, she could not find the time to attend classes because she lived far from the hospital. When she did attend a class she felt guilty because it took time away from her infant.

> I'd like to suggest this hospital to have classes for yoga, since it was really good for me… I tried to go to yoga for focusing on myself, release myself, yes too stressed out… I tried to go there at least every 2 days, that was really helped… It should be here, just for parents. (Mother-03, p.7)

Being involved in infant care.

When parents took an active role in the care provided to their MFI they felt more confident in their ability to care for their infant, which contributed parental feelings that they were having a positive impact on their infant's well-being. Providing care to their MFI decreased parental stress.

> Spend more time with him. Cuz at first when you have a very sick child, you're so wary of, you forget sometimes that he would benefit from that as well. You're just like "Oh I

> don't wanna disturb him" but then you realize, now I look back… and the bond that's formed between you when you are holding him and doing things, it's hard to do in the hospital but if you do that it actually improves the care for, at least for me emotionally and mentally right. Which is I know as important. (Father-17, p. 11)

Leaning on faith, religion, or spirituality.

Parents, who had a strong belief that there was a greater being who was orchestrating the events in their infant's life appeared to cope better with their situation. Parents with a strong and active religion (Christian, Muslim, or Sikh) managed their stressors better, were able to relinquish control to HCP, had a more positive outlook, and established trusting relationships with HCP. One mother held a strong Muslim belief that Allah chose her to parent her infant and would give her the strength to do so. This belief enabled her to relinquish control and worry less about the future.

> In my religion there is this thing that my sister told me and it really means a lot to me. I cried for like days cuz I didn't know what to do and then she said… "kids like these, she's rare, it's a rare disease and she's special. She was given to you, it's a gift that's wrapped so you have to slowly unwrap it to see what's in the bottom." So it kind of means, like whenever I look at her that's what I think. I'm still unwrapping it… the present that's in there will be worth it you just got to wait and watch. (Mother-07, p. 5)

Another mother described her Christian faith in God who was in control and knew the final outcome. She believed that her son was ultimately in God's hands. This belief gave her peace amidst much uncertainty.

> I think it's just faith that gives me strong with everything what's going on… like all of us here we are doing all our jobs but God is just controlling everything. That's what I think yeah. He knows the outcome already but it is just us who is doing everything through that outcome. (Mother-14, p. 8)

Belief in a higher power who was in charge of directing the path of their MFI gave parents a sense of peace and hope, helped decrease their stress, and increase their ability to cope with their stressors.

Detective and master of coordination.

MFI underwent a plethora of tests and treatments to better understand and find solutions for their symptoms and conditions. As a result, parents went into ‘detective mode’, attempting to problem solve and alleviate symptoms as well as prevent setbacks. Detective mode included: keeping track, monitoring, making suggestions, and advocating. Parents worked extremely hard at their detective work, constantly searching for answers to enhance the health and well-being of their infant.

> It’s watching and stuff…, they do tests and there’s nothing in the test but then you feel like there’s something. It’s just a lot of complicated to figure out, like the NG tube, the NJ… it’s hard to say from my part which is working and which is not cuz sometimes it’s probably the NJ but sometimes she is way better than she is and the stress [symptom] is cuz of the tube or is it cuz she’s just feeling better today. (Mother-07, p. 11)

Coupled with the role of detective, parents also became masters of coordination. Parents became responsible for managing the complex medical needs and treatments of their MFI, coupled with the responsibilities of parenting. Most parents had to continue to manage a household, and for some, care for siblings while spending a majority of their time in the hospital with their MFI. Thus, parents had a plethora of responsibilities that they had to coordinate. One mother had a toddler, her husband worked at two full time jobs, she had no supports, and pumped expressed breast milk. She ran her household, cared for her toddler and hospitalized infant, and managed to exercise thirty minutes a day. “But having to do it [pumping] three to four times a day, I feel like I’m able to manage my time so well…. I pump at the same time I fold the clothes, I cook” (Mother-14, p. 21).

Engaging in detective work gave parents a sense of control amidst great uncertainty, and coordinating multifaceted responsibilities helped parents manage and cope with their stressors.

Mental Health Implications of Parenting MFI

Parents described how they experienced emotional and mental health difficulties. Three distinct concepts within mental health emerged: (a) physical manifestations of stress, (b) trauma, and (c) stress and anxiety. One mother stated she was diagnosed with depression, and most parents indicated they felt sad about their situation. Most parents stated they felt anxious and stressed.

Physical manifestations of stress in parents.

Some mothers, and a few fathers, described experiencing physical symptoms that were troublesome. One mother's face went numb and she had to go for a Computerized Tomography (CT) scan, along with multiple visits to the emergency room (ER). She also had hives over her body during times of intense stress. One mother experienced episodes of severe chest pain, could not feel her legs, and could not breath. After testing in the ER, she was diagnosed with panic attacks. Another mother was also experiencing severe panic attacks, not sleeping, and cried frequently. She also experienced heart arrythmias and often felt like she was having a heart attack and dying. Another mother spoke to experiencing a situation where she was shaking and then fainted in the middle of the night; she was then subsequently rushed to the emergency room. These symptoms were extremely stressful for parents to navigate while also having to care for their MFI and, for some, other siblings.

> My face is numb, it's been happening for a few months. So I had a CT here, I was supposed to have an MRI back home but that was the day after we got admitted here so I couldn't go to it. So I eventually went to the ER here and they did a CT scan and that was clean which is good so there's no big scary thing. My face is still numb and during really stressful times it gets even worse. So I think that's a lot of emotional. Like I don't know if it's strictly because of stress and all that but it's definitely like increased… Plus I also get hives. And so I went for allergy testing that's part of it but I know it's also just part of stress that I get hives, cuz I've been covered in hives this whole time. (Mother-05, p. 24)

Trauma.

Parents used the word *'traumatic'* to portray what they were experiencing. Some parents stated without being directly asked that they were suffering from PTSD. One mother had been diagnosed with PTSD by a physician, and three parents identified symptoms including difficulty sleeping, disturbing flash images of the infant, hyperarousal, always expecting the worse, being constantly on edge, memory loss, and difficulty coping with their situation. One mother was a registered mental health nurse who recognized symptoms of PTSD within herself and her husband:

> I think both of us had a little bit of PTSD or a lot just from everything that's going on. So I think we're very hyperaroused with situations, if there's a change in his status… we're not very, I guess rational… We'd go to extremes a bit so you know when he got meningitis the first time he was doing so well then such a huge step back and when we got transferred… he started doing better but he'd have you know the standard NICU two steps forward one step back or the roller coaster. Every time he'd have that one step back we'd immediately go to the worst-case scenario. (Mother-08, p. 7)

The parents in this study experienced life altering, traumatic, and unexpected events while parenting their MFI. As a result, some entered a state where they constantly expected the worse. Because of experiencing heartbreaking setbacks and disappointments along their journey, they began to lose hope and expect continued disappointments.

> I'm always nervous she's gonna regurge and we gonna go backwards. Like when we get so close to going home like we are now hopefully… she always does something that sets her like ten steps back. I'm always, I just have that anxiety and stress in the back of my mind that something is gonna go wrong. (Mother-12, p. 8)

Stress and anxiety.

A majority of parents described feeling stress and anxiety due to the uncertain nature of their infant's condition. Based on parental personality, available support, and health status of the infant, stress and anxiety appeared to vary in degree. Parents with more perfectionist personalities, fewer supports, and more unstable infants appeared to experience greater stress and anxiety. All mothers described feeling anxious and extremely worried when they had to leave their infant in the hospital unattended.

> It’s hard because, the depression hasn’t gotten worse, but the anxiety does, because when I leave to go home at night I worry is he going to throw up, is he going to aspirate, is E. [husband] even going to hear him and wake up if he is choking, because there have been times at home when none of us have heard him and he’s thrown up and wakes up in his vomit and that’s kinda gross. (Mother-02, p. 3)

Parents experienced emotional and mental health difficulties as they parented their hospitalized MFI. The extent to which each parent experienced such difficulties differed according to their unique situation and ability to cope with their stressors and grief.

Summary of Parental Experiences

Parents of hospitalized MFI grieved the loss of not being able to parent a healthy infant at home. They also experienced multiple stressors. Internal and external coping mechanisms were utilized by parents to cope with their grief and manage their stressors. When parents were unable to cope with their grief and stressors they experienced mental health difficulties, including stress, anxiety, and PTSD. Following, HCP experiences will be presented and described.

Chapter 6: HCP Findings

Characteristics of HCP

There was a total of 26 HCP who participated in this study: 12 nurses, seven pediatricians, and seven allied health care professionals (dieticians, occupational therapists, social workers, and physical therapists). The average age of the HCP was 45 years; 25 were female and one was male; and six had master's degrees. HCP worked with MFI at the Alberta Children's Hospital for an average of 14 years. A total of 17 interviews were conducted with HCP; five were focus group interviews that included nurses, pediatricians, social workers, occupational therapists, physical therapists, and dieticians; 12 were individual interviews with nurses and pediatricians.

Based on availability of HCP, focus groups and individual interviews were scheduled. Data analyses occurred simultaneously for focus groups and individual interviews. Thus, coding and emerging themes were integrated into subsequent interviews and focus group discussion. The same interview guide was utilized during focus group discussions and individual interviews and was altered according the data analysis of both. Therefore, data from individual and focus group were integrated into one another during data collection and analysis.

HCP Experiences

HCP aimed at improving the health of MFI through providing medical and basic care. HCP aimed to include parents in the care provided to MFI: they educated, empowered, and enabled parents to provide both medical and basic care. They accomplished this by earning parental trust and establishing a supportive relationship. The parent-HCP relationship was a means to an end, to meet the needs and enhance the health of MFI within a collaborative effort with the parents.

Trust was the foundation of the parent-HCP relationship. Trust gave parents faith that their infant was safe and helped them believe that HCP were making good medical decisions and recommendations. Trust enabled HCP and parents to work well together as a team towards a common goal, that of enhancing the health and well-being of the infant. Importantly, trust formed the relationship that empowered parents and HCP to collaborate and create a partnership with one another. “I just really try and establish some sort of trust. Often that means building the relationship” (NSG-02, p. 22). Problematic interactions between parents and HCP occurred when trust was broken. Once trust was broken, it was difficult to get it back. “It’s very complicated… it’s a really hard situation and once the trust has sort of been broken it is so hard to get it back” (NSG-02, p. 7).

A trusting relationship developed through multiple interactions. Parents and HCP came to know and better understand each other through continuous and ongoing interactions. Parents gained trust in HCP when they observed and felt that the HCP were providing care that was safe and in the best interest of the infant and their family. Repeated interactions allowed the HCP to know and understand the history, health status, and specific care required for MFI. When the HCP became proficient in this knowledge parents began to trust them.

> You always have to gain respect and trust right? It takes a while sometimes, then I find once you break that barrier just the ease that the families, you can just see it when they come it, it’s just comfortable for them right because they totally trust you. (NSG-08, p. 6)

Aids to Establishing Trust and Developing a Supportive Relationship

HCP recognized that parents experienced stress when caring for their MFI. The supportive relationship built on trust was utilized by HCP to help decrease parental stress and foster collaboration as they worked together with parents to meet the individual needs of each infant. HCP utilized five factors to gain trust and build a supportive parent-HCP relationship, including: (a) normalizing and building confidence, (b) tailoring care and being flexible, (c) empathizing, (d) providing parent care, and (e) optimal communication.

Normalizing and building confidence.

HCP recognized that providing medical care to MFI was not normal or comfortable for most parents because they were not trained medical professionals. HCP noted that parents were often hesitant and afraid to provide medical and basic care to their MFI infant surrounded by medical technology.

> I'd say for the most part it dissipates. Some families… it takes more time, or some of them are always an anxious person. But I think, when you can help to normalize it for them, and to help them feel confident in what they're doing. (NSG-10, p. 8)

HCP identified that parental care of MFI was very different than that of a full-term healthy infant. They tried to help parents find and feel a new normal by involving them in the care of their infant to help them smoothly transition into their new world, that of caring for a medically fragile infant. It was important to include them right away, so parents could become proficient and confident early on. "There's a variety on unit two right, like TPN, G-tube, NG whatever but um, yeah as long as you know… they're definitely involved right away and taught, or not even taught just get them doing, maybe normalizing it right" (NSG-06, p. 18).

Tailoring care and being flexible.

HCP recognized that each parent-infant dyad encompassed different needs, diagnoses, personalities, values, beliefs, and goals. As a result, HCP aimed to tailor care to meet the specific needs of each MFI and parent.

> You know what works for one family is not gonna work for another family because everyone is unique and different. So I won't say and do the same things for everybody, because it's not gonna work for everybody. (NSG-05, p. 12)

Having a flexible approach to care was important for HCP to build trust with parents. Nurses noted that it was important to involve parents in scheduling tasks, such as feeds and assessments. Nurses were aware that parents understood their infant best, and it was important to involve them in scheduling tasks.

> Being able to just be flexible with yourself and say “You know this assessment doesn’t have to be done at 12 o’clock on the dot, I can do this at 1 o’clock.” I don’t feel like the doctors get angry at that. No one is gonna be “I can’t believe you did that.” So yeah, I think just having a bit more flexibility for sure. I feel like sometimes we get so task oriented we forget about that emotional piece. (NSG-06, p. 8)

Nurses identified that one way to be flexible and tailor care was to do small things. Often small things, like bundling their infant in a particular way, holding the bottle at a specific angle, or using a particular cream with diaper changes, enabled HCP to decrease parental stress and help them to relax during intense situations. “It’s those little things that just – it just relaxes them” (NSG-07, p. 14).

> For me it’s those little small things like “How do they like being bundled, how do they like to sleep at night, do they lie on their side, do they lie on their back?” You know, those kind of things. Even sometimes how much do you prefer to flush with and some families are so nervous about it being flushed too fast. Just those really tiny things that make a huge difference for those families. Which… is no scratch on our backs. We can flush for an extra 5 seconds if that’s what families need. (NSG-05, p. 1)

Empathizing: Putting themselves in parents’ shoes.

HCP often had difficult encounters and problematic interactions when parents were upset regarding aspects of their infant’s care. During such moments HCP sought to understand parental experiences by imagining themselves in the parent’s shoes. HCP considered how difficult it was for parents to have MFI hospitalized for extended periods of time. HCP found it easier to offset the stress of difficult encounters and problematic interactions when they had empathy for parental experiences. Empathy helped HCP to remain open with parents and fostered a supportive relationship.

> Kind, supportive, because of what they're going through. You know, I think key that you can't forget as a nurse is putting yourself in their shoes, and you know really thinking what would it be like to have a baby with a trach [tracheostomy] or major heart defect and you know it changes their whole life you know. So I think it's just empathy. (NSG-03, p. 4)

Having empathy helped prevent HCP from becoming judgmental during difficult encounters. To develop and maintain a trusting relationship with the parents, it was vital for HCP to recognize that most often difficult interactions were not directed at them. Rather, difficult interactions were the result of multiple frustrations and difficulties combined. Thus, it was important for HCP to not take these challenging encounters personally.

> Even with that difficult family… when they say things to me, again you just gotta let it go. It's not you, it's the word nurse that they have an issue with. Even with that family I haven't had any major issues we've been able to talk and yeah just not taking things personally I think is so important. (NSG-05, p. 6)

Providing care for parents.

HCP often witnessed that parents became exhausted due to coping with their multiple stressors and did not get adequate sleep, nourishment, and breaks. HCP sought to care for parental well-being by encouraging them to take breaks, such as going home to sleep. They also provided nutrition, such as water and snacks. HCP found that ensuring parents' physical needs were met enabled parents to be more present with their MFI and helped them better cope with stressors. "And having to intervene, and making sure they're eating, and drinking water, and sleeping" (NSG-09, p. 21).

HCP recognized that parents were struggling emotionally and mentally. HCP, specifically nurses, felt that caring for parent's emotional well-being was part of their role.

> That's [emotional care] part of… family-centered care is we're not just taking care of the patient, I mean the patients are our focus, but in order for the patient to be doing well, the family has to be doing well too. And so I think it's kind of all tied in together. (NSG-10, p. 15)

Nurses sought to be present and support parents emotionally as they coped with their stressors and grief. Most often emotional support was provided through conversations and communication. "Pulling up a chair and just saying, you know, 'How are you really doing today? Like really, *how* are you doing?'" (NSG-07, p. 5).

Optimal Communication.

The parent-HCP relationship most often became fragmented due to lack of communication. Parents gained trust in HCP when they communicated and kept them informed of test results and care decisions. Communication made parents feel included, acknowledged, and part of the team. HCP identified that knowledge and information were empowering for parents, because it made them feel in control and prepared.

> I think that's all they need is just explanations. Communication I think is huge. I think there's a lot of communication breakdown in the hospital. So I feel like if you're open with parents um, very open, explaining to them why you're doing something. (NSG-03, p. 5)

HCP aimed to establish trusting relationships with parents by normalizing, tailoring care, being flexible, empathizing, caring for parents, and communicating. These were key actions HCP engaged in to collaborate with parents in the care provided to MFI. However, at times trust was not established and the parent-HCP relationship suffered as described below.

Hindrances to the Establishment of Parental Trust in HCP

Hindrances that prevented or eroded trust included: (a) intricate nature of MFI, (b) lack of social supports, (c) inconsistency, (d) moral struggle, (e) staff burnout, and (f) struggle to gain control.

Intricate nature of MFI: Increase in numbers, complexity, and acuity.

HCP reported that the current number of MFI has increased because more MFI are surviving. “Well… it was a simpler, like some of the kids are surviving that would never survive before” (NSG-01, p. 9)

HCP indicated that MFI are a complex population because they were small and fragile, and their diagnoses were multifaceted with often uncertain trajectories. As a result, MFI were difficult to care for because they had intricate multi-system diagnoses and were very fragile.

> I feel like the population has changed… I’ll often say where are my bronchiolitics [patients with diagnosis of bronchiolitis], they just get better and go home. There’s some but there doesn’t seem to be as many. It feels like we have more kids staying longer, more severely ill. (NSG-02, p. 9-10)

The inpatient unit received infants who were more acutely ill and required more monitoring and complex medical care than in the past. For example, the inpatient unit historically did not receive ventilated patients, and rarely had an infant with a tracheostomy. Currently, there is a six-bed hallway dedicated to complex airway children who regularly have ventilators and tracheostomies.

> I think unit two is quite acute. I think the kids can be pretty sick there. Especially, now I can’t really compare the two because we didn’t have trach’s or ventilators on the units back then so that being said, I think the kids are sicker on the units now. It is busier, more acute for sure. (NSG-03, p. 2)

As the infants have become more complex and fragile, HCP noted that it has added more stress and burden on them to provide highly technological medical treatments and assessments, and coordinate and plan care in uncertain scenarios. Despite this increase in demand, the HCP to patient ratio has remained the same. Thus, HCP have been imparted heavier workloads without an increase in staff to offset the increased workloads.

> As the babies are sicker I feel like more responsibility is on our assessments. The doctors are still there and they're still as brilliant as they always were but there's more, I feel more responsibility on our assessments to see if something's off. (NSG-02, p. 11)

HCP noted that there was a current increase in numbers of MFI on the inpatient unit, increased in acuity of MFI, and an increase in complexity of MFI diagnosis. These three factors have led to increased stress experienced by HCP in managing the complex and intricate care provided to the MFI and their parents.

Lack of social supports.

HCP recognized that MFI and their parents are a complex population with complex social needs. HCP recognized that parents often struggled emotionally and mentally and that they required supports. "Let's face it our unit could use a full time plus social worker. It's getting to be more the norm where you constantly, constantly like every admission you're like 'this family could use a social worker'" (NSG-08, p. 1). However, due to the acute and complex nature of medical care and heavy workloads, HCP time was focused primarily on meeting immediate physical and medical needs of the MFI. "When there's acute medical things going on that always trumps everything else" (NSG-04, p.13). The exception was social work who focused their attention on parental health and well-being.

HCP identified that parental health and well-being were important because parents were key in providing care and support to the infant. However, all HCP noted that there was a lack in services and supports to aid parents in their emotional and mental health. The focus of care provided to this population was on the infant.

> I think that one of the things that comes up for me, not infrequently, that we don't have access to services other than social work that are trained in adult mental health, so postpartum depression. When I did stuff in Australia, they actually had a psychiatry consultant who would come on visits and would see the parents. Um, so I don't feel like we have that support, other than going to social work, if the parent is clearly not coping, and I don't actually know what to do. (MDFG, p. 21)
>
> And so having a medically fragile infant where you're the long term, like you've got to reset your expectations and you've got to let go of a lot of hopes and dreams and make new hopes and dreams. I think that's the hard part is sometimes no one helps them with new hopes and dreams that sound positive to them, it sounds just terrible right? (MD-01, p. 11-12)

Most often HCP first line of defense to help parents cope with parenting their MFI was to consult social work. "We consult social work on everybody. Like who doesn't social work see right now. They see every patient I feel like. And whether it's from resources or just coping support" (NSG-02, p. 15). Social work noted that they have heavy caseloads and are often pressed for time. They indicated that they do not have the 'luxury' to spend extended periods of time with parents like they did in the past. Occupational Therapy noted that their access to social work was limited as well due to health care cutbacks: "We have seen such pullback in… these support services from our social workers… and we see… how that plays out with the families, because a lot of them are double-, triple-booked" (OTFG, p. 8).

As a result of sparse social work supports, the responsibility of emotional care often fell to the nurses. Most nurses believed it was their responsibility to provide emotional support to parents; however, some of the nurses noted they did not feel qualified to provide such care and often lacked time. Therefore, parents were often left to fend for themselves, with limited supports to help them cope with their extreme situation.

> That's where it maybe falls on the nurses' laps right to do a little bit of that but we're not trained really in counselling. Yeah I think a lot of the time our parents at the Children's are left on – to their own defenses. Which is why you see a lot of marriage breakdowns, abuse, yelling at staff, that's how they deal with it. Right? (NSG-03, p. 8)

HCP noted that they did not have professional psychological counselling for parents. Subsequently, HCP cared for MFI with parents who suffered emotionally and mentally and recognized that this was a factor that contributed to the frustrating encounters with parents and broken HCP-parent relationships.

> I can think of a few families with us that I think having like trained counsellor psychologists and having access to that, and then… if it's something that's an extra cost to the family, because like having people skip it because it costs something. But I think if we said this is a model of parent healthiness is to go and talk to someone about this, what you're going through and what you're transitioning yourself through. Um, cuz this is hard. (MD-01, p. 12)

Some nurses noted that they did not engage in providing emotional care to parents because they had not been trained or encouraged to provide emotional care to parents.

> Sometimes we don't have time, quite frankly, for sure. But there are many times when we do have time… Whether we're just not skilled at it or nervous about doing it, I don't know. But it's not very often that you'll hear, or that I will hear another nurse saying, "You know, I really had a nice talk with that mom." Or, "You know what? I'm glad I took the time, because she's really." You don't hear those conversations ever... (NSG-07, p. 8)

HCP recognized that parents of MFI need emotional support to aid their mental health and ability to cope with stressors. However, such supports are inadequate due to social work shortage, lack of time from providing complex medically focused care, and limited training for HCP on how to provide emotional support to parents of MFI.

Inconsistency.

HCP recognized that inconsistency was a barrier that prevented them from gaining parental trust and creating a parent-HCP relationship. Inconsistency emerged in three distinct areas: (a) lack of continuity of care, (b) inconsistent processes of care from unit to unit, and (c) inconsistent plans of care.

Lack of continuity of care.

HCP perceived some parents of MFI as demanding, because they were particular; they knew what worked best for their infant and had specific requests and expectations.

> What comes to mind is MFI are rewarding but it can also be very stressful. There is lot of pressure I feel from the families for sure. They are very knowledgeable in their children's care and stuff. They've been taught a lot and they know a lot so you feel a lot of pressure. (NSG-06, p. 1)

Creating a relationship with parents developed during repeated interactions. However, current shift rotations and patient assignments of HCP often resulted in inconsistent HCP managing MFI care. The constant rotating of HCP made it difficult for parents to establish trust because they did not engage in repeated interactions. HCP were not familiar with MFI' care, and each HCP had different approaches to care. One physician termed it "parachuting in and out" of MFI and their parents care (MD-01, p. 6). Unfamiliarity with MFI and their family decreased HCP ability to provide optimal care and meet the individual needs of MFI and their parents. This increased parental frustrations, which subsequently prevent the establishment of trust and increased parental stress.

> Part of being casual and then also part time is, you know sometimes you're there for like just little bits, and so I think that makes it's even harder to build a relationship like a trusting relationship. When they're seeing so many people all the time. I don't know how much trust they build all the time with certain individuals. (NSG-04, p. 4)

> I notice when I care for kids that I've known for like a long time you know, our Z. [infant], I just know him so well and I know his personality and I feel like if things are going on cuz he's by himself too right and nonverbal. I feel like I know him so well now that I feel like if stuffs changing I feel like I'd be more in tune to it quicker. It just makes me feel more confident in providing good care for him. So I can see how that [primary nursing] would be great for these kids and their families. Yeah where sometimes it's like subtle you know, the subtle things that… can happen that need attention that might not

> get picked up all the time if there's always like a new person every single shift. (NSG-04, p. 4-5)

Inconsistent processes of care.

When parents transitioned to the inpatient unit with their MFI from the NICU or Pediatric Intensive Care Unit (PICU) they encountered variations in policies and processes of care. For example, the nurse to infant ratio in the NICU and PICU was one nurse to one to two patients, whereas the ratio on the inpatient unit was one nurse to two to four patients.

> It's how a child is nursed in the NICU is very different. It sets us up to look bad. You go there, they have to wash [their] hands for like 5, 10 minutes; everything is very clean. You've got one to two nurses, nurses eyes are on that baby constantly. And they come here, and you're in a room, and sometimes that door is shut, and that nurse doesn't come in for two hours…. And from their eyes, I get it a 100%, because I would think, "How can you just go from yesterday, from having a nurse that was 2:1, who was there all the time, who was in, you know. I was constantly watching her care for my baby, to go to a unit the next day." (NSG-07, p. 11)

It was challenging for HCP to gain parental trust following transition from the NICU or PICU to the inpatient unit because of parental frustration and tension associated with differences in the care environments.

Inconsistent plans of care.

Nurses stated they did not have time to review the MFI' chart and know their history due to heavy workloads on the inpatient unit. Also, HCP were not easily able to access care plans. This caused confusion and frustration for parents because care was inconsistent, and parents felt HCP did not know their infant and required care well.

> The care plan on the computer… is finicky. I can see why people don't really fill it out. And I've looked and said, "Oh this isn't filled out." If I get to this today that would be great and I'd never get to it. There's so many other things to do… Especially for those NICU transfers if there was somebody who was responsible for filling that out and even just talking to mom's and dad's before they come like, what care would you like us to leave for you? Would you like the babe to be bathed when you come here at 10 o'clock

> with the 4 other siblings or do you want to bathe the babe every day? Do you do the feeds, do you. (NSG-02, p. 25)

Given the complex nature of MFI, physicians often had difficulty developing consistent plans of care. Multiple specialties and disciplines were often involved in planning care who rarely had team meetings or conversed in person when planning care.

> It's not like you have pneumonia, there's kind of like a first choice, and you treat others, and we rarely disagree on what that might be. We have cases where our management ends up being very opinion-based, and we can generally agree if we talk about it, but it's not absolute that what I'm thinking might not be the same as the surgeon. (MDFG, p. 8)

Thus, contradictory and inconsistent plans of care caused confusion and frustration for parents.

> It's a pretty good team already, I think communication could be better. Um, especially between nurses and doctors. I find a lot of the time doctors don't… let you know the plan… They go in the room and then they walk right past you… They don't stop to tell you. I just think that's so wrong, it's a team, and nobody learns that way. Nurses don't learn. Then you'll see they've ordered something an hour later and you're like "Wow I had no idea that they were thinking of this." (NSG-03, p. 22)

Lack of continuity of care, inconsistent processes of care among unit environments, and inconsistent plans of care prevented the development of parent-HCP relationships. When HCP, processes of care, and plans of care were inconsistent parents became confused and frustrated.

Moral struggle.

Nurses encountered moral dilemmas in the provision of care to MFI in two respects: (a) absent parents, and (b) infant's quality of life. When parents were absent for extended periods nurses experienced MFI laying alone in their crib crying excessively. Given the demands placed on nurses they often did not have time to cuddle and console such infants. This caused inner turmoil and moral distress for the nurses because they were unable to meet the emotional needs of MFI and it was difficult to witness infants crying without parental nurturing and support.

> We call it orphan alley, sometimes down the yellow hallway. I just think that's unacceptable. I think… there's no reason those parents shouldn't be there. And I'm not sure why if it's ever been explored why they're not there… I mean when you see these little guys left in their crib by themselves all the time there's no development. It's crazy. That's hard so I'm not sure what could be done about that. I mean there's only so many volunteers you can get, I mean and that doesn't seem right. I mean if you have a child you should be there as a parent. I mean I know that there's a lot of good reasons why parents aren't there but in some cases there's not. (NSG-03, p. 16)

HCP experienced moral distress providing medical care to keep MFI alive who they believed did not have a good quality of life. Specifically, nurses found it difficult to provide medical care that inflicted pain and discomfort to MFI when such care did not improve the infant's quality of life. At times nurses felt that they provided care to appease the parent's emotional needs but not in the best interest of the MFI.

> We do have very broken babies, and I think sometimes I wonder like what their quality of life will ever be… I love all the advances that we've had and the technology and things, but sometimes I wonder, like, if that's even beneficial. Or who are we doing this for? Like, and it's hard… it's like an inner struggle for me, for sure. Cuz you see them and the technology's helping, but then it's also preventing – or causing further issues elsewhere… they'll for always be dependent on this… That will cause all these other problems… Sometimes it's-it's hard to put into words how that makes you feel. (NSG-10, p. 21)

Nurses experienced moral dilemmas when they witnessed MFI alone crying in their crib without parents and provided care to MFI that they felt did not have good quality of life. These situations caused moral distress, increased nurses' stress, and increased their risk for burn out.

Staff burnout.

Regularly caring for MFI and their parents was exhausting and emotionally draining for some HCP. As a result, HCP became burnt out due to the demands of providing complex medical care to MFI and their parents who struggled emotionally and mentally. The difficult and uncertain situations that parents went through was sad for HCP to witness and cope with.

> A couple of times I've come on shift and just think, "Oh I just, I just can't even." It's the only way to describe it. I know this family needs more TLC I know this family needs more time and I just can't. I don't have it to give and that was sort of the breaking point. (NSG-02, p. 9)

Most nurses indicated that they had to work part time due to the high stress and demands they encountered while caring for MFI and their parents. Self-care helped nurses to avoid burnout by aiding them in establishing balance and preventing chronic stress that caused exhaustion and affected their personal lives.

> Like the stuff that you deal with is crazy. So I think the hard thing is… the not knowing and walking in, and sometimes day to day, like I'm not full time, if I was full time, and I know for myself that's the one reason I'm not a full time person because I can't take care of these children and work full time and keep my sanity. Because you cannot help but get involved in the stories and it's really heartbreaking when kids take steps back… like we get involved in these kids and we get emotionally invested in these families and so it's very hard to walk through with the kids and people going through mini-crisis… this is our job, this is what we do daily, or three times a week or whatever… It really can be hard depending on how you process it. I think that's a really key thing for taking care of medically fragile kids, is how does the caregiver process it and how do they find balance and health within these situations where we're literally, we have the lives of children in our hands. (NSGFG, p. 1)

HCP reported that parents of MFI were becoming increasingly demanding and more difficult to work with, and some cases refused to allow certain nurses to care for their infant. HCP felt that these demands were due to increased parental access to knowledge via the internet, social media, and other parents via online chat rooms. HCP reported that parents believed they were entitled to a certain level of care, which in some situations, increased parental perceptions of authority to demand specific care and to 'fire' staff who were not appeasing their demands. This was disheartening for staff. Senior nurses noted that this level of demand was a recent occurrence.

> Afraid – there's this other thing that I struggle with, and I don't have the answer. But this happens more commonly than not, and I have ideas about this, but whether they be right

> or wrong: but we have a lot of families that fire nurses all the time now. And *that's* something, 20 years ago, never happened. (NSG-07, p. 7)

This notion of firing staff may be related to the power struggle that occurred between parents and HCP.

Struggle to gain control.

At times parents and HCP experienced a struggle for control. Parents felt uncertain and confused due to inconsistent staff, inconsistent processes of care, and inconsistent plans of care. As a result, they became frustrated and protective of their infant, and demanded care and decisions be approached their way.

> When things are maybe going a little sideways, or when emotions are high… they start to gain that power and maybe feel like that power gets taken away again… Cuz I think a lot of things is a power struggle sometimes, not so much of them… wanting power or thinking we're taking over power, but just feeling like they don't have control over anything, because their child is… sick. And, you know, they can make decisions, but they can only make so many decisions. (NSG-10, p. 17)

HCP recognized that at times they took control away from parents because of the complexity and fragility of MFI. Also, HCP recognized that occasionally parents had to fight and advocate to regain control.

> They completely lose all control which is awful. I couldn't even imagine what that would be like. Especially when you're pregnant with this child, especially if you've had a baby before and you've known what control you have and then all that control is taken away from you at the hospital. I think at ACH we do a fair job of being able to give parents back that control, or at least some control. But for some families they really have to fight. And I don't think it should be a fight, it should be something that is automatically given to them as a parent. Especially the families that there's no issue with them. (NSG-05, p. 5)

Parents had access to information via the internet that was occasionally contradictory to HCP' plan of care. When parents disagreed with the medical decisions, stress and tension increased between parents and HCP.

> Sometimes my biggest problem with the long-term complex kids is that I feel that oftentimes it changes from family-centered care to family-driven care, where their perceptions are often confused and I get how it guides it, and that's totally fair. They're being the advocate, but sometimes they're so strongly advocating that they're missing the… they're not willing to hear the medical side of things, and that we're coming at it from a place of understanding and from knowledge, that we're trying to *help* [emphasis added]. (DIET, p. 1)

Summary of HCP Experiences

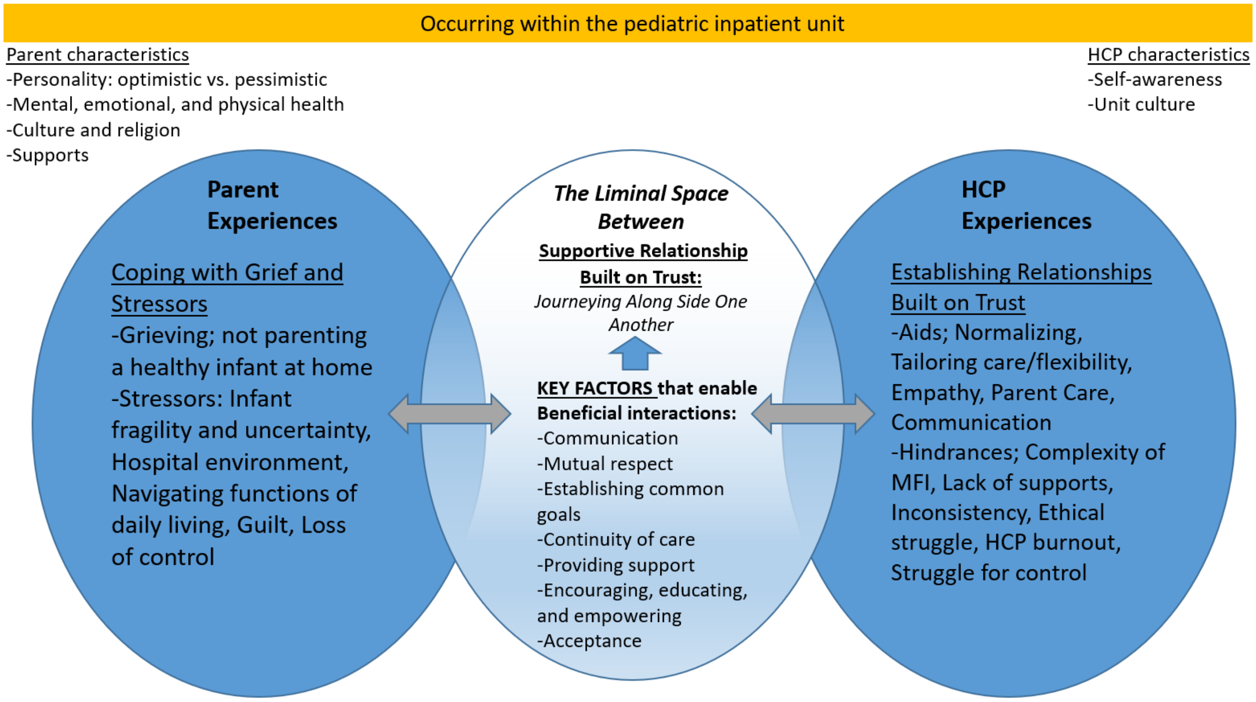
HCP aimed to establish trust and a supportive relationship with parents of MFI as a means to collaboratively provide care. Often there were barriers that prevented HCP from establishing supportive relationships and factors that eroded trust. This resulted in HCP experiencing burn out, moral dilemmas, increased stress, and emotional exhaustion. HCP recognized that occasionally parents experienced a struggle to gain control and did not agree with HCP' care decisions, which also increased HCP' stress. The upmost importance of parent-HCP relationships was identified when parental experiences were compared and contrasted with HCP experiences. The relationship was identified as the foundation of the theory 'Journeying Along Side One Another,' which is described in detail below in Chapter 7.

Chapter 7: Theory of Journeying Along Side One Another

This chapter presents the data analysis and theorizing of the theory 'Journeying Along Side One Another'. The purpose of the chapter will be to explain the main concern of the study of caring for a hospitalized MFI. The theory that emerged is not one truth or set of truths, rather it sought to find a collective meaning of parents and HCP' experiences and processes of caring for MFI. The research questions that guided this study were: (a) what is the experience of being a parent of a hospitalized medically fragile infant, and (b) what is the experiences of HCP providing care to MFI and their parents (both mothers and fathers) in the hospital setting?

As presented in Chapter 5, parents experienced stressors and grief that they coped with by utilizing internal and external coping mechanisms. When they were unable to adequately cope, their mental and physical health was impacted. As presented in Chapter 6, HCP experienced stress, struggle to gain control, burn out, and moral dilemmas while providing care to MFI and their parents. HCP aimed to gain parental trust to establish a supportive relationship: they utilized aids to establish this relationship, however, they often encountered barriers that eroded trust. Although parental and HCP experiences were different, they remained interconnected and joined. The grounded theory model of 'Journeying Along Side One Another' (see Figure 1) illustrates how the parental and HCP' experiences are distinct from each other yet significantly interdependent in the process of caring for MFI. Parents and HCP in relationship deeply influenced and shaped the relational experience as they cared for MFI together. The integrated state of these experiences (both positive and negative in nature) on the relationship is represented by 'the space in between', a liminal space where transformation or transition takes place. Liminality from the Latin word *limen,* is a threshold where relationships of parents and HCP unfolds. This space is dynamic and can be sometimes hard to tolerate and represents the therapeutic connection (or lack thereof) between parents and HCP within their relationship. The space between formed the relational foundations for interactions between parents and HCP that were deemed necessary to optimize care of MFI.

Figure 2. Theory of Journeying Along Side One Another



The liminal space between parental and HCP experiences is where interactions transpired. This space is central to the theorizing in understanding the meanings and actions of parents and HCP. Each encounter that parents and HCP had with one another, represented by engaging in and responding to verbal and nonverbal communication, occurred within the liminal space. Within the encounter is where parents and HCP' different yet interconnected experiences came together, which is represented by an interaction. When the interactions were mutually beneficial, trust was established and a supportive relationship was developed, which led to parents and HCP journeying together. Journeying together represents the continuous occurrence of beneficial interactions between parents and HCP that resulted in the continued establishment of a supportive relationship built on trust.

The connecting force that brought the two experiences together and allowed them to overlap within the liminal space between the parent and HCP experiences was the supportive relationship built on trust. When a trusting relationship was formed, parents were able to live with ambiguity and entrust HCP to become able to journey together. "Ya, they just help me get through all this long journey, they were, right next to me, they were all there, they gave me the shoulder to cry on sometimes, it was so sweet" (Mother-03, p. 2).

The space between the parent and HCP experiences was dynamic. There were times when the experiences were not successfully joined together, when parents and HCP did not journey alongside one another. This most often occurred when parents and HCP were unable to engage in mutually beneficial interactions and trust was fractured. Such times were characterized by parental inability to cope with grief and stressors, setbacks in the infant's condition, or when HCP or the health care system were unable to meet the needs of MFI and their parents. A father spoke to a situation where his son acquired an infection and HCP did not recognize symptoms nor agree with his concerns. This broke his trust in HCP and thwarted the establishment of future relationships with HCP.

> I remember the morning he did get sick, I mean S. [wife] called me in the morning and said, "I can't do it today you gotta come here" and I went. Then that evening we both recognized, "No something is really wrong here and something needs to be done". Then it was kind of almost a fight for them to be like, "Oh no he seems ok". We were at that point both adamant that something was wrong… And it's hard cuz you're told by staff that are working with babies, "Your baby doesn't look sick he looks totally fine". Part of me wanted to be like, "you see this all the time"… You want to have confidence in their opinions and their assessments so it's hard. (Father-08, p. 7-8)

When beneficial interactions failed to occur, HCP were less effective in enhancing parental ability to care for their MFI and parents became increasingly stressed. The liminal space between HCP and parents was dependent on the parent and HCP' ability to engage in beneficial interactions, develop trust, and establish a relationship with one another.

Key factors that enabled parents and HCP to engage in beneficial interactions and journey together included: (a) open and honest communication, (b) mutual respect through acknowledging each other's expertise, (c) establishing common goals, (d) consistency, (e) providing support, (f) encouraging, educating and empowering, and (g) acceptance that everyone does provide care differently. Beneficial interactions were also affected by parent and HCP personal characteristics. Parent characteristics that affected their interactions with HCP included: (a) personality; optimistic versus pessimistic, (b) mental, emotional, and physical health, (c) culture, and (d) supports and ability to cope. HCP characteristics that affected their interactions with parents included: (a) self-awareness and (b) culture of the unit.

Factors to Beneficial Interactions

Open and honest communication.

Communication was vitally important to both parents and HCP. Parents felt empowered when HCP took time to sit down and explain situations and results because it increased their certainty, stability, knowledge, and confidence.

> Then I met Dr. M., one of the [specialty] she's amazing woman so nice. When they feed her the pictures and everything she came with heart [model] in her hands and she explain nicely and slowly what is the problem… She said this problem with heart it's happen all the time and it's not something new and super danger. So she make me feel a little bit relaxed. (Mother-09, p. 1).

Communication made parents feel valued and acknowledged as important and active participants in the journey. Furthermore, when communication was open, honest, and informative, less conflict arose between parents and HCP.

> They ask you, "Do you understand" and if you don't, and say, "You need to tell me in idiot human terms" they do. They figure out a way to tell you that you understand. Like when they told me what was going on with her I kind of looked at them. It wasn't sinking in. So he goes, "Here let me draw you a picture" and he did and he explained it he said "This is this, this is what's going on, now do you understand?" Yes. Thank you. (Mother-10, p. 31)

> I think a lot of… the conflict sometimes happens because of miscommunication or stress or… people not feeling like they're being listened to or heard… I feel like if I'm feeling like a conflict with a family I just try and convey the best that I can that I wanna work with them. I wanna resolve this conflict with you; and you and your child are the most important thing here and that it's my job. So I feel like if I always come from that place we can work things out. (NSG-04, p. 21)

HCP recognized that communication and providing parents with information decreased their stress and worry; thus, communication was a way that HCP helped parents cope and establish trust.

> I think communication is so important. And, and I feel like so many issues would be resolved with more communication. So letting families know that they have a space to communicate with you and being able to um…. I would say if it's a brand-new nurse work on your communication skills and just these families need communication. They want to know more that you're open to their suggestions and you're open to them, more often times more than how smart you are. (NSG-05, p. 33)

> They keep getting mixed messages, and I think families would say it's the mixed messages and the different ways of doing things that they don't ever feel comfortable and never really get that sense of, "Yup, I can do this." Um, or "I trust enough in that – in the healthcare system to believe in myself? That I can do this."" (NSG-01, p. 1)

It was important to HCP that parents voiced their concerns and asked questions. Nurses often encouraged parents to write down their questions to ask their infant's physician during rounds. Along the journey, frustrations would emerge as a result of differing perspectives, lack of understanding, or not identifying issues. One nurse indicated she often told parents, "Make sure you write them down so that if we don't get to all of this stuff today, we can get to it tomorrow" (NSG-10, p. 25).

For a trusting relationship to remain intact, frustrations had to be adequately addressed. This was accomplished through open and honest communication between parents and HCP.

> I'm like, "If you wanna listen to me, I told you she was in pain and you didn't wanna listen to me". That's the hardest part is sometimes they don't wanna listen to you because they have the medical degree and they think they know best. Not to be rude the doctors are very, very good, A. [daughter] would not be doing as well as she is without them. But sometimes the mom knows best. (Mother-10, p. 14)

One father and mother had concerns about their infant's care and become upset. They voiced their concerns and HCP acknowledged their concerns, which resulted in positive changes in their infant's care. These actions dissipated their frustrations. Thus, this father learned that communication was an important avenue to addressing his and his wife's concerns and resolving conflict, and that voicing such concerns was important to ensure the health of his infant and maintain trusting relationships with HCP. "I mean communications been the whole topic, you could boil it down to everything that we've talked about today. How it goes back and forth and just communicate with each other you know, it's ok to be upset" (Father-17, p. 56).

Communication was the foundation of beneficial interactions. It was the main avenue that parents and HCP utilized to bring their differing experiences into contact with one another within interactions. Communication was key in establishing common goals, fostering understanding, dealing with difficult situations and frustrations, and collectively making progress towards transitioning the infant home.

Mutual respect: Acknowledging each other's expertise.

Parents of MFI became the expert on their infant's history, treatments, goals, and plan of care. Because parents of MFI were knowledgeable about their infants, they often held their own set of ideas and expectations about how the journey should transpire. Respecting and acknowledging parental expertise and expectations enabled HCP to engage in beneficial interactions with them. When HCP did not acknowledge parental expectations, expertise, and desired approaches to care, parents became upset and frustrated. Therefore, HCP recognized that they must provide opportunities for parents to voice their knowledge and be involved in the planning and delivery of care to the infant.

> I hope to create an atmosphere of mutual respect. When I first go in a room, when I first meet them. Listen to them rather than just doing. An honest relationship try and be open with them and communicate and I think that's all they want is to hear the truth. (NSG-03, p. 27)

Parents recognized that they relied heavily on the knowledge and expertise of HCP in meeting the complex medical needs of their infant. It was important for parents to respect and acknowledge HCP medical knowledge and insight into the complex diagnosis and treatment of their MFI. HCP wanted to be viewed as holding knowledge and information that was beneficial in enhancing care and health of MFI. It was difficult for HCP when their knowledge was questioned, or their ideas and plans of care were disregarded by parents.

> I looked after a child the other night. And the mother wouldn't let me touch her. This child had been through several surgeries and her main focus was keeping that child quiet and comfortable. To the point that it wasn't even normal anymore. So she wouldn't let me assess her. She wouldn't let me do anything with her and she wanted, she didn't want her lorazapem weaned, she wanted Tylenol given, you know, sooner. And I finally said to her, you know, "you forget that it's normal for a baby to cry. And what I see is her settling in your arms in a few minutes. I saw her lying on the bed cooing with dad. These are all normal things, a baby will cry normally. You have to, you know, allow us to get her off the drugs, and we're doing it gradually and I cannot see giving the lorazapam at the old schedule." From what I see. I didn't know if I'd overstepped, but you know what? She left it, and I gave the lorazapam later. They settled her very quickly to bed and left her early, so you never know. But I agree with J. [nurse], sometimes we go along too much with them. And it's finding that balance, because sometimes you can really wreck a relationship too by trying to step in, but you can also see where there's times where you have to step in. That they're not doing what's best for the child anymore. (NSGFG, p. 2-3)

Listening to each other's perspectives, ideas, knowledge, and opinions fostered mutual respect among parents and HCP. Mutual respect established trust, which aided in the development of a strong relationship that enabled parents and HCP to walk alongside one another on the journey.

> You have to work with others and it just comes from I think that place of you know, open and treating everyone with dignity and respect and, and, you know we're experts in certain types of knowledge but you also have to acknowledge other people's expertise. Like the doctor and the family and even the baby has their own expertise. (NSG-04, p. 21)

Establishing common goals and plans of care.

Each medically fragile infant in this study had a different diagnosis that involved different care and treatments. Parents lived amidst great uncertainty and longed to have definite goals and plans of care to help enhance their infants' health, ease their uncertainty, and provide them with concrete tangible actions they could actively engage in. Physicians recognized the need for a plan and goals of care and were dedicated to formulating and establishing such collaboratively with parents and other HCP. Allied health and nursing relied on physician's medical plans of care to collaboratively work alongside parents in moving the infant closer to discharge and achieving goals.

> Because as much as we're working towards getting kids home, sometimes some of them are trying to determine what's going on, figure out a plan, and seeing if that gets us getting closer to going home. (MDFG, p. 1)

When specific plans of care were not established, or due to the infant's medical complexity developing a definitive plan was unattainable, both parents and HCP entered a sense of uncertainty, which added stress to the journeying alongside one another. One mother described the difficulty and stress she experienced witnessing her son experience uncomfortable symptoms while the medical team tried to find answers and make a plan.

> It is hard to constantly hear, well it might be this, but, we're gonna do this, it's hard to watch him barf, it's hard, he screams and he pukes out of his nose and it comes out of everywhere and its just gross… I know when I throw up if it comes out of my nose it burns, so, I can't imagine he feels any better, and it's a little baby, it's worse for them, they don't understand what's going on, you can't reason with them, you can't explain to them, when he's got people shoving cameras up his nose and you know he's gagging away, and he doesn't understand what they're doing, he just thinks they're hurting him. (Mother-02, p. 5)

Parents and HCP worked diligently at collaborating and working to piece together information and knowledge to develop common goals and plans of care that they could actively participate in. To establish common goals, it was vitally important that both parents and HCP engaged in open communication, mutual respect, and collaboration.

> I think for a lot of these other ones that are longer term or are unclear, the uncertainty is harder for the healthcare team, because it's not as easy to tell families. How long is your child going to be in-hospital? Are we going to get a diagnosis? Are we going to have a plan that works? It's a lot more trial and error. And I think that's going to be particularly harder for families as well. And of having to adjust to the life that's full of even more unknowns, less certainty, predictability, less being able to know when that next phase of their life, whatever that is with their child, is going to end, because it's just so unclear. (MDFG, p. 2-3)

When multiple HCP and specialties with different foci were involved in establishing MFI' plans of care, communication often broke down and multiple conflicting plans of care were developed. Thus, a cohesive plan of care was not established and communicated to all parties involved, including all HCP and parents. Lack of consistency in care plans combined with lack of communication fractured parental trust in HCP. A father described how communication broke down among multiple HCP that resulted in great confusion and frustration for him and his wife. Eventually he no longer participated in decision making for his daughter.

> But I haven't really been privy to the actual plan. I know D. [mom] has heard bits and pieces of what can potentially go down the line but as far as, it's all news. The one thing that I've noticed is that the doctors don't communicate… With each other. Like one, one, like for instance when we originally heard about the esophagus that was a problem, just prior to D. [mom] having the baby maybe a week, the doctor came in and started talking

> about the heart. We didn’t even know anything about the heart. He assumed that he was talking to us as if it was common knowledge right so we were completely caught off guard. And then of course, we talked to…the neonatologist… said no you don’t need to worry about that if I saw that I wouldn’t think it was an issue… Yeah and then of course there was an issue with the heart, it’s almost like I don’t do rounds there’s no point because at the end of the day what can I do. I’m getting all this information that isn’t gonna change anything, I can’t – I’m not a doctor so what am I gonna have a valid opinion? So it’s just gonna worry. I don’t think rounds is beneficial, I think what is more beneficial which we haven’t had is like a bimonthly meeting of the minds with all the doctors. (Father-18, p. 1)

Continuity of care.

Consistently engaging in beneficial interactions with the same HCP was key to the establishment of trust. Physicians identified that they often felt as though they were parachuting in and out of the journey of MFI and their families, and that they often presented different plans of care that conflict with previous physicians’ plan. Continuity of HCP caring for MFI built parental confidence in HCP ability to meet the specific needs of each individual infant. One mother described how she greatly appreciated having a familiar nurse who understood her infant’s dangerous choking episodes and how to manage them. When nurses changed frequently, they were often unfamiliar with how to adequately and safely care for her daughter. This increased parental stress and uncertainty.

> I don’t know if people just call in sick, so we have four nurses in one day so that was really frustrating because then you have to explain about their gagging and what to do and, “Please watch out for this” and it’s a whole new person to trust… But when we rang the bell she [familiar nurse] heard C. [infant] coughing and she would come in and check and make sure everything was good. (Mother-05, p. 18)

Continuity of HCP was foundational to developing common goals and plans of care that did not change and cause confusion for parents, “[w]hich is also helpful to have consistency between care-providers and so that the plan doesn’t change… And that’s really important, that consistency. If they're getting different messages, that's like a lot…Which happens all the time" (MDFG, p. 5).

> So this physician, who was on teams with me for 2 weeks, and I were on the exact same page. Then this person – this physician comes on, and they're not on that same page. So now the whole thing changes. (DIET, p. 17-18)

Continuity in HCP fostered a sense of confidence in parents that HCP understood their infant's history and complex medical needs, and that they knew directly how to meet those needs. When parents knew, were familiar with, and felt comfortable with the HCP involved in their infant's care, the interactions that transpired during the journey were more positive, meaningful, and influential. Familiarity with HCP who provided consistent care to MFI was a direct link to improving and strengthening parental trust in HCP abilities to care for their infant. Therefore, continuity helped parents develop trust in HCP and successfully form a relationship that enabled them to engage in beneficial interactions. "I ask for the nurse to stay with us to be like our primary nurse… because she knows him, she knows the signs, she knows how quick he can change the numbers and how quick he can be sick" (Mother-09, p. 24).

Providing support.

Parents experienced a great deal of stress and grief. Some parents identified HCP as being a source of support and strength that helped them cope. Particularly, social work and nursing were HCP who parents felt comfortable talking to about their difficult emotions and frustrations. In addition, social workers were viewed as beneficial in assisting with financial issues. Parents viewed nurses as a friendly support who conducted small acts of kindness, which helped foster a sense in parents that they mattered and were considered. When nurses engaged in small acts of kindness their relationship with parents flourished. Nurses and social workers became a source of support when they made themselves available and approachable for parents to connect with, including discussing their difficult emotions and frustrations.

> Yes, yes, yes. They [social work] are very, very actively involved with us, from day 1 now. Anytime we call them, they're here. The best thing is like when we, when the premature thing happened when my baby born, like we were going through a lot of stuff like, cuz I lost my job too at that time… But when I spoke to social work people they always support me, they give me support like if there's anything we can do for you like a shopping card, or even a gas card too. They always trying to help you financially too… It helps us it is great help. Even now still we are here, it's more than 5 months we are here in this hospital. Every time we need anything they always just come, we just have to page them. They are such a big support you know for my family, for my baby, and for all of us. I don't know if it's a tough time you go through when you go home, you know your baby's here, but their support is incredible. (Father-13, p. 5-6)

HCP identified that they were positioned to support parents and help them navigate their infant's hospitalization. HCP recognized that parents were undergoing extreme stressors and tried their best to establish empathy for what they were going through. Specifically, one social worker noted that they aimed to provide parents with support by being a liaison for improving understanding of protocols and procedures, helping them deal with upsetting situations, being a sounding board, and at times providing counselling of emotional issues. "So I'm finding that we do a lot of that liaising and kind of understanding of protocols and procedures that we have in place here" (SWFG, p. 1). "Other parents actually want to do some of the work and map out… coping strategies… that's also counseling too… being a sounding board" (SWFG, p. 33).

Nurses noted that it was their responsibility to support parents in dealing with their emotions; however, they often did not have the time to invest in emotional support. Nurses indicated that they made an effort to identify emotional struggles and either support the parents themselves with a quick conversation or consult social work to provide greater assistance. When asked if she felt it was part of her role to provide emotional care to parents, one nurse responded:

> Absolutely. Cuz I feel we are definitely those, we might not be able to say the thing or do the thing that's gonna be able to fix or help them. But… we can connect them to people because we're the ones seeing how they are in between those hours that the doctors are in or the social workers just popped by to say hello. Especially if we're being attentive to those things and we're trying to see those things. You're definitely gonna be able to connect them to who they need to be connected to. Or at least just have a conversation with them, which could even fix everything. A couple of times it's happened where you just needed to have a conversation and they've said "Ok I'm really grateful that you've been able to notice that I was having a hard time, these are just the small things that are gonna make me feel better and then that's it." (NSG-05, p. 3-4)

As HCP engaged in actions that fostered support for parents, it created an atmosphere where parents felt valued and cared for. This helped parents establish a trusting relationship with HCP, because they felt safe and secure with HCP who considered and cared for their personal well-being in conjunction with their infants. As HCP engaged in small acts of kindness that made parents feel considered and provided emotional support to parents, parents and HCP became connected in deeper and more trusting relationship.

> Yeah I trust C. [nurse], I trust H. [nurse], I trust E. [nurse], she also nice. I trust… D. [nurse],… she's also nice. Before the surgery I was super nervous and scared and everything and she see then I'm not happy that I'm not feeling well and she can't do nothing too much but those donations downstairs two or three days and she go downstairs and grab the toys for N. [daughter] and grab the toys for M. [infant] and grab the blanket for M. [baby]. I didn't know then the donations were downstairs but she came and say, "Look blanket for M. [infant]," so nice. She make that I am feeling ok, at that moment and I'm happy because M. [infant] get a toy or something. Somebody thinking about my child on that moment. (Mother-09, p. 33)

> I found the nurses were very beneficial like they were very friendly. They talked to you, they get your mind off a lot of things cuz they'll talk to you about everything and anything. I found that helped. (Mother-10, p. 12)

Some nurses recognized their lack of experience and confidence in meeting parents emotional and mental health needs, which resulted in them consulting social work or not being able to adequately meet parental needs. Physicians identified that they were aware that parents suffered with their emotions and mental health, however, they often did not have the time or expertise to invest in caring for parents in such a manner. They often referred parents to social work and identified that parents need more psychological supports available.

> Our system is so problematic for us saying that the parents need to adjust. We have social work, who does an amazing job, but they're not – they're not psychologists; they're not actually there to treat the health of the parents per se. And their skillsets are in a slightly different realm. Um, we ask a lot of them to manage, and uh, and technically they're the social worker for the child. (MDFG, p. 21)

It was identified by both parents and HCP that parents lacked adequate emotional and mental health supports. Parents noted that they would appreciate an increase in emotional and mental health supports by trained psychological professionals. Most HCP also identified having trained psychological professionals available would be beneficial to helping parents cope.

> The mental health side of it is really critical… I wasn't handling it well, I was having panic attacks, severe anxiety, no sleeping, crying all the time… Care [psychology] was good at Foothills [NICU] and then once I got here there was no mental health services… That was my biggest shock. Was how come there's a missing component here? Here I am on the pregnancy ward. (Mother-19, p. 2)

Encouraging, educating, and empowering.

Parents identified that HCP, particularly nursing staff, were essential in teaching and enabling them to provide care, both basic and medical, to their infant. At times parents were hesitant and fearful to participate in their infant's medical and basic care because they viewed their infant as difficult due to their medical fragility and being surrounded by medical technology. Nurses needed to take time to encourage parents that they were capable of participating in and providing basic and medical care to their infant. Parents noted that HCP were integral in building their confidence to participate, interact, and engage with their infant. Taking time to be present with parents and enable their participation in the care of their infant enhanced parents trust in HCP. "There's three ostomy nurses here and they taught me how to change it [ostomy] properly and how to do it as efficient as possible and if she's fussy cuz she's hungry, feed her first and then do the ostomy" (Parent-10, p. 3).

When HCP took time to 'do with' parents and not just 'do for' infants, it strengthened the parent-HCP relationship. 'Doing with parents' increased time and amount of interactions that occurred between parents and HCP, and during these interactions a space was created for communication, sharing of ideas, and respecting one another's expertise. When HCP took time to collaborate with parents and have them participate in care, parental trust towards HCP increased and a strong relationship developed.

> [S]ometimes you do have to be a bit stern because they don't want to do that care cuz they're anxious. Just being able to say, "No you need to but we'll do it together." Making it a safe and comfortable place. Making sure they know if you need to suction this trach [tracheostomy] and you're still anxious, call me and I'll come and watch you do it. And so just making sure that they feel comfortable because the more they do it, they're gonna get more comfortable with it. (NSG-05, p. 27)

HCP noted that encouraging, educating, and empowering parents to participate in the care of their infant should occur early in the infant's hospitalization as a means to transition parents and their MFI home as soon as possible. Parental hesitation or lack of ability to manage their MFI basic and medical care could result in extended hospitalizations and prolonged transition home. In particular, physicians identified the vital necessity to have parents confident and able to safely manage their infant at home in order to prevent re-admissions and problematic events from occurring.

> I think a lot of what we need to do is more preparation, obviously figuring out what's going on and treating, but these are the five things that need to happen before a discharge, and this is what we're aiming for. So the families seem to know what to grasp onto, like, "Okay, checkmark, checkmark, I'm getting closer." And how can we support that discharge, because it's really different to care for a child like this in-hospital, where they've been for almost their entire life, and now they have to go home. (MDFG, p. 5)

Acceptance: Everyone does it differently.

HCP recognized that each parent had different needs, social backgrounds, and comfort levels providing care to their unique infant. Some parents were confident early on in their infant's journey and participated in basic and medical care, while some were more hesitant and uneasy participating in infant care. HCP also recognized that parents came from a variety of social situations that influenced how they coped and managed their journey in the hospital. "They're different physically, medically, emotionally. There's no clear cut" (NSG-06, p. 8). HCP recognized that judgments and prejudices towards parents and their approach to parenting were a hindrance that prevented them from walking alongside the parents on their journey and developing a trusting relationship where beneficial interactions could occur.

> Moms pick up on that a lot. And there's this underlying sense of being judged if I don't make what the nurse thinks is the right decision. And that can be very detrimental and damaging to the relationship. Yeah, cuz it influences everything else, I find. (SWFG, p. 16)

HCP recognized that they needed to meet the parents and their infant where they are at, that every parent and infant was at a different place in their journey and that every journey was different – one size did not fit all. HCP had to be accepting of the parents' differences and adapt and tailor their care in order to formulate trust and establish a relationship.

> Like I'm not rigid in my care. You know what works for one family is not gonna work for another family because everyone is so unique and different. So I won't say and do the same things for everybody, because it's not gonna work for everybody. (NSG-05, p. 12)

Parents identified that each HCP provided and planned care differently. This was difficult at times; however, it was something that they had to learn to adapt to and accept to establish trust. Parents had to come to understand that there were differences and variances among HCP and view those differences in a positive light, or else they could become overwhelmed and find great difficultly establishing trust.

> Sometimes that's a really good thing because now you have a new set of eyes, and a new way of thinking about things… in my work… if I got stumped on something you know I would go and ask somebody else… getting a different set of eyes or a different brain on something is sometimes very very good… it can it can help you know try different things. (Father-01, p. 8)

Personal Attributes of Parents and HCP that Influenced Journeying Together

There were situations where parent and HCP experiences did not come together and the liminal space remained distant, resulting in a difficult or suboptimal journeying together. At times HCP engaged in factors to establish beneficial interactions; however, they were unsuccessful. Such instances were often characterized by parental exhaustion, inability to cope with stressors, grief, loss of control, and missing siblings. Also, situations occurred that eroded parental trust in HCP, such as medical errors. Such circumstances occasionally resulted in the establishment of a wall that prevented the develop a relationship despite HCP best attempts. This was difficult for HCP to navigate, and often lead to continued difficult interactions with parents.

> Those are the times [parental loss of control] when I start to see families get really exhausted or really frustrated. And then trying to figure out how you can support them, so they still feel like we're a team and not, you know, them versus us. (Nurse-10, p. 18)

Specific health care professional and parental characteristics shaped how their experiences enabled them to journey alongside each other. Parental characteristics included: (a) personality, optimistic vs. pessimistic, (b) mental, emotional, and physical health, (c) culture, and (d) supports and ability to cope. HCP characteristics included: (a) self-awareness and (b) unit culture.

Parental characteristics.

Personality.

Some parents had an ability to see the good in their situation, to focus on the positive amidst much difficulty. One mother enjoyed creating relationships with HCP, and HCP noted they enjoyed interacting with her. Despite her daughter's diagnosis of a debilitating syndrome that translated to poor outcomes, as well as medical errors occurring during hospitalization, this mother remained positive and easily trusted HCP.

> Like when you have your hopes high, I guess it helps you take stuff really positive and see them go better. Like she's better, she, she's smiling, she makes baby noises and everything. If I think negative I'm not gonna see all this stuff I'm just gonna see her syndrome. (Mother-07, p. 14-15)

However, some parents became easily fixated on medical errors and focused on the negative aspects of their situation. Such parents tended to expect the worst case scenario and did not easily trust HCP. Therefore, parents with a tendency to view their situation negatively did not easily enter a supportive relationship with HCP, nor did they successfully journey alongside HCP. The mother below described being concerned about her son's health status. The medical team did not reciprocate her concerns and waited for the development of further symptoms to warrant medical attention. This broke her trust in HCP.

> But just to be on antibiotics and start because he was on Gentamicin. I don't know had we not advocated so hard at that time waiting an extra 12 hours I don't know what difference that could have made. So for us it makes it really hard to trust the staff. I think we're very now kind of yeah it's given a bad taste in terms of all that, kinda how the system and the health care. (Mother-08, p. 9)

Mental health.

HCP recognized that some parents were likely experiencing and suffering with their mental health. HCP identified that interactions with these parents were often more difficult and wrought with frustrations compared to interactions with parents who did not exhibit mental health problems.

> There's mental health issues and stuff like that going on. And so to have to fight to do your care that you know is appropriate is exhausting. And not knowing who you're going to get when you come in the room. Is this mother going to love me or hate me today? This hour. Is she going to yell at me, or fire me? (NSFG, p. 3)

Culture and spirituality.

Culture was influential in how parents coped with their extreme situation. Nine of the 21 parents were immigrants. Various ways in which parents responded to their extreme situation was accounted for by their values and beliefs stemming from their culture. One mother was from a Pakistani culture and lived with her extended family; thus, she had unlimited access to child care provided by family members who had well-established relationships with her children. Her sister-in-law did the grocery shopping, cooking, and cleaning in her home while she was in the hospital with her MFI. Also, her parents were present to help with her functions of daily living, as well as spend ample time with her in hospital, caring for her ill infant and providing constant emotional support. Because of her culture and how her family lived, she had ample supports to help her with her MFI. Another mother who immigrated from Serbia indicated that her culture informed her tendency to worry extensively about her son. During stressful events she would outwardly become very emotional, which at times could make HCP uncomfortable and was a source of tension.

> Then in that moment I am not, I don't thinking about the words, I'm not thinking about my face or my grimace, or my hair, I'm just thinking about him. At that moment I am scared and made and everything all emotions. One of the doctors tell me, "You worry too much and you are so emotional." I am sorry I am from Serbia where people are super emotion. (Mother-09, p. 23)

Parents who identified that they had spiritual or religious beliefs stated that they utilized their beliefs to cope with the difficulty and uncertainty of their situation. They found rest and peace in their faith that a higher power was protecting their MFI and guiding their steps.

> But God kind of gave us a hand with all the people surrounding us. Yeah all the people from church even E. [name], I never met those people around like nurses try to help us and I think that's kind of in God's hands. Yeah, they're kind of guiding us um, and God is telling me you're not alone and he's there for us and he kind of have a, he definitely have a plan… I just don't know. (Mother-10, p. 4)

> It's Sikh. We have a holy book so I always kind of read that then we have this tape, electronic device that goes 24/7 beside her. They start from morning prayers to evening to afternoon and everything. So we have… six different kind of prayers that start from morning to evening. That always runs beside her and the amazing thing… I don't think I've seen in anywhere else, but this hospital have a spiritual section where this person like they're master here. So he goes to each and every room, and he finds that "Ok, she's going to a surgery," I believe that if this person come and pray for her that's gonna make a big difference. That's my belief. I don't know what other people can think "Oh yeah what are you talking about this is medical science, they will take care of everything." But I still believe there is a power if you believe. And I believe that. It's not only that they also call people from my religion, from my temple they used to come and pray for her. (Father-13, p. 4-5)

Spiritual beliefs helped parents to relinquish control and allowed them to put more trust in HCP. One mother stated when she prayed, she trusted that God would take care of her son so she could leave to do her chores and care for her other son. Her faith allowed her to leave and trust HCP to care for her son.

> We pray and I would just leave everything to God and I will just tell Him, now I going back home, I have to do the chores, I have to be a mom too, and everything I need to do at home and now I will just leave C. [baby] to You. That would just make me feel actually at peace. I'm comfortable leaving C. [baby] because I know that God is with him and he will take care of C. [baby], he'll look after C. [baby]. I don't know, maybe it's just me but that's what I believe. (Mother-14, p. 7-8)

Supports and ability to cope.

Parents who had ample supports in place where better able to cope with their stressors. Stressors such as grocery shopping, cleaning the house, taking care of pets, and children were overwhelming for parents. When they had family and friends who helped them to manage the stressors of daily living, it alleviated the load off parents. “Having family help around definitely helps with the stress, A. [wife]’s mom is great about helping out with K. [daughter] she’s really helped us a ton” (Father-01, p. 7).

Parents who had the resourcefulness to utilize their external and internal coping mechanisms to cope with their grief and stressors were better able to manage their situation.

> It seems to be the lower socio-economic population has a harder time dealing with chronic kids. Now that could be just what we’ve seen on the outside, but they don’t seem to have the same tools as someone that is higher educated. I’m just thinking of a few examples of moms that are professionals that are, they learn fast, they ask questions, I think they just have, they pick it up quicker. They seem to have a better access to resources and does that make sense? (NSG-03, p. 8-9)

When parents had a positive outlook, minimal mental health difficulties, strong spiritual beliefs, supports, and an ability to cope with grief and stressors, they were more likely to enter into a trusting relationship with HCP. How HCP characteristics influenced the establishment of parent-HCP relationships as discussed below.

HCP characteristics.

Self-awareness.

HCP identified that working with MFI and their parents could be very difficult and stressful. It was emotionally difficult for some HCP to interact with parents of MFI because parents were often viewed as demanding and could easily became upset if expectations for care were unmet. One nurse described difficult interactions with a mother about her son’s care; this mother never seemed happy with how care was provided. “She was super particular about how he got suctioned. So sometimes [laughing] your just like, ‘Well, if you’re this particular, why don’t you just do it.’” (NSG-05, p. 29).

HCP often found it difficult to witness parents struggle to care for their MFI. As a result, HCP had great empathy for parents and sometimes burdened themselves with the emotional difficulties that parents experienced. HCP identified that they needed to be aware of the emotional stress accompanied in caring for this population and how it could influence their personal life. Frequently HCP managed this stress by working part time to establish a work life balance.

> I've dropped or given up my line and my casual status will… start on Monday. I think part of that has to do with the stress of it. There's a lot of stress at work and then having young kids at home, I've been feeling the stress of it and the pull of it and my personal life is a little bit suffering right now… I really think a lot of that is from the chronic outpouring of myself that you have to do at work. And I feel like I give it all there and then I come home and I have nothing to give to my own family. (NSG-02, p. 2-3)

Unit culture.

HCP identified that the inpatient unit was extremely demanding and busy. Nurses described having up to four patients to care for during a shift. This resulted in limited nursing time spent with each infant and their parents. Both HCP and parents recognized that due to high patient loads, less time was spent by HCP observing each infant, which was stressful for parents and difficult for HCP to manage.

Many MFI were transferred to the inpatient unit from the NICU and PICU. Parents and nurses recognized that the NICU and PICU care environments are much more controlled compared to the inpatient unit. This added stress for parents when they transitioned to the inpatient unit because they lost a sense of control and safety they perceived in the intensive care environments.

> There [NICU] they were already thinking that their child is getting… an inferior level of care. Then you move to [current unit] where now… you don't have your own nurse anymore. Now your nurse is being shared… Potentially could be four patients to one nurse. So you're already, as a parent, "Oh my God, my kid! It could've been a month

> ago: my kid was under lockdown in the NICU, and now we're up where it just seems like [they are not receiving adequate care]". (SWFG, p. 11)

The inpatient care environment was highly medicalized with advanced technology. HCP spent increased time at computers, which equated to less time at the bedside.

> Because there's sooo much demand on them to sit on a computer and put everything into the computer that way, right? At Christmas time, I was talking to my family or whatever. I said, "In an average 8-hour day, how many hours do you think nurses spend a day on a computer?" They said, "Oh, maybe an hour, an hour and a half?" I said, "Probably closer to five. Five out of those eight hours is spent on a computer." (NSG-01, p. 10)

Within the inpatient care setting both parents and HCP recognized lack of continuity in staff who worked with MFI and their families. As previously described, this was a factor that caused difficulty establishing trust with parents. Also, care plans were not utilized, which nursing identified as a tool that could improve consistency in care provided. "The care plan on the computer… is finicky. I can see why people don't really fill it out… Having a way to communicate those things so that you're not walking into the situation blindly would help you and the family as well" (NSG-02, p. 27).

HCP identified, specifically nursing and allied health, that they are often have heavy patient loads with little support. Roles such as the resource nurse was noted to be helpful in managing tasks and enhancing quality of care; however, this role was cut from the budget.

> I think it went the best when we had a resource nurse. Because she could be available to a new staff that was having problems, to special procedures, or if your child had to go down… it's when I felt the most comfortable that I ever have on a, in this hospital. (NSFG, p. 13)

Allied health identified that due to health care cutbacks their care was less than optimal, it was not of the quality it once was.

> We had the 2 FTE full-time for OTs. I felt like that's where we got connected, is that some of these families needed to see us daily, and even 2 or 3 times a day, especially for these medically fragile feeding kids… they just need that support… I don't come back to

> see a lot of these kids as often as I used to. And some of these kids get discharged before we even [know]… And so we just have to treat… we can't really do the follow-up. (OTFG, p. 17)

Lack of primary nursing and primary care physicians, lack of care plans, heavy workloads, and health care cut backs were all factors that impeded beneficial interactions between parents and HCP.

Conclusion

In this chapter the interpreted theory of 'Journeying Along Side One Another' was presented through the voices of the parents and HCP. How parental and HCP' experiences were joined within the liminal space through the development of (or lack thereof) a supportive relationship was described. When interactions were mutually beneficial parents and HCP journeyed alongside one another, successfully working together to enhance the health of MFI and transition them home. When the interactions were not mutually beneficial, the experiences did not come together and a relationship between parents and HCP was not established: parents and HCP did not did not journey together. Key factors were crucial for parents and HCP to engage in mutually beneficial interactions. As described above, key factors included: (a) open and honest communication, (b) mutual respect through acknowledging each other's expertise, (c) establishing common goals, (d) consistency, (e) providing support, (f) encouraging, educating and empowering, and (g) acceptance that everyone does provide care differently. Beneficial interactions were also affected by parent and HCP' personal characteristics. Parent characteristics that affected their interactions with HCP included: (a) personality; optimistic versus pessimistic, (b) mental, emotional, and physical health, (c) culture, and (d) supports and ability to cope. HCP characteristics that affected their interactions with parents included: (a) self-awareness and (b) culture of the unit.

In the next chapter the study findings will be discussed in regard to findings in the literature on MFI. Also, recommendations for practice and research stemming for the current study data and findings will be presented.

Chapter 8: Discussion and Recommendations

The purpose of this study was to create a deeper understanding of the processes of care provided to MFI from the perspectives of parents and HCP. Parental and HCP experiences were explored using Charmaz' (2014) approach to grounded theory. Charmazian grounded theory accounts for what happens within an environment, identifies the processes of how it unfolds, and seeks to determine why it occurs (Charmaz, 2014a). The findings suggest that parents and HCP have different yet interconnected experiences caring for hospitalized MFI. Parents coped with grief and multiple stressors to support and care for their MFI. HCP aimed at developing trust so they could establish a supportive relationship with parents. The relationship was a means to educate and empower parents to care for their hospitalized infant and work collaboratively with parents in the planning and delivery of care.

Parental and HCP' experiences were compared and contrasted, areas where concepts and themes overlapped were identified, and the grounded theory: "*Journeying Along Side One Another*" emerged. The space where parent and HCP' different yet interconnected experiences came together was in a liminal space between their experiences, where parents and HCP interacted with one another. When key factors were present beneficial interactions transpired, and supportive relationships built on trust were established; experiences and interactions became shared and interconnected, and parents and HCP journeyed together. When the key factors were absent, parents and HCP were unable to engage in mutually beneficial interactions, and supportive relationships built on trust were not established; difficult interactions transpired between parents and HCP, and they did not journey together. Key factors as described in Chapter 7 included: (a) open and honest communication, (b) mutual respect through acknowledging each other's expertise, (c) establishing common goals, (d) consistency, (e) providing support, (f) encouraging, educating and empowering, and (g) acceptance that everyone does provide care differently (see Figure 2). Beneficial interactions were also affected by parent and HCP personal characteristics. Parent characteristics that affected their interactions with HCP included: (a) personality; optimistic versus pessimistic, (b) mental, emotional, and physical health, (c) culture, and (d) supports and ability to cope. HCP characteristics that affected their interactions with parents included: (a) self-awareness and (b) culture of the unit (see Figure 2).

Relationship-Based Care

A supportive relationship built on trust was the force that brought parent and HCP experiences together in a joint space where they journeyed together. This relationship was identified by most parents in this current study to be a source of support. It was also a means for HCP to enhance the health of the infants and enable parents to engage in care. Parents and HCP in this current study indicated that open and honest communication was important to building a relationship. Guidance and assistance by nurses supported parents to care for their infant and established trust. Also, emotional support and parental care provided by HCP helped meet parental needs and establish trust. Similarly, in a qualitative study, mothers (*n* = 97) and fathers (*n*=63) of infants who underwent cardiac surgery reported that relationships with hospital personal were helpful (Kosta et al. (2015) . Specifically, parents reported that providing information, answering questions, practical assistance, and emotional support were beneficial (Kosta et al., 2015).

In the current study, some parents reported the relationship with HCP was a source of stress, especially when beneficial interactions did not occur and conflict arose. This was characterized by lack of communication, continuity of care, common goals, and parental support. As a result, trust was not formed nor was a relationship established. These findings are similar to

Kosta et al. (2015) who found that difficulties within the parent-HCP relationship were associated with (a) unhelpful communication styles; (b) unavailability of staff, (c) inconsistency in opinions and treatment approaches; and (d) feeling excluded from decision making. In addition, parents wanted more emotional support.

The nature and quality of relationships between individuals and HCP is central to health care (Beach & Inui, 2006). The findings from the current study are congruent with the care approach of Relationship-Centered Care (RCC), which espouses that illness, care, and the process of healing occur within relationships (Beach & Inui, 2006; Soklaridis, Ravitz, Nevo, & Leiff, 2016). RCC is founded on 4 guiding principles: (a) relationships within health care need to include personhood; (b) affect and emotion are important mechanisms of relationships; (c) relationships are reciprocal in nature; and (d) the maintenance of genuine relationships are valuable within health care delivery systems (Beach & Inui, 2006). The findings from the current study are aligned by the four guiding principles of RCC as described below.

Acceptance was important in the establishment of supportive relationships within the current study; recognizing that each parent and HCP approached caring for MFI differently due to their diverse social backgrounds, beliefs, culture, and values. This is similar to the first principle of RCC that espouses patients and HCP are unique and have individual experiences, values, and perspectives (Beach & Inui, 2006).

In the current study, the mental health characteristics of parents influenced the development of a supportive relationship. HCP in this study emphasized the importance of providing emotional support to parents to help them cope with their MFI. HCP empathized with parents and tried to understand their feelings and emotions to connect and create relationships with them. This is similar to principle two of RCC that espouses affect and emotion are central to developing and maintaining relationships, and emotional support is provided to patients through HCP emotional presence (Beach & Inui, 2006).

Parents and HCP developed a trusting relationship within the interactional space between their experiences. Both parents and HCP had to engage in key factors for interactions to be mutually beneficial and reciprocal. Principle three of RCC states that relationships occur within the context of reciprocal influence where HCP and patients enter into an interactional exchange (Beach & Inui, 2006).

In the current study, it was vital for HCP to develop relationships with parents because the relationship was a means that enabled HCP to (a) enhance the health and well-being of, and (b) meet the needs of MFI and their parents. HCP aimed to successfully meet the needs of MFI and their parent. The rewarding nature of the relationship encouraged HCP to interact and care for MFI and their parents. Difficult and frustrating interactions were stressful and emotionally taxing on HCP. A supportive relationship helped to avoid difficult and frustrating interactions. This supports principle four of RCC, which states relationships are morally valuable because through relationships HCP become invested to serve others and become renewed.

The number of MFI is increasing and their conditions are more complex due to improvements in health care (Browne & Talmi, 2017; Devereaux & Kon, 2017; Tolomeo et al., 2017). As care of MFI becomes more specialized, HCP need to develop more nuanced approaches to improving care (Soklaridis et al., 2016). Central to this improvement is identifying how to develop relationships that can positively impact the course and outcomes of care provided (Soklaridis et al., 2016). The findings from this study have to potential to guide HCP in establishing supportive relationships built on trust with parents by focusing on the key factors when interacting with them. Within this relationship HCP have the ability to impact the course and outcomes of MFI and their parents.

Parental Mental Health

In the current study, parental mental health was impacted during the hospitalization of their MFI. All parents experienced sorrow because their infant was ill and they had to parent in the hospital. However, rates of depressive symptoms or level of depression were not measured in the current study. In other studies of mothers of MFI, depressive symptoms above the clinical cut-off were common (Cho et al., 2008; Hancock et al., 2018; Solberg et al., 2011a). Similarly, fathers of MFI suffer increased rates of depression (Bevilacqua et al., 2013).

Parents in the current study used the term ‘stress’ to describe what they were experiencing and stated they worried about their infant. Some parents noted that they were also experiencing anxiety. The literature on mental health of parents of MFI uses a variety of terms including: stress, worry, anxiety, distress, and psychological distress. To bring clarity, a review of the terminology as presented in the literature is described. Goodnite (2013) found in her concept analysis that the term stress is often ambiguous in the literature. Her findings support that the term stress is defined as “an individual’s perception of a stimulus as overwhelming, which in turn elicits a measurable response resulting in a transformed state” (p. 1). Ridner’s (2004) working definition of stress is “a non-specific biologic response to a demand or stressor that is not necessarily harmful to the individual” (p. 539). Thus, stress is when an individual experiences a response to a stimulus that is perceived as being overwhelming. Anxiety is “a generalized state consisting of perceived mismatch and a subjective feeling of dread or impending doom that is transformed to a more objective behavioral state” (Bay & Algase, 1999, p. 110). Therefore, anxiety is a continuous experience characterized by feelings of dread and doom, whereas, stress is a short-lived response. Worry is different than stress and anxiety, it is "a chain of thoughts and images, negatively affect-laden and relatively uncontrollable" (Borkovec, Robinson, Pruzinsky, & DePree, 1983, p. 10). Worry is a process where an individual attempts to mentally problem-solve an issue in which the outcome is uncertain with the possibility it may be negative (Borkovec et al., 1983).

Ridner (2004) found in her concept analysis of psychological distress that distress is "a non-specific, biologic or emotional response to a demand or stressor that is harmful to the individual" (p. 539). Therefore, distress builds on stress, it is when one suffers physically or emotionally as a result of a stressor placed upon them. Psychological distress was defined by Ridner (2004) as, "the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person" (Ridner, 2004, p. 539). Psychological distress is proposed by: (a) arousal, (b) signaling, (c) failure of coping skills, and (d) negative impact on an individual (Ridner, 2004). Arousal may result in hypoactivation and sadness, or hyperactivation, irritability, or anger (Ridner, 2004). Signaling is communicating discomfort, verbally or non-verbally. Failure to cope frequently occurs, which then leads to a negative impact on a person. Psychological distress may describe parents of MFI who are unable to cope with stressors, which results in mental health challenges, inability to parent, and emotional suffering. Also, arousal presented in the form of irritability and anger may describe why parents of MFI encounter difficult interactions with HCP, because they are aroused from the multiple stressors of parenting MFI.

All parents in the current study worried about the health status of their MFI, specifically setbacks and fear that the infant might die. Docherty et al. (2002) found in their descriptive correlational study that mothers (*N* = 78) experienced moderately high levels of worry associated their infant's health status, setbacks, and possibility that their infant could die. Parents in the current study found the appearance of their infant stressful, specifically the small size and fragility, as well as witnessing their infant in pain. Mothers of MFI who frequently choked stated it was stressful to witness them having difficulty breathing. A descriptive correlational study aimed at identifying stressors for mothers of MFI (*N* = 57) found similar results in that parental role alteration and appearance and behaviors of MFI were stressful, especially when seeing the infant in pain or experiencing difficulty breathing (Brunssen & Miles, 1996). This finding is consistent with Miles et al. (1999) and Miles et al. (2002) who also found mothers experienced high levels of stress associated with the appearance of their infant. Miles et al. (2002) found in their descriptive correlational study that mothers (*N* = 69) of MFI in the NICU and PICU experienced elevated levels of stress due to (a) separation from their infant, (b) being unable to protect the infant from pain or provide comfort, and (c) visualizing the infant in an unresponsive state. Parents in the current study did not state visualizing the infant in an unresponsive state was a source of stress, which is most likely because infants were on an inpatient unit and more medically stable than if they were in a NICU or PICU.

In the current study, both mothers and fathers experienced distress while parenting their hospitalized MFI. Similarly, Doherty et al. (2009) found in their descriptive correlational study that mothers and fathers of 70 infants with severe congenital heart disease experienced clinically significant psychological distress, and that psychological distress occurred more often among mothers than fathers. In the current study both parents experienced distress; however, it is unknown if distress was different for mothers and fathers because psychological distress was not measured.

In the current study, both mothers and fathers identified stressors related to the health of their MFI and stressors related to parenting their MFI in hospital. Sarajuuri et al. (2012) found in their descriptive correlational study of 28 parents of infants with hypoplastic left heart syndrome (HLHS) that total parenting stress was significantly higher among both mothers and fathers of infants born with HLHS when compared to healthy controls (*N* = 46). Mothers of infants with HLHS in Sarajuuri et al. (2012) study reported less child-related stress and significantly more parent-related stress than fathers of infants with HLHS (Sarajuuri et al., 2012).

In the current study, parents found the physical hospital environment to be stressful, specifically monitor alarms and seeing their infant in a fragile state. Contrary to our findings, mothers in Miles et al. (2002) study and Brunssen and Miles (1996) study reported that they did not experience stress from the sights and sounds of the hospital environment. Parents in the current study experienced increased stress when they were unaware of available services and had to spend time navigating and finding resources they required while in hospital. This is similar to a qualitative study by Kosta et al. (2015) that reported parents (91 mothers and 63 fathers) of MFI had trouble negotiating available facilities and resources, such as accommodations, parking, food. Parents in the current study stated that travelling to and from the hospital was disruptive to daily routines, and they struggled to care for other children in conjunction with their hospitalized MFI. Fathers indicated that their work suffered because of spending time in hospital caring for their MFI and supporting the infant’s mother: two fathers took parental leave and two fathers lost their jobs. Parents in Kosta et al. (2015) study also identified travel to and from hospital was difficult, while managing other children and work demands. Similarly, fathers in Cantwell-Bartl and Tibballs (2013) mixed methods (*N* = 29) study indicated that travelling long distances to the hospital disrupted routines and that they were separated from their partner and other children; and also experienced financial difficulties.

Described within this research, the lack of open and honest communication between parents and HCP hindered beneficial interactions and increased parental stress. Providing information in ways that was understandable and clear was empowering for parents amidst their very uncertain situation. This is similar findings from the Cantwell-Bartl and Tibballs (2013) study that indicated relationships with staff were a source of stress, specifically when communication was insensitive and inadequately provided. Parents and HCP in this current study found inconsistency of staffing and lack of mutual respect during the development of plans of care increased parental stress. Similarly, Kosta et al. (2015) found that parents experienced challenges with unhelpful communication styles and became frustrated with inconsistency among staff and not being included in decision making.

Parents in this current study reported they experienced PTSD or symptoms of PTSD. Some HCP identified that they often recognized symptoms of PTSD among parents of MFI within the inpatient hospital setting. This is supported by Cantwell-Bartl and Tibballs (2013) retrospective study that combined interview data with psychometric testing to identify that PTSD developed in 24/29 of parents of infants with HLHS.

This study provides clarity on the stressors that parents of MFI experience. It supports the findings in the literature that reflect parents of MFI experience worry, stress, distress, depression, and PTSD symptoms. It solidifies the need for parents to receive enhanced mental and emotional health support as they parent their hospitalized MFI.

Grief and Uncertainty

Grief results when an individual experiences deep distress caused by bereavement, when something valued is taken away (Webster, 2018). This coincides with what parents in the current study described; that their hopes and dreams of parenting a healthy and thriving child were dashed because of their infant's diagnosis and illness trajectory. According to Phillips and Boyd (2015), when parents give birth to an infant with a syndrome their dreams are altered and expectations of parenthood are unmet. Also, Cho et al. (2008) stated that mothers of MFI may experience grief from learning about their infant's diagnosis.

Hunfeld et al. (1999) found in their descriptive correlational study among parents (*N* = 25 couples) of infants with congenital anomalies that grief and burden were positively correlated with low perceived functional health of the infant and diagnosis of multiple congenital anomalies (Hunfeld et al., 1999). There was no difference in grief experienced by mothers and fathers (Hunfeld et al., 1999). According to Discenza (2017), unresolved grief can influence an individual's physical, emotional, and mental health. Therefore, grief in combination with stress could possibly account for the decline in parental physical, emotional, and mental health status in the current study.

Three mothers in the current study, who received a prenatal diagnosis, described in detail that receiving the diagnosis antenatal was accompanied with intense uncertainty, difficult emotions, and high levels of stress. Upon receiving the antenatal diagnosis each immediately feared the worst and were overcome with worry. Hunfeld et al. (1999) found that parents had increased grief and strain correlated with a prenatal diagnosis than mothers without a prenatal diagnosis. Perhaps parents of MFI began grieving the loss of parenting a healthy infant upon receiving an antenatal diagnosis. Increased grief and strain during pregnancy can negatively impact the infant’s later motor and mental development (Huizink, Robles de Medina, Mulder, Visser, & Buitelaar, 2003). Together these findings suggest that supports should be provided to parents who receive an antenatal diagnosis.

Parents noted that they were uncertain of when their infant could go home and of their infant’s future health and development. Parents engaged diligently in detective work, striving to find solutions to alleviate their infant’s debilitating symptoms and gain stability and control. Parents in Kosta et al. (2015) study stated that the uncertain and unfolding nature of their infant’s diagnoses and surgery was difficult. Parents wished that they did not have to “go through it all” (p. 41). Giving birth to a MFI forced parents to endure great hardship, grief, and uncertainty; they had no other way to go but through.

Coping and Supports

Parents in the current study coped with their grief and stressors while parenting their hospitalized MFI. They utilized cognitive strategies such as engaging in leisurely activities to cope with stress. Kosta et al. (2015) also found parents of MFI engaged in hobbies for distraction. Parents in the current study engaged in detective work to cope with parenting their MFI and gain a sense of control. They focused on monitoring their infant’s medical course and symptoms, and worked diligently to become experts on their infant’s medical diagnosis and plan of care. This is similar to what Sikora and Janusz (2015) found in their narrative interviews with four mothers of infants with surgically treated heart defects. In that study, mothers suppressed their unpleasant feelings to survive their strong fears associated with their infant’s uncertain future. They accomplished this by focusing on their infant’s medical course, mastering medical concepts, and learning about their infant’s diagnosis (Sikora & Janusz, 2015).

Some mothers in the current study reported that they were proud of themselves for persevering and not giving up, for learning to provide complex medical care and continuing to go the hospital to parent their infant despite major obstacles and difficult emotions. They were amazed at the strength they discovered within themselves. Miles et al. (1999) found in their longitudinal descriptive correlational study that mothers of MFI (*N* = 67) often experienced personal growth because of struggling to care for their infants. Similarly, mothers (*N* = 5) in Docherty et al. (2007) multi-case qualitative study articulated perceptions of growth in their role as a mother due to successfully learning to care for their infant, and reported a profound and new-found sense of competence due to their developed expertise.

Parents in the current study engaged in relational activities to cope with their stress. They expressed their emotions, feelings, and frustrations to HCP, family members, and friends. Some parents noted that they would benefit from someone (e.g., psychologist) other than their partner to discuss their emotions and experiences. Parents of MFI in Kosta et al. (2015) utilized talking to others to cope with their stress, which was similar to parents in Doherty et al. (2009) study who coped by venting and utilizing social supports for emotional factors.

One mother in the current study encouraged her husband go to work to get a break from their extreme situation; however, two fathers took paternity leave to help their wives manage caring for their fragile infant and other children, and two fathers lost their jobs. This finding partially contradicts Clark and Miles (1999) who found in the longitudinal qualitative study that fathers (*N* = 8) tried to maintain a sense of control while feeling a loss of control by continuing to work. Clark and Miles (1999) study was conducted two decades ago in the United States, whereas the current study was conducted in Canada where some fathers are offered parental leave and unemployment insurance in the event that they cannot work. Also, fathers in the current study may be more involved in parenting compared to fathers two decades ago. In the current study, one father was identified to be using alcohol to cope with stress; however, parents were not directly asked if they used alcohol to cope. Doherty et al. (2009) found using self-reported questionnaires that fathers often turned to alcohol to cope with stress. Therefore, paternal coping strategies in this current study differ from what is reflected in the literature.

Spirituality and religious beliefs emerged from the current study as a coping mechanism for some parents. Prayer and belief in God's divine intervention and destiny were sources of strength and hope and were ways that some parents coped with uncertainty. This is similar to Doherty et al. (2009) who also found that mothers coped with their situation by leaning on their religious beliefs. Similarly, Harper et al. (2014) found that parental religious/spiritual beliefs influenced their affective state when their child with cancer received treatment. These beliefs also increased parental confidence in caring for their child during painful procedures. Heidari, Hasanpour, and Fooladi (2017) found in their qualitative study that parents (*N* = 21) in the NICU utilized their belief in God and spirituality and prayer to remain calm, gain hope, and cope with stress. Thus, spiritual beliefs are an effective and commonly used coping strategy for parents of hospitalized infants and children.

In the current study parents identified that engaging with and providing care to their MFI was a way to establish a relationship with their infant and attained their role as a parent. This finding is consistent with parents (*N* = 16, 8 couples) in Graungaard et al. (2011) longitudinal qualitative study who utilized emotional bonding with their infant with severe disabilities to cope with parenting. Fifty percent of mothers (*n* = 16) and 38% of fathers (*n* =13) in Cantwell-Bartl and Tibballs (2013) study experienced difficulties creating a parent-infant relationship while their infant was in an intensive care unit. Therefore, developing a parental relationship with MFI is beneficial to parents; however, doing so may be challenging.

Establishing parent-infant relationships is important among MFI because parenting behaviors predict cognitive and language outcomes of children with disabilities (Innocenti et al., 2013). The quality of interaction between parents and children with disabilities can influence children's development. Karaaslan, Diken, and Mahoney (2013) conducted a randomized control trial with mothers (*N* = 19) of children with disabilities to evaluate effectiveness of responsive teaching compared to standard preschool classroom services over 6 months. Mothers in the responsive teaching group showed significant increases in their responsiveness and affect, and their children made greater improvements in engagement. The quality of parent-child interactions is affected by parental mental health. Barfoot, Meredith, Ziviani, and Whittingham (2015) found in their descriptive correlational study that increased distress in mothers (*N* = 23) of children with cerebral palsy was correlated with reduced emotional availability within the parent-child relationship. Mothers with depressive symptoms demonstrated less sensitivity during interactions, structured less activity to meet developmental needs, and were more hostile during interactions. Further research on the association between parent-infant interactions and development among MFI would be beneficial, especially since parents of MFI are at increased risk of mental health difficulties.

Parents in the current study described working as a team with their partner to cope with their stress and effectively parent their MFI. Most mothers in the current study described how their partners helped with aids to daily living, as well some fathers provided emotional support to the mothers by allowing them to talk about their feelings and experiences. Our findings are similar to three studies where mothers of MFI found their relationship with their partner to be a significant source of support (Kaul & Lakey, 2003; T. Y. Lee et al., 2006; Sikora & Janusz, 2015). Partners were the most frequently recognized source of support, along with extended family, most often grandmothers. Grandmother's helped care for other siblings and with household duties. In a descriptive correlational study, mothers (*N* = 60) of MFI reported other supportive relationships included their mothers, sisters, or close friends (Kaul & Lakey, 2003).

Parents in this study described utilizing cognitive, emotional, spiritual, and relational (with partner, infant, and grandmother) coping strategies to manage their stress. These findings were supported by the literature. This study adds to the literature by describing how parents of MFI engaged in team work with partners and utilized the role of detective work to further cope with stressors.

Strengths and Limitations

Data saturation was attained within this current study. Theoretical sampling occurred, and ample data were collected to ensure robustness and thorough development of key concepts and themes. Concepts and themes were fully saturated to provide support for the theory. The identified theory of 'Journeying Along Side One Another' aligns with the theory of Family-Centered Care. Factors that lead to beneficial factors are closely related to core concepts of Family Centered Care: (a) dignity and respect, (b) information sharing, (c) participation, and (d) collaboration (Institute for Patient- and Family-Centered Care, 2019). Parent and HCP' experiences were different, however, during abstract theorizing their interconnectedness emerged. Integrating themes and categories from two different samples with differing perspectives lead to the successful development of the grounded theory.

Limitations to this study include the theory emerged through researchers' interpretation of data. L.M. is a pediatric nurse and mother of two healthy preterm infants who were hospitalized for 6 and 3 weeks. Thus, she has ample lived experiences that may have influenced or biased the way in which data were collected and analyzed. Data were collected from parents of MFI on one inpatient unit in one Canadian pediatric hospital. Therefore, findings may be specific to the processes of care and environment in that setting. Transferability of findings to other pediatric in patient units and hospitals will need to be done with caution. Due to inability to recruit parents that HCP identified as significantly struggling and not coping well, results reflect a sample of parents that coped relatively well and may not be representative of parents of MFI as a whole. Therefore, the true parental experience that is wrought by severe difficulty may not have been captured in its fullness. As a result, findings may not be transferable to all parents of MFI.

Recommendations and Implications for Practice

Parents and HCP suggested recommendations to improve care of MFI. Also, interventional strategies emerged from this current study's findings that have potential to improve care, better meet the needs of MFI and their parents, and promote an environment for the establishment of a supportive relationship built on trust.

Model of parent healthiness.

One physician described how HCP needed to provide care to MFI and their parents within a 'model of parent healthiness.' Parents needed support to alleviate the suffering that resulted from traumatic and life altering events associated with parenting their MFI. Yet, there are currently few supports available to parents. Psychological counseling, parental screening for mental health and coping abilities, and having an exercise facility/programs available for parents emerged from study findings and were recommended strategies for promoting a model of parent healthiness.

Increase psychological supports.

Parents and HCP in the current study recognized that increasing psychological supports may alleviate suffering and help parents to better cope with their multiple stressors. Two avenues were identified to increase psychological supports: (a) via a professional psychologist specifically for parents of MFI, hired by ACH and available to all parents, and (b) an increase in parent to parent interactions should occur so they can build supportive relationships with other parents of MFI. Numerous studies conducted among parents of MFI recommended the development of interventions that provide psychological supports to parents to help them cope and manage parenting their ill infant (Brosig et al., 2007; Cantwell-Bartl & Tibballs, 2013; Cho et al., 2008; Doherty et al., 2009; Graungaard et al., 2011; Hearps et al., 2014; Holditch-Davis et al., 1999; Kaul & Lakey, 2003; Kosta et al., 2015; Miles et al., 2002).

Parents in this current study recognized that having asses to psychological counselling would be beneficial. One mother received psychological counseling at the tertiary NICU her daughter was admitted to prior to being transferred to the ACH. She noted that this service was essential to her current well-being and ability to bond with her daughter. She stated she wished she had continued psychological counselling to help her continue to cope with the unpredicted setbacks in her daughter's illness trajectory. HCP recognized that they often collaborated with parents that struggled to cope and suffered with their mental health. They stated they had no training on how to counsel parents enduring such hardships. HCP identified having access to a professional psychological counselor would help parents cope with their extreme situation better and alleviate their mental health difficulties, and thus, enable them to better enter a supportive relationship.

Aite et al. (2003) implemented an intervention for mothers with an infant born with a congenital anomaly that required surgical correction. The intervention involved weekly counseling sessions with a psychologist and weekly team meetings for 16 mothers. Standard of care was provided for 14 mothers who formed the comparison group. Anxiety levels were initially high for both groups; however, the anxiety levels in the intervention group were significantly lower than the control group upon discharge. According to Aite et al. (2003), having trained psychologists support parents of MFI is extremely important because they can provide supportive interventions to the parents, as well as, promote HCP understanding of the family’s response and adaptation to their crisis. The results from this study confirm that providing psychological supports to parents of MFI may help alleviate parental suffering and improve their outcomes, which coincides with the recommendation made by parents and HCP within this current study.

Hancock et al. (2018) implemented early palliative care with 38 mothers of MFI. The intervention involved helping mothers to better cope with their extreme situation. Mothers who received early palliative care demonstrated a significant reduction in anxiety when compared to the control group, as well as positive change in communication and family relationships and improved maternal positive reframing. Thus, mothers of MFI were able to cope significantly better because of psychological support from palliative care. Therefore, the palliative care team at the ACH could be a service that is utilized to help parents of MFI cope with their extreme and complex situations.

Parents in the current study identified that other parents were a source of support, hope, and strength that helped them cope and endure their extreme situation. It was comforting for parents to create relationships with other parents of MFI who understood the pain and suffering they were experiencing. Most parents wished they had more opportunities to meet other parents and form relationships with them. According to Discenza (2017), parents who have a medically complex infant feel isolated during times of profound grief. Connecting with other families who experience similar situations gives them hope and strength in their daily lives to move forward (Discenza, 2017). Kosta et al. (2015) also identified that parents found it helpful to create relationships with other parents at the hospital. Therefore, it is recommended that parents be offered opportunities to meet one another within the inpatient unit by holding coffee times or support groups.

Screening.

In order to identify which parents need a referral to professional psychological supports, parents of MFI should be screened for mental health difficulties. One mother in this study was screened for depression in the NICU because she partook in a study. It helped her reach out to spiritual care for support and re-organize her priorities to better care for herself. However, no other parents in this study were screened for depression, or other mental health difficulties. Therefore, it is recommended that parents of MFI be screened for depression, anxiety, distress, and PTSD while in hospital. Such screening should occur early in the infant’s illness trajectory to allow for assessments and early interventions and supports (Hearps et al., 2014; Solberg et al., 2011a). This screening can be done by registered nurses, nurse practitioners, physicians, and social workers. Screening should occur upon admission and regularly the hospitalization. Cho et al. (2008) and P. Lee (2007) both identified that mothers of MFI should be screened for symptoms of depression, psychological distress, and PTSD.

Increase parents' access to physical activity.

Parents in the current study wanted to engage in physical activity so they could feel better mentally, physically, and emotionally. Parents were unable to engage in physical activity while at the hospital because they did not have time to travel to a fitness facility to partake in exercise classes or attend a gym. Most parents stated they would benefit from physical activity classes offered at the hospital or having access to the hospital gym. It has been well established in the literature that physical activity conducted regularly is correlated to decreased symptoms of anxiety and depression (ten Have, de Graaf, & Monshouwer, 2011). ten Have et al. (2011) found in their study conducted among 7,076 Dutch adults that physical exercise was associated with lower prevalence of mood and anxiety disorders. Parents in the current study suggested that physical activity at the hospital would provide them with a mental break while also remaining in close proximity to their infant. Parents in Kosta et al. (2015) study also identified that they wanted more onsite services to meet their own health and well-being needs. Therefore, it is recommended that physical exercise classes for parents of MFI be held in the gymnasium at ACH. Also, it is recommended that parents have access to the fitness room at the ACH.

Improving processes of care.

Primary nursing and continuity of care.

Parents in this study recommended primary nursing to improve care provided to their infant. They believed that primary nursing was related to safety, fostered deeper relationships, and enabled parents to take breaks. Primary nursing has been associated with increased patient satisfaction with nursing care, improved staff competence, improved educational skills, and improved nursing-sensitive patient outcomes (i.e., urinary tract infections) (Molin et al., 2017). Specifically, Wan, Hu, Thobaben, Hou, and Yin (2011) found in their randomized control trial of

470 hospitalized pregnant woman that when compared to traditional task-centered nursing care, primary nursing was associated with increased satisfaction, enhanced breastfeeding, enhanced interpersonal relationships with nurses, and a reduction in early postpartum urinary retention and breast discomfort. Primary nursing enabled nurses to provide continuous, coherent, individualized, patient-centered, and holistic nursing care to pregnant and new mothers.

Primary nursing has the possibility to improve relationships between parents and HCP. Faber (2013) and team implemented relationship-based care and primary nursing within a NICU environment as an innovation to improve family-centered care. They promoted relationship-based care by emphasizing and creating caring relationships with themselves, their colleagues, the infants, and the infants' families. The needs and resources of the infant, family, and HCP were identified and respectful partnerships with families and the healthcare team were developed. Faber and colleagues also implemented primary nursing by promoting consistent patient assignments that increased nurse autonomy; they offered ongoing staff education and self-assessments through weekly team meetings. Parent satisfaction with care significantly improved and parents felt increased trust in staff. Nurses felt stronger connections with the infants and their families, were more effective at putting the infant and families at the core of their care and had improved relationships. Therefore, it is recommended that inpatient unit at ACH implement primary nursing.

HCP, specifically physicians, recommended the implementation of a nurse navigator to improve consistency in care. The nurse navigator was identified as a role that could provide parents with a consistent relationship over the course of the infant's illness trajectory. It is recommended that the role of the nurse navigator be initiated at ACH to work with MFI and their parents. The nurse navigator should begin working with MFI from birth or diagnosis, follow infant and parents during transfers among units, and through to transition home. The nurse navigator could ensure consistent care is provided to MFI, participate in creating plans of care tailored to meet MFI and their parents' needs, and provide support to parents and the health care team. This role should include expertise and training as an Infant Mental Health (IMH) provider as described below.

Care plans and team meetings.

Nurses did not utilize care plans because they were electronic, cumbersome, and difficult to locate. As a result, care was often inconsistent, HCP were unaware of the infant's history, and care did not meet the specific needs of infant's or their parents. Jansson, Pilhammar-Andersson, and Forsberg (2009) found in their retrospective, cross-sectional design study that the use of documented care plans ($N = 87$) resulted in more individualized care, collaboration in decision making, and shortened length of stay. Therefore, it is recommended that a care plan template be developed that includes distinct plans of care, infant history, infant and parent needs, parental social issues, and specific parental preferences for providing individualized care. Such care plans should be stored at the bedside to ensure utilization by all HCP since most nurses admitted that the current computerized care plan was hard to find and underutilized.

Multiple medical specialties were often involved in the care of MFI, which resulted in fragmented communication and incoherent plans of care. As suggested by parents in this current study, it is recommended that care provided to MFI on the inpatient unit include weekly team meetings attended parents and all HCP involved in MFI care. Weekly team meetings should aim at promoting open and honest communication, continuity of care, and collective planning of care. Such plans of care need to be communicated and made available to all HCP caring for MFI.

Possible Models to Utilize or Adapt in the Development of an Intervention

Alberta FICare©™ model.

Family-Integrated Care (FICare) is a model of care that ensures parents are an integral part of care provided to infants in Level III NICUs (Bracht, O'Leary, Lee, & O'Brien, 2013). O'Brien et al. (2013) conducted a pilot cohort study to determine the feasibility, safety, and potential of implementing FICare in a Canadian NICU. It was shown to be safe and benefit the NICU setting by having improved weight gain among preterm infants and reduced psychological stress for mothers (O'Brien et al., 2013). This model of care may be beneficial for the pediatric inpatient care unit because MFI are often transferred from the NICU care environment.

Benzies and team adapted the FICare model to fit the Level II NICU environment in Alberta, Canada (Benzies et al., 2017). It encompasses three components: (a) information sharing, (b) parent education, and (c) parent support (Benzies et al., 2017). Alberta FICare©™ is a psycho-educational intervention that empowers parents to sequentially build their skills, knowledge, and confidence, and aims to prepare parents to care for their infant prior to discharge (Benzies et al., 2017). Alberta FICare is dynamic in nature as it encourages and supports parents and HCP to negotiate equitable caregiving roles, and parents are encouraged and directed on how to provide non-medical care (Benzies et al., 2017). This model could be effective within the pediatric inpatient care environment by providing HCP with strategies and guidance, specifically nurses, on how to better encourage, empower, and enable parents to care for their infants. Also, it could enhance HCP skills on how to interact with parents and negotiate care roles, which could increase parental participation in care early in the infant's illness trajectory. Thus, the Alberta FICare model could increase parent's confidence providing care, strengthened parent-infant relationships, and enable infants to move quicker towards transitioning home. Also, better negotiation of roles between parents and HCP could increase mutual respect for each other's knowledge and expertise, which in turn could enhance beneficial interactions between parents and HCP. However, the Alberta FICare would need to be adapted to include aiding parents in providing medical care to MFI.

Embedded in Alberta FICare is that of relational communication skills, HCP are provided with strategies to dynamically negotiate roles while the infant is in hospital (Benzies, 2016; Benzies et al., 2017). Within the current study communication was a key factor that aided parents and HCP in engaging in beneficial interactions that led to the development of trust. Thus, relational communication skills from the Alberta FICare model could be utilized among HCP who care for MFI as strategies to enhance communication with parents and better develop supportive relationships.

Promoting first relationships.

Lehner and Sadler (2015) found in their extensive literature review that children who are hospitalized for greater than 30 days had less physical space to practice fine and gross motor skills and fewer opportunities to engage in educational play. They were often overwhelmed with frightening and painful sensory stimuli such as medical procedures, loud noises, altered sleep-wake cycles, and rigid schedules. The mental development of 23 MFI with bronchopulmonary dysplasia and 39 MFI without bronchopulmonary dysplasia were more than 1 standard deviation below the normative group means (Holditch-Davis et al., 2001). As well, the adaptive behavior scores among MFI were lower than normative group means (Holditch-Davis et al., 2001). Clark et al. (2015) found that 31.6% of MFI (*N* 310) who underwent life-saving therapies had receptive communication delay, and 40% had expressive communication delay at 21.5 months of age. Therefore, MFI live in a hospitalized environment that is not supportive of development and their developmental outcomes are less than optimal. It is important that MFI have a buffer to the stressful hospital environment to help them grow and develop. Secure attachment and sensitive care provided by a caregiver has been found to have protective factors against early childhood adversities (Belsky & Fearon, 2002). Thus, strengthening the attachment between parents and their MFI may be a strategy that improves infant development and outcomes.

Promoting First Relationships (PFR) is a program that emphasizes infants and young children need nurturing, responsive, and sensitive caregivers to meet their needs and foster optimal social and emotional development (Kelly et al., 2016). It offers strategies that providers can utilize to support parents in meeting the needs of their infants and engage in beneficial caregiver-infant interactions, which leads to secure attachment. HCP working with MFI could utilize these strategies to enhance parent-infant interactions and aid in the establishment of secure parent-infant attachment, which could buffer MFI against the stressful hospital environment.

A foundation to PFR is teaching providers how to establish a strong supportive relationship with caregivers, who then in return provide a similar environment for their infant (Kelly et al., 2016). It teaches providers how to focus on the caregiver’s strengths with a non-judgmental approach to increase the caregiver’s feelings of confidence (Kelly et al., 2016). Therefore, principles and strategies from PFR may be beneficial in providing HCP with practical strategies and approaches they can utilize to enhance their relationships with parents. Using a non-judgmental approach may increase mutual respect, enhance open and honest communication, and help establish trust.

MFI do not elicit clear social cues that increase parental awareness of their immediate needs because (a) they are surrounded by technology (Docherty et al., 2002), (b) they are less alert and sleep more (Holditch-Davis et al., 2003), and (c) display less social behaviors such as vocalization (Cho et al., 2008; Holditch-Davis et al., 2011). As a result, parents are less able to engage in contingent and reciprocal parent-infant interactions. Maternal depression may lead to impairments in the parent-infant relationship and attachment because mothers are less responsive to their infant when depressed (Kelly et al., 2016). Given that parents of MFI experience increased rates of depression than the general postpartum population, they are at greater risk for problematic interactions. PFR equips HCP with sensitive and responsive ways to help guide parents in the development a supportive relationship with their infant (Kelly et al., 2016). Therefore, PFR may be advantageous in providing HCP with knowledge and skills to promote developmentally sensitive parent-infant interactions and establish secure attachment despite the infant's condition.

Infant mental health provider.

The role of an Infant Mental Health (IMH) provider may have beneficial aspects that could help improve relationships among parents and HCP within the hospital setting. IMH providers cultivate nurturing, supportive, and safe relationships with parents and HCP (Browne & Talmi, 2017). They work alongside HCP to identify and address stressors and challenges that parents experience (Browne & Talmi, 2017). Specifically, IMH providers interpret parents' suffering, assess and intervene when parental psychosocial stressors are present, or make referrals. They explore and clarify parental psychological and emotional difficulties to HCP and work with HCP who experience distress. When HCP are involved in difficult interactions or witness worrisome situations the IMH providers are a go between, helping to increase understanding between parents and HCP and support both the parents and HCP in their distress. Therefore, the role of the IMH provider could help to create an environment where mutually beneficial interactions occur between parents and HCP that leads to the establishment of a relationship built on trust. This role and training could be incorporated into the role of Nurse Navigator as described above.

Future Research

Stemming from the recommendations, future research that is implicated from this study involves interventional and evaluative studies. Interventional studies that include: (a) screening parents, (b) parental psychological supports via parent to parent support, trained psychologists, and palliative care involvement, (c) parental physical activity programming, (d) primary nursing, (e) care plans, and (f) nurse navigator. Interventional research could include developing programs that involve aspects of Alberta FICare, Promoting First Relationships, and the role of an Infant Mental Health Specialist can be utilized and included. Future research would encompass feasibility and pilot testing of such interventions, and evaluative research identifying usefulness and effectiveness.

Conclusion

In this grounded theory study parental and HCP' experiences caring for MFI were explored. This study was grounded in the philosophy of pragmatism, symbolic interactionism, and social constructivism; the philosophical underpinnings of Charmaz' approach to grounded theory (Charmaz, 2014a). Theoretical sampling was utilized to recruit 21 parents and 26 HCP who engaged in intensive interviewing via one-to-one interviews and focus groups. Themes and concepts emerged during data analysis that provided rich descriptions of parental and HCP' experiences caring for hospitalized MFI. When the different yet interconnected experiences of parents and HCP were compared and contrasted, the theory of 'Journeying Along Side One Another' emerged. Data analysis presented a thick description via themes and concepts of how parental and HCP different yet interconnect experiences come together in a liminal space, that of the interaction.

The findings from this current grounded theory study are reflected in the literature: parents of MFI suffer mental health difficulties, experience multiple stressors, utilize coping strategies, and encounter difficulties with HCP. Strengthening the relationship between parents and HCP is a possible strategy to improve care provided to MFI and their parents. Implications for practice include: adopting a model of parent healthiness, improving inpatient care processes, and adapting interventional strategies identified in the literature.

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Appendix A

Supplementary Table of Study Characteristics

Author	Purpose	Sample	Design	Concepts	Measures	Main results
Aite, Trucchi, Nahom, Zaccara, Casaccia & Bagolan (2003) **Italy**	To assess the impact of a short-term intervention on maternal anxiety among mothers whose infants underwent a surgical correction of a congenital anomaly after a missed prenatal diagnosis.	30 mothers (16 in the intervention group and 14 in the control group) of infants admitted for the surgical correction	Descriptive Intervention	Maternal anxiety	Spielberger State–Trait Anxiety Inventory (STAI–S)	No significant difference was found in maternal anxiety levels at birth between the two groups. At discharge, the intervention group, who received weekly meetings with a psychologist and team meetings, had much lower maternal anxiety levels than those who received standard care.
Bevilacqua, Palatta, Mirante, Cuttini, Seganti, Dotta & Piersigilli (2013) **Italy**	To evaluate emotional distress, depression and quality of life in parents of infants with severe CHD admitted for the first time to the hospital within first 3 months of life. To investigate differences in these variables between mothers and fathers and between parents receiving a prenatal and postnatal diagnosis.	Parents (38 mothers and 36 fathers) of 38 infants with severe CHD	Single-center pilot study, descriptive, between group comparison	Emotional distress, depression, quality of life	General Health Questionnaire-30 (GHQ-30), Beck Depression Inventory – Second Edition (BDI-II), Health Survey-36 (SF-36)	Stress and depression levels were significantly higher in mothers than in fathers. Mothers and fathers who received a prenatal diagnosis were more depressed and mothers and fathers who received postnatal diagnosis were more stressed.
Black, Holditch-Davis & Miles (2009)	To examine ambiguous and liminal aspects of becoming a mother to a medically fragile preterm infant,	34 mothers of MFI; who were diagnosed with a high-risk	Longitudinal qualitative	N/A	Semi-structured individual interviews	Mothers encountered challenges facing preterm birth and mothering MFI. Before mothers established social ties with their infant

United States	identifying significant turning points at which women moved from a liminal state to explicit identification as mother of this infant.	prenatal condition such as pre-eclampsia, and delivered a preterm singleton infant				they had to make critical decisions. Mothers had limited involvement initially, and mothers worked to know their infant and establish a bond with them.
Brosig, Whitstone, Frommelt, Frisbee & Leuthner (2007) **United States**	To evaluate coping and psychological functioning of parents of children prenatally or postnatally diagnosed with CHD.	Mothers and fathers of 17 infants with CHD (10 diagnosed prenatally and 7 diagnosed postnatally)	Prospective longitudinal descriptive between group comparison	Psychological distress	Brief Symptom Inventory (BFI), semi-structured evaluated interviews	Both groups had higher distress scores than test norms at the time of diagnosis with no significant difference between groups. Six months after birth the prenatal group scores remained significantly higher than test norms, postnatal group did not differ from test norms. Parents with infants that had more severe diagnosis had higher distress scores.
Browne & Talmi (2017) **United States**	Article addresses preparation, resources, and interventions that can be provided by infant mental health providers through case studies and examples for appropriate referrals in an intensive care setting.	3 medically fragile infants	Case study of infant mental health specialist within a NICU setting	Infant mental health specialist: cultivates relationships between parents and infant, and parents and health care professionals.	Description of the infant mental health specialist role and benefits	Infant mental health specialists were valuable in dissipating parent-staff conflict, supporting infant-maternal interactions, decreasing parental stress, improving parental coping, and strengthening parental relationships with staff.
Brunssen & Miles (1996)	To identify the significant stressors for mothers of MFI while their	57 mothers of MFI	Descriptive correlational	Stress, perception of	Parental Stressor Scale: Hospitalized Infant	Factors that mothers found to be most stressful were parental role alteration and infant

United States	infant is in the hospital. To describe maternal perception of infant's illness severity, degree of worry about the infant, and perceived satisfaction with social support. To examine the contribution of above factors to the maternal experience of stress.			infant's illness severity, worry about infant's condition, perceived satisfaction with social support	(PSS:HI), Severity/Worry Scale, Stress Support Scale (Satisfaction Subscale)	behavior and appearance. Factors of the hospitalization that mothers found the most stressful were seeing infant in pain and difficulty breathing. Stress scores were predicted by maternal worry score, hospital environment dimensions, satisfaction with social support, and perception of severity score.
Cho, Holditch-Davis & Miles (2008) **United States**	To examine the effects of maternal depressive symptoms and infant gender on interactions between mothers and medically at-risk infants.	108 preterm infants and their mothers, 67 MFI and their mothers, and 83 infants seropositive for HIV and their primary caregivers	Longitudinal descriptive, between group comparison	Mother-infant interactions (incl. mother attention and mother restrictiveness), depression	Home observation for measurement of the environment (HOME), Center for Epidemiologic Studies Depression Scale (CES-D)	Mothers of MFI had higher levels of depressive symptoms than mothers of preterm infants at 6 months corrected age, and similar depressive symptoms to HIV-positive mothers at 12 months. Mothers of MFI with elevated depressive symptoms were more restrictive and less attentive to their infants. Infant gender was not related to level of depressive symptoms.
Cho, Miles, Holditch-Davis & Belyea (2009) **United States**	To examine the effects of infant characteristics (gender), and the effects of maternal characteristics (age, education, and marital status) on the interactions between mother and her MFI.	108 preterm infants and their mothers, 67 MFI and their mothers, and 83 infants seropositive	Longitudinal descriptive between group comparison	Mother-infant interactions (incl. mother attention, mother restrictiveness, infant social	Home observation for measurement of the environment (HOME)	There was no difference in mother-infant interactions based on gender of the infant. MFI demonstrated an increase in social behaviors over time. Mothers of preterm MFI were more restrictive with their infants. Mothers who were older, married, and had

		for HIV and their primary caregivers		behaviours, and infant negativism)		more years of education were more attentive and less restrictive to their infants.
Clark & Miles (1999) **United States**	To explore experiences of fathers of infants newly diagnosed with severe congenital heart disease.	8 fathers who had infants with severe congenital heart disease	Longitudinal qualitative	Parenting	Semi-structured interviews conducted longitudinally	Fathers underwent 4 interrelated conflicting reactions: a) joy seeing the infant born mixed with sadness and loss about the infant's illness, b) challenge becoming attached and dealing with fears of loosing infant, c) need of trying to maintain control because feeling loss of control, d) struggling to remain strong and hiding intense emotions.
Contwell-Bartl & Tibballs (2013) **Australia**	To evaluate the psychosocial status of mothers and fathers of infants with hypoplastic left heart syndrome (HLHS) while in the PICU.	29 parents (16 mothers and 13 fathers) of surviving children who had had a stage I repair of HLHS.	Retrospective mixed methods: descriptive + qualitative	Parental experiences, acute stress disorder (ASD), posttraumatic stress disorder (PTSD)	Semi structured interviews, PTSD module of the Clinical Version of the Structured Clinical Interview for Diagnosis (SCID-CV)	ASD or PTSD developed in 24 parents (83%). No difference in prevalence of stress-related disorders was found between mothers and fathers. Only 5 parents were free of traumatic stress-related illness. Many parents were distanced from their infants due to the intensive care environment. Fifty four percent of mothers had difficulties bonding with their infant.
De Stasio, Coletti, Boldrini, Bevilacqua, Dotta & Gentile (2018)	To evaluate potential differences in the levels of stress perceived by mothers of infants at one year of age either affected by a congenital	40 mothers of infants with congenital heart disease, 34 mothers of preterm babies	Multidisciplinary longitudinal between group	Parental stress in the mother-child system; infant's cognitive,	Parenting Stress Index Short Form (PSI-SF), Bayley Scales of Infant and Toddler	Mothers of preterm infants reported higher levels of stress than did mothers of babies with congenital heart disease or those in the control group. Mothers of infants with congenital

Italy	heart disease or preterm with favourable clinical and developmental outcomes. To investigate in each group the potential association between mothers' stress, neonatal risk factors and maternal socio-demographic factors.	with favourable clinical and developmental outcome, control: 26 mothers of healthy infants born at term	comparison correlational	language and motor skills	Development - Third Edition (BSID-III), medical records	heart disease did not perceive their infants as more stressful than healthy infants. Mothers of preterm infants found interacting with their infant more emotionally difficult and demanding than mothers from the two other groups. Higher maternal education correlated with lower levels of maternal stress.
Docherty, Miles & Holditch-Davis (2002) **United States**	To examine the sources and levels of child health worry among mothers of MFI with differing health problems and to identify factors associated with maternal worry.	78 mothers of MFI	Descriptive correlational	Worry about child's health, satisfaction with family, illness-related stress, illness-related factors, maternal characteristics	Child Health Worry Scale, Family Apgar Scale (FAPGAR), Parental Stressor Scale: Infant Hospitalization (PSS:HI), Technology Dependence (TD) scale, medical record	Highest sources of maternal worry were medical problems, then worry if infant would be normal, followed by whether the infant would always be sick. There was no significant difference in maternal worry among mothers of infants with chronic lung disease, congenital airway anomalies, severe gastrointestinal problems, complex congenital heart disease, neurologic diagnoses, and infants grouped as other. Less days in hospital, lower maternal education, and elevated stress levels associated to infant’s appearance and behavior were related to an increase level of maternal worry.

Docherty, Lowry & Miles (2007) United States	To explore the influence of poverty on the parenting experience and maternal developmental trajectory of Lumbee mothers with MFI.	5 Lumbee Indians low income mothers of MFI	Multi-case study, qualitative	Poverty, parenting MFI	Semi-structured interviews conducted longitudinally	Five inductively derived themes related to poverty described maternal parenting experiences, including a) poverty and maternal resources, b) single parenting, c) community influences, d) culture and kinship support, and e) maternal developmental impact.
Doherty, McCusker, Molloy, Mullholland, Rooney, Craig, Sands, Stewart & Casey (2009) United Kingdom	To examine mental health and coping styles in both mothers and fathers of. infants born with severe congenital heart defect.	Mothers and fathers of 70 infants with severe congenital heart defects	Descriptive correlational between group comparison	Psychological functioning; coping; infant's medical/surgical variables; parent's psychosocial variables: socioeconomic status, knowledge and understanding child's condition, parental subjective worry, pre-existing family functioning	Brief Symptom Inventory (BSI); Carver, Scheier and Weintraub multidimensional coping inventory (COPE); medical record; cardiac symptom checklist; Townsend Score; rated interviews; Maternal Worry Scale; Significant Others Scale; cohesion and conflict subscales on Family Environment Scale	Mothers experienced higher levels of psychopathology when compared to fathers. Mothers and fathers utilized different coping styles. Coping styles, subjective worry, knowledge, and family functioning were significant predictive variables of mental health difficulties in both mothers and fathers. Disease, surgical, number of symptoms, presence of developmental syndrome, socioeconomic status, and social support were not predictive variables of parental mental health difficulties.

Graungaard, Andersen & Skov (2011) **Denmark**	To explore the relationship between personal resources and coping in the stressful life-situation of becoming a parent to a severely disabled child.	8 couples (16 parents) of children with inborn severe mental and physical disabilities that had been recently diagnosed.	Longitudinal qualitative	Parental coping	Semi-structured interviews - Grounded Theory analysis	Parents constantly created and sustained personal resources by way of positive cognitive reappraisals of their current situation, consequences of their current circumstances, and their coping abilities. Nine main coping strategies emerged. Coping and resources were identified as interrelated. The theory of resource creation was developed.
Hancock, Pituch, Uzark, Bhat, Fifer, Silveira, Yu, Welch, Donohue, Lowery & Aiyagari (2018) **United States**	To examine the benefit of early paediatric palliative care consultation on maternal stress in mothers of infants with single ventricle heart disease.	38 mothers of infants with single-ventricle heart disease: 18 in the early paediatric palliative care group, and 20 in the standard care group.	Interventional	Depression, anxiety, coping, quality of life	Beck Depression Inventory II (BDI-II), State-Trait Anxiety Index, The Brief Cope Inventory, PedsQL Family Impact Module	Baseline depression and anxiety scores were higher than normal pregnant mothers. Mothers that received early palliative care intervention had a significant decrease in anxiety scores, higher coping scores (improved maternal positive reframing), and improved communication and relationships with their families than mothers who received standard care.
Hearps, McCarthy, Muscara, Hearps, Burke, Jones & Anderson (2014) **Australia**	To investigate the frequency and nature of parent psychosocial risk occurring after infant's surgery for congenital heart disease and the impact of the time of diagnosis, antenatal or postnatal, using	29 families (29 mothers and 11 fathers) of infants who underwent cardiac surgery within the first month of life	Descriptive crossectional	Parents' psychosocial risk (stratified into Universal, Targeted and Clinical risk)	Psychosocial Assessment Tool, medical record	Sixty two percent of parents were at low, 35.9% at targeted, and 3.6% at clinical psychosocial risk of experiencing increased rates of emotional distress. There was no difference among parents that received prenatal vs. postnatal diagnoses. Higher parental education was positively correlated

	Kazak's Paediatric Psychosocial Preventative Health Model.					with a lower psychosocial score. Thus, some parents were able to adapt to the acute stress of cardiac surgery.
Holditch-Davis, Tesh, Miles & Burchinal (1999) United States	To examine the interactions of 56 MFI and their mothers and to determine the influence of infant age, neurological status, maternal education, ethnicity, and observation location on the interactions.	56 MFI and their mothers	Longitudinal descriptive	Maternal-infant interaction (maternal activities and behaviours, infant's state and behaviour)	Maternal-infant interaction coding system	MFI' age was the most effective factor on mother-infant interaction. Mothers spent less time involved, feeding, holding, looking at, in body contact, rocking, touching and gesturing as the infants grew older. Mothers played more and were more vocal with older infants. Older infants vocalized more, were more alert, and slept less. Mothers of neurologically normal infants moved them more often. Mothers with higher education looked at and fed their infants more.
Holditch-Davis, Cox, Miles & Belyea (2003) United States	To compare the interactions of mothers and their MFI with those of mothers and premature infants without chronic illnesses.	41 MFI premature infants, 20 MFI full-term infants, 28 non-chronically ill premature infants, and their mothers	Descriptive correlational between group comparison	Maternal interactive behaviours and caregiving activities, infant behaviours and states	Maternal-infant interaction coding system, Home Observation for Measurement of Environment (HOME)	Mothers of non-chronically ill preterm infants spent less time gesturing, touching, looking at, time interacting, and were uninvolved longer with their infants when compared to mothers of MFI. Non-chronically ill preterm infants slept less than MFI. MFI had less mature behaviors but interacted more with their mothers when compared to non-chronically ill preterm infants.

Holditch-Davis, Miles, Burchinal & Goldman (2011) **United States**	To examine the extent to which Maternal Role Attainment (MRA) of mothers of medically fragile infants during the first year influences the quality of parenting at 6 and at 12–16 months, after controlling for maternal education and child illness severity.	72 mothers of MFI and their infants	Longitudinal descriptive correlational	MRA components: maternal identity, maternal presence and competence, maternal interactions; Parenting quality components: responsiveness, caregiving, perceptions of the child; maternal education; child illness severity	Maternal Identity Scale: Critically Ill Infant; Interview ratings of maternal presence and competence; Maternal-infant interaction coding system; Home Observation for Measurement of Environment (HOME); Mother-Child Rating Scales; rating scale for caregiving quality outcomes; About My Baby Questionnaire (AMB); Vulnerable Child Scale; Technology Dependence Scale; Mental Development Index (MDI) of Bayley Scales of Infant Development-II (BSID-II)	Mothers who were more competent were also more responsive. Mothers who were more present and had infants with more technology dependence were less active in the infant's care. Mothers with more competence and higher education provided better normal caregiving. Mothers provided more medical care to their infant if they were less present and more competent. Mothers that had less competence and infants with more technology dependence perceived their infant to be more vulnerable and that their infant displayed cues that were difficult to read. Mothers who reported to have successfully attain their role as a mother provided better quality care to their infants. The severity of the infant's illness was not as influential on quality of care provided to the infant as maternal role attainment.

Hunfeld, Tempels, Passchier, Hazebroek & Tibboel (1999) **Netherlands**	To assess parental burden and grief one year after having a child with a congenital anomaly. To investigate differences in burden and grief between mothers and fathers, and the impact of having foreknowledge from prenatal diagnosis, the nature of the diagnosis, and the child’s functional health status on parental burden and grief.	25 couples - parents of infants with a congenital anomaly	Descriptive correlational between group comparison	Parental burden, parental grief, perception of the mother about the health of her child	Impact on Family Scale (IFS), Perinatal Grief Scale (PGS), FS II-R	Burden and grief were increased when parents received a prenatal diagnosis, perceived their infant to have low functional health, and their infant had multiple congenital anomalies. There was no significant difference in overall burden and grief between mothers and fathers.
Kaul & Lakey (2003) **United States**	To examine the roles of enacted support and generic relationship satisfaction in accounting for perceived support's relation to low emotional distress in a sample of mothers of infants with serious congenital heart defects.	60 mothers whose children were diagnosed with congenital heart defects within the first year of life.	Descriptive correlational	Perceived social support, enacted support, generic relationship satisfaction, emotional distress, stress, infant's medical severity, maternal perception of medical severity	Social Provisions Scale (SPS), semi-structured interview, Depth subscale of the Quality of Relationship Inventory (QRI), Profile of Mood States (POMS), Life Experiences Survey (LES), Cardiologist Perception of Medical Severity Scale	Perceived support was more related to relationship satisfaction than to enacted support. Low distress was accounted for by perceived support and relationships satisfaction. Enacted support was not significantly related to low distress and could not account for perceived support.

Kosta, Harms, Franich-Ray, Anderson, Northam, Cochrane, Menahem and Jordan (2015) **Australia**	To explore parental experiences of their infant's hospitalization for cardiac surgery and to identify factors that may be targeted in the future to alleviate sources of parental distress.	154 parents from 97 families (91 mothers and 63 fathers) whose infants underwent cardiac surgery	Qualitative	Interview questions categories: "What was difficult", "What would parents have liked to be different", "What helped"	Interview using a structured interview guide, medical record	Parental difficulties included dealing with infant's unfolding illness, surgery and recovery, and structural and systemic issues. Parents struggled to be near their infant. Parents recommended more available facilities and resources, improved quality of information, and more emotional support. Relationships with staff were the most common source of support.
Lee, Miles, & Holditch-Davis (2006) **United States**	To examine the perceptions of mothers of MFI regarding the helpfulness of and satisfaction with paternal support over the 1st year after birth.	60 mothers of MFI	Longitudinal descriptive correlational	Paternal Support, marital status, infant characteristics	Stress Support Scale, Technology Dependence Scale, medical record	Mothers perceived high levels of help from fathers at enrolment. Married mothers' perceptions of helpfulness of support did not differ from unmarried mothers, but reported more satisfaction with support from fathers. Mothers of female infants reported more help from fathers than did mothers of male infants, and this difference increased over time. Mothers of female infants did not report being more satisfied with paternal support than the mothers of male infants. Technology dependence and birthweight did not impact maternal perceptions of paternal support.

Lee, Holditch-Davis & Miles (2007) **United States**	To examine the extent to which maternal characteristics (depressive symptoms, education), infant characteristics (birthweight, amount of technological dependence), and family environment factors (maternal perception of paternal support) affected maternal interactive behaviours of positive involvement and maternal developmental stimulation at 6 and 12 months corrected for prematurity.	59 mothers and their MFI	Longitudinal descriptive correlational	Maternal interactions (including positive involvement and developmental stimulation), depression, education, paternal support, infant's characteristics	Maternal-infant interaction coding system; The Home Observation for Measurement of the Environment (HOME), Center for Epidemiologic Studies Depression Scale (CESD), Stress Support Scale (SSS); infant's medical record, Infant Technology Dependence Score (TD)	Mothers with higher education had greater positive involvement. Lower maternal positive involvement was correlated with increased depressive symptoms, higher infant technology dependence, and lower infant birthweights at 6 months, but greater involvement at 12 months. More paternal helpfulness facilitated more maternal positive involvement in mothers with low depressive symptoms, but not in mothers with high symptoms. More developmental stimulation was provided by mothers with higher education and more depressive symptoms.
Miles, Holditch-Davis, Burchinal & Nelson (1999) **United States**	To examine the extent to which attributes of the mother, the mother's level of parental role attainment with the infant, characteristics of the infant's illness, and maternal illness-related distress influence adjustment in mothers caring for MFI.	67 Mothers of MFI	Longitudinal descriptive correlational	Distress, growth, depression, marital status, educational level, personal control and satisfaction with family, sense of control over problems, maternal identity,	Semi-structured interviews, behavioural observations, Center for Epidemiologic Studies Depression Scale (CES-D), The Sense of Mastery Scale (SOM), Parental Stressor Scale (PSS), Child Health Worry Scale (CHWS),	Mothers experienced distress and growth from parenting MFI. Depression scores were moderately high at 6 and 16 months of age, and majority of mothers were at risk for depressive symptoms. Maternal developmental impact ratings were neutral to slightly negative at 6 months and neutral and positive at 16 months. Mothers with higher depressive symptoms had more negative developmental impact ratings. Distress was

				maternal presence, maternal competence, child-illness characteristics, level of technology dependence, level of mental development.	The Family Apgar (FAPGAR), Maternal Role Attainment, Maternal Identity, Developmental Impact Rating Scale, observational coding system of Holditch-Davis, The Home Observation for Measurement of the Environment (HOME), Mental development Index (MDI) of the Bayley II Scale, technology dependence score, medical records	correlated to maternal characteristics, hospital environmental stress, and worry about infant's health. Growth was correlated to severity of infant's illness, hospital environmental stress, concern about infants' health, and maternal role attainment.
Miles, Burchinal, Hoditch-Davis, Brunsses & Wilson (2002) **United States**	To describe maternal perceptions about hospital-related stressors, worry about the infant's health, and support from the health care team in mothers of MFI. To explore the possible differences between Black	31 Black and 38 White mothers of MFI	Descriptive correlational between group comparison	Stress, perception of infant's illness severity, worry, support, maternal characteristics (age, education,	Parental Stressor Scale: Infant Hospitalization (PSS), Parental Perception of Severity Scale, Child Health Worry Scale, Nurse-Parent Support Tool,	Mothers reported high stress levels associated with the appearance of their infants, moderate stress levels associated with their altered parental role, high levels of worry about their infants' health problems, and high support from nursing and the health care team. Black mothers reported moderately more stress from

	and While mothers on these variables.			marital status, socioeconomic status, number of children), child's health status	Stress Support Scale; medical records	the sights and sounds of the hospital environment. Mothers with less education reported less worry about their infants compared to mothers with more education.
Miles, Holditch-Davis, Burchinal & Brunssen (2011) United States	To extend knowledge on maternal role attainment (MRA) among mothers of MFI. To capture MRA change over time in the first year of infant's life, with a focus on all three MRA components: maternal identity, maternal competence and maternal presence.	81 mothers of MFI	Longitudinal descriptive correlational	Maternal Role Attainment (MRA): maternal identity, presence and competence; infant's characteristics: social-adaptive behaviour, alertness, severity of illness; maternal characteristics: illness related distress, worry, satisfaction with family, health	Maternal Identity Scale: Critically ill infant (MIS), Naturalistic observations of mother-infant interactions (coding system of Holditch-Davis), Home observation for measurement of the environment (HOME), rated interviews, Vineland Adaptive Behaviour Scale (VABS), modified Technology Dependence Scale (TD), Parental Stressor Scale:Infant Hospitalization	Mothers who worried less had higher levels of maternal identity. Mothers were more present with infants who were less alert. Maternal competence was higher among mothers of infants who were more alert and mothers who had lower parental stress, higher education, and were married.

					(PSS:IH) - it's subscale to asses parental role alteration stress (PRAS) , Child Health Worry Scale (CHWS), Family Apgar (FAPGAR), enrolment questionnaire, medical records	
Sarajuuri, Lonnqvist, Schmitt, Almqvist & Jokinen (2012) Finland	To assess perceptions of child behavior and parenting stress among the parents of young children with hypoplastic left heart syndrome and other forms of functionally univentricular heart defects.	28 patients with HLHS, 15 with UVH, and 46 healthy gender-matched newborns as controls, and their parents (mothers and fathers)	Descriptive, correlational, between group comparison	Child mental health, parenting stress	Child Behaviour Checklist (CBCL), Parenting Stress Index (PSI), medical records	Parents reported more parenting stress with infants diagnosed with HLHS than controls. Parents of infants with HLHS reported more total internalizing behavior problems than controls. Parents of UVH infants did not report more parenting stress or emotional problems than controls.
Scharer & Brooks (1994) United States	To explore how primary nurses and mothers interact and whether the relationship that develops is satisfactory in promoting the development and maturation of the mother in her role as a mother of a chronically ill neonate.	9 primary nurses and 10 corresponding mothers of chronically ill neonates	Qualitative, Grounded Theory	Mother – nurse interaction, maternal role attainment	Interviews - semi structured interview guides	Four stages in the process of transferring the care of the infant from nurse to mother were identified: a) nurse provides care, b) sharing normal infant care, c) sharing normal care and technical care, d) parent does all care. Factors influencing the transfer of care were: the status of the infant, mother's physical status, level of

						support, and nurses' expectations of the mothers
Sikora & Janusz (2014) **Poland**	To describe the experience of being a mother by women who together with their children stay on the ward after cardiac surgical correction of congenital heart defects.	4 first-time mothers whose children were born with a heart defect and were surgically treated	Qualitative	Maternal experience, parenting	Narrative interviews	Infant cardiac treatment can impact maternal care patterns and the mother-infant bonding process. Intermittent contact with the infant can initiate loss of control and loss of competence in care for the infant. Medical staff encounter challenges in supporting parents as they build relationships with their infant. Health care professionals are in a position to aid parents in caring for their infant and enhance their competence.
Solberg, Dale, Holmstrom, Eskedal, Landolt & Vollrath (2011) **Norway**	To examine the role of emotional reactivity in infants with congenital heart defects (CHD) in relation to their mothers' symptoms of postnatal depression.	169 mild/moderate CHD infants and their mothers, 73 severe CHD infants and their mothers	Descriptive correlational between group comparison	Depression (prenatal and postnatal), infant's emotional reactivity	A 4-item version (SCL-4Dep) of the Symptom Checklist (SCL-8), 6-item version of the Edinburgh Postnatal Depression Scale (EPDS-6), 7-item fussy/difficult subscale (ICQ-D/F-7) from the Infant Characteristic Questionnaire, medical records	Mothers of infants with severe CHD had significantly elevated depressive symptoms compared to mothers of infants with mild CHD.

Solberg, Dale, Holmstrom, Eskedal, Landolt & Vollrath (2011) Norway	To examine the relationship between the severity of infants' congenital heart defects (CHD) and their mothers' symptoms of depression and anxiety from pregnancy to 18 months postpartum.	162 mothers of infants with mild, moderate or severe CHD, and 44 400 control mothers	Longitudinal descriptive between group comparison	Depression, anxiety	An 8-item version (SCL-8) of the Hopkins Symptom Checklist-25	Mothers of infants with severe CHD showed significantly elevated levels of depression and anxiety symptoms at 6 and 18 months postpartum compared with mothers in a control group. No difference in scores was found prenatally.
Warshausky, MacKenzie, Roth & Barlett (1995) United States	To assess the relationship among selected medical and sociodemographic variables, maternal perceptions of infant development, and maternal distress for mothers of newborns who suffer persistent pulmonary hypertension at birth (PPHN) and require treatment by either extracorporeal membrane oxygenation (ECMO) or conventional ventilation (CV).	34 mothers of neonates born with PPHN	Descriptive correlational between group comparison	Psychological distress, infant development	Brief Symptom Inventory (BFI), Minnesota Infant Development Index (MIDI), medical records	ECMO and CV infants did not differ developmentaly, and mothers did not differ in their reports of psychological distress. Length of treatment for ECMO was related to maternal distress. Maternal distress was related to increase perception of language delay.

Abbreviations: ASD – acute stress disorder, CHS – congenital heart disease, CV – conventional ventilation, ECMO - extracorporeal membrane oxygenation, HLHS – hypoplastic left heart syndrome, MRA – maternal role attainment, PICU – perinatal intensive care unit, PTSD – post traumatic stress disorder, PPHN – persistent pulmonary hypertension, UVH – univentricular heart defect

Appendix B

Socio-Demographic Characteristics Form: Parents

Participant Identifier	
Parent Information	
1. Gender	Male ☐ Female ☐
2. Date of Birth	yy/mm/dd _____/____/____
3. What is the highest education level that you have completed?	Primary school ☐ College/University ☐ High-school ☐ Other (i.e. trade school, technical school) ☐
4. Number of children at home	
5. Occupation	
Infant Information	
1. Male or Female	Male ☐ Female ☐
2. Date of Birth	yy/mm/dd _____/____/____
3. Gestational Age at Birth	
4. Primary Diagnosis	
5. Secondary Diagnosis	
6. Other Diagnosis’	

7. Days in Hospital	
8. Admit from Home?	Yes ☐ No ☐
9. If transferred, area of transfer	
10. Technology Dependence	a. b. c. d. e.
11. How Infant is Fed	

Appendix C

Socio-Demographic Characteristics Form: HCP

Participant Identifier	
Gender	Male ☐ Female ☐
Date of Birth	yy/mm/dd _____/____/____
Occupation	
Your highest post-secondary educational achievement? If you feel more than one apply, please choose more than one.	Diploma ☐ Undergraduate degree (bachelors) ☐ MD ☐ Masters ☐ PhD ☐
Years working in your current current role At the Alberta Children's Hospital (ACH):	# Years ______
Years working in pediatric healthcare (this can include work in a pediatric setting outside of ACH or a hospital setting):	# Years ______

Appendix D

Semi-Structured Interview Guide: Parents

1. Tell me about your infant and his/her medical journey thus far.
    a. How long has he/she been hospitalized?
    b. What services have been involved in care?
    c. What services have you found helpful?
    d. What services have you found detrimental?
2. What has helped/aided you in parenting/caring for your infant?
3. What has hindered you from being able to parent/care for your infant?
4. Have you every felt overwhelmed or stressed?
    a. Tell me about a situation?
    b. What increases your stress?
    c. What decreases your stress?
    d. Have you felt sad?
    e. Have you ever felt guilt?
5. How has having a MFI impacted/effected your life? Your personal health/life, your family life, your social life?
    a. What helps you to manage being a parent/caregiver of a MFI?
6. Do you worry about your infant?
    a. What causes you to worry?
    b. What helps you to worry less?
7. Tell me about your interactions with the Health Care Team.
    a. Have you had a good experience interacting with the Health Care Team?
    b. Tell me about a situation that could have been improved upon.
    c. Describe what enables you to have a good relationship and communication with the Health Care Team.
    d. Do you feel you have a relationship with the Health Care Team? Please tell me about your current relationship with the Health Care Team.
8. Do you feel you are able to openly communicate with the Health Care Team?
    a. What helps your communication with the team?
    b. What hinders your communication with the team?
    c. Who has been the most helpful to you in caring for your MFI?
9. Do you feel involved with the care of your infant?
    a. What hinders you from being involved?
    b. What helps you to be involved?
    c. Do you wish that you could be more involved?
    d. Do you wish you could be more encouraged to participate and care for your infant?
    e. How would you like to be more involved? What could the Health Care Team do to involve you more?
10. Do you feel prepared to go home with your infant?
    a. Has the Health Care Team helped teach you or prepare you to take on the role of caring for your infant?
11. Tell me about your role as the mother/father of your infant.
    a. Do you feel like you are able to ‘parent’ your infant while in hospital?
    b. How could the Health Care Team help encourage your role as a parent?
    c. Have you ever felt that your role as a parent was hindered while in hospital?
12. Are there any events that stand out in your mind of caring for your infant?

13. Can you tell me the most important lesson you have learned from parenting/caring for a MFI?
    a. Have you grown personally?
    b. Tell me about the strengths you have discovered or developed.
14. What advice would you give a parent of a newly born MFI?
15. Is there anything you would like to ask me?

Appendix E

Semi-Structured Interview Guide: HCP

1. How long have you been involved in the care provided to MFIs?
2. What do you like about caring for MFIs and their families?
3. What do find challenging about caring for a MFI and their family?
    a. Have you ever encountered difficulty or tension in a relationship with a parent/caregiver of a MFI?
    b. What did you do to resolve the conflict?
4. Tell me about an experience when you feel you were able to positively impacted a parent/caregiver of a MFI.
    a. What went well?
    b. What could have been improved?
5. Are you able to create relationships with the parents/caregivers?
    a. What aids you in creating relationships?
    b. What hinders you in creating relationships?
6. What do you think health care professionals could improve in the care provided to MFIs and their parent/caregivers?
7. Do you feel parents struggle to parent a MFI?
    a. What hinders them from being involved and adequately parenting their infant?
    b. What aids them in being involved with their infant?
8. Do you think health care professionals can take steps and measures to involve parents in care and help them parent their infant?
    a. Can health care professionals aid in the mother-infant bonding experience, parent interactions?
9. Can you explain the most important lesson you have learned from caring for a MFI and their parent/caregiver?
10. What helps you to manage the care provided to MFIs and their parent/caregiver?
    a. What services/personal do you find most beneficial?
11. Do you use any specific interpersonal/communication skills when creating relationships and interacting with parents/caregivers?
12. How do you approach parents that you feel are difficult to deal with?
    a. What helps you to manage such situations?
13. How do you handle situations when parents are upset?
    a. Do you use any strategies?
    b. Whom do you consult if parents are upset?
    c. Who is the most beneficial person in times when things are ‘heated’?
14. As you look back on caring for MFIs, do any events or situations stand out to you?
15. What do you think are the most important ways to create relationships with parents/caregivers of MFIs?
16. Can you tell me about how your views of caring for MFIs have changed over time with experience?
17. What advice would you give a novice health care professional caring for MFIs and their parents/caregivers?
18. Is there anything else you think I should know or understand in regards to caring for MFIs and their parents/caregivers?
19. Is there anything you would like to ask me?

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