The Medical Parent

Identity Formation and Community Building Among Parents of Medically Fragile Children in Newfoundland and Labrador

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This project was a very personal labour of love for me from both the research perspective and the subject material, with a 14-year+ personal history. Proper acknowledgments for this project would require a stand-alone chapter, but I will try to mention the highlights.

To all the Janeway staff: During Minxie's life, you always made everything okay. NICU nurses encouraged photo shoots and dress-ups. They entertained my oldest daughter when she accompanied me for visits, they offered drinks and snacks, and they answered questions and provided support. Susan, the music therapist, I have no doubt you were Minxie's favourite staff member. The photo of you both during a therapy session is a treasured favourite. Thank you so much to all the staff who shared with me during appointments and admissions. Then, your interactions were a welcome break from the monotony of time, but now they are cherished moments and memories. To the PICU nurses, thank you for caring for my daughter and sharing your wisdom and dark humour with me. Dr. Jill, you were on when Minxie first arrived from NICU and have been with us ever since. I met you as a respected doctor, but I now also consider you a treasured friend; thank you for everything you did for my daughter and all your trust in me. Lastly, to those who cannot be named; spending extended periods in intensive care settings inevitably leads to observing other people's trauma and sorrow. Three situations, in particular, stand out as exceptionally traumatizing and memorable for me. In my experience, witnessing someone else's trauma is difficult because there are no legitimate paths to closure. If there was a child in the next bed in critical condition, but the next day they were gone, I had no legitimate way to closure; is the child dead? Were they

transferred? Was this the expected outcome? In those three situations, someone gave me closure, and I cannot thank you enough for giving me that peace of mind.

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On a Personal Note: When I decided to pursue this project for my thesis, I expected it would be emotionally draining and challenging. During one interview, my participant and I paused so she could feed her daughter, and she asked me if it was painful for me to see her daughter. Her daughter's condition was very similar to my own daughter's. I told her it was not painful; it was familiar and comforting—and it was. It provided me with an unexpected connection. The mother and I chatted in her daughter's bedroom while she fed her, and when we left, I almost unconsciously tapped the child on the nose. Minxie was deaf; any time I left her bedside, I tapped her on the nose twice—it was our signal for "I love you, I'll be back soon." The sights, sounds, and activities in her daughter's room felt intimately familiar at that moment.

A line in a Stephen King movie goes, "Now I know how easy it is to be plucked out of the world" (Baxley, 1999), and I have used that exact phrase to describe parenting my daughter. I felt like I was in a different world for the 11 years I parented her. I had been ripped out of the world I knew and thrown into a new medical and isolated one that I did not understand. When she died, I felt like I was ripped away from the world again—except now the familiar, comfortable world was the medical one, and the strange new world I was thrown back into was the same one I had known before she was born. I felt like I had lost my place in the medical world I knew. For 11 years, I was her primary caregiver. I was her parent, but I also had a position within a community of other parents and with hospital staff. And I felt like I lost all my connections in the world I knew when

I lost her. While searching the literature for my thesis, I found the four stages of role exit (Kendall et al., 2004). Through this research project, I realized I had found a new place and position with other parents and hospital staff; they were not gone forever—my place in the world was recalibrating, just as Kendall et al. (2004) wrote. I still have a membership; it's just in a new position.

When Minxie died, my youngest child, Marley, was four years old and used to sleep in his own bed and room. After she died, I started waking up at night, compelled to check on Marley to ensure he was still breathing, sometimes multiple times a night. Usually, I would wake him in the process, and it did not take long before I moved him out of his bed entirely and into mine. It was easier to check on him during the night if he was beside me. I only had to reach my hand, place it on his back, and wait to feel his breath. That routine continued until I began this research project. Now, I feel comfortable enough to let him sleep in his room again, and I do not check to ensure he is breathing. This project has provided me with unique and unexpected self-reflection and healing, and my increased comfort with Marley's longevity reflects that.

Abstract

This thesis is about the experiences of parents of medically-fragile children. Through a symbolic interactionist lens, I interviewed parents of medically-fragile children in Newfoundland and Labrador using open-ended, qualitative research methods to ascertain how they framed their lived experiences. My data revealed that these parents developed a “medical parent” identity through their interactions with others, and this identity was the lens through which they filtered and interacted with the world. These parents engaged with temporality, boundary work, normalization, and medical knowledge as part of their everyday parenting experiences. My data showed that these parents engage with 13 identifiable hazards as part of performing the medical parent identity, which overlaps and correlates with each other.

Keywords: Identity, medical parent, parenting, child, medically-fragile, temporality, normalization, hazards.

Summary

Chapter 1 begins with a review of the literature on parenting medically-fragile children and introduces my theoretical framework. Chapter 2 discusses my methods—how I conducted my research and with whom.

Chapter 3 discusses the identity of a medical parent, including how this identity is formed and engages with boundary work, temporality, and normalization. Chapter 4 continues this theme by detailing how the identity of a medical parent manifests in parents' everyday lives. The previous chapter established the frame through which these parents view the world, and this chapter provides an understanding of what they see in the world based on this viewing frame.

My data also revealed many nuanced elements related to my overarching concept of the medical parent, such as their relationships with their other children, and so on. I develop them in Chapter 5, which records my findings on the child, faith, siblings, and the father.

Chapter 6 provides my concluding discussion on the data, reflections on the process, limitations to the data, and possible directions for future work.

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Chapter 1 Introduction: Getting to the Research

Many have asked how I came to this project or why I decided to do this. I wish I could respond with some grandiose academic answer, but I cannot. No matter how hard I try to reframe it, it all began one Winter night.

It was mid-December 2018. I had four children then, and I was completing my undergraduate degree as a mature student. One of my children (nine-year-old Minxie) had just been admitted to the children's pediatric intensive care unit (PICU) at the Janeway. Nothing strange. Minxie was severely disabled and medically-fragile. She was born with severe cerebral palsy (CP) and chronic lung disease (among her more prominent ailments). She could not sit, stand, walk, talk, or eat on her own. Often, she could not breathe on her own either, and that was the predicament we found ourselves in that morning. She had been unwell with a viral-type illness for a few days (nothing unusual for her), but when she awoke this morning, she was unstable (also nothing unusual for her). Even while she was awake, with extra supplemental oxygen, her blood oxygen levels were lower than acceptable, and they would dip quickly with any slight cough. Oxygen saturation levels are higher when awake, so I knew there would be trouble when she went to sleep. I gave her Ventolin and a deep suctioning to clear her airway, packed her into our van, and drove her to the Janeway hospital—an hour away. We arrived by early afternoon, and she was quickly assessed in emergency and transferred to the PICU. The doctor decided to try her on bi-pap, and she settled—stable for the moment, but a developing illness in a medically-fragile child can be severe and turn very quickly. It was now 6 p.m., and I had to make a decision—I had to write a final exam at 7 p.m. across the road at Memorial University. So, I went and wrote it. The attending physician said she was still debating putting her on a ventilator. I left instructions with her: do whatever you need to do while I am gone, and we will deal with it when I return. And I crossed the road and wrote my exam. What was the alternative, I thought to myself, defer my exam? Until when? The next time she is in the hospital? Because one day is just as unstable and unpredictable as the next anyway.

But even though I knew it was the right decision for me in those circumstances, at that time, I still shook my head walking across the road: this is just not right. There is something about this whole situation that does not make sense. And the idea sat: this does not make sense. And it sat until July 2020 when Minxie passed away. Her death marked a change in my experiences. Parenting her was no longer something I was doing in the present. It was something I had done in the past, and that allowed me to see and understand what I had experienced as part of parenting my daughter outside of the frame of necessity and to consider my experiences as exceptional. Eleven years of carrying her, changing diapers, tube feedings, surgeries, CPR at home, sleepless nights, medication regimes, and countless hospital admissions—those things were not part of the typical parenting experience. They were exceptional circumstances and very exceptional undertakings. But I knew many other parents who did the same things I did. None of them considered themselves unique, not that I knew of. But it shined as remarkable when I looked at it all as part of my past experiences. I decided that was what I wanted to research for my masters thesis: the experiences of parents not unlike myself who face exceptional parenting circumstances daily.

Parents of medically-fragile (MF) children encounter a different level of challenges. The circumstances they face, the things they are required to do as part of their parenting, and the support systems they have around them differ from those experienced by typical parents. We frame parenting as something that bonds us to others through shared experiences and milestones. Parents have common ground to build on; they share birthing stories, tales of diaper disasters, recommendations on extracurricular activities, and so on. Parents of medically-fragile children also have shared experiences, but they are different. When I related the story of writing my exam while my daughter was in the PICU to another parent of an MF child, she understood and agreed with my decision.

Although there has been extensive work on medically-fragile children and their families, we have a unique situation in Newfoundland and Labrador. Firstly, this province has a higher-than-average concentration of MF children. Children with medical complexities comprise 948 per 100,000 of the children's population across Canada (*Children and Youth With Medical Complexity in Canada*, 2020), while Newfoundland and Labrador boasts the highest rates for both respiratory and neurological impairments; a whopping 53% higher than the national average (*Children and Youth With Medical Complexity in Canada*, 2020). In addition, many of the studies involving medically-fragile children have taken place in the U.S., which does not have a universal or socialized healthcare system, while Canada, and Newfoundland and Labrador do.

The Janeway Children's Hospital is also well-suited for research on parents of MF children. Newfoundland and Labrador has one hospital which services the entire child population. Children with chronic conditions receive ongoing care and treatment from the Janeway hospital staff, which has a low-end turnover staffing rate. These children receive continuing care from the same staff members and medical professionals and in the exact spatial location as all other complex children in the province.

1.1 Defining the Population

The existing literature often leaves the term "medically-fragile" undefined; therefore, I pieced together a definition based on who qualifies as medically-fragile according to the research. Thus, to be medically-fragile means to have complex medical conditions/disabilities (Grossberg et al., 2013; Ng et al., 2015; Spratling, 2012, 2013; Woodnorth, 2004), often associated with regular or long-term dependency on medical equipment to sustain life (Grossberg et al., 2013; MacKay et al., 2021; Rehm & Bradley, 2005; Spratling, 2012, 2013; Woodnorth, 2004), long-term hospitalization(s) (MacKay et al., 2021), and decreased life expectancy (Grossberg et al., 2013). Such individuals are medically-vulnerable (Spratling, 2012) and need extra care, consideration, and protection.

That is the technical definition. But my inductive conceptualization of medically-fragile is medically unstable; children who have disabilities which are long-term, chronic, and fluctuating—children with unrecoverable but potentially deadly conditions; the children who are unlikely to graduate from the Janeway Children's Hospital.

1.2 The Literature

Being the parent of a medically-fragile child requires highly-complex role negotiation across vast, competing venues (Feeley, 2012; Hewitt-Taylor, 2008). Parents may first experience role ambiguity and overload as they begin to navigate their child's diagnosis and medical conditions (Major, 2003) while being unsure of their place and position in their child's treatment process and procedures (Kirk, 2001). As parents become increasingly comfortable in their role and begin to assert themselves as the authority in their child's care, they perform role negotiation (Major, 2003). Such negotiations may result in boundary ambiguity between parents and healthcare providers (Berge & Holm, 2007) as both parties claim authority over the child—however, these are not fixed positions; they are negotiated through interaction. The party asserting lead authority over the child's care fluctuates depending on changing health and illness.

It is worth noting that most of the literature focuses on the experience of mothers parenting their MF child. Some authors suggest this is because women bear the disproportionate burden of care for their child in such circumstances (Brekke & Nadim, 2017; Feeley, 2012; Gravdal Kvarme et al., 2016; Katzman, 2013; Knafl & Deatrick, 2002; Nygard & Clancy, 2018). Other researchers state that this disproportionate burden is an illusion because both parents carry it equally but portray it differently (Scott, 2017). Mothers often feel their sense of identity is linked with the well-being of their child (Katzman, 2013) and, as a result, think that it is their place to be with their child and that their presence is crucial to the child's well-being (Murdoch & Franck, 2011). This portrays them as the "good mother" in the eyes of the health care practitioners. In juxtaposition to this stands the "bad father," who is absent from the hospital setting and is viewed by healthcare professionals as disinterested and not "doing his share" (Handley, 2011). Research shows that fathers carry the financial burden of providing for the family during the child's illness (Scott, 2017) as well as ensuring the emotional support of the mother in addition to undertaking home responsibilities such as preparing meals, caring for siblings, and cleaning medical supplies (Mackay et al., 2020). These specific responsibilities may also correspond with how men report more anger at the situation than women and cannot express their feelings as openly as the mothers (Sallfors & Hallberg, 2003; Valizadeh et al., 2013).

Primary responsibility for disease management rests with the parents, including administering medications, monitoring for changes, performing required medical treatments, making decisions regarding when the child's condition requires the attention of healthcare professionals (Knoll, 1989; Morawska et al., 2015; Murdoch & Franck, 2011; Page et al., 2020; Swallow et al., 2011), and undertaking procedures at home that are usually performed by doctors and specialists while in a hospital setting (Page et al., 2020); this designation of responsibility begins within the hospital (Kirk, 2001). During hospital admissions, parental responsibility is passively employed to pressure parents to undertake the advanced medical care the child requires (Lindahl & Lindblad, 2013). For many doctors and nurses, there is no limit on how far such parental responsibility can be extended (Kirk, 2001). For parents, knowing that their child is tied to the hospital unit unless they undertake performing these medical procedures themselves (Kirk, 2001) leaves them feeling they have no choice (Hewitt-Taylor, 2008; Kirk, 2001). They feel morally obligated to provide advanced medical care for their child at home as part of being a “good parent” (Linderholm & Friedrichsen, 2010; Woodgate et al., 2015). Healthcare professionals are aware of this internalized responsibility on the parent’s part and use this to train parents to undertake medical care (including such things as changing tracheostomy tubes, administering intravenous injections, providing oxygen treatments, and so on) outside of the hospital setting (Kirk, 2001; Page et al., 2020). Even though parents had not been asked about their comfort with such treatments, “hospital staff unquestioningly accepted that they would continue to care for their child following discharge home” (Kirk, 2001, p. 597).

MF parents often note feelings of guilt (Ashton & Ashton, 2018; Findler et al., 2016; Katzman, 2013; MacKay et al., 2021; Nygard & Clancy, 2018) as they consider themselves to blame for their child’s medical condition (MacKay et al., 2021; Nygard & Clancy, 2018) and question whether their own behaviours may have contributed to the outcomes (MacKay et al., 2021). Ashton & Ashton (2018) point out that parents are taught to shoulder the responsibility for their children, so it comes as little surprise when parents turn to themselves as possible contributors to their child’s condition.

Fear and stress are also recurring themes across the literature (Bruce et al., 2013; Carlsson et al., 2019; Coffey, 2006; Feeley, 2012; Findler et al., 2016; MacKay et al., 2021; Ronan et al., 2019; Williamson, 2019). Parents report generally high levels of stress (Feeley, 2012; Williamson, 2019), which became exacerbated during the child’s periods of ill health (Carolan et al., 2014), which researchers also link to decreased quality of life for parents of MF children (Feeley, 2012). Coffey (2006) termed the experience of spina bifida parents as “living worried” as the parents reported experiencing differing (but always existent) levels of worry every day. Scholars noted that parents disclosed feelings of fear in two ways: for those leaving the hospital setting, they experienced fear associated with the possibility of readmission and the potential outcomes for their child at home without medical personnel (Ronan et al., 2019); for those experiencing a lull or remission of their child’s condition, fear was associated with the possibility of future recurrences (Carlsson et al., 2019).

Researchers also note high levels of grief and sorrow among such parents (Ashton & Ashton, 2018; Batchelor & Duke, 2019; Lowes, 2007; MacKay et al., 2021). Grief is presented as a regular part of parenting such complex children and is specifically tied to things such as uncertainty (Batchelor & Duke, 2019; MacKay et al., 2021), balancing work and MF parenting (Batchelor & Duke, 2019), and the perceived loss of parenting a healthy child (Currie & Szabo, 2019; MacKay et al., 2021). Beyond this, parents of MF children also exhibit chronic sorrow, which occurs when grief becomes a continued, repetitive, unresolved event, which often happens with parents of MF children as their child’s condition does not resolve but instead ebbs and flows between periods of increased and decreased illness (Batchelor & Duke, 2019; Lowes, 2007).

With the increased level of care associated with parenting such children, parents often report feeling as though they are always “on duty,” always caring for and monitoring their child (Lindahl & Lindblad, 2013; McCann et al., 2012; Sallfors & Hallberg, 2003; Whitmore & Snethen, 2018). Feeley (2012) writes that associated with this; parents also experience poorer quality of life in general and lower levels of sleep quality in particular. Parents may alleviate some of this burden by using in-home caregivers to care for their child; however, this also decreases privacy (Charmaz, 1991; Currie & Szabo, 2019; Knoll, 1989). Additionally, choosing and allowing someone into your home also requires considerations about how that person will fit with the family and how they will view and interact with your child (Lindahl & Lindblad, 2013).

As parents undertake the journey through their child's illness, many researchers note that they employ methods of normalization to reconcile their position as being typical (Carolan et al., 2014; Knafl & Deatrick, 2002; Murdoch & Franck, 2011; Page et al., 2020; Rehm & Bradley, 2005; Sallfors & Hallberg, 2003). The pursuit of normality is one of the key features in their narratives (Knafl & Deatrick, 2002; Page et al., 2020; Rehm & Bradley, 2005) as they reference a desire to reach a point where they can partake in activities that "normal" children avail of (Page et al., 2020; Sallfors & Hallberg, 2003). Some families achieve normalization by altering the concept of normal (rather than conforming to previous notions of normal) (Carolan et al., 2014; Rehm & Bradley, 2005). For example, when asked if they consider their family to be "normal," the mother of an 11-year-old child with trisomy 18 stated that "we see her as a normal child who's got, you know, specifics" (Rehm & Bradley, 2005, p. 814). Other families achieve normalcy by integrating the child's illness, equipment, and procedures into the regular rhythm of family life (Carolan et al., 2014).

Parents report playing the part of coordinator or advocate between different facets of their child's life, including among doctors and between doctors and service providers (including educational providers) (Bruce et al., 2013; Crooks, 2015; Jacoby et al., 2021; Katzman, 2013; McCann et al., 2012; Miller et al., 2009; Rothing et al., 2015; Woodgate et al., 2015). This pushes them into both teacher and student roles; they are required to learn and understand their child's condition and then, in turn, forward that knowledge to others involved as part of the child's extended care team (Woodgate et al., 2015). Thus, parents are thrust into the role of "expert parents" (Hewitt-Taylor, 2008; Page et al., 2020) and experience an increased burden of care (Batchelor & Duke, 2019; Bristow et al., 2018; Feeley, 2012; Green, 2006; Page et al., 2020; Williams et al., 2015). When combined with the demands of parenting an MF child, the aggregate effect often leaves parents feeling trapped in their situation and sometimes even trapped in their homes (Coffey, 2006; Page et al., 2020; Pinto Taylor & Doolittle, 2019). Parents are obligated to undertake this role as they feel if they do not, no one else will, and their child will not receive adequate care otherwise (Woodgate et al., 2015), as evidenced by Katzman (2013) who spoke with one mother who had purchased appropriate cleaning supplies and sent them to her child's school when the school had not followed instructions from the doctor that only natural cleaning products were to be used in the child's classroom areas.

The time and effort required to manage coordination between team members is an additional source of stress for families (Miller et al., 2009). Therefore, it is not surprising that parents of MF children experience increased physical and emotional workload and are more likely to suffer from physical and emotional health problems (Hewitt-Taylor, 2008), including feeling hopeless (Batchelor & Duke, 2019). These elevated demands may leave parents feeling pulled between competing responsibilities; those of their MF child and those of their other children and regular household responsibilities (Murdoch & Franck, 2011) or leave them feeling that they exist only for the provision of their child's needs (Maxton, 2008). It is worth noting here that the impact of illness on the parents is subject to fluctuation based on the child's current situation and progressions/prognoses.

Despite the hardships of parenting an MF child, parents report the experience as positive, beneficial, and rewarding (Green, 2006; Hewitt-Taylor, 2008; Lindahl & Lindblad, 2013). Even those who report experiencing loss and trauma frame it as positively impacting their physical and emotional health (Green, 2006). Researchers found that MF parenting allowed parents the opportunity for personal growth (Hewitt-Taylor, 2008) and awakened their inner strength (Mackay et al., 2020). Even though parents face such incredible circumstances, they often approach them positively and have positive, hopeful outlooks toward the situation and the future (Biaggi Leite et al., 2019; Mackay et al., 2020; Nygard & Clancy, 2018). Katzman writes,

> All of the mothers put their hearts and souls into their families and spent every day caring for their children with chronic illness. When asked about their children, mothers' faces brightened. The fears vanished as they were given an opportunity to reflect on what made their children so special…"she's my baby" (2013, p. 120).

In addition to their parenting role, researchers have noted various types of time-reckoning to deal with their circumstances.

Some families dealing with an MF child adopt a "one day at a time/live for today" attitude, which allows them to focus solely on today to the exclusion of the things to come (Charmaz, 1991; Knoll, 1989). For example, if a child has 60 days of treatment ahead of them, a "live for today" mentality allows the family to focus on getting through just this one treatment rather than the whole 60. While this can focus energy in one place and may help parents avoid feeling overwhelmed, it also reinforces the fragility of life (Charmaz, 1991). Living one day at a time can be a reminder that no future days are guaranteed or, in some circumstances, expected.

During hospital admissions, the parents become shared partners in the temporal coordination (Zerubavel, 1979) exercised by the health care practitioners around them. Their flow of time readjusts to these rhythms. Some cycles begin with the patient (such as the time between medication doses given per patient requirement). In contrast, others are measured around practitioner schedules (such as bedside checks of patients after a change of shift). Parents must re-orient themselves to these flows on the health care professionals' schedules. For example, MF parents often arrive in the unit before rounds to be an active member in the planning process for the day. Parents also mark hospital admission time through the progression of medical events (Black et al., 2008). For example, Black et al. (2008) noted that mothers in the neonatal intensive care unit (NICU) mark the passage of time through changes to ventilator settings and oxygen requirements. Davis (1956) observed similar definitions of time, noting the shift in perception of ultimate recovery goals (such as walking) to smaller, more attainable goals (such as moving a specific muscle).

The day becomes an interesting measure of time for MF parents as well. When dealing with complex needs, a parent often feels like they are never off duty (Currie & Szabo, 2019; Page et al., 2020a). The day consists of feedings, medicine administration, therapy, equipment manipulation, and monitoring changes in the child's demeanour and output, stretching from one morning into the night until the beginning of the next day; medical needs do not abide by a standard 24-hour clock. Some parents counterbalance this overload by scaling down other activities to reduce the overall pace of life (Charmaz, 1991; Page et al., 2020). However, over an extended period, this reduces the family's existence to only those required activities, resulting in a narrowing of time (Charmaz, 1991), which can feel like time is unchanging (Charmaz, 1991). Instead of experiencing one day leading into a new day, into a new day, on and on like dominos, "days slip by. The same day keeps slipping by" (Charmaz, 1991, p. 88); an unchanging, monochromatic time ensues (Bluedorn et al., 1992). Other families experience the opposite; instead of their day being devoid of everything aside from medical care, they pack them to overflowing, which may reflect their awareness of a shortened time to enjoy life (Charmaz, 1991).

Being the parent of a medically-fragile child means dealing with frequently reoccurring severe episodes or crises that disrupt the routine of life. For many parents, these episodes can be life-consuming (Charmaz, 1991). “During a crisis, the present teeters with uncertainty, and the future seems remote” (Charmaz, 1991, p. 35). However, it is essential to note that for many parents, experiencing crises is a routine part of their existence. As such, they often fail to view such episodes as extraordinary circumstances (Knoll, 1989). When this happens, it indicates that dealing with the fragility of their child’s condition has become predictable. While the specific circumstances of the current episode may be unpredictable, the overarching illness or disability itself has become predictable (Charmaz, 1991).

Though everyone uses anchor points to orient past time to past events (Zerubavel, 1982), parents of medically-fragile children often anchor time to events related to their child’s circumstances or progression. For example, instead of remarking that “Daniel was two when we moved into our house,” they may say, "Janice was recovering from her fundoplication surgery when we moved.” These markers become significant events that stand out in memory (Charmaz, 1991). Because they are easily accessible as markers, they serve as the recall anchor points that orient past time with past events.

Beyond such time work (Flaherty, 2003), parents also engage with the reality of their child’s upcoming death. For most parents, their child’s diagnosis comes with an expected trajectory of progression, often including shortened timelines toward death (Charmaz, 1991). The expectation of a child’s death often leads to anticipatory grief for the parents (Ashton & Ashton, 2018), which “facilitates one’s acceptance of the reality of the diagnosis and ultimate impending death, gradually” (Ashton & Ashton, 2018, p. 18). For many parents, mourning their child's death begins after the child is diagnosed as medically-fragile and continues until long after they pass away. It becomes a series of ebbs and flows throughout the child's life as advances and losses occur. For example, mobility gained from surgery may improve the projected outlook for the child, while further loss of mobility may lead to renewed feelings of loss of a “normal child” (Black et al., 2008). In addition to the grief process, parents often face existential uncertainty following their child's actualized or anticipated death because the event defies what we consider to be the natural order of life events (Rogers et al., 2008).

Death talk does not occur in a vacuum. Most parents have discussed such things with doctors in preparation for life-saving treatments and procedures during hospital admissions (Pinto Taylor & Doolittle, 2019; Wilkinson, 2013). Not using life-saving treatments in a hospital setting can be classified into two categories: not providing life-saving treatment (such as CPR or mechanical ventilation), referred to as “passive euthanasia,” or withdrawing life-saving treatments that have been put in place, which is termed “active euthanasia” (Wilkinson, 2013). Edwardsen (1983) stated that when parents experience elevated uncertainty about their child’s illness, they are likely to defer to doctors as the professionals in the circumstances, as they are the “moral and technical authority.” Parents are likely to experience such increased uncertainty when life-saving treatments are discussed, as these conversations often occur in anticipation of using such measures in the immediate future. Aside from the practical importance of a shared understanding of life-saving treatments, such discussions help prepare families for expected or eventual outcomes of the child’s situation (Steinhauser et al., 2000) and facilitate information-sharing and communication between the family and health care practitioners. Healthcare professionals report that families want to know about coming events, and answering their questions or providing such information helps to ensure the families are calmer during the process (Steinhauser et al., 2000). Given this candour and familiarity, it may not be surprising that many families consider healthcare professionals as partners in this process, even to the point of referring to them as “family” (Berrett-Abebe et al., 2017) and that many bereaved parents report higher levels of satisfaction with the care they received in-hospital as compared to non-bereaved parents, who would be more likely to be treated by in-patient staff rather than critical care personnel (Hjorth et al., 2019).

Following the death of their child, many parents experienced increased distress from being faced with the “stark reality of a life without their child” (Dias et al., 2017), along with elevated levels of depression (Rogers et al., 2008). Parents who had witnessed resuscitation efforts as part of the child’s demise said the events were less traumatic than expected and did not lead to increased emotional trauma (Maxton, 2008). Rogers et al. (2008) said they expected bereaved parents to report higher levels of purpose in life than parents who had not lost a child. Their collected evidence showed their theory to be incorrect. While their findings did not substantiate the idea that parents felt an increased life-purpose, their observations of parental activity may have led them to such a conclusion. Parents have found themselves seeking “busyness” and “overactivity” following the loss of their child to validate their worth (Ashton & Ashton, 2018). Rogers et al. (2008) may have observed increased busyness and interpreted it as a renewed sense of purpose in life rather than an attempt at maintaining a prior level of importance.

Scholars have called the idea that the end goal of grief is to “move on” with life without the deceased a mundane idea of grief (Christensen et al., 2017). Today, theorists replace this with a more nuanced view of the grief process that provides for “keeping hold” of the deceased through the continuing bonds paradigm (Christensen et al., 2017), which states that “grieving is not time specific (a period of mourning), but rather a mode of being re-occurring with various intensities and durations in the continued life of the bereaved” (Christensen et al., 2017, p. 59).

1.3 Symbolic Interaction

My research perspective begins with the theory of symbolic interactionism (Blumer, 1969) and a phenomenological approach to interviewing (Heidegger, 1962; Seidman, 2019). Symbolic interactionism focuses on meaning-making. People interact with and experience things in the world that have no previously invested or inherent meaning; we invest meaning into these things through our interactions and then respond to them based on the meaning we have attributed to them. For example, the same image of a gun has a different meaning for a correctional officer who carries one as part of their job than for a convicted offender subject to the rules enforced by the officer.

These ongoing meaning-making processes form streams of individual lived experience (Seidman, 2019). For example, an individual's first day at work involves meaning-making processes, but their 10-year career at that job highlights a stream of lived experience relating to that occupation, the work environment, the changing job structure, and so on. A phenomenological interviewing approach is an attempt to access the long-term, lived experience of meaning-making of the interviewees (van Manen, 1990); "the descriptive study of lived experience is an attempt to enrich lived experience by mining its meaning" (Seidman, 2019, p 19).

1.4 Identity Formation and Master Status Through a Symbolic Interactionist Lens

Identity formation is a social process (Brekhus, 2008; Eifert et al., 2015) that involves both internal and external interaction (Eifert et al., 2015), which operates in reaction and conjunction with each other (Mann, 2007). As this action/reaction aspect suggests, identity is fluid (Brekhus, 2008; Eifert et al., 2015; Hamilton, 1979; Kendall et al., 2004). As life shifts, individuals meet new people through differing roles, identity shifts, and reforms (Brekhus, 2008; Eifert et al., 2015; Hamilton, 1979; Hayes et al., 2009). Identity forms through an interplay of internalized and externalized selves (Brekhus, 2008; Ghaziani, 2004). Individuals internalize a sense of themselves and then reflect their sense of self back into the world using what they understand as the socially acceptable way of being in the world (Mann, 2007). The generalized others either accept the sense of self the individual has projected out or reject it. Both acceptance and rejection are then redirected to the internal self, where the individual's perceptions of self are either reaffirmed by the confirmation of the generalized other[1] (Brekhus, 2008) or deconstructed through the rejection of the other. However, the individual strives to avoid judgment by projecting outwardly the "correct" ways of being (Mann, 2007), which fosters a sense of belonging (Kemmery & Compton, 2014).

Because we live in a complex society, identity is also multidimensional (Brekhus, 2008; Valdez & Golash-Boza, 2020) and salient—who we are and how we present ourselves to the world shifts depending on who we interact with and the social context of that interaction (Brekhus, 2008; Mann, 2007; Valdez & Golash-Boza, 2020) and each person possesses multi social identities at a time. When I am at school, I am a student; at home, I am a mother; and at work, I am an employee.

Interactions between the individual and the generalized other representing specific social groups are meaning-making interactions (Mann, 2007; Mead, 1934). Neither objects nor interactions have inherent meaning. Our interactions invest meaning into objects; we then act and interact with those objects based on the meaning we have attributed to them. As we continue interacting with these objects, their meaning is revised based on reception (Mann, 2007). Consider the game of charades as an example—someone pantomimes while others try to guess what the individual is trying to

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[1] The generalized other is an imaginary person who stands in place for the social community and the individual judges their outward project of self in relation to the perceived judgments of the generalized other (Mann, 2007; Mead 1934).

communicate. The game hinges on shared understanding and experiences. Individuals interact with the generalized other according to the meaning they attribute to interactions and the response they receive from the generalized other. These interactions redefine that meaning and their place within the shared social group. While the individual is an active agent in projecting themselves into the world, their actions are guided by social roles and social groups—not determined by them (Mann, 2007). These social interactions usually take place according to standard patterns; social groups have shared ways of being and shared meaning, so an individual entering into that group embodies the pre-established meanings and forms of being for that group (Mann, 2007).

Sometimes, one identity in our shifting social lives rises to the forefront as essential and more identifiable than any other, a master status (Eifert et al., 2015; Hughes, 1937). Master status permeates all other aspects of the individual's identity and affects all interactions between the individual and others (Valdez & Golash-Boza, 2020). For example, if an individual is black, that may be a master status (Hughes, 1937; Valdez & Golash-Boza, 2020) because everything about them relates to their blackness. If the police pull them over, their blackness may determine the police's response and vice versa. An individual's master status may convey personal worth and dignity derived from the acceptance of this status by the generalized other (Hughes, 1937).

Thus, my research revealed that these parents conceptualized their combined parenting and caregiving role as an identity: the medical parent. This identity functions as the lens through which they view and interact with the world—it is a master status.

1.5 Conclusion

The experiences of parenting a medically-fragile child are well-represented in the existing research—however, it is parochial. This literature provides a solid foundation on the experiences of parents of medically-fragile children, but it is not representative of the messy, complicated, and contradictory reality of their lives and identities. For example, they experience continual worry and stress related to their parenting; they also experience bereavement and engage with aspects of timework through their parenting—but these concepts overlap and intersect throughout all their parenting experiences. I seek to address this gap by asking: What is the lived experience of parents of medically fragile children in Newfoundland and Labrador? My thesis works to connect the disjointed ideas in the existing literature, dive into the messiness of these parents' lives, and provide a more nuanced understanding of their identity. From here, I discuss my methods, and the following empirical chapters provide a thick development of the identity of medical parent.

Chapter 2 Methods & Context

In this chapter, I explore recruitment, the methods I used for data collection and dissemination, and my positionality. I begin with some relevant information about the Janeway Children's Hospital and the Canadian healthcare system.

The Janeway is located in the capital city of St. John's, Newfoundland and Labrador. It is a square-shaped four-story building. The hospital is medium-sized, including all the areas restricted to staff only. For non-staff, is it a smaller size facility. The second floor is the hospital's main area, with most out-patient services for the typical child: the emergency department; blood collection; dentistry; diagnostic imaging; audiology; the gift shop; the ears, nose, and throat clinic; and the eye clinic. If a child arrived at the hospital with a potentially broken arm, they would go to the emergency room and from there, an x-ray is to the left in diagnostic imaging; bloodwork to the right; broken bone casting straight across the hall; and a visit to the giftshop before leaving—across the hall and to the left. In-patient ward units occupy the entire fourth floor, except for a small area at the end of the hall for day patient clinics. The critical components are located on the third floor. The PICU is at one end of the hallway; the NICU at the other. In between is the day-patients area; the respiratory therapy clinic, and the operating rooms behind the staff-only access doors. The bottom floor of the hospital plays a critical role in the medical care management for families with medically complex children. Some of the social work offices are located on this floor, along with physiotherapy, speech-language pathology, orthotics, developmental pediatricians, and rotating clinics. This floor houses the rehabilitation clinics and areas for the ongoing care of these children. To illustrate, let me take you through a cerebral palsy clinic appointment. My daughter and I wait in the first-floor clinic waiting area. It is a small area with seating for approximately eight people. The clinic usually books four appointments simultaneously, so most chairs are filled. All the families in the small waiting area have a child with CP. They are called into their appointments one or two at a time, where each family is assigned a private examination room. The CP team members[2] enter individually, take notes and ask questions individually, then send in another team member. The physiotherapist wants to check Minxie's range of motion, so after the CP clinic, we go straight down the hallway to the physiotherapy clinic, where some other parents are now waiting with their children, too. Physiotherapy sessions are completed in a large treatment room with each therapist and patient on their individual therapy mat, with the parents in attendance. After physiotherapy, it is time for lunch, and the families make their way back down the hall, past the CP clinic waiting area and through an unmarked door that looks like it should be access restricted. From there, the family room is two doors down and on the left. This area has a kitchen, couches, books, and a television set. If the children attending the clinic can eat orally, the kitchen will send their hospital-provided lunch to this family room. Clinic appointments resume at 2 p.m. Families usually spend the time in-between in this secluded and comfortable family room.

The centralized location of hospital services for complex children combined with the fixed schedule delivery method means this area is a critical juncture for families to encounter and interact with each other. For example, I met a mom and her teenage son in the family room one day. My daughter's wheelchair headrest was not supporting her upper body correctly, and I noticed that the teenage boy had a different style headrest on his wheelchair that I had not seen before. When I next met with the physiotherapist, I asked if we could try a different style of headrest, and she inquired if I had a particular

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[2] Typically, the CP team consists of a neurologist, physiotherapist, occupational therapist, speech-language pathologist, social worker, a pediatrician with expertise in bone development, a clinic nurse, and someone from the child life deparment.

one in mind, to which I replied, “Jason’s.” Can we try one like Jason’s?” She immediately knew who I was referring to, and we tested the other headrest within minutes. This illustrates how the shared spatial location of the hospital and the subsequent interactions between families and staff create a network of shared experiences and knowledge. This shared location of services provided the opportunity to meet and interact with other families experiencing similar circumstances.

The Janeway hospital has low-staff numbers and low staff turnover, which means families who avail of the hospital's services establish long-term relationships with the staff members. Parents become familiar with the staff; the staff know each other; these interactions form engaging networks for parents and medical professionals. Even if the staff are not directly involved in the ongoing care of a specific complex child, they often become familiar with the child and family through informal interactions or emergency room assignments.

Additionally, the Janeway’s PICU structure provides a similar opportunity for parents to interact with other families and with unit staff. The PICU is a 6-bed unit reserved for children who require an elevated and critical level of care. Two beds are situated within isolation rooms and earmarked for children with contagious illnesses, those needing a sterile environment (such as a child with a severe burn), and those not expected to recover. The other four beds are in the “big room,” similar to a typical ward room but with additional space between beds and in the center to accommodate staff and any required medical equipment. The nursing staff spends their entire shift in the “big room” (unless they are on break or assigned to a patient in an isolation room), and when adequately staffed, the unit has a 1-1 ratio (1 patient to 1 nurse) plus a charge nurse who has no assigned patient. Each bed has a curtain that can be drawn around it, but considering the critical condition of the patients, curtains are usually open. During certain times (such as shift change), parents are asked to leave the unit and wait in the nearby family waiting area. Families are close to each other and to nursing staff, which allows them to interact, learn from one another, and share their personal experiences.

This hospital is located in the province of Newfoundland and Labrador, Canada, which means it is situated within a universal healthcare system, with no patient fees at the point of service for hospital care (Blackwell, Martinez, Gentleman, Sanmartin, & Berthelot, 2009; Sanmartin, Berthelot, Ng, Murphy, Blackwell, Gentleman, Martinez, & Simile, 2006); instead of such costs being billed to patients, they are government funded (Pylypchuk, & Sarpong, 2013). However, this link between government funding and healthcare means the resources of the Canadian system are connected with fiscal spending (Lasser, Himmelstein, & Woolhandler, 2006). And in periods of restraint, funding cuts may compromise services, leading to decreased care, and lower levels of satisfaction in care (Lasser, Himmelstein, & Woolhandler, 2006). Some hospitals run on fixed annual government-funded budgets and may use hospital-specific approaches to minimize their expenses (Freedman, Roskind, Schuh, VanBuren, Norris, Tarr, Hurley, Levine, Rogers, Bhatt, Gouin, Mahajan, Vance, Powell, Farion, Sapien, O’Connell, Poonai, & Schnadower, 2021). In comparison to most Western European countries, Canada has a highly narrowed view of universal healthcare coverage, which excludes outpatient prescription drug coverage, dental care, social care, and most vision care (Marchildon, Cafaro, & Brown, 2018)

Most of the research to date about the experiences of parents of medically-fragile children is from the United States, which has a different healthcare system than Canada. The US uses a mix of employer-based private insurance and public insurance (for those in vulnerable positions, such as older adults, and those living below the poverty line) (Blackwell, Martinez, Gentleman, Sanmartin, & Berthelot, 2009; Sanmartin, Berthelot, Ng, Murphy, Blackwell, Gentleman, Martinez, & Simile, 2006) which leaves a large percentage of the population either underinsured, or uninsured (Pylypchuk, & Sarpong, 2013). The US is the only developed country currently lacking universal coverage for core health benefits (Blackwell, Martinez, Gentleman, Sanmartin, & Berthelot, 2009). And even though they have the highest per capita medical costs, the US does not boast a corresponding association with improved health-related outcomes (Freedman, Roskind, Schuh, VanBuren, Norris, Tarr, Hurley, Levine, Rogers, Bhatt, Gouin, Mahajan, Vance, Powell, Farion, Sapien, O'Connell, Poonai, & Schnadower, 2021; Sanmartin, Berthelot, Ng, Murphy, Blackwell, Gentleman, Martinez, & Simile, 2006)

Such differences between healthcare systems result in differences in healthcare usage and citizen experiences. With the link between employer-based private healthcare insurance for US citizens, research findings recorded higher income-related disparities in accessing healthcare services in the States compared to access in Canada (Blackwell, Martinez, Gentleman, Sanmartin, & Berthelot, 2009), which seem to be natural outcomes. Scholars have found that access to and utilization of healthcare services were significantly reduced for Americans as compared to Canadians (Sanmartin, Berthelot, Ng, Murphy, Blackwell, Gentleman, Martinez, & Simile, 2006), but not for Canadians when compared across income categories (Pylypchuk, & Sarpong, 2013). That is to say, in Canada, those in higher income brackets had similar access to healthcare when compared to those in the lowest income bracket. But while income was not a reported barrier to accessing healthcare services in Canada, long wait times to access such services were (Sanmartin, Berthelot, Ng, Murphy, Blackwell, Gentleman, Martinez, & Simile, 2006). Overall, between both countries, researchers found that Americans were more likely than Canadians to have unmet healthcare needs (Sanmartin, Berthelot, Ng, Murphy, Blackwell, Gentleman, Martinez, & Simile, 2006); income disparities played a more prominent role in overall outcomes than did waiting times. In general, being a Canadian, living in Canada, with access to the Canadian healthcare system yielded similar results related to unmet healthcare needs and access to healthcare services as being an affluent US citizen, living in the United States, and having adequate healthcare insurance coverage (Sanmartin, Berthelot, Ng, Murphy, Blackwell, Gentleman, Martinez, & Simile, 2006).

The Janeway hospital is the only children's hospital in the province—there is no option to have your child admitted to a private children's hospital; but there is also no bill for such emergency medical services. One of my participants lives in Central Newfoundland. Her child has required medical transportation by air numerous times to safely and quickly transport him from the general hospital in Central to the Janeway hospital, which the government covers. This government-funded health care structure, coupled with the lack of potential private options, within a small geographic location means Newfoundland and Labrador has a relatively-small population served by the hospital, who interact with a small number of service providers and medical personnel, who provide the same level of services to everyone. No hospital-level care distinctions within this structure are based on income or resources.

2.1 Recruitment

After ethics research approval from the Interdisciplinary Committee on Ethics in Human Research (ICEHR), I advertised for participants through digital and physical formats (a copy of both is provided in Appendix A). I posted in two Facebook closed groups I am a member of. These groups are oriented toward parents of children with special needs. I also contacted various organizations (such as Rainbow Riders, the Newfoundland Cerebral Palsy Association, and The Wish Foundation), asking if they would circulate my call for participants through their networks. I hung posters at the Ronald McDonald House and various points within the Janeway hospital, where they would be easily accessible to parents. Most parents contacted me through Facebook, indicating that they were responding to my Facebook posting.

All participants and potential participants contacted me digitally (through Facebook Messenger or email). I replied to each initial contact by providing detailed information on my research topic, attaching the informed consent form for their review (see Appendix B), and closing my message with a question, providing an action item. I used this to ensure mutual understanding on the next step in the process; I posed a query requiring a response, and the question signified I was waiting for their response. I asked about their general availability as my initial closing question and proposed multiple interview times based on their subsequent reply. For example, if the individual said they would prefer a weekday in the evening, I offered 2-3 options fitting the general criteria for the participant to choose from.

After we agreed on a date and time, I asked them to bring something to the interview which represented the positive of parenting their child and something that represented the negative. The day before the interview, I would message them for final confirmation.

Several parents messaged me requesting an interview but stopped responding before we decided on a date and time. I sent a follow-up inquiry if I did not receive a response to my email within four days. If they still did not reply, I did not message them again unless or until they messaged me. One parent messaged me, and I sent her my initial response. When she did not reply, I messaged her again four days later to inquire if she was still interested, but I received no response. Approximately a month later, she messaged, and we scheduled an interview.

I had hoped to conduct between 15-20 interviews, and I explored all recruitment options available to me to do so. However, I conducted nine interviews with a total of 11 participants, a significant proportion of a tiny group. Further interviews would have opened new lines of inquiry and directions of thought. Still, I reached theoretical saturation on most of my original lines of inquiry (Seidman, 2019; van den Hoonaard & van den Scott, 2022). For example, the role of faith emerged during interview 4, and I could relate it to information from two initial discussions. Afterward, I probed interviewees regarding faith if the opportunity presented. While this new direction was important and revealing, it did not directly relate to or extend my original lines of inquiry, which focused on identity and community among parents.

2.2 Interviews

I approached interviewees recognizing that these parents are the experts in their own lives (Seidman, 2019). I wanted to learn from them, and I was interested in learning and understanding (Seidman, 2019) what they wanted me to know rather than what I wanted to ask them. Those who have lived experience of something are the experts on those experiences (van den Hoonaard & van den Scott, 2022). My research method began from the starting point that parents of medically fragile children are the experts on what it means to live through this. My job as the researcher was to provide them an opportunity to discuss their experiences and what those experiences meant to them (van den Hoonaard & van den Scott, 2022); to mine their experiences for meaning.

I designed my interview questions to be open-ended (Seidman, 2019), allowing interviewees to direct the flow of the conversation. I also included a modified form of photovoice (van den Hoonaard & van den Scott, 2022), allowing participants greater control over the direction and flow of questioning (a copy of my Interview Guide is provided in Appendix C). As I completed interviews and patterns emerged, I integrated some themes into later interviews as direct questions or probes. For example, my first two participants said the worst thing about parenting their child was the financial impact, and the struggle to afford and obtain equipment and services. This was a completely unexpected development, given Canada's universal healthcare. After these initial interviews, I probed for more information if an interviewee mentioned the financial struggle they faced with their child. In the following three interviews, my participants discussed the financial strain they experienced as well, so I modified my interview questions to include this unplanned line of inquiry.

I conducted all interviews using a semi-structured interview format except for one. Although there were some interviewees I knew beforehand, one individual offered to participate whom I would describe as a close friend. She and I met in the PICU when our children were admitted at the same time, and we continued to meet that way periodically until my daughter passed away. This mother came to my daughter's funeral, and afterward, when I cleaned out my daughter's medical supplies, I gave them all to her. Because we had such an intimate relationship, I felt that a semi-structured interview would be inappropriate (Seidman, 2019), so we met for supper, and I recorded our unstructured conversation about our respective experiences with parenting. This format allowed for a greater back-and-forth flow and became a vital part of how I conceived identity formation in my findings because we interacted and reacted to each other as two parents, rather than one parent, and one researcher[3]. It also allowed me to consider my thoughts and feelings through a frame I had not previously considered. For example,

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[3] An example of how this dynamic shaped our exchange can be found in the Internalization section of Chapter 3.

while we were discussing in-patient experiences, I told her that moving from the PICU to the fourth floor[4] was more challenging than my daughter's death, which was something I had not considered as side-by-side comparisons on emotional impact before.

I provided all interviewees with a digital copy of the informed consent prior to our scheduled interview. When we met at our scheduled interview time, I removed my voice recorder from my interview materials bag, turned it on with the interviewee beside me, and handed them a paper copy of the informed consent to sign before beginning the formal interview.

2.3 Memos

I used various memoing processes throughout my data collection. I wrote self-reflexive memos to consider my personal experiences through a researcher's gaze using a personal journal approach (Neuman, 2007). I concentrated on situations I had experienced first-hand, including traumatizing events my daughter had experienced, the aftereffects of her death, and how I considered my position within the parental community and as a researcher. I recorded memos using a video and audio capture device and transcribed them into a written format. This method allowed me to think and capture my thoughts without regard for sentence structure, topic flow, or continuity (Emerson, Fretz & Shaw, 2011). After the initial transcription, I rewrote and added additional material to ensure each memo was coherent and captured the ideas I intended to record. I included these memos in my findings but minimized their weight and my personal experiences. If an idea was difficult to access from participants, I included my memos as an interpretative lens.

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[4] General inpatient ward.

Immediately following an interview, I recorded my initial interview memos using video and voice recording following a freewriting exploratory method (Stone Sunstein & Chiseri-Strater, 2012) to record inference and analytic information (Neuman, 2007). I always recorded my interview memo directly following an interview while driving. If I missed anything during the interview (for example, if the interviewee talked about something after I turned off the recorder), it was the first thing I discussed while recording my interview memo. I also used this time to reflect on my experience during the interview process (for example, I wish I had packed a clipboard to use), re-evaluate my interview questions, and any other practical considerations. I also used this opportunity to think about things interviewees had said that I considered exciting or unexpected, including noticing themes which connected across interviews. The morning after each interview, I transcribed my video memo into a typewritten format and added any relevant information or further thoughts.

Lastly, I made transcription memos based on each interview while transcribing each recording. I recorded these directly into a typewritten format. These memos had a similar function to my interview memos (Neuman, 2007), except that I wrote them during the transcription process rather than the interview process, often allowing for additional time between operations and new direction of thought.

I wrote reflexive memos whenever I thought of something I wanted to record, and transcription memos were made during transcription. Interview memos were the most structured because I dedicated an uninterrupted 10-minute block of time to them (Stone Sunstein & Chiseri-Strater, 2012). Even if I felt I had nothing to say, I concentrated on the interview for 10 minutes, which often allowed thoughts and ideas to develop that I had not considered before I began recording my memo (Emerson, Fretz & Shaw, 2011). Most of my interview memos ran longer than 15 minutes as I did not stop recording them until I had discussed all my thoughts and ideas. Even where I began the note with no ideas to discuss, as I concentrated on the interview, ideas developed and expanded well over the 10-minute mark.

2.4 Data Analysis

I was interested in understanding what my participants said through the frames they understood them (Emerson, Fretz & Shaw, 2011; van den Hoonaard & van den Scott, 2022). I used my memos as the beginning point for my grounded approach (Gilman & Fenn, 2019; van den Hoonaard & van den Scott, 2022) to coding my data because the memos provided cross-interview information (Emerson, Fretz & Shaw, 2011). For example, if two participants talked about their interactions with other medical parents, I usually recorded who said it and the context of the comment in my memos. Based on that cross-interview information, “interactions between the interviewee and other medical parents” became a code that emerged through my data (Emerson, Fretz & Shaw, 2011; Charmaz, 2001). I uploaded all my interview transcripts to a qualitative data analysis computer program and coded them according to these initial codes. I used this method as an efficient means to group coded quotes. After coding, I printed the interview sections coded under each theme to study them as groups. I used these grouped quotes to develop and understand my codes and the meaning of the information contained within them.

After this initial open-coding process (van den Hoonaard & van den Scott, 2022), I re-read my coded data to develop a deeper understanding of each code, and to develop focused codes (van den Hoonaard & van den Scott, 2022) of data within my larger, open-codes. As before, I used qualitative data analysis software to compile all my interview quotes according to the codes I applied to sections of the interviews, and I then printed all my interview quotes grouped into my codes. Printing allowed me to study each code as a thematic compilation to gain a deeper understanding of what each interviewee was describing and how that related to what other interviewees were describing.

2.5 Insider/Outsider Status

I entered this process with an awareness of my insider status and re-evaluated what that seemed to mean during data collection. Before I conducted my research, my understanding was that my position would probably lead interviewees to open up to me about their experiences while also causing them to skip over things they may have explained to an outsider. For example, some interviewees told me they were “on the fourth floor” without explaining that the hospital's fourth floor contains general inpatient wards. Or, they would tell me a doctor's name without providing the doctor's specialization. I understood or was presumed to know this information because of our shared positionality.

Some interviewees also asked me questions during the process, and this was not something I had anticipated. For example, one interviewee asked how my daughter had passed away and told me her perception of my daughter’s death. None of my interviewees had experienced the death of their medically-fragile child at the point of our interview. I realized I represented an opportunity for participants to inquire about that from a colleague. I suspect the interview process also allowed these parents a venue to ask questions that may be difficult to access or socially unacceptable in other circumstances.

During my data analysis, I also noticed a back-and-forth rapport between the interviewee and myself, which gave me a deeper understanding of the data than I could otherwise obtain. For example, when one mother and I discussed our personal experiences with the oxygen saturation monitor, I noticed how such interactions reflect community membership and identity building among parents of medically-fragile children. This rapport proved to be a critical aspect of my development of the identity of the medical parent.

While writing my thesis, I drew on my personal experiences as a parent while analyzing them through a researcher’s gaze; especially when writing about internalized perceptions of parents. I cannot access the internal understandings of my interviewees unless they tell them to me. However I can access my internal interpretations and provide them in my write-up where this inner perception of the situation furthers my overall conceptualization while being aware that this caries implicit bias.

Lastly, while my positionality provided an excellent starting point for this research and led to unexpected lines of inquiry, I also realized it created potential blind spots in my write-up and analysis. When my supervisor reviewed the first draft of my thesis, she noted the salience of normalization—it was a recurring theme within my quotes, even when my quotes explored other themes. I read her comment and thought, “Well, of course it’s normal—these things are normal.” I had engaged with this concept as an insider parent rather than through a researcher’s gaze and missed that concept until she pointed it out to me.

2.6 Demographics

My research participants' confidentiality is paramount as part of ethical research practices. Providing an interviewee with a pseudonym is typically sufficient to cover their identity. However, special populations may require special considerations and measures (Khayatt, 1992; van den Hoonaard & van den Scott, 2022; van den Hoonaard & van den Hoonaard, 2013). I set out to research the experiences of parents of medically fragile children—any dissemination of this research must preserve the humanness of this project. If people read this and they do not see other people, and they do not see the children, then

I have failed to achieve what I set out to accomplish. But balancing individual humanness while maintaining confidentiality within a small population requires increased ethical considerations.

Therefore, I use discontinuous identities (van den Hoonaard & van den Scott, 2022) to keep participants' identities confidential. I mask identifying characteristics, such as geographic area, age, and disabilities (van den Hoonaard & van den Hoonaard, 2013) using general terms. If a quote requires specific information to ensure clarity, I altered the information as necessary to preserve the humanness of the passage while ensuring additional confidentiality for participants. This may include changing the sex of the child, their age, or the number of siblings. Any alternations will be noted in my records and undertaken using a consistent methodology. For example, if I alter the age, the age will be a constant, so the modified age would always be the child’s correct age plus X. I further masked identity using multiple pseudonyms (van den Hoonaard & van den Scott, 2022). I assigned three pseudonyms to each child and parent participant, and my write-up will cycle through the participant's pseudonyms when using direct quotes. I altered identifying characteristics to ensure confidentiality for my participants while maintaining the integrity of all information integral to my analysis. However, I also want to ensure the personalization and humanness of my participants is maintained within my data. Therefore, I include a general indication of the age of the interviewee's child. If the child is under ten, the interviewee's pseudonym will have a* next to it. If there is no asterisk, the child is older than ten years of age.

I inductively knew the population I wished to study, but defining that population was a challenge because the literature used terms such as “chronically ill,” “complex disabilities,” or “medically fragile” without explaining what the words meant. Rather than relying on a piecemeal assemblage, I define “medically fragile” as it relates to this study.

When I use the term "medically fragile," I mean children with chronic conditions[5] who require complex care,[6] with early-onset conditions,[7] which rendered their overall health and longevity unstable and likely to end at any time with little to no notice.

As a brief overview of my participants, I conducted nine interviews with a combined 11 participants. I completed two interviews with couples rather than individually. When we spoke, two of those nine families lived outside the Eastern Health region, and three were separated or divorced from the other parent. All parents in a relationship at the time of the interview presented as male/female couples. The number of children in the family ranged from one to five, and within multiple-child families, the medically-fragile child occupied every available position (youngest, oldest, middle). Three interviewees had only one child.

The medically-fragile children represented a broad mixture of demographics and complexities. Three of the children were female, while six were male. Three were in the preschool age range, five were school-age (two were preparing for the adult world at the time of the interview), and one was a Janeway graduate.[8] Four children had one primary medical diagnosis, while the other five had multiple concerns, totalling 13 identified diagnoses.[9] Of those 13,[10] I noted four repeated conditions. For example, more than one child had epilepsy. Some children were diagnosed with common disabilities (such as cerebral palsy), while others had very rare conditions, which I generalize to preserve

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[5] They were not terminal but also incurable.

[6] Such as seizure management, g-tube feeds, and oxygen monitoring.

[7] Either in-utero or shortly after birth.

[8] The Janeway hospital provides treatment until the child reaches the age of 18 when their care is transferred to the "adult world."

[9] Only one child had been diagnosed with a condition(s) that was behavioral-based. All other children had been diagnosed with physically-based conditions alone.

[10] The parents' answers did not reflect all their child's diagnoses. As the interview progressed, they discussed other secondary conditions as well. These 13 encompass their understanding of their child's major diagnoses.

confidentiality. Seven children were non-verbal, and eight used a wheelchair as their primary transportation.

2.7 Writing My Results

A critical aspect of qualitative research is that it engages with people. Individuals inform it, and such research should highlight them as people. Although confidentiality is crucial in the context of this research, so is preserving the humanness of my participants. My thesis provides a deep understanding of the ideas presented but also maintains the individuality and humanness of my interviewees, which is why the quotes I have included give the context along with the segment of interest. I also used bold typeface throughout to draw attention to the crux within the context. This ensures that my data backs up my statement and that the data is wrapped up in the humanness of my participants.

Life is messy, but writing is clean and organized. I have provided categorical distinctions throughout my thesis to organize my findings, but messy reality does not fit neatly into constructed categories. There are ways that these distinctions overlap and intersect with each other. But each categorization I have developed stands apart from others while overlapping them. Life is messy, categorizations are arbitrary, and combining the two means interacting with one facet of a chaotic reality at a time. These distinctions are ideal types (Schutz, 1967; Weber, [1919] 2014).

Lastly, I wrote the medical commentary in the footnotes based on my understanding and experience of those situations rather than a formal medical definition or interpretation of the term. They may not provide wholly accurate or complete accounts if applied to concepts in the adult world or even across distinctions within the pediatric world—such as between chronic care and in-patient care, but they are representative of the situation within the interview context.

Chapter 3: Being the “Medical Parent”

> I don’t know. [Living this life] It’s just so weird. But still, I can’t imagine my life any different. I wouldn’t want it any different–I really wouldn’t. Because **I learned so much from being a medical parent.** I’ve met people I never would have met otherwise, you know. So a lot of good came out of it. And I know a lot of parents that are not happy because of their children—and I get that. I get it; I do. I’ve had times where it’s like, ‘I don’t know if I want to do this.’ ‘I don’t know if I’m strong enough to do this.’ (Christine)

As Christine’s comment illustrates, the “medical parent” concept emerged from the data, and I begin this chapter by defining the term. The medical parent exists at the intersection of medical professional, caregiver, and parent. A medical parent is not a medical professional in the strict application of the term—they do not have medical degrees or formalized medical training. Neither is the medical parent a parent in the strict sense of the word. Parenting a child requires an ongoing interaction driven toward fostering the child into independent adulthood (Peterson, 2022). Without the requisite idea of the child becoming a fully functioning adult, the parent simply responds to the child's immediate needs (caregiving), as is the case for medical parents. To be a medical parent is to be the overseer of your child’s physical and medical needs; sometimes, their emotional needs, if time and energy allow. But parents concentrate most of their efforts on maintaining the child’s immediate existence; to be a medical parent is to be continually versed in keeping the child alive for another year, month, day, hour, or moment. It becomes an immersive experience for the parent; medical parent becomes their identity.

This chapter develops the active behind-the-scenes processes which emerged from my data. I begin with a detailed discussion of the identity formation process of the medical parent, followed by the boundary work medical parents use. From there, I discuss how this identity engages with temporality, and I finish by developing the theme of normalization processes.

3.1 The Identity Formation Process

As Chapter 1 explains, identity forms through social groups. Individuals interact with groups, internalize the attitudes and behaviours of those groups, exhibit those behaviours and attitudes, and become identifiable members of that social group through acceptance by other group members. But if “medical parent” is the identity, who is involved in the interactions that lead to identity formation? If social groups are gatekeepers to membership, which social group can admit medical parents as members? How does a parent become a medical parent? Beagan (2007) considered the works of *Boys in White* by Becker et al. and *Student Physician* by Merton et al. in her study on the identity formation of medical students into doctors, which coincides nicely with the construction of the identity of medical par ent. I used her framework to map the emergent identity formation of the medical parent.

Experience

Beagan (2007) begins by separating the experiences of medical students as different from those of other people. Being in a behind-the-scenes medical setting exposes students to situations and knowledge they cannot access outside of that setting, partitioning off the experiences of medical professionals from all who are “non-medical.” She says these exposures are at first novel but become natural through repetition. Medical students experience things available only to medical professionals and continue to experience them repeatedly. Christine speaks about a similar experience. Her son’s medical condition required frequent intubation, and the doctor offered Christine the choice to stay in the room, observe the process, or leave the room and return when it was finished. While she initially declined to stay, she eventually did.

> I remember before when they would… have to put the tube in [breathing tube for the ventilator] and stuff. I mean, I would leave the room 'cause that was a bit much for me, and then one time finally, it was like, **man, this is my life like this is happening every 3 or 4 weeks, it's just as well to stick around and see what it's all about**. (Christine)

Christine chose to leave the room while her son was intubated, feeling it "Was a bit much" for her to handle as it was something outside her typical experience. Eventually, she decided to stay in the room to witness the process, and now, she usually plays Candy Crush at his bedside during the intubation procedure. This illustrates the situational arc in identity formation—a procedure that Christine first experienced as traumatizing became something she willingly engaged with and has now become familiar to the point of disinterest.

Internalization

Becoming a medical student involves internalizing medical standards, which the author noted as being reflected in the clothing choices of medical students (Beagan, 2001). No one had to tell students how to dress; they perceived the dress code from exposure to medical professionals and responded to it by wearing similar types of clothing. This concept was trickier to place in my data. There is no dress code for medical parents. But their internalization of medical standards can be discerned through their interpretation and externalized confirmations of appropriate and inappropriate behaviour.

> Kathy: We were in the big room [in PICU] and…we were in bedspace three, and there was a kid in bedspace 2, a girl—a teenager, and she was…on a vent
> Me: right
> Kathy: and [the nurses] would have to suction[11] her, and every time they went to suction her, her mom ran from the room crying…and at one point…we all

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[11] If a child cannot clear their own oral secretions (usually through coughing or swallowing) they can be cleared through the use of suction. A long, thin, soft, hollow catheter tube is connected to a vaccumm

> had to leave. So I was out in the family room, and Dr. Cameron[12] came out. I hadn't seen her up until this point, and so she's walking down the hallway, and she's like, 'Where's my favourite mommy?' And the other mom comes out of the sleep room right—cause she thinks Dr. Cameron is talking to her [both laugh]. and I'm thinking to myself…**you friggin run from the room when your daughter is being suctioned—you ain't earned that title yet**
> Me: she don't even know your name. Like, go back to bed
> Kathy: Stay in your own lane, missus.

Kathy's comment suggests that the other mother (who is not a medical parent and whose child is not medically-fragile) exhibits behaviour she considers inappropriate[13] when the other mother cries and leaves the room while her child is suctioned. My agreement reaffirms the deviance of the other parent to Kathy. And Kathy and I use this exchange as a medium for projecting our internalized ideas of what it means to be a medical parent onto the other mother, whom we relegate as being outside of that grouping. Medical students used their chosen attire to externalize their internalized medical standards (Beagan, 2001); Kathy and I used the other mother as an externalized symbol of our internalized understanding of medical parent identity.

Externalization

As part of their identity formation, medical students hear medical terms and ways of speaking which they reproduce, differentiating them from others who are non-medical individuals and helping to situate their position of belonging within the medical field. Medical parents experience a similar exposure to medicalized language, which they reproduce in conversation with medical professionals and each other.

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suction and the end of the catheter is manauvered around the inside of the child's mouth to pull any secretions out of the mouth and into the tube. If secretions have built up in the child's throat, the catheter can be inserted into the child's nose and down into the throat to remove the build up.

[12] The names of all medical personnel have been changed using the same discontinuous identities method I used for participants.

[13] It is also worth noting that Kathy and I are presuming how Dr. Cameron would interpret both our behaviour, and the behaviour of the other mother. We presume Dr. Cameron considers our behaviour as being appropriate, and by extension, the behaviour of the other mother as inappropriate.

> Shelley: So **even with the g[-tube[14]], he [the doctor] wanted you to keep going with the continuous [feeds]?**
> **Me: Yeah, because the fundoplication[15] was undone.**
> **Shelley: Right.**
> Me: And she couldn't handle [the volume] …she was aspirating[16]
> Shelley: That was us—oh my God. And then he was like micro aspirating for a while [and] we didn't know he was aspirating, so that's when they did the g-j.[17]

When Shelley and I spoke about our children's feeding issues, there was a shared understanding of the terminology and the underlying medical mechanisms related to these conditions. Shelley questions the utility of continuous feeds through a g-tube because ordinarily, continuous feeding is only required with a j-tube because the stomach can hold more liquid than the intestines.

I noticed a similar development in language with a comment made by Olive.

> That actually became the benchmark because, after that, there would be times we'd be in [emergency at another hospital]…and they would be thinking about intubating her and…they would consult with the Janeway. So they would consult with PICU…they would contact Dr. Leslie [PICU doctor in charge of the unit during that week], **and she would ask to speak to me, right. And her question would be, 'Is she as bad as Florida?'[18] I mean, it literally became the benchmark. I don't think normal people have shared experiences with medical professionals that they can like refer to by nickname like this.** (Olive)

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[14] Gastronomy feeding tube. A feeding tube which delivers nutrients directly into the stomach through a surgically placed tube. The tube is visible on the outside of the child's abdomen and connects to the stomach through a hole in their belly.

[15] A surgical operation. The surgeon the top part of the child's stomach around the bottom of the esophagus and sutures it in place. Ideally, the surgery should make the child's digestive tract a one-way route; anything that enters the stomach can only exit through the intestines because if it travels to the upper part of the stomach, the fundoplication will choke off the bottom part of the esophagus, making it impossible for stomach contents to enter the upper sections of the esophagus, the mouth, or the airway.

[16] Stomach contents were being pushed up through her esophagus and into her lungs. Micro aspirating is similar except only a minute volume enters the lungs, making it difficult to detect. For children who cannot cough to clear the contents from their lungs, aspirations can easily lead to pneumonia and put the child in a critical medical condition.

[17] Gastronomy-jejunostomy tube. Similar to a g-tube, except it provides direct access to the small intestine instead of the stomach.

[18] The question refers to a trip the parent and child had taken to Florida where the child got sick, ended up in respiratory failure and spent 2 weeks in ICU on a ventilator. 'Is she as bad as Florida?' is a question asking for the mother's interpretation of the child's current ability to breathe on her own.

Olive commented on having a shared understanding of meaning between her and the doctor conceptualized by using the word "Florida," which they both understood as a reference to her child's breathing capabilities and the potential need for mechanical ventilation.

Socialization in the medical profession involves medicalizing the human body; medical professionals view the person as a system or organ, depending on context (Beagan, 2001). A doctor regards the patient seeking treatment for a broken arm as "a broken arm." Medical doctors view the individual patient as the extent of their ailment; the patient becomes devoid of completeness and humanness. Medical parents described a similar phenomenon when talking about their child.

> Me: So, tell me about Richard.
> Olive: He's a doll [laughter from another room]. That's him. Like medically?
> Me: Whatever you want to tell me.
> Olive: Well, **he's non-verbal, he has spina bifida, he has CP. Like cause he's spastic and flaccid[19], he goes between both. He has hydrocephalus** [and other conditions[20]]. 'Not compatible with life,' said the first report. So, they came and said, 'You know, you can leave him here 'til you go home,' I said, Look, all that's getting me through now is getting him home. I don't care if it's for an hour.

Most of my interviews began with the question, "Tell me about your child." If the parent asked for clarification, as Quinn did, I told them, "Whatever you want to tell me." Parents chose what should be included and excluded from their answers. Most parents, like Quinn, responded with a medical breakdown of their child's conditions devoid of personalization: no physical characteristics, nothing related to what Richard enjoys, nothing about his age—a child seen through the medical gaze (Foucault, 1973).

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[19] Spasticity is a type of CP associated with muscle tightness. Non-spastic CP is characterized by low muscle tone or flaccidity.

[20] Additional diagnoses redacted to ensure confidentiality.

Understanding and Accepting the Hierarchy

New medical students quickly understand that they occupy the bottom of the medical hierarchy structure (Beagan, 2001). First-year students learn from second-year students, second-year from third-year, and so on. The longer a student is part of the medical profession, the higher their status becomes with other students. The epitome of that hierarchy is the doctor who has completed their training or studies (Beagan, 2001).

There is also a definitive hierarchy structure for medical parents, but they do not occupy the bottom rung. Kathy's previous comment speaks to one portion of this hierarchy. The medical parent occupies an elevated position over non-medical parents. They also occupy a status that ranks above doctors in training.

> He [trainee working with Dr. Michaels] came down one night…the feeding tube[21] came out, and he said, 'Dr. Michaels said I can do it.' I said, 'Have you ever done one?' He said, 'No, it's not rocket science' I said, 'No, it's probably not rocket science. However, have you done one?' 'No, it's not rocket science.' **'Let me talk to Dr. Michaels.' So anyway, they called Dr. Michaels and got him on the phone. I said, 'Is Twitface able to do that? Like really?'** He said, 'Yeah, but he's got to use a 12.'[22] I said, 'Ok, let me go out and see if Twitface knows what a 12 is.' So he had to go up to the OR [operating room], and he came back with a 10. I said, '10 is too small.' He said, 'But I'd have to go back up to the OR again.' [Olive shrugs, indicating that is not her problem] So he went back to the OR and came back with a 14 [laughs]. I said, '12' [slower]. He said, 'But [pause] alright, I go.' He came back. Anyway, he was putting it in. I said, 'I'm going to watch you.' (Olive)

This was a doctor who had already completed extensive medical training. Still, Olive did not consider him competent enough to change the feeding tube without reassurance from someone with a higher status—Dr. Michaels. Olive interpreted Dr. Michaels' reply as an indication of her competence in the situation and responded by

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[21] This type of feeding tube is inserted through a hole in the child's stomach. It is a soft, hollow tube that can be used to pour nutrients directly into the stomach. The part located inside the stomach is wider than the part outside the body, which works as an anchor holding the tube in place. It is inserted with a blunt metal device.

[22] 10, 12, and 14 correspond to circumference of the feeding tube.

assuming the position of the overseer of the procedure. The doctor in training confirmed Olive's status by following her directions.

This example illustrates who medical parents consider authority figures and who warrants respect. Olive shows she feels she occupies the power position here through her directions and disrespect for the trainee by referring to him as "Twitface."

Olive's language shows her lack of respect for this doctor, but in other situations, medical parents used language to indicate occupying a commonplace position in the hierarchy structure.

> [My son's] testicles didn't drop. It's all part of the syndrome. I said like, 'So, um, **about his 'nads,' 'cause again, me and Dr. Kane have a very good relationship. He's like, 'Sure, what do you want them for?'** 'I don't know. I just feel like it's probably a good idea if they're there like, you know to bring them on down.' (Christine)

Christine illustrates that she perceives that she holds a shared position in the hierarchy by using unconventional language and banter with her son's surgeon. Generally, there is a professional distance between the doctor and the parent. As the perceived expert in the field, the doctor occupies status over the parent, and this expertise, coupled with professional distance, would render this language and banter unacceptable. But, with the ongoing relationship between this parent and the surgeon, it was normalized and acceptable. And while this illustrates a shared position and a rapport between the parties, sometimes parents expressed they felt they occupied an elevated position over specialized doctors.

> [Dr. Stevens] did one thing that I did not like. And I really didn't fucking like it. Willow was home on continuous feeds at this point because her fundoplication had come undone. And we were talking about possibly doing a J, redoing the G tube, doing [a] fundoplication. Like doing something right. And this was a conversation we were having in PICU with Dr. Andrews [surgeon], of course, and Dr. Stevens cause he was the one who was on [doctor in charge of the ICU for that week]. And the conversation that I had

> with Dr. Andrews, we were both pretty much on the same page about redoing the g tube. Then [Dr. Andrews] came back in later, and he was sort of trying to convince me to just keep the continuous feeds, right? Like, 'No, no—we want the tube. we want to be able to do the feeds—the belly emptying.' The normal-ish stuff. Dr. Stevens mentioned about probably trying to keep the continuous as well [and] I found out after that [Dr. Stevens] had had a conversation with Dr. Andrews about pushing this **behind my back. Like honey, I don't know who the fuck you think you are—I'm the Panama Canal; everything goes through me. One thing we don't do is have conversations behind my back. Oh, I was fucking livid**. (Rees)

Doctors regularly consult with each other about patient care. The doctors did not do anything wrong or outside of normal parameters by discussing the options between them, but Rees' comment indicates that she felt this was inappropriate behaviour—that the doctors should include her in all conversations about resolving her daughter's feeding issues.

Medical parents developed relationships and shared understanding with the healthcare providers they associated with regularly. Most parents spent more time with PICU nurses than with ward nurses. Medical parents considered themselves equal to PICU nurses and above ward nurses.[23]

> So anyway, it came time [for] cough assist.[24] [The nurse said,] 'Ok, well, RT's[25] going to come up' and all that sort of thing. Anyway, so **Jennifer was the RT that came up**, and **she said to the nursing student**, 'Did you want to suction or will I?' And the student was like, 'What?' And the nurse was like, 'Oh no, we don't' She was about to say, 'We don't do that up here' type thing. And Jennifer was like, 'Well, someone gotta do it.' And their all looking at me. And Jennifer is like, 'No, no—one of you can suction, and I'll do the cough assist.' It's a no-brainer here. Anyway, **the nurse was honest to**

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[23] Parents who had regular, on-going interactions with ward nurses rather than ICU nurses said they felt they occupied a shared status with ward nurses instead.

[24] Cough assist is a procedure that involves providing the child with an influx of high-pressure air through a medical mask followed by removal of the mask/pressure and repeated three to four times per session. This process triggers a cough reflex in the child which helps to loosen and move mucous in the lower airway. It is used in patients who are unable to produce productive coughs on their own. Two people are required for this procedure: one to hold and operate the mask and the other to suction the mucous, which involves inserting a catheter into either the nose or mouth and down into the throat to pull the mucous from the airway using suction. Timing is crucial in this procedure. Removing the mask triggers the child's cough almost immediately. The catheter must be in the proper position to remove the mucous as soon as the child coughs. Therefore, it is impractical for one person to maneuver the catheter and the mask..

[25] Respiratory Therapist. They specialize in lungs and breathing support.

> **God, like [it was] embarrassing. Like actually embarrassing, right? She's like going in like the very tip of the nose, and she's like, 'Oh, never got anything.' Jennifer was like, 'You didn't even go in his nose! Like you're supposed to be down in his fucking stomach by now, b'y!**' Oh my god. (Kathy)

Kathy has suction capabilities at home and uses them on her son regularly, so ward nurses who do not competently perform procedures parents undertake at home are deemed incompetent and lacking compared to medical parents. This power differential between medical parents and staff, and within different levels among staff, is understood and used by medical parents.

> Me: (The man [Dr. Jones] has power.)
> Monica: We were admitted to the PICU for the surgery cause [Dr. Jones] insisted on that. And then, when she was ready to go up to the floor, she went up to the floor under Dr. Jones in surgery, right? So **we got up to the 4th floor, and I tell them I'm like, 'Can she get constant nursing?' 'No, she doesn't qualify for constant nursing.' Fine. Dr. Jones comes in, 'How are you?' 'We're great. Listen, by the way, could you write a thing for constant nursing?' Done deal**.[26]

When the nursing staff denied constant nursing because Monica's child did not fit within the policy parameters for this elevated level of care, she circumvented the authority of the nursing staff by asking her child's surgeon instead. She recognized the doctor had power over the nursing staff and he could effect change in such circumstances, and she leveraged that power differential to obtain her desired outcome.

As part of training, medical students learn from those above them in the hierarchy: first-year students learn from second-year students, second-year students from third-year, and so on (Beagan, 2001). A similar pattern exists for medical parents in both formal and informal settings.

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[26] Meaning Dr. Jones wrote the order and she was provided with constant nursing even though Monica was advised her daughter did not qualify.

In some situations, medical professionals facilitate and structure learning opportunities among medical parents.

> So, **our genetic counselor** said he knew of parents that had a child born in the 80s [with a similar condition]. I think he lived for a little over a year. And, at that point, **he said, 'You know, the family is very open, and they would certainly accept like if you wanted to reach out to them**.' (Jackie*)

Other times, medical professionals may formally present medical parents as teachers for medical students.

> **Dr. Elliott asked me to speak to the medical students with Brian,** and I said, 'Sure,' so I went in, and the students loved me. We just had a ball. So anyway, we were there, and I was telling a story. I got to the part where we saw the pediatric blah blah blah I [gestured toward Dr. Elliott], and they lost it. He said, 'That's ok,' oh my god. Anyway, they came up and shook my hand and everything after, and I said, 'First of all,' and I started in. I said, 'You're not God. You never will be.' And just explained to the people that medicine is not an exact science, and the sooner they realize that, the better, you know. It can't be. It was a ball; I loved doing that. (Wanda)

Dr. Elliott was a specialized doctor working at the Janeway. He asked Wanda to speak to the medical students about her parenting experiences with Brian, assembled the students, arranged the venue, and provided her with the platform to discuss her experiences.

In other situations, learning is unstructured and spontaneous, shared learning experiences between parents fostered by the shared occupation of common spaces. Shelley and I met in the PICU while our children were staying "in the big room." At the time, I was trying to lose weight, and I joked with the nurses that my weight loss goal was to fit into the same pant size as Steven Tyler so I could meet him and say, "Now, I can get into your pants." When we spoke, Shelley recounted the story;

> Shelley: **You have you have no idea how much you got me through.** Oh my god, no idea. From the time you
> Me: I'm working on getting back into his pants now.

> Shelley: Oh my god, yes, that is exactly what I was going to say! That was literally the best day ever**. I was just like, oh my god, I literally want to be just like you when I grow up!** Like just like Minxie's over in the bed, like you know. Leo's over in the bed, and you're talking about getting in Steven Tyler's pants. I was like, it brings so much warmth into this whole life. And I thought, well, if she can do this and smile at the same time, I guess **I can do it too**[27].

Leo was younger than Minxie. When we met, being a medical parent was new for Shelley but not for me. Making this joke was an attempt at infusing humour into the situation, and for Shelley, it set an example that parents could deal with hard things but still find joy at the same time.

Relationships

The complex nature of relationships between medical students, staff, and patients highlights hierarchal complexity. While medical students occupy a lower status compared to other medical professionals, they hold an elevated position of power over patients, and an emotional detachment toward patient pain (Beagan, 2001). Medical parents experience similar hierarchical complexity through relationships, which is best illustrated through the relationship forged between parents and staff members.

> I think that the funniest thing for me [when admitted to the ICU] used to be doing the admission form stuff with Ruby [nurse]. I used to love doing that. I told her once we should make this a sitcom and like go on the road because **I'd be giving her these answers like totally deadpan, and she'd be looking back at me just as stone-faced**. But like Candice [nurse] would be there laughing her ass off like, 'What's your understanding of why your child is admitted?' 'Because we don't have oxygen in our walls-write it down. We don't—that's where the high flow comes from.' Sometimes they [nursing staff] would actually leave it there. **They'd be like, 'Yeah, we have the paperwork. But Ruby is on tomorrow, so we're going to leave the paperwork for you to do with her.'** (Helen)

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[27] Shelley attended my daughter's funeral and that is where she told me the Steven Tyler story of how we first met. I remembered making the joke but I did not remember her or Leo being in the unit at the time. The behaviours and attitudes medical parents exhibit are noticed and remembered by other parents they interact with, even when medical parents are unaware of this.

Medical parents develop an intimate relationship with nurses and doctors. They create shared banter and behaviours that mimic those of co-workers or friends, which parents view as a natural part of their parenting experiences. Parents consider this as a relationship between themselves and medical professionals.

> I was like, how do you not form a relationship with these people [PICU nurses and doctors] though like, how do you not?...if I was in there once and that was it, fine…but **like how do you save my son's life over and over again (and see me at my worst) and not form a relationship, a bond. Are you fucking serious?** I'm closer to these [nurses] than half of my legit family. It's bullshit. (Kathy)

Kathy added a nurse to her social media with whom she had ongoing contact because of her son's medical conditions. The nurse denied the request but explained to Kathy that she had to because of policy, prompting Kathy to remark how experiencing shared trauma bonds her with the nurses.

Kathy had an ongoing relationship with this nurse, with clearly defined boundaries. While friendly, all their interactions revolved around her son's medical care, and her social media request attempted to extend or alter that relationship, which was denied. In other situations, nurses did seem to expand their interactions with parents beyond the work-related boundaries.

> Alesha [specialty nurse], I remember when **she was leaving-her retiring party**. We were up on the 4th floor, and **she came up, showing me pictures.** [And] I said something along the lines like, 'Man, you know I'm really going to miss you. I really am.' She's like, 'Why? Sure, I'm just a shit nurse.'[28] (Kathy)

This interaction between Kathy and Alesha illustrates this altered boundary. Alesha came to Kathy's room without professional contextual interaction and showed her photographs from her retirement party. Although this happened in a professional

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[28] Among other things, Alesha specialized in colon and intestine issues and care. Her comment of "shit nurse" refers to dealing with the area of the body that produces fecal matter.

workplace setting, this was an interaction beyond the parameters of established professionalism because there was no correlating work-related context. Alesha did not show her the photographs during a check-up; she came to Kathy's room to discuss her retirement party.

And while parents spoke about an intimate relationship with staff, there was also a distance between the parent and their child.

> That was another thing too, like I never ever realized that that wasn't normal to be in PICU every 3 or 4 weeks, for like a week or two at a time. Sometimes a month at a time, vented. Like that wasn't normal, and I remember Dr. Jacobs came in one time and asked me about a DNR. And I'm like, 'What's that?' She said, 'Do not resuscitate [quieter voice].' 'What! What's that for? What? What are you? No, we'll just keep doing this.' 'That's probably not the best idea.' I'm like, 'What do you mean?' **Like it didn't dawn on me what this was doing to him. I just couldn't let him go. That's the thing**. So you know, I mean, I felt bad about it after. But once they got his sleep apnea and stuff figured out, and he was on the bi-pap like, he's been stable. (Shelley)

Though, I would also like to add a personal experience to this. One day my mother called, and after some preliminary chit-chat, she commented, "You know, that suctioning is hard on Minxie." And her comment made me very angry. I asked if she would rather I let her choke on her phlegm. And if I would be a better parent if I cried when I had to suction her. She responded no to both. Suctioning the mucous was a better option than allowing her to choke on it, and becoming upset about having to provide her with the required care would have resulted in a miserable existence for me. Detachment felt like the best of the bad options available in the circumstances, and while it did not emerge from the data, other parents may have had similar experiences.

From Role Play to Embodiment

An essential part of medical socialization is learning to accept uncertainty while also displaying competence (Beagan, 2001).

> I think, and it goes to a question you asked earlier about how does it make you feel to be the advocate. I'm both really proud**. I feel really positive about myself that I am the person telling the doctor what we need**. Like it's kind of a bit of like, yeah, like I'm doing it for my kid, like. Kind of get a bit of a chest-pound-like. **And on the second hand, it's terrifying** because, oh—I'm the one doing it? Like, I'm nobody, like I said this to Monica a bunch of times. The fact that it's both **empowering but also terrifying at the same time.** (Brandon*)

Brandon's comment highlights this aspect perfectly. Competence and uncertainty mesh in everyday existence for medical parents. While he talks about feeling empowered by this position, it is also terrifying for him to realize he occupies it.

Medical students spoke about the transition from feeling like they were playing a role to accepting and feeling comfortable in their position (Beagan, 2001), as did medical parents.

> **The second seizure, I wasn't confident enough to give him the midazolam**. He had a seizure, and I caught it, and we called 911. We were on the phone with the operator, I was like, 'I have Midazolam[29]. Can I give it to him?' And the operator is like, 'I'm not actually qualified to answer that question.' I was like, 'That does not instill confidence in me.' And from there, like it's a liability thing, I guess, and so we ended up waiting for the ambulance, and they got here, and they gave it. **[The third seizure], I gave him the midazolam before we called the ambulance.** I had the medications in his dresser in the room. So I just got it out and drew it up, **and I was more confident this time** cause after the last time, and I wasn't confident, **we had a good conversation with the neurologist and the neurology nurse. And they kinda reassured us that like it's not rocket science.** (Jackie*)

Jackie's comment reflects this experience of feeling as though she was playing a role, through to feeling comfortable in that role and accepting it. When Noah had his second seizure, although his neurologist had prescribed rescue medications and Jackie had them on hand, she did not feel qualified to make the decision to administer the drug. But she was comfortable with the procedure when he had his third seizure a few months later because "it's not rocket science." During his second seizure, she sought permission to

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[29] A rescue seizure medication.

administer the medication, but she felt confident with the process and her abilities during his third seizure.

Responses From Others

For medical students, an essential part of accepting the role of the doctor is having that role validated and confirmed by other members of the medical profession (Beagan, 2001). The experience is very similar for medical parents who have comparable confirmations. Christine arrived at the PICU, asked how her son's night had been, and reached for the nurse's chart to read through the notes. The nurse took the chart and told Christine she could not look at it. Christine looked at the chart every morning; she was taken aback.

> Susan [told me after] she was like, 'There was no need for you to treat Christine like that; you know **she's literally one of us.**' (Christine)

Afterward, Susan (another nurse who had witnessed the encounter) reassured Christine that she had done nothing wrong by looking at the chart and assured her she had advised the nurse accordingly.

In this situation, one nurse admonished a colleague regarding what she considered inappropriate behaviour and confirmed to the parent that her professional medical behaviour (i.e., checking the chart) was acceptable because of her status position.

> [The emergency department] knows us**. I don't go in and register. I just take him in. We take him in through the ambulance doors; I don't even triage him** 'cause, like I've said to them before, if I come here, there's something really wrong. I'm not going to wait out in the waiting room. (Valerie*)

Valerie notes a similar confirmation of her status when she says that the emergency department does not require her to triage her son. She does not even frame it as something they allow her to do; instead, she has asserted jurisdiction over it, and the staff has complied with her assertion. She brings her son into the emergency department using an entrance not available to the public, and her son is seen immediately. It represents quite a remarkable position for the parents; emergency rooms are heavily surveilled, and breaking the rules is not viewed favourably. Valerie obtains access to closed areas, and the staff trusts her conceptualization that if she brings her son into the department, he requires immediate care.

I close this section with a caveat; in print, the identity formation of the medical parent seems clinical and sterile; simply a matter of repeated interactions between parties across time. But an essential part of socialization and parenting processes for medical parents includes the emotional pain, turmoil, and trauma of having a child with a chronic medical condition. Acknowledging the pain and anguish these parents endured alongside this identity formation was essential.

3.2 The Medical Parent Boundaries

People create boundaries to order and understand their environment (Ashforth et al., 2000; Bange et al., 2022) by constructing "mental fences" (Zerubavel, 1991) around things they consider to be similar. People create meaning around activities, and boundaries provide them with predictable dynamics for interaction based on how an individual perceives the positionality of the person they are interacting with (Sundaramurthy, Chamu & Kreiner, 2008) and the appropriate tools for interaction with that person based on their respective positionalities (Bange et al., 2022). Such interactions are exercises in meaning-making between and within perceived social groups (Mann, 2007; Mead, 1934); I am a medical parent, and I identify the person I am speaking with as a fellow medical parent; therefore, I have underlying assumptions about the things they have experienced, and whom they have interacted with as part of this shared identity.

While such boundaries change and shift through meaning-making interactions, there must be similarities medical parents can draw from to identify who else fits inside the demarcation of medical parent based on their understanding of what it means to be a medical parent.

The presence of such boundaries aid in interactions with other group members but also works to keep those identified as outsiders away from group membership (Ashforth et al., 2000); I am an “insider” of this group, I place you as an “outsider” and, therefore there are differences between us that are in the forefront of my mind during our interactions. Feeling that you have insider membership within a group with some status can feel rewarding, resulting in group members working harder to protect their boundaries from permeations (Capitano et al., 2017). Where a role is less permeable, there is often less conflict between roles (Capitano et al., 2017); if there is less conflict between roles, such roles become highly valued, and so—on it goes.

Identity formation is about belonging; it indicates being part of a collective. But, if belonging is synonymous with inclusion, the opposite is also present—there must be others who do not belong to that group and are thus excluded. Medical parents engage in boundary work as part of their identity—they interact with others who are either inside or outside that boundary and, in doing so, reaffirm or shift meaning and membership.

Boundaries Determined through Medical Parent Interactions

Who do medical parents identify as other members of their group; how do they determine membership? Having a child with special needs is a starting point, but sharing medical personnel is also important.

> Shelley: [Dr. Mitchell] was like, don’t know what’s going on. We need to send you out of province, and we don’t do that, you know…we don’t do it lightly. And he was almost embarrassed like ‘cause they couldn’t figure it out

> Me: Sounds like him
> Shelley: Right! **How did you find him?**
> **Me: Dr. Mitchell?**
> Shelley: Yeah
> Me: I found him pretty good
> Shelley: Yeah
> Me: I found him fairly straightforward
> Shelley: Very straightforward
> **Me: God, I think he had some kind of a fucking fetish with that CO2 machine**
> **Shelley: Right**
> Me: The transcontaionus monitor[30]
> Shelley: Yes! And I was like, 'But it's burning,' 'But we need it.' 'Here's what we're going to do; No, we're not going to do that [use the transcontanious CO2 monitor]. No, we're not doing it. Like it's hurting him.' And see, he's the reason why I'm such a numbers person, and then Dr. Jacoby, on the other hand, is like, 'it's not all about the numbers—volumes.'… Now I loved [Dr. Mitchell] I really, truly did. I had great respect for him. But…none of the nurses really liked him either
> Me: No, **he got along really well with Collette**
> **Shelley: Well, Collette can get along with anybody anyway**

Having medical professionals in common establishes a foundation for medical parents to build a relationship. Shelley asked my opinion of Dr. Mitchell, leading us to discuss our interactions with him and his place with other medical personnel as we understood it. Shelley and I use our shared experiences centred around the medical care of our respective children to build our deeper emotional connection. Having these shared similarities is the starting point here, but our mutual agreement on the situation is also critical to figure out where we position ourselves relative to the identity of the medical parent, and where we position the other person we are interacting with as well; Shelly and I agree Dr. Mitchell was straightforward, we both agree on Collette's personability, and those agreements foster our mutual understanding of being within the boundary of the medical parent.

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[30] A small, round sensor that sits on the skin around the upper chest that provides a continuous readout of carbon dioxide levels. If the sensor was left in place too long, it caused a red mark or possibly a burn on the child's skin. The general time was fours on a location but, if a child had sensitive skin, they could develop a mark within a shorter time.

Medical parents may also view other parents as being either within or outside the boundary of the medical parent through the interactions other parents have with medical professionals whom the medical parent trusts.

> When I have a concern, **Dr. James** is the only one I find really good for that. **He shut other doctors down to hear what I had to say**. He says, 'We're the medical professionals, but we can't do anything until mom tells us what's going on. So if you don't listen to her, how are you even going to know what to do?' **When everybody else was trying to give their opinions earlier this month about trach or high flow[31], my husband [asked me] he was like, 'What's Dr. James think of it?**' I said, 'You know Dr. James doesn't do trachs.' He said, 'I don't care—he's like the only doctor I trust. Now, what does he say about this?' 'Actually [he] says that we're probably going to be relieved after we get it……' 'Perfect—let's do it.'…**I've had parents come to me like, 'Dr. James told me I was starving my child; I'm not happy.' And I'm like, 'You're probably starving your kid then.** He's pretty blunt, but if Dr. James told you you were starving your child, he thinks your child needs more nutrition, and it's starving.' (Eileen*)

Eileen's comment illustrates multiple facets of this idea. We did not know each other before the interview, but Dr. James' is a doctor whom I know and trust—if he responds to her as a competent medical parent, that signifies belonging for me. She made a similar observation but in the opposite direction. If Dr. James told the other mom she was starving her kid, Eileen agrees that the other mom is starving her child. We both used the opinion of a doctor we trusted (the same doctor) to evaluate our perception of the competency of another parent. We both trust Dr. James, and by extension, his perception of the circumstances also influenced our perceptions of them.

Parents may use the opinions of medical professionals to conceptualize the insider/outsider status of the person they are interacting with. Similarly, parents may also confirm and reaffirm their shared identity through interaction with other parents.

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[31] Different forms of breathing support. Tracheotomy or high flow oxygen. The tracheostomy requires surgery where a hole is made in the throat to bi-pass the upper airway. High flow oxygen is provided through a mask or nasal prongs into the child's nasal passage.

> You know, the worst part of my day is the morning when I wake up. And I'll always take a deep [breath] every day, and I'm like, 'What am I going to face this morning?' 'Cause so many, and **I'm sure you can relate**, but so many of my friend's kids have passed away in their sleep, you know….I wake up every morning I'm like [gasp], 'Ok, I've gotta go [check on my daughter],' right? But it's always there. (Iris)

Iris has been a medical parent for a long time; when discussing the possibility of her daughter dying in her sleep, we interact as insiders; she confirms my position as someone who shares a similar concern as a fellow medical parent. And part of this shared positionality illustrates the most crucial interactional indicator of belonging: war stories.

> Me: [My experience] started fairly similar [to yours] because my daughter was a Janeway frequent flyer, right? So she was in PICU every time I turned around. Every time I had an exam, and it was actually a running joke
> Gemma: Exams are coming; guess where we're going
> Me: Yeah, yeah—mom's gotta study, yeah. So, at one point, I remember it was the end of the fall semester [I tell her my narrative from Chapter 1]… and I was walking across [the road] in a snowstorm. **It sounds like one of those old-generation stories, right**
> **Gemma: It's like—I know, but it's a war story is what it is**
> Me: Like, I don't even understand why or how I'm doing this. Like my daughter is up in ICU—I don't know what state I'm gonna find her in when I come back, but I gotta go write my exam. Yeah, I gotta go do that now
> Gemma: So you gotta go put that in a box
> Me: Exactly; close that box
> Gemma: And go back to this one
> Me: Yeah, and then when this one's over—this one opens up again. That's exactly what it was like
> Gemma: Yeah

Gemma and I did not know each other before the interview, but she shared her experience of balancing education and parenting and then asked about mine. The first few lines illustrate the playful banter we formed around the situation, and the concluding part shows our shared conceptualization of dealing with competing priorities, but the middle comment forms the lens through which we filter these interactions. They are war stories; illustrations of experience and survival. Gemma and I respond to each other as insiders, and we position having war stories as part of this insider position; medical parents have war stories about their parenting experiences as part of being an insider. Most of the war stories in my data were told to me using minimizing tones and word choices. My comment above is an example; I reduce the experience by comparing it to an "old generation story," and many parents spoke of their experiences as though they were reciting their grocery list:

> Sometimes she'll have the long [seizures] where it's like, you know, she can seize for like two and a half hours straight and not come out and, you know. But a lot of times, the other thing is **she can cluster right; so she'll go in, she'll come out for a minute, she goes in for two minutes, she comes out for 2 minutes, and she can do that for long periods of time**. And I remember being [in emerge] bed number one, observation is Scarlett's bed and they brought this other little boy and he was after having a seizure…. So anyway, [the nurse] would come over to me, and they're like, 'How you doin'?' And I'm like, 'good, she's had 10 [seizures],' you know…But that's the difference, right—**he [the little boy] had one [seizure], they rushed him in an ambulance, Scarlett's clustered, Emma drove her in herself**. (Emma)

Parents recall traumatizing experiences using minimizing narratives to indicate experience and perform "good medical parent" framing. As I said, Emma related Scarlett's cluster and the comparison with how she handled it as though she were reciting a grocery list, "we need eggs, milk, I've got to get sugar…" Another tactic parents used to minimize their experiences was filler phrases, such as "blah, blah, blah" or "and all that stuff."

War stories may not just signify insider status in a situation; they may illustrate elevated position within that membership.

> Valerie: I work at home with him, so it's not like we've got maybe a sitter or a caretaker watching him and not quite knowing—it's me—I know [his needs]
> Me: What do you mean you work at home with him?
> Valerie: I'm his respite worker
> Me: You're *paid* as his respite worker? [emphasis in original]
> **Valerie: I fought for**
> **Me: I bet you did!** [emphasis in original]
> **Valerie*: For almost a year**
> **Me: That is not easy to get! I think I've only—in 13 years—heard of 1 other person who's been able to get that approved!**

Valerie is paid as her son's respite worker, which is an arduous approval process. As my comments indicate, her ability to achieve such status signifies an elevated insider position to me.

> Iris: Lily has been known to drop down into the 60s
> Me: Oh, that's just grey[32]
> Iris: The lowest I've ever gone is 61, which is probably every other night, but they [the doctors] don't need to know that
> Me: I was thinking of having a box of crayons done up for the nurses, but instead of like Crayola like 'every shade of Minxie,' so like '90s, '40s, '20s
> **Iris: Has she gone that low?**
> **Me: I've seen her in the teens**
> **Iris: [gasp]**
> **Me: Oh yeah**
> **Iris: With the oxygen?**
> **Me: Yep**
> **Iris: Oh wow. No, my lowest is 61—you wanna see nurses run**

Iris and I discuss our shared experiences with oxygen desaturation, which shows her reaction; when she learned I had seen my daughter in the teens, she gaps, indicating her amazement at the situation.

When parents frame other parents as being medical parent insiders, how does that influence their interaction? When insiders interact with others they perceive as fellow insiders, they invoke a shared understanding of situations and circumstances, and one of the ways parents respond to that assumed shared knowledge is through a lack of explanation. Most of the footnotes throughout my paper illustrate this; parents did not explain medical terms or concepts to me, but I wrote this thesis knowing that the primary audience would not be fellow medical parents. Most of the footnotes provide the context parents assume other parents will know and understand and what those who are not medical parents may not understand. However, another way parents interact with each

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[32] Oxygen desaturation has corresponding visual changes as well. If a child's saturation is around 80%, their lips and face may appear pale. From there, as oxygen levels drop, their face and lips become grayer. In the lower numbers, their face appears purple or blue, possibly even black looking. My comment is directed at the color of her daughter's face with 61% oxygen saturation.

other is worth specifying as it runs across each of my interviews regardless of whether I knew the interviewee beforehand, and it is conventionally taboo; dark humour. All the parents I spoke with used dark humour when talking about their situations:

> Kathy: Why do we do that [refuse to ask for help]? And I know I'm not the only one; I can't be the only one
> Me: No, I wouldn't ask for help
> Kathy: No?
> Me: The only time that I ever really did reach out and ask somebody for help when they had offered help was [when Minxie died]. I asked a friend of mine if she would babysit for Minxie's funeral so I could leave Marley home
> Kathy: Seriously?
> Me: Yep. I knew she was capable, and she had offered to help in any way that she could
> Kathy: Right
> Me: So I asked her, and she did
> Kathy: Ok.[33]I was gonna say I didn't see him running around naked[34] or anything. Can you imagine, oh my God
> **Me: I can just see me looking at [my partner] now, 'I mean, the casket is open; let's just pretend—see if it straightens him out.' Dark, dark humour man**
> **Kathy: I love it, I love it, 'Minxie shove over now, c'mon.'**
> **Me: She was on her side, like kinda cuddled over this way. I mean, we could have just stuck him down there cuddle in together**
> **Kathy: It could have been really cute, actually. Oh my God, and that's the thing, like—you have to make that stuff normal.**

Being a medical parent is a heavy emotional and mental weight; engaging with humour breaks the weight, making it easier to bear. Kathy and I were having a serious discussion about our self-imposed isolation from other parents because we do not ask for help, but when I provided my daughter's funeral as an example, we quickly switched from serious conversation to light-hearted humour.[35]

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[33] Kathy's tone indicated that she was concerned that I had reached out for help and been denied. Later in our interview, she told me she would have babysat for me, if she had known I needed a sitter for the funeral.

[34] Marley was a toddler at the time and did not like to wear clothes.

[35] This was a common tactic throughout my interviews. Parents balanced serious conversation and topics with minimizing humour. I did not explore this with my participants, but from my personal experience I conceptualize it as a coping technique. If I were to focus on the seriousness of my daughter's situation for too long, it would be too painful, too hard; too real. Engaging with humour allowed me to assert agency in how I framed the situation—I could re-orient negatives into light-hearted positives.

But if medical parents interact with others as insiders, there must be others they interact with as outsiders; the most obvious being parents without experience in a medical setting.

> How many more times can [my son] go through [respiratory failure] before it's enough? **That's when the DNR conversations started happening…**I had come to terms with, you know—we're going to get to a point…**And then to hear people talking like, you know, having trouble getting their kids to hockey? Wahoo—like seriously!** Really, you don't know if you need to carpool or not? Oh my God, you poor thing…I remember, you know, being angry with people I didn't even know…and it wasn't a case of like, 'Oh my God, if you only knew what I was going through.' [It was] like, '**How can I have all of this on my plate [and] this fucker over here is pushing his kid on a swing?' Something I'll never be able to do?** I was angry, I gotta say, I was angry at the world. (Christine)

Boundaries surround us with the familiar and represent part of normalization; I am a parent going through serious medical issues with my child, and I am part of a community of others going through that as well. And because we are going through these shared medical experiences, I am not "different," I am not an "outsider;" I am just average and ordinary. Christine's comment highlights a typical response for medical parents when they engage in boundary-work; she is inside this community, but bearing witness to the lives of other parents who are outside the boundary makes her feel like the outsider—she cannot push her son on a swing, or take him to hockey and she feels angry with the outside world because of that, which results in distancing herself by using mockery, "You don't know if you need to carpool or not? Oh my God, you poor thing."

As I stated at the beginning of this section, having a child with special needs is a starting point for an insider identity, but successful navigation and acceptance of that role is much more nuanced.

> I just got to the point that I couldn't deal with [the other parents]. I mean, they had a meeting of the mothers or something over to [a retreat], and you know something? **They were the rudest, rudest to me**…I just left. And then about two years later [one of them] chased me around fucking Costco cause [her

> son] had had a seizure [saying], 'I don't know how you do it, I don't know how you do it—it was horrible.' I said, 'Yep, it is, yep.' Anyway, she kept chasing me up and down the aisles like, fuck off, woman—I didn't like you before, I don't like you now, **like really, you're that rude to me, and now you want me to be your friend? Don't work like that**. (Quinn)

Quinn's comment highlights this navigation from multiple angles. First, Quinn talks about how she felt rejected by the mothers during the retreat—all of whom were fellow parents of children with complex disabilities. Then she talks about how she rejected the collegial interactions of one of those mothers when they ran into each other at Costco. Quinn felt like an outsider among the group of mothers at the retreat, and she responded by treating the mother at Costco like an outsider as well. During our interview, Quinn talked about multiple medical professionals but only referred to two respectfully; she was dismissive toward the others. During my other interviews, the parents referred to medical professionals respectfully, even if they disagreed with their opinions and ideas. I suspect the mothers at the retreat interacted with Quinn as an outsider rather than an insider because they may have responded to her demeanor towards shared medical professionals as a breach of boundaries.

As I explained above, parents had many healthcare professionals within their circle, but they considered specific staff as outsiders and they modified how they interacted with them. Most of the parents I interviewed referred to ward nurses as outsiders, so it follows that parents would engage with them as such.

> I remember, oh my God, [one of the nurses on the floor] was trying to prime the pump and like she couldn't get it to work. So anyway, I was like, '**Ok, I'll leave you alone for a second.**' Anyway, same thing, she changed the bag—I mean threw out the formula, threw out the bag, all the stuff, put a new bag on, filled it up—same thing. I'm like, 'See, **what's happening right now is that you don't have the plastic cover off the bag**—off the tube thing. Just try that and see what happens.' Like, oh my God, missus—**and you're taking care of my son today? I don't think so; I'll be staying**. (Bonnie)

Bonnie's son was in the ward, and the nurse was preparing his feed using a feeding pump similar to an IV pump. The nurse filled the bag and fed the tubing into the feeding pump. But when she tried to prime the pump, it would shut off. Bonnie watched her complete this procedure twice before advising her that she had not removed the tip from the feeding bag, which airlocked the tube and prevented priming. Bonnie entered this engagement, judged the ward nurse incompetent, and responded to her accordingly. Forgetting to remove the cover is a silly but understandable and forgivable mistake. If it were to have happened in PICU, Bonnie likely would have laughed at the nurse, told her the cover was still on, and considered it an anomaly rather than a reflection of the nurse's competence. Once people form boundaries, they engage with others based on those boundaries, and they become self-fulfilling; PICU nurses are competent—if they forget something, it is an anomaly. Ward nurses are incompetent—if they forget something, it is because they are incompetent.

Boundaries Experienced by the Medical Parent

Bonnie's experience above provides a starting point for this discussion; medical parents perform boundary-work to identify and respond to their environment, but so does everyone else they interact with. And just as parents identify who is outside their boundaries, others identify medical parents as outsiders.

> **It's like they know better [than I do in PICU]. They know more than I do**. And if I say anything, I find I just get met with to the extreme then so like, 'Please don't give him any medications that were not previously discussed or agreed upon without talking to me first,' and then everything is, 'Do you think he should have some morphine?' **I almost feel like they're mocking me.** Like you don't have to take it from one extreme to the other. (Laura*)

Most parents I spoke with preferred PICU nursing care over ward care. But most of Laura's admissions involved the ward. She felt comfortable and appreciated by ward nurses. But when her son was admitted to PICU, she thought they did not respond to her the way ward nurses would. She had a reputation and a position with the ward nurses but not with PICU nurses, and this lack of shared knowledge of each other resulted in misunderstanding. It seems the PICU nurses and Laura are unsure of how to interact with each other, or may be performing competing boundary-work, over the medication. Does Laura’s instruction mean new drugs, new doses of pre-approved medicines, or both? She feels these nurses dismiss her, and how they respond to her request about the medication forms part of that dismissal.

Laura’s experience hinged on her being treated like an outsider in a setting where she felt like an outsider, but sometimes parents were treated like an outsider when they expected to be treated as an insider.

> I remember I went in rounds one time, and I asked how his night was, and **I went to go look at the chart, and [his nurse] was like, ‘You can’t look at that’ Why the fuck not? Like, I’ve been here longer than you have,** like—what are you talking about? She said, ‘No, you can’t look at that.’ And I was like, ‘Ok, woah, what are we hiding here? What’s going on? I look at the chart every single morning I come in here.’ (Monica)

Monica felt like an insider in the PICU. Her son was admitted frequently, she knew all the staff, and she performed her role as an insider by doing nursing activities, including reviewing her son’s chart each morning. But this time, the nurse assigned to her son’s care refused to let her see the chart. Monica felt like an insider in this situation, but the nurse's reaction demarcated Monica as an outsider.

3.3 Temporality

The self stands in the present and pulls on both the future and the past (Mead, 1932). The individual is always moving towards something informed and shaped by their past; the self becomes the navigator of the voyage (Hitlin & Elder, 2007). The self conceptualizes the potential of the future based on past experiences and acts accordingly.

There is a continual connection between the past, present, and future; the past is not forgotten or completed—it shapes the present because past experiences are projected into the future. But the past is not objective—it is mediated and interpreted by the self (Kaplan & Orlikowski, 2013); the self responds to the past through its mediated understanding of it and uses that understanding to develop plans or lines of action (Flaherty & Fine, 2001; Mead, 1932; Mullaney, 2019) for the future.

Unexpected events alter our conceptions of the future, and as the self stands in the present, it draws on understandings from the past to reformulate how to proceed into the immediate future; I am a new mother, and my baby is seizing in my arms—my understanding of past experiences informs me to seek immediate medical attention from a doctor because doctors are the experts in medical care and diagnosis. As this unexpected present comes into focus, the anticipated trajectories of the future recalibrate.

> **My second thought [after the diagnosis] was, 'Oh, we're moving' cause I was like living in [a small community in central Newfoundland],** and there's no health care out there, and there's no services, and I would have been driving over to [the closest hospital, 100 kilometers one-way] all the time, and I was [working] at the time…I mean, it was devastating. And I'm the type of person who immediately goes into survival mode, so I was like, 'Ok, we're moving,' and nine months later, we had sold everything [and moved close to the hospital]. **We were in the process of buying our [home for life] home like literally when she was diagnosed.** I got stuck in the hospital; I signed the papers with my lawyer in the Janeway lobby for the second house that we were buying in [the small community in central]….**I had babysitters lined up [for when I went back to work]; it's a wonderful community…I had everything arranged,** but I knew I was ultimately going to be on my own for long periods of time and over the road to [the hospital] anytime there was physio or OT or anything and…**I knew all this from talking to the Janeway when I was in for the diagnosis**. (Gemma)

Gemma's daughter was admitted to the Janeway as an infant and was diagnosed with a severe, chronic medical condition. At the time, Gemma and her family had planned a long-term life in a rural Newfoundland community; they purchased a home, she was working in the area, she had arrangements in place for babysitting, and so on, but her anticipated future trajectory was altered when the Janeway staff detailed the ongoing medical interventions her daughter would need. Gemma relied on her past understanding of medical professionals as the experts in this situation, and their future-oriented plans influenced her decision in the present to move to a location better suited to her daughter's needs.

One thing important to note here is that Gemma's appraisal of the present is situated on the past experience of the medical professionals as experts. But for medical parents, the orientation of the expert in the child's care shifts over time.

> **You know much more about medicine—I'm sure you do. But you'll never know Aiden like I know him—none of you know. So let's just get that out of the way now—listen to me when I'm talking to you about [my son].** Ludicrous, like, can't talk to none of them, you know, 'Oh, he's doing good now.' Things are going to change. Things are going to change quickly. [The resident is] like, 'No, they won't.' I'd rather be as certain as [I am about this], you know, [in other areas of] my life—but you cannot stump me on anything Aiden. Nothing. (Christine)

Christine took her son to the emergency room because she observed what she interpreted as signs of distress in his behaviour. She explained what she saw and what that meant to the resident, who dismissed Christine's appraisal of the situation.[36] We conceptualize medical professionals as the experts in medical care, but as Christine's comment clearly illustrates; she is now the expert in her son's care—not the medical staff. Our interpretations of the past change over time—Christine previously considered doctors as the experts in medical care, but she has now accumulated substantial knowledge about her son and his care—she has replaced the medical professional as the expert in her son's ongoing care.

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[36] To conclude the narrative, the resident consulted with the attending physician about the situation but when the physician entered the room and saw Christine and Aiden, he advised the resident to assume Christine was correct, "This mom knows what she's doing."

The two preceding excepts deal with change as mediated through the past, present, and future. But the past also provides continuity through the present and into the future.

> Leo's made it pretty obvious that…it's coming. [He's] not going to live, you know, to be 20 or 30 years old….**I'll never forget** it…[Dr. Mercer**] was like, 'You know, he might see 10**, maybe.'…It's always still there. **Every time he goes in [to the hospital], I'm like thinking, 'Oh my God, is this the last time?** Is this the last time?' So it's always in the back of your mind. Always. (Shelley)

The doctor providing Shelley with her son's predicted life expectancy is an anchor point in her past. Every time her son is admitted to the hospital, she is reminded of what the doctor said and worries that this may be his last admission—this may be the admission where he dies. This anchor point in her thinking represents a break from how we typically construct the past, present, and future; past experiences inform the predicted outcome for future anticipations. If the past results inform predictability for the future, then Shelley's son will likely survive the following hospital admission because he has survived all the hospital admissions before this one. Instead, the doctor's past prediction serves as a potentially emergent present (Mead, 1932) during each hospital admission.

My discussion thus far has conceptualized the past, present, and future as interrelated but separate. The past informs the present toward an anticipated future—connected but also clearly separated from each other. The past shapes future happenings, but the past itself is unreachable. If you were involved in a car accident in the past, the accident might shape your future driving habits. Some parents experience a collapse of temporality; where the present is similar to the past, the past collapses onto the present to where they are indistinguishable.

> My doctor tells me I have continuous traumatic stress disorder. So it's not just post. It's past, present, future, continuous traumatic stress disorder. Because it's post-traumatic—every time he coughs now or gets admitted now, you're under that stress and worry, and you don't know what the future is going to bring, so there's a constant traumatic stress going on… **I had my baby [and]**

> **she was keeping her hands closed too much when she was born, and I was like, 'B'y's I get it—I'm probably crazy, but do something and tell me my child doesn't have cerebral palsy like her brother.**' And they were going through, you know, they might not…call in the experts, but they will go through the motions of at least giving her a little check, explaining to me why she's doing that instead of [dismissing my concern]. She probably doesn't have it, but you have a mom who's hypersensitive now. Maybe you do need to just take a look. (Laura*)

Laura has multiple children, and one of them is severely disabled. When she had her youngest child, she felt the past collapse onto the present—her daughter exhibited a movement that she feared may indicate she has the same condition as her older brother. Laura responded by seeking help to alleviate her concerns—she asked the doctor to check her daughter to ensure she was healthy even though her daughter's movements did not qualify diagnostically. For her, the weight of her past experiences with her son made her daughter's actions much more concerning and likely to be cerebral palsy. She did not experience the past as being distant while informing the future—the concern and trauma she experienced in the past with her son's condition were alive in the present.

3.4 Normalization and Medical Knowledge

The processes of normalization and navigating medical knowledge are intertwined; parents normalize their circumstances (Carolan et al., 2014; Knafl & Deatrick, 2002; Murdoch & Franck, 2011; Page et al., 2020; Rehm & Bradley, 2005; Sallfors & Hallberg, 2003), others around them reinforce this normalization, others provide parents with medical knowledge as part of their parenting experiences, parents become the keepers of this medical knowledge, navigating medical knowledge and work become part of their normalized parenting experience.

People do not want to feel alone. They want to feel like other people understand what they are going through and can share in those experiences—it is a positive way to cope with life situations (MacDonald & Gibson, 2010). When people perceive they have a commonality with others, they use it to build a connection; two pregnant women in an obstetrical waiting room will likely talk about their pregnancies, dog owners at a dog park will talk about their pets, and so on—this is normal. Medical professionals often encourage this normalization (MacDonald & Gibson, 2010), and my experience bears this out. During my daughter's first hospital admission, I remember one doctor used to tell me stories about other children; the little girl who had to stay in the hospital so long she learned to skip using her oxygen tubing as the rope, the camping trips one family used to take with their son even though he was vented, the young sibling who would suction her brother's trach with ease. The doctor was straightforward with the meaning of these stories; your daughter's condition is not unusual, nor is your situation—this is normal. If it is normal, I can do it—just like all the other ordinary families who do it too.

Without normalization, the emotional weight of the situation and the circumstances would be too heavy to bear. But if this is normal, it should not warrant special attention or consideration—because normal is only average; my daughter's respiratory failure and intubation are typical for me as a medical parent, so I should not be emotional or upset—this is just another average day, just a new normal. The first time Andrea's son had a seizure, and she had rescue medications at home, she did not administer them—she sought clarification and permission from the 911 operator. But she administered the drug the second time he had a seizure because "It's not rocket science." Her uncertainty was replaced with confidence; this is just normal—her appraisal of the rescue medications changed, as did her overall conceptualization of the situation.

> **He has periods of being quite well** and like not having issues…Flu season is rough, and this year, he was sick this year from like March to July like, just back-to-back viral illnesses. He had a seizure in May, he had a stomach bug. It's like once he gets something, it's really hard for him to shake it. Again, **most of the care we can do at home like we're pretty skilled that way. And the G-tube helps a lot** because we can keep him hydrated, and if he didn't have the feeding tube, he'd be hospitalized a lot more. (Andrea*)

Andrea’s son has a rare condition with substantial complexities. He has seizures, requires nutrition via a g-tube, cannot walk or talk, and his condition has altered his physical presentation. But Andrea describes him as being “quite well,” unless intervening circumstances, such as flu season, dictate otherwise—for Andrea, his complexities are part of normal (Carolan et al., 2014; Rehm & Bradley, 2005). And her reconceptualization of the rescue medications illustrates her extending engagement with normalcy, and those things that are normal do not require an exceptional emotional response; “It’s not rocket science.”

This normalization reorients the parent's place with medical professionals and works to transfer medical work onto parents (Woodgate et al., 2015). When Andrea’s son had his first seizure, his neurologist prescribed seizure medication and an injectable rescue medication. Andrea was advised on how to administer it and trusted to do so. When she did not feel confident with her abilities, the doctor reassured her on how to undertake the administration. Now she has the injectable medication in her home, she has administered it, and she feels confident in her abilities and would do it again. As Andrea’s experiences with such undertakings continue, she illustrates her capabilities and medical competence to medical professionals. If she is competent and capable, then things she reports to doctors are also validated, her voice can be heard, and shared medical decision-making begins.

Shared decision-making between doctors and parents has become a significant aspect of clinical medicine over the past 20 years (Kon & Morrison, 2018). Shared decision-making requires respect (Orkin et al., 2020) and trust (Mouradian, 2006) between doctors and parents. It is considered the cornerstone of patient-centered medical care (Gutman et al., 2018); it is a collaborative (Adams & Levy, 2017) partnership

(Kerklaan et al., 2022). To be collaborative and patient-centred, shared decision-making must be informed (Adams & Levy, 2017; Kerklaan et al., 2022; Lin et al., 2020; Orkin et al., 2020; Wyatt et al., 2015); doctors must provide parents with information, and value their opinions and decisions. The first experience I recall with shared decision-making occurred in the NICU. Minxie was three months old, and she had been ventilated since birth. The neonatologist felt she was progressing well enough to be extubated soon. The doctor offered me the option of administering dexamethasone to speed up the extubation process and its potential success. The drug would improve the overall quality of her lungs in the short term, and the longer she was on the ventilator, the more damage her lungs would sustain. But the drug also increased her likelihood of developing cerebral palsy; here are your options, Mom—what's your pleasure? The reasoning behind shared decision-making is sound, but the result is that parents have to make these medical decisions instead. But who am I to be shouldered with the authority of making medical decisions for my daughter? I have no medical knowledge. As April said, "The only thing that makes me qualified is that I pushed him out of me." Parents have no medical knowledge and may not have a conceptualization of the potential outcomes of their decisions, even when provided with all the information.

But the longer parents are immersed in chronic illness care, the more medical knowledge they obtain, and the greater their competence with making medical decisions—I did not agonize over the possible implications or the necessity of surgery a few years later when I decided my daughter should have a port placed. I was the one who presented the option and the reasoning to my daughter's surgeon for his agreement. I took my daughter in for her regular follow-up, I told the surgeon she was difficult to access; I told him how often she required an IV, how long they would last before they would blow, and the ratio of IV attempts versus success. He looked at my daughter silently for a few minutes, mentally balancing the pros and the cons, and then he turned to me and said, “If you want a port, I’ll put one in.” Minxie was around five years old at this time, and he had been her surgeon and provided ongoing care to her since birth. This exchange highlights the downloading of medical knowledge onto the parent and the rising medical competence of the parent, which go hand in hand. I knew the information he would request before his decision; the details surrounding access—and I framed my request using those details, “She needs IVs regularly, and she’s a very difficult poke.” He responded by asking me for further information, which I provided, and he decided to operate on her based solely on that information—he did not consult with colleagues or check her medical records of hospitalization; he considered my report to be a valid representation of the circumstances and made his decision based on my reporting authority.

The medical parent becomes immersed in medical knowledge, and this immersion becomes normalized; events that are normal are not exceptional and do not warrant an increased emotional response; the medical parent has less affect; they appear more confident; their confidence raises their shared decision-making capacity; which leads to the offloading of more medical knowledge and work onto the parent.

But, there is also a nefarious side to normalization.

> [**SCWA told me they were not increasing my respite hours**] 'cause a lot of the things that we were listing, like bathing, [they said,] ‘All parents have to bath their children. I’m like, ‘Yeah, but if I’m with Kyle…there's still other kids wreaking havoc somewhere there.’ So, if [doesn’t] falls under any of the normal scales. Like, ‘**Everybody needs a bath, so you shouldn’t need extra help bathing the kids,**’ you know, I get it—everybody needs a bath. [But if] all of a sudden Kyle is choking, and I can't leave a child in the bathroom unattended—what do I do? (Laura*)

Normalization fosters belonging for families; however, sometimes, parents experience normalization as erasure. Laura has multiple children, her youngest being a toddler, and Kyle is one of her middle children. She asked SCWA for increased respite hours because of the intense hands-on care her son requires; they denied the request because most of the examples she provided were normal parenting events—all parents have to bathe their children. Therefore, you should not need extra help to wash your children. Although all her children are young, I will concentrate on Kyle and her toddler in this example. Suppose Laura has Kyle in his bed while bathing the toddler in the bathroom. But she hears Kyle choking, and the alarm on his oxygen saturation monitor begins to sound, indicating his oxygen saturation has dropped. Kyle is probably lying in his bed with his throat filled with secretions, obstructing his airway. He cannot clear the secretions himself, but Laura has a suction machine and can effectively clear them using the device. If no one clears them, they will likely end up in his lungs and may either cause him to drown or lead to pneumonia, hospitalization, and emergency medical intervention. Laura has to suction Kyle immediately. But she also has a toddler in the bathtub who has a significant risk of drowning if she leaves the child there. This is an emergency—she does not have time to remove the toddler from the bath, ensure he is safe elsewhere, and suction Kyle before the secretions enter his lungs.

If Kyle were in the bath, the same problem would exist. Suppose she secured the toddler in his crib, then put Kyle in the bathtub, and while bathing him, the toddler falls out of the crib and knocks himself unconscious. Kyle may drown in the bathtub if left unattended—he cannot sit unassisted, so if he were to slide off the bath seat, he could easily drown while Laura tends to the unconscious toddler. Between Kyle’s disabilities and the developmental stage of his younger sibling, both scenarios are plausible outcomes of bathing one of these children while being responsible for both. Still, SCWA insists that bathing children is a normal part of parenting, and because it is normal, it does not qualify for increased support. Normalization can be a coping mechanism for parents where they define it themselves, but where bureaucracy uses normalization to erase challenges or deny resources—such as this example—a process that could establish agency and belonging instead works to strip them of agency; bathing your children is a normal part of parenting, and if you cannot handle that, your parenting is lacking.

3.5 Conclusion

As I noted at the beginning, this chapter develops the active behind-the-scenes processes which emerged from my data. They highlight the identity formation process for the medical parent through interactions with others because we perform identity work based on our interpretation of the situation we are experiencing. The identity of the medical parent is more subjective than that of the medical doctor, for example, because there are no formalized, recognizable distinctions that cement a parent as being a medical parent. It is an identity for these parents, but it is also an identity in flux, subject to the surrounding social interactions. However, as parents interact with other parents and with medical professionals, they experience fewer instances where their identity as the medical parent is questioned or denied. For a medical student, the identity formation process is formalized when they are granted their official status as a doctor. But since no such status exists for these parents, there are no corresponding identifiable final markers to becoming a medical parent.

I began with the conceptualization of the identity of medical parent using Beagan's (2007) identity formation framework. From there, I discussed boundary work around the medical parent identity as expressed through shared meaning-making interactions. Next, I developed the emergent concept of temporality through engagement with the past, present, and future. Lastly, I discussed the intertwined ideas of normalization and medical knowledge and how they inform and interact with each other.

These processes are the lenses through which these individuals see the world and doing medical parent (Chapter 5) details how the medical parent interacts in the world based on this orientation.

Chapter 4: Juggling Balls and Managing Boxes—Doing Medical Parent

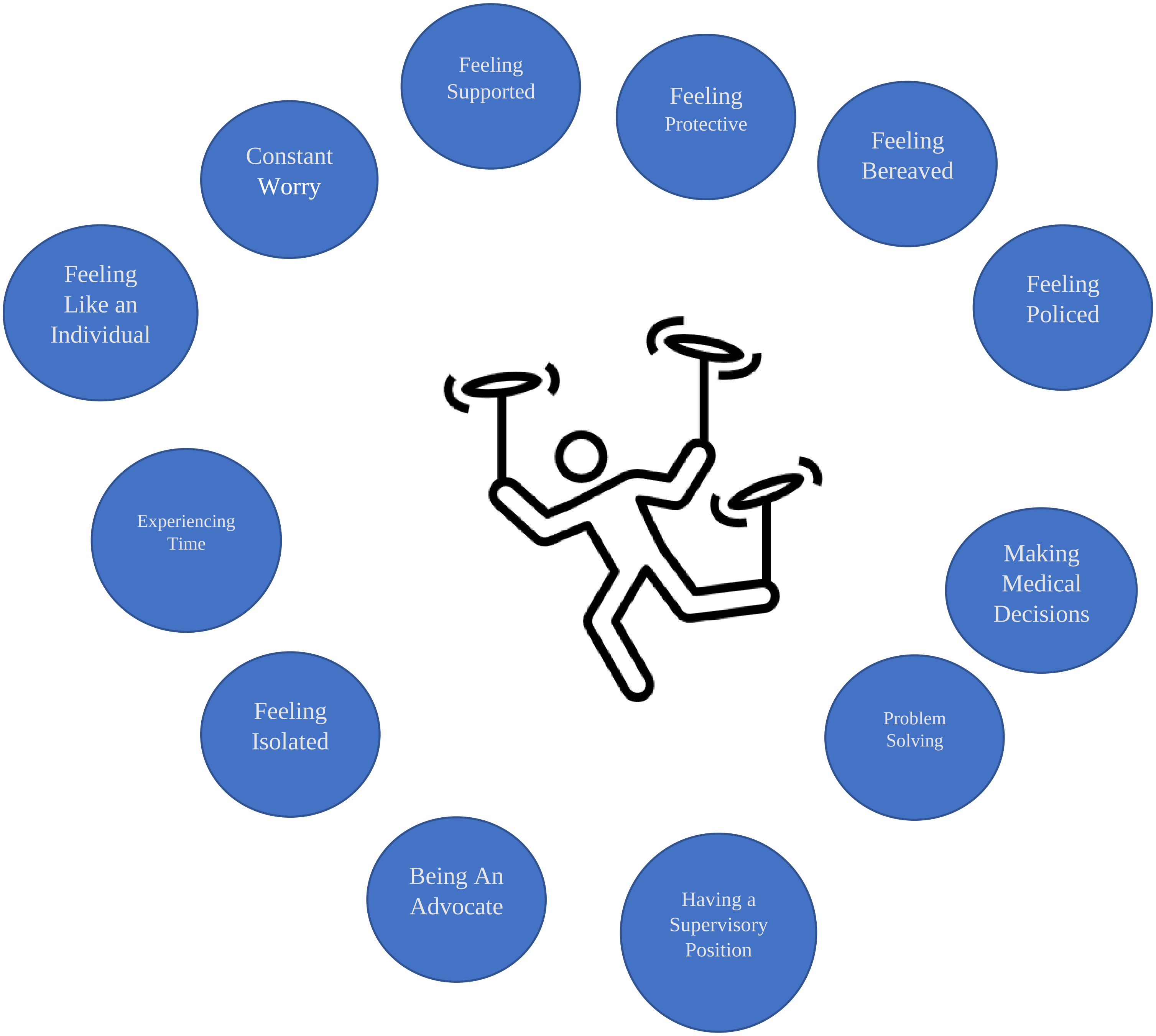
> **I've got all of these balls in the air. And you're trying not to drop one**. But sometimes you do. Sometimes you drop three or four of them 'cause that's what it's like parenting Diane, you know. Most people can juggle three balls. But you have ten balls, and you are trying to juggle all of them. But sometimes they fall, and you're just trying not to let too many of them fall. [I'm] trying to keep all these balls in the air, and sometimes I'll just think, 'I don't know if I can keep all these balls in the air.' I'm working, and you know you got Diane, you got Anne [other daughter], you got your husband, and trying to take care of the place. And you're doing this, and you're doing that. You have so many balls in the air—things that you have to worry about. I've gotta make sure her meds are right, and I have to make sure that you know she's going to breathe all day today cause she'll stop right. You guys [parents who don't have a medically fragile child] don't have to worry about that. (Ursula)

> Like the way I vision it, **it's like you know when you have like an organizer with little tiny boxes in it.** If you're organizing like office supplies or something, It's like there are just different piles**. I am very good at doing one thing at a time. And just with the understanding of there's nothing I can do for the rest of the things right now, so there's no point in thinking about five of them** 'cause then I'll just do a shit job with one I'm supposed to be doing right now. So I just sort of compartmentalize and just put things where their supposed to be. So if I've gotta be employer to like, you know, figure out why my worker is not showing up every day. The caregiving for Jessica, [and] like being emotionally present for a [pre-teen], which is intense. And then for a [teenager], which is like a whole other thing. And then having to do like family things. And then I have a senior father just to throw in some real fun. (Gemma)

I begin this chapter with the example of blackness as a master status from Chapter 3. Everything a black person experiences relates to their skin colour in a predominantly white culture (Hughes, 1937; Valdez & Golash-Boza, 2020). If the police stop a black driver, that driver is acutely aware of their skin colour and responds with this in their mind, due to the soci-historical context. If they apply for a job, they are acutely aware of their skin colour when they hand in their resume. When they walk down the road with their date, they are aware of their skin colour and the potential perceptions of the situation.

Applying for a job has no direct relationship with being pulled over by the police. Both experiences relate to skin colour across differing experiences. Being a medical parent is similar to a master status. For a medical parent, everything relates to being a medical parent, but they still need to navigate all the other roles and responsibilities of their lives as well. Lee et al. (2015) described this as meta-parenting. Ursula and Gemma’s comments above both illustrate these overlapping roles and responsibilities. Gemma referred to this with boxes. She has everything in its own box, opening and concentrating on one package at a time. Ursula’s comment illustrates another perspective. To be a medical parent is to continually engage with complementary and competing concerns. To use Ursula’s description, let us consider the act of juggling. The juggler keeps all the balls in the air by providing hands-on intervention for some while waiting for others to drop. The juggler’s gaze is fixed on some juggling balls while they work to re-direct attention to those that have fallen, even while waiting for successive balls to drop. It is a constant process of active engagement with a small number of items, knowing that more things are coming.

Figure 4.1 Illustration of the Medical Parent in Action



The medical parent is the authority figure in their child’s care, and they bear the overarching responsibility for their child’s well-being (Katzman, 2013). As part of this responsibility, medical parents feel they are always “on” and that their duty to their child never ceases; even when the child is in someone else’s care, the parent is still responsible for that child's well-being. Parents experience ongoing concerns or “constant hazards” related to their child’s care (Katzman, 2013).

I illustrate the constant hazards parents experience through Ursula’s juggling description. 13 hazards emerged from my interview data (see Figure 5.1); parents talked about experiencing constant worry; feeling bereaved; feeling isolated; feeling supported; being an advocate for their child and their child’s conditions; being a problem solver; making medical decisions; having a supervisory position; feeling policed; experiencing time; feeling like an individual; and feeling protective.[37]

4.1 Experiencing Constant Worry

Of course, everyone carries a certain amount of worry with them, and indeed, all parents have a certain amount of worry over their child’s care. But medical parents are also tasked with overseeing every aspect of their child’s healthcare needs (Woodgate et al., 2015). Medical parents “live worried” (Coffey, 2006; Nygard & Clancy, 2018). Worry is an inherent part of their everyday existence. They worry about the things in the present, those upcoming in the future, and they experience worry in a matrix. While this worry encompasses all aspects of their lives, it always traces back to their child; I am worried about my finances because of my sons’ expenses; I am worried about the lack of attention I provide to my other children because my daughter’s care takes up so much of my time, and so on.

> **You really don’t get a chance to walk away cause even if you do have someone watching him, do they know everything**? And some people don’t even realize when I tell them the common cold could take him down, and until they see that he gets a common cold and he’s in the hospital, they don’t actually fully believe it or something. Like they don’t actually comprehend that it is that simple, just the around-the-clock care, like he starts getting meds

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[37] Woodgate et al., 2015 noted a similar concept of categorizations of the good parent, the health care provider, the case manager, the student, the teacher, the detective, the guard, and the advocate which they stated as all being parts of “intense parenting.”

> at 6 am, and his last round of meds and his feed is 12 am at night. So **if he doesn’t sleep, sometimes his 6 am med is a little late cause I didn’t get up til 7:30, then you got constant guilt with him, with the other kids that you try, like. You know you can't really blame yourself—only one person who is trying to do the work of three and four, but that does not take mother's guilt away at all.** (Eileen*)

Eileen’s comment illustrates two present and overlapping worries; she is worried about the lack of attention she can provide to her other children, and she is worried about the care her son receives when she is not there as two separate concerns that exist simultaneously. This is interesting because they also inform each other; if Eileen has someone else care for her son so she can spend time with her other children, she is asserting agency over one worry, but the weight of the other increases. If she provides her son’s care, she can alleviate that worry, while her concern about her other children increases.

For these parents, worry is ever-present and extends into unexpected realms. Parents may calm these worries, but they are never alleviated. They may ebb and flow at times, but they continue to fester. And while some worries relate to situations that are presently unfolding, others are oriented toward future situations.

> I remember when we were first told about Ethan’s diagnosis, my mind went right to Sara [sister]. **And, like, what is this going to be like for her growing up?** Yes, having a sibling with a disability, I think it’s rewarding, in a way, because they do learn. [But] when that sibling then passes. It’s just not something a parent wants for their children. Obviously, you don’t want your child to pass; you also don’t want your children to experience their sibling passing either. (Debra*)

As Debra’s comment highlights, she worries about Ethan, but she also worries about the effect Ethan’s condition will have on Sara now and into the future when her brother passes away. The worries these parents experience carry over and expand into the future, so current choices and actions may be partially based on potential upcoming problems and outcomes. For Debra, this possible future loss and its effect on Sara, as

Ethan's only sibling, factored into her decision to have another child. With another sibling, Sara would not be alone if Ethan were to pass away, nor would she be expected to shoulder the sole responsibility of caring for her, should he live and the parents die.

Worry in the present refers to the current moment, worry in the future relates to future happenings, but worry in a matrix encompasses both in a moment-by-moment conceptualization where the present constantly becomes the past. The self stands in the present, continually imagining the future, watching it become the past, reimagining it again, and so on. It reminds me of Spiderman. He propels himself forward on a thread and continually re-directs his movement along his path, using new threads as new things and directions come into view.

> If she is sick, then I can't send her to school. If I can't send her to school, I need a worker to come look after her…If I can't get a worker to look after her, **I can't go to work. If I can't go to work, I lose money…If I lose money, we can't afford the rent**. (Emma)

Emma's comment illustrates this idea; a continual redirection in the present based on the potential futures as they manifest. Each morning holds the potential for her daughter to attend or not attend school. If her daughter does not go to school, Emma may find someone to care for her, or she may not. Each worry exists in the present, and each present carries all the potentially linked futures that may manifest from that present. Emma is ever standing in the present, making choices about the future, while the future slips into the past, and another choice must be made.

Living worried (Coffey, 2006) for these families exists alongside regularly occurring crises (Knoll, 1989); they are worried about the continuity and experiences of their families, but they also experience regularly occurring medical crisis events as part of their everyday existence.

I need to make sure she's going to breathe all day [jokingly]. (Iris)

These parents worry about many things. And they have a lot to worry about. But they also experience a contradictory lack of worry regarding regularly occurring crisis events. Iris' daughter regularly stops breathing. Although alarming, she does not share that worry in the same way she experiences concern about financing her daughter's care needs, for example. Crisis medical experiences become regular everyday occurrences.

4.2 Feeling Bereaved

Medical parents experience high levels of grief (Ashton & Ashton, 2018; Batchelor & Duke, 2019; Lowes, 2007; MacKay et al., 2021). They face the ongoing loss of the child they thought they would have (Currie & Szabo, 2019; MacKay et al., 2021), the ever-present knowledge that their child may die (Carlsson et al., 2019), and the possibility that they may die, leaving their child without a caregiver (Coffey, 2006). While closely related to the concept of experiencing constant worry, there are critical differences. Worry encompasses all aspects of the medical parent's life—this conceptualization focuses solely on loss. While that makes this section much smaller in scope, it is also much more significant—even when medical parents joke about this, they take it seriously.

For the parents I spoke with, the first loss they experienced was the loss of the child they did not have. Although their child is alive, they experience grief for the loss of the child they expected; a typical child (MacKay et al., 2021).

> I remember when they gave us a diagnosis. I just I kinda kept looking at them, going like, 'No, no.' 'Cause they were talking about things. And I don't even—I can't tell you what they were talking about…Dr. Michaels and Dana, his neural nurse at the time, and [another] nurse were in the room. [They were] telling us the diagnosis, and I guess they were telling me, telling us like expectancies and what could and ifs and all this other stuff. And I remember I could hear words. It was like mumble. And all I kept thinking was, **'No, no,**

> **no, no. My job is to teach him how to be a good person, how to, you know, be a good friend, how not to be a bully.** How to, you know the birds and the bees, and how to be a good boyfriend. Or how to have a girlfriend or boyfriend or what have you—like how love is love—this this is my job. My job is not medical.' And I remember saying this to Michaels like, 'My job is to teach him how not to be a bully and how to go to school and how to do well.' And he's like, 'And you will do that.' I'm like, 'How?' And they all just kinda look at you. (Frances*)

> It comes at me out of nowhere sometimes; just bam! Like it hit me the other day—and it was the foolishness thing, but **all of a sudden, it hit me Aiden will never go on a sleepover.** Now, why did that—where the hell did that come from? I have no idea. But it just out of nowhere. I sat and cried about that for an hour. Why would I cry about that? I have no idea, but again—we have a sleepover every night in my bedroom. So like, Oh my God, but it is; it's just little things sometimes. (Kathy)

Frances and Kathy both comment on experiencing the loss of the child they thought they would parent from different points in time. Frances felt this loss when the doctors detailed her son's diagnosis, and Kathy's comment highlights its continuity. The loss of the typical parenting experience of sleepovers occurred years after her son was born. As she said, she realizes this loss at unexpected times and concerning unexpected events.

As noted above, such moments also come with clarity: Aiden has a sleepover every night in his mom's bed. This brings comfort and works as a form of redefinition of circumstances (Batchelor & Duke, 2019; MacKay et al., 2021), supporting normalization. We consider sleepovers "normal" for a 10-year-old boy and sleeping in mom's bed not to be "normal." But Kathy reframes the situation by calling it a sleepover a "normal" event; sleeping in mom's bed is normalized.

Experiencing the loss of the child they did not have is a continual process. But for the parents I spoke with, the death of their child was a future-oriented event. Medical parents walk a line between parenting their child and preparing for that child's death, termed anticipatory grief (Edwardson, 1983). And both ways of being co-exist. Parents may plan their child's birthday one week but pre-plan for managing that child's demise simultaneously. They live in the moment (Knoll, 1989) while preparing and planning for the future.

> **What I hope I can do is just get in bed with him and hold him,** you know? 'Cause what's the rush then on calling anybody and just call in the people he loves—around ten [people], and we're just going to have a small viewing the next day. No embalming, nothing like that, and then he'll be cremated right away. (Quinn)

Quinn has a plan arranged for her son's death, and she hopes it will happen at home. She wants to get in bed and hold him until he is gone. But we also spoke about the experiences she has had with her son and the memories they have made together. She approached both his life and death through her parenting—Quinn ensured his life was rich and fulfilled because it would also be short. And she prepared both his experiences and detailed plans for his passing hand-in-hand.

Medical parents know other children who have passed away—it is expected within the community. They learn from these experiences and draw on them to conceptualize their own potential futures.

> Like, [the doctors have never talked to me] about his expectancy. The only thing they've ever said to me is that he would probably get trached by the time he was five. **But watching the [other child in the hospital] this week, I don't think we're gonna get as long as I've been thinking all these years**. I thought he was going to be into adulthood, and I think we'll be lucky if his conditions even allow him to see adulthood. (Laura*)

Laura has not talked with doctors about her son's potential life expectancy. But when we spoke, she had recently witnessed the death of another child in the hospital, and the experience re-conceptualizes her son's condition for her. These experiences give parents access to these potential futures, which may alter how they engage with their situation in the present—Kathy told me that Aiden's sleepovers in her bed began after Minxie passed away as it marked a point of foreshadowing for her.

Parents continually engage with the potential upcoming death of their child, but they usually leverage humour in the conversation.

> **I made him a promise when he was born.** I said, ‘I will do every single thing I can for you to make your life a happy good one.**’ I just didn’t think it would be this long** [both laugh], as horrible as that sounds. It was only last year that I admitted that to myself. I thought he’d live a couple of months, a year, two. (Quinn)

As Quinn’s comment indicates, conversations relating to the potential death of their child are often relayed through humour, allowing conversation about essential ideas while relieving some of the heavy emotional burdens of discussing such topics.

Parents expressed concerns about the impending death of their child but also engaged with the possibility of their own death. But conversations regarding their own potential death were framed around their fears of the effect their own death would have on their child rather than their own loss of life.

> Shelley: **I made a list of what he does every day and when he does it. And you know, that in itself is scary. Knowing that I gotta depend on somebody to follow it to a tee [if something happens to me].** And will they do it the same way that I do?
> Me: [And] who is going to do it?
> Shelley: That one, yeah—that one really freaks me out.

When Shelley thought about her potential death, she realized that no one else knew her son’s needs or would be capable of providing his care unless she ensured the continuity of his care. So she wrote down his schedule, medication regimes, and needs. This helps to reassure her that the details of his needs are readily available for someone else to undertake—but provides no comfort for her about who will undertake her son’s care.

The medical parent bears the weight of the loss of the child they thought they would have, the impending loss of the child they do have, and the potential loss of their child’s caregiver following their own death. And while they use their agency to alleviate some of their concerns, others fester and cannot be calmed.

4.3 Feeling Isolated

The idea of the isolated parent is a slippery concept. It is both multi-faceted and contradictory; self-imposed and forced upon parents. It flows from unexpected areas and manifests in unexpected ways. It relates to boundaries; how parents engage with boundaries, and where they see themselves concerning those boundaries. Therefore, I construct this section by engaging with the imagined idea of the “typical parent” in contrast to the medical parent. For the typical parent, parenting experiences are straightforward—when your child is young, you engage them with activities such as play dates or taking them to the playground. When they reach the appropriate age, you enroll them in school so they can obtain an education. Parents register their children in activities, become involved with parenting or activity-related organizations, and the parents participate in their own lives (socializing, working, and spending time with their significant other). But, for medical parents, each of these possible communal parenting experiences is altered, and how they conceptualize those interactions results in feeling as though they are isolated.

Our social world provides access to numerous activities. But medical parents often feel disconnected from these experiences.

> **Playgrounds** trigger me because they represent what he can't do, and **they're a barrier.** (Linda*)

Playgrounds are designed for children to facilitate play. But if your child uses a wheelchair, they are inaccessible. Regular wheelchair tires get stuck on small rocks, so pushing a chair through the layer of gravel that lines most playgrounds is impossible.

Where Linda lives, there are no playgrounds with accessible equipment for small children, so her son cannot use any playground facilities, nor can his chair be wheeled through it; engaging children through events and activities requires specialized equipment.

> Well, **the hippocamp**[38] was huge. That was from the Wish Foundation. **That's been life-changing**. Got that not this past summer, but the summer before. And that has been huge. Like, **even just going to soccer games** for my nine-year-old—that stroller can go on the soccer pitches. And I can get up the grass, and I can get over the rocks. (Helen)

Linda feels excluded from participating in playgrounds because her son's condition precludes him from using typical playground equipment. But Helen engages with this from both sides—she experiences the isolation caused by the incompatibility of her daughter's wheelchair with the built environment, and she comments on her increased potential because of the hippocamp.

Participation in activities refers to structured activities as those above but also includes informal social participation.

> It was great when Taytum was little. Oh, it was like babies all around. But as **they grew and Taytum didn't**, our friends got less and less. (Zoey)

For Zoey, the differences between her daughter, Taytum, and her friend's children were not issues when all the children were babies. But as they grew and developed while Taytum did not, Zoey felt isolated, and her engagement with them dissipated. When individuals share commonalities, they can foster those commonalities into a relationship. For Zoey, the commonalities between her daughter and other children shrunk as time

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[38] A very expensive wheelchair specially designed to navigate terrain typical wheelchairs cannot. For example, there are wheels designed for sand, a different set for navigating over rocks, and skies for travelling over snow. However, it's lowered design coupled with a lack of support for specific body parts makes it unsuitable as a child's primary wheelchair. A hippocamp is like a luxury accessory that provides equitable access for children.

passed. For other medical parents, these differences present much earlier in the child's life.

> **The medication** [emergency rescue seizure medication]. None of our friends have to carry that around with them. To me, **it's another reminder that Noah is different. And that we're different and we're going through stuff that not many other people can relate to**. None of our friends, none of our family. No one that jumps out at me at the moment right that are close to us. (Aaron*)

Aaron's comment touches on this point. His son is very young, but the differences he perceives between his parenting experiences and those of typical parents are already salient—ordinary parents do not carry narcotics and syringes with them every moment as part of their typical parenting experience.

While parents noted their isolation surrounding activities and general parenting, one of the most salient boundaries exists around schooling.

> Like, **we dont know if Mason is really going to be able to go to school out on the West Coast**. We don't have the resources or the trained individual staff. (Valerie*)

Sending your child to school is one of the most basic shared experiences of parenthood. It is an ordinary expectation that children will attend school, but for medical parents, the school's capabilities for providing the level of care your child requires are questionable—if the school cannot provide adequate care, the parent cannot send their child to school. They are barred from this basic form of social participation. Indeed, if your child cannot go to school with other children, your child is isolated from their peers. And the parents are separated from other parents.

But enrollment is only the beginning of the potential isolation parents experience within the school setting. Two parents specifically detailed the neglect and abuse their children endured in school. Neither child could inform the parents about the situation, and the parents had to rely on others to tell them what had occurred—the offending behaviour continued until someone informed the parents, well after the incidents began. The abuse and neglect were directly related to the children's medical conditions; they were inflicted on the children because of their conditions, and the offenders knew the children could not report the behaviour to anyone.

Although this emerged from my personal experiences and not my interview data, the school's built environment further increases isolation as well. For example, my daughter's school was a two-story building, and her grade four classroom was on the second floor. The principal contacted me at the beginning of the school year because having her classroom on the second floor required a fire escape plan. At first, she proposed that if a fire occurred while Minxie was upstairs, she would be wheeled to the stairwell to await the fire rescue team. I told her this was unacceptable. I was not willing to endanger the life of the student assistant who would be tasked with staying with her during such an emergency, nor would I be willing to allow the student assistant to leave my daughter alone at the top of the stairs during a fire. After four months of back-and-forth conversation, we settled on a plan; during those months, Minxie was limited to the special needs classroom, the cafeteria, and the music room during her school days.

Feeling isolated through school and activities focuses on how the child is isolated in these experiences, but parenting a medically-fragile child also separates the parents.

> I've tried to go back to work. I went back to Walmart last year for probably nine months. And in the nine months I was there, Tommy had three separate 1-week hospitalizations. **I literally cannot work outside the home. And where am I going where someone's like, 'That's fine, every three months you need a week off—that's fine?**' It's no big deal. It's not going to happen. (Monica)

Monica feels as though she cannot work because her son's condition is too unpredictable—his repeating, unexpected hospital admissions result in her potentially being able to work one day but then unable to work for a week. And this makes her feel isolated from other parents who work and balance parenting.

But even where parents could juggle both, the demands were daunting.

> [My employer is] really, really, really good. But I find **that I put in 150% to make up for, you know, that I might have to leave at a certain moment's notice**. Or you know, you never know. So I always put in a whole lot more. (Emma)

Emma recognizes that the unpredictable nature of her daughter’s condition makes her an unstable employee. To compensate for this, she works harder to remain productive. She also works while her daughter is an inpatient, minimizing her potential lost time.

I also worked outside the home while I had my daughter. First as a grocery store cashier and later as a university student. Juggling the obligations of a student alongside parenting was straightforward. I opted for online courses whenever possible and stayed home unless required to be in class. If parenting conflicted with schooling, I could skip classes. The cashier position was difficult. I worked part-time, and my employer was very understanding of the situation. But I felt a heavy emotional burden because I knew if I could not go to work, someone else would have to cover my shift, creating extra work for my co-workers. I also felt as though I had no break from work time. If I was at work, I was working, and when I came home, I was working there too.

As Emma’s comment alludes, working medical parents also experience social isolation in their workplace. Employment provides income, but it is also the venue for off-time socialization; co-workers plan to spend time together outside of work, and employers may engage employees with after-work team-building opportunities. And medical parents are often isolated from such opportunities. When we spoke, Penny said she has 40 hours per week of respite care which covers all her work hours plus travel time; she has no extra time available to engage with her co-workers socially.

In addition to feeling isolated from work and co-workers, parents may feel isolated from their partners.

> **There's no dates. There's no nothing.** I've moved out to [my other daughter] Maggie’s bed now so I can hear her in the nighttime. Jim had to start working from home ‘cause our respite worker, you know, was nervous. Even today, when she came in today, she's like, ‘Somebody's going to be home with me, right?’ ‘Cause Jim’s on vacation today. I'm like, ‘Oh yeah, yeah, somebody will still be here.’ But like he had to move his office home. And yeah, there's no, like—we can’t go out anywhere. **If I go out, then he says home. If he stays home, then I go**. (Iris)

Iris sees their relationship as non-existent because they cannot engage with each other as romantic partners—they cannot go out on dates. When one person leaves for a social event, the other has to provide for their daughter’s care needs during that time. Sometimes this strain may be too much for the couple.

> [My husband] doesn’t even know what medicine Oliver takes. Like, I was compounding all the medication, you know. I had everything wrote out on a list and all that sort of thing. But, like, but I think that **was partly my fault. I just kind of took over**. Cause I felt like nobody could do it like I could. I know that’s a little, you know, foolish**. But it was my everyday thing. So I didn’t take the time to teach him how to do it,** which again was my own stupid fault. But then just got to a point where it’s like he distanced himself from that whole situation. But then, so what choice do you have? You’ve got, you know you gotta do it. Do it all. Do it all the time. (Kathy)

Kathy’s husband was not as familiar with Oliver’s schedule or medications as Kathy was. She took on the role of Oliver’s primary caregiver, and without realizing it, she excluded him from that work. Eventually, Kathy’s husband stopped trying to participate in Oliver’s care work, reinforcing Kathy as his primary provider and further isolating each parent from the other, and Kathy’s husband left.

As the above illustrations highlight, medical parents may feel as though their world has narrowed (Charmaz, 1991). They pull into themselves and have less involvement with the people around them; they push others away. Parents immersed in illness tend to isolate themselves (Carlsson et al., 2019; Hewitt-Taylor, 2008). But parents want to be part of a community. They want to connect with others who understand what they are going through (Bruce et al., 2013). The presence of disability results in a narrowed world, not by choice, but because these disabilities limit the options for engagement (Williamson, 2019). It creates a boundary around participation in life, and medical parents feel as though they are outside this boundary.

Participation in activities outside the home requires support from others; whether the child is involved in these activities or whether they remain at home, extra support is essential. But if no additional supports exist, there can be no outside involvement.

> **We had [hired] one lady**. She was a mom of 3, and she wanted something that was going to keep her in the community. And I figured she was going to be perfect until she really got to know what came with [the job**]. And she messaged me the next day, and she gracefully bowed down.** Like, 'Yeah, I'm sorry. I really just can't.' And I know what it was—and I know she kind of felt bad cause I think she wanted to. But yet, in the same sense, she was scared to do it. (Frances*)

Frances had hired a respite worker to care for her son. But the worker decided caring for the child was more than she could handle and declined the job offer. Frances has been advertising the position through respite agencies for over a year, and no one else has applied. Without a support worker at home, it is difficult to participate in activities outside their home. And the child's care needs often dictate how or if an activity can be accomplished.

> **We can't even get her into my dad's house.** Like, we can't even go to family events 'cause I can't get her in the houses, you know. We wanted to attend a funeral last week and how are you supposed to? You can't go, right? **She needs to lie down at certain points.** And how you going to lie her down if

> you go around the bay? Nobody’s going to [care for] her, so **one of us has to stay home**. (Emma)

Emma’s daughter Grace is a teenager with significant disabilities. Throughout the day, she has to be lifted, laid down to be changed, and allowed time to rest because being positioned in her wheelchair for too long is difficult. Taking Grace somewhere requires that the location is wheelchair accessible, has a safe place to lay her down without the possibility of rolling off, the privacy to allow for diaper changes, and someone strong enough to lift and carry her. This combination limits their options.

Additionally, parenting a medically complex child requires substantial energy, which may leave parents depleted and unable to engage with others (Ashton & Ashton, 2018).

> **There’s no help** with the lifting. There’s no help with the bathing. You know, all the hard stuff. **So it’s starting to hit me**. Like, glad he’s not gonna get a whole lot bigger—another beautiful aspect of the syndrome. But you know, it's still it’s a lot**. I don’t want people to think that I’m, you know, distancing myself** 'cause I’m not. **There’s just days I literally don’t want to get out of bed.** I’ve had to, of course. ‘Cause, you know what’s going to happen if I don’t? And I know the parents will get it. (Shelley)

Between parenting her other children and caring for her son with complex needs, Shelley sometimes feels depleted. And with no outside help, she is blocked from engaging with parents or participating in activities outside of her children. As she comments, she does not want to isolate herself, but it is a by-product of her situation and circumstances.

In addition to the isolation imposed on parents because of their child’s disabilities, some have been advised to increase their isolation to acquire assistance.

> Me: Has anybody ever suggested to you guys to break up?
> Ursula: Yeah, we can break up. But if you break up, you can spend three nights together like we did think about it. [My husband] won’t go for it. 'Cause I said to him I said, **‘Like you know, we're paying $1000 a month [co-pay for respite care]. Why don’t you move downstairs?**’ He was like,

> ‘No, this is our marriage. Like we're not going at that like.’ And I said, ‘No, like, why don't we do that?’ We kind of get some more support and stuff [now], but fighting for support was crazy.

If Ursula and her husband split up, she would qualify for services as a single parent. So the government program providing her daughter’s respite care would only use Ursula’s income to calculate their co-pay for services. If Ursula and her husband claimed they were separated, and he moved into their basement as a tenant, they could spend three nights a week together, and have their co-pay reduced, lessening the financial burden on their family. Ursula and her husband are both isolated from social engagement but experience this isolation together. Their financial situation would be improved if they split up, so to avail of adequate support, they would have to further isolate themselves from each other. Many parents I spoke with said social workers had advised them they should separate, or they knew other parents who had been advised to do so.

Parents want to engage with others who understand what they are going through (Page et al., 2020). They want to feel like they belong and are part of shared social groups. Feeling isolated creates a heavy burden on the individual and family. But a natural part of this isolation involves seeking validation and inclusion. Medical parents are outsiders in many aspects of typical societal interaction, but it does present the opportunity for creating new boundaries which redefine who is an insider and who is not.

> **We're going camping this weekend with another family**. They invited all their family to something, and their family didn't show up. The first person that they reached out to was me. [And said,] ‘I know you guys talked about [being excluded], and I wanted to reach out and say that now we are experiencing it too.’ And I'm like, ‘Well, you know what? Let's go—**you guys like doing that, we like doing that**—**let's go do it together.’** And you know, I probably would never have met those people if it wasn't for Charlotte. Or doing the things that we have done, or advocated for helping the people that we have helped. (Nancy)

Nancy had spoken earlier in our interview about her daughter being left out of activities for other children because other parents did not want to ensure such activities were accessible for her daughter.[39] Another family with a younger child contacted her and said they were now experiencing the same thing—the extended family was excluding their child from activities. Nancy suggested that since both families enjoy camping and their children can both participate and enjoy camping, too, they should start camping together, and they did. Their exclusion from typical activities with their regular peer groups provided the opportunity and became the catalyst for both families to seek and form new activities and peer groups that would include them.

The feeling of isolation in parenting is a complex concept and shares similarities with the parental experience of grief for the typical-child experience. The time requirements related to caring for their children, the physical and emotional cost of parenting, the inaccessibility of locations and services, and the lack of shared experiences with other parents require parents to redefine what constitutes inclusion and exclusion and how they fit within that paradigm. Although none of the parents framed their experiences using these terms, Nancy's comment above provides an example. Both families felt excluded from their expected social circles, so they constructed a new circle together. Iris[40] and Taylor's comments about their relationships with their husbands also illustrate this paradigm.

> We co-sleep, you know. We don't get much alone time, like outside the house together. But we don't hate each other—**we still love each other very, very much** like you know. I'll be doing dishes, and he'll still slap me on the arse—things like that. Like, I think if we stopped doing those things, as silly as it sounds, I think if we stopped doing that, then I feel like that's when love starts to go away. But we love each other very much. And **we appreciate the little stolen moments, even if it's just out like we were folding laundry when Taytum was in the bedroom. We had her video monitor, and two of us are laughing, you know**. Like just little stupid stuff. Or sitting on the front deck in the chair [while] Taytum's [in bed]. Just sitting outside and laughing like at the nippers biting us, you know. Like we still appreciate the little moments we get with each other. (Taylor)

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[39] Her understanding of the motivation.

[40] See above comment from Iris on page 87.

Iris said she has no intimate relationship with her husband because they do not have dates or time together. Taylor made a similar observation that she and her husband do not have dates or sleep together as a couple, but they use “stolen moments” to create opportunities for intimacy. They re-defined what constitutes relationship-time to fit into the parameters of their available options to make space for intimacy. In doing so, they can have their relationship within their family schedule. Neither Taylor nor Iris has the chance for “date night” with their husbands, where they can leave the house alone and enjoy each other one-on-one; however, both reported differing outcomes because of this situation.

Medical parents feel as though they are outside an imagined typical society, looking in. The world presents to them as a series of inaccessible places and circumstances. But isolation also carries the potential for inclusion—medical parents can redefine and re-conceptualize the boundaries to fit their situation. They can leverage their isolation to form new experiences for inclusion and belonging.

4.4 Feeling Supported

Just as isolation is a slippery concept, so too is feeling supported. If isolation stems from exclusion, then support is linked to inclusion. When I asked parents where they find support, they often noted it as being in unexpected ways or areas (Batchelor & Duke, 2019; Berrett-Abebe et al., 2017).

> The support like from our friends from our community. Just **the overwhelming love that comes with that, like from people you don't see frequently or you wouldn't expect to kind of make a gesture in that way.** Like [Gabriel] was diagnosed, and I remember sending an e-mail to my colleagues. That week, two of my colleagues came [to our house]. They had like collected money amongst themselves, they went and did our grocery shopping, and they came down with like a car full of stuff. And, like, it was really thoughtful. Like they went to Costco and got like the pre-made meals that we could just pop in the oven right. Like that was one gesture. We got mail from [unexpected] people like. So it [was from] Dominick’s sister's ex-partners parents in Port aux Basque. They sent us a basket of gift cards. So I think that's positive for us. Is just, and then, of course, our family, like our families—we have tons of support that way. Like I know a lot of people don't have that level of support

> in their families or in their communities. But we're very lucky that way both. (Debra*)

Debra’s comment stands as both an example and a contradiction. They felt immediate and far-reaching support for their family and their son from both expected and unexpected sources. Although most participants said they felt supported at some point, only Debra noted such far-reaching support. This may result from a combination of factors: Debra and her husband worked full-time before their son was born; they live in the general area where they grew up and where their parents still live; and their son is preschool-aged. Some parents noted shifting help and support from unofficial sites as their children grew along with increased caregiving demands. When her daughter was initially diagnosed, Nancy’s family was supportive, but it dissipated over time. As their daughter’s needs grew, her husband’s employer terminated his position rather than provide accommodation for time off. Debra and Nancy’s comments may illustrate the same experience at differing points in time—a significant age gap separates their children. Nancy said that while people were initially supportive, things changed over time. Debra’s son is very young—Nancy’s comment may represent her future.[41]

If support is linked with feeling included; naturally, most parents consider their child’s hospital team a source of support.

> I find the girls in the **physio and rehab. And like OT** [occupational therapy]. So I don’t know. I find like **their very good to us.** I find, like, I think a big part of why we've gotten such luck out of getting [funding for] stuff is because, like, **they made sure that we got looked after**. They made sure that things got done 'cause they were like, ‘Ok, Jack’s a special case. [His condition is very rare]. I feel like they try extra hard. He has a very a dedicated team. (Rees*)

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[41] If we think about the idea of normalization, it seems logical that Nancy will experience similar outcomes. Other people reach out to help because they understand that the parents are “going through something” and because they are going through something extraordinary, extraordinary help may be needed. But if parents normalize their experiences, then it makes sense that others would as well, and if others normalize that the parents are experiencing, they stop offering help because help is offered for exceptional circumstances and the ongoing experiences of the medical parent are no longer exceptional for them—they are ordinary.

Ironically though, the exceptional support Rees experiences from her son's rehabilitation team is linked not only to his disability but specifically to the rarity of his condition—the condition which prevents him from obtaining inclusion in the outside world is redefined as inclusion to the point of exclusive treatment in his healthcare setting.

Outside the healthcare setting, some parents noted friends and other parents as sources of support as well.

> **The parent friends of the kids that are involved in similar activities are very supportive.** Like they know I'm a single parent. And if she needs a ride home and I can't get they like they'll carpool. We'll do things [like] that. That's really helpful, you know. They know my situation, **and my own friends are super helpful, like you know, in many ways**. Not so much caring for Mia but, like, you know, the emotional support. Back in September, again, my friends are amazing. [My friend] comes down with her husband. So, they're on their lunch break, working from home. I'm on my way home with Ava [after her dental surgery], and I have no idea how I'm getting her up over the stairs. I'm just pulling into the driveway, this kid's dripping blood [like drool] in the back of the car, and she's just a dead weight. Like, I got no idea what I'm gonna do. **So I texted my friend, and they both came down. And he takes one side of her, and I take the other side of her, and we lift her up over the stairs.** (Gemma)

Gemma regularly relies on her friends for help with her other children; in this instance, she reached out for help to transport her daughter into the house. This illustrates how she conceptualizes her positionality—she regularly accepts help from other people and feels comfortable enough to ask for help, if necessary—both reveal that she feels supported and included within this social group. It is often difficult to ask for help, but impossible to ask for it unless we feel connected to those people.

Gemma's comment relates to hands-on help, but parents also discussed emotional support.

> I find, you know, my friends are very, very supportive. My work is very, very supportive. Cory's work is very, very supportive. The church has been very supportive. Like my family and friends have been awesome. But the Janeway moms like they're always there**. I remember this one time I had like this really bad day,**

> **and a couple of them called me up; they were like, ‘Ok, now we’re going to go for a coffee 'cause you need to just chill.**’ (Iris)

Support is intricately connected with belonging. And how parents defined and interpreted the idea of support was reflected in the varied answers they provided. Most parents noted support from strangers, and in unexpected circumstances; some talked about being supported by friends and co-workers. Feeling supported signifies to parents that they are a part of that group, or reaffirms membership they already had—either way, support and belonging inform each other.

4.5 Being an Advocate

As parents embrace the identity of the medical parent, and become immersed in medical knowledge, they become advocates—they become the mediators of information between various team members, they become the receptacle of knowledge other people draw on to further their own understanding, and they become the one responsible for providing all of their child’s overarching needs. The role of the medical parent as an advocate was apparent across multiple contexts and circumstances in my data. I loosely frame them as “non-combative” and “combative” advocacy experiences based on whether parents described the incident as one between two parties sharing common goals or one wherein the parents represented one side, and someone else represented an opposing side.

Non-combative advocacy presented itself across numerous contexts. For example, where medical parents feel forced into the role of educator/advocate simply by existing in the world.

> **What I hate the most is where there’s a child, you know, wanting to ask a question. Or wanting to come over, and the parents like [shushing them].** It’s not contagious like seriously—come over, pull up a chair. **I’ll tell you whatever you want to know**. So they're teaching their children to be afraid of difference. How does that make the world go round? (Christine)

Christine's comment highlights this advocacy as well as the paradox of it. She does not say she enjoys educating others about her son's condition or wants to do so. But she acknowledges that when other people lack an understanding, they react with fear, and providing information and education counteracts that fear. Christine's comment suggests her desire that people not be afraid of her son's condition, and educating others about it is the path to achieving it. The forced educator role is the means to achieving the desired end goal—understanding and acceptance.

Medical parents also continually occupy the positions of both student and teacher (Woodgate et al., 2015) as they learn new treatment options, present them to medical professionals, and then pass the knowledge on to other families and caregivers. Sometimes, medical professionals foster this position.

> **[The doctor] said it doesn't hurt to be informed.** So, I like that because a lot of people like, 'Don't go on Google. Don't be doctor Google.' But **information is what I need. And I need to find it from somebody, from somewhere**. And **so I had joined a [support group for Carl's condition] on Facebook**. It was a closed group, which which I liked because it wasn't just everybody in there. It was parents or caregivers, and there was there so many stages of [disease], so there's kids there that, [well] in their 40s kids. I say kids, but I mean there's individuals. There's a mom—she has two kids that have [this condition], and they're totally different, totally different. Some children will walk, talk, go to school. Others you know are like Carl or worse. (Frances*)

Frances' example highlights advocacy side-by-side with her son's doctor. The doctor supported her effort to obtain outside information about her son's condition, which led her to find a Facebook group organized by and based around families who are dealing with the same medical condition (advocacy between families) where they can share their experiences and support each other. Rees' experience expands on this side-by-side advocacy.

> Daniel was on some other meds prior. Like you know, trial and tribulations of trying to find what will work best for him. Um, that didn't work, so we would get off. **CBD oil—they were saying that they didn't put children on it until they were about 3.** So we kept saying, 'You know, like, but it's semi-medicinal. Like this is, it's

> medicinal oil. It’s not THC, it’s CBD,’ **It’s like we kept asking Dr. Roache like, ‘Can we try? Like, can we please?’ And at a year and a half [old], he finally succumbed to us pleading, and it changed him.** (Rees*)

Rees and her husband researched CBD oil independently and advocated for the drug to their neurologist, who eventually agreed and wrote them a prescription. This highlights the next step in side-by-side advocacy. Frances’ doctor supported her search for additional information—additional information may inform potential new avenues of treatment, which would have to be undertaken with the doctor. Rees’ example highlights this advocacy portion—finding the information and partnering with the doctor for change based on the information.

Medical parents spoke about non-combative advocacy situations such as these, where they partnered with others to provide care for the child. But they also talked at length about combative advocacy situations where they felt like they were fighting against someone else who was not working in their child's best interests.

Even though my participants lived in different areas of the province, hailed from different walks of life, and had children of different ages, one word appeared across all the interviews—“fight.” Often, this was how parents described trying to access supports and services for their child.

> It's hard. It’s a hard life. But, I mean to avail of services and equipment and everything else it shouldn't be…life is hard enough for a person, for a family. **Parents with a child with a disability or special needs—they shouldn't have to fight for services.** They should not. That should be the last thing **‘cause life, in general, is fucking hard enough as it is for a typical** person. But when you gets a curveball thrown at you, and then you have to constantly fight and defend your questions and reasoning. Like Linda, she [said to them], ‘You really fucking think I'm asking for this because I want it? You think I'd rather not? I'd be grateful not to have to ask for it.’ (Michael*)

Michael recalls their struggle when trying to obtain a prescription for a suction machine for his son. His son could not clear his mucous and needed the device to breathe well. This illustrates medical parents' complex position—medical professionals should work side-by-side with medical parents, especially considering the specialized care and depth of medical knowledge these parents engage with. When parents encounter someone who does not respond to them as shared experts in the child's care, parents may feel they must defend their requests for care. Helen noted a similar situation;

> **I fought for years to get the number of [respite] hours that I have.** I've written many, many letters to fight for it. I have 40 hours a week. But, I have to because if she's home sick all week, I gotta get to work. So there are some weeks that those 40 hours are just enough for me to get out the door and get back in the door. There's no grocery shopping. There's no activities. (Helen)

Michael's fight was with a doctor involved in his son's care, and Helen's was related to her struggle against accessing adequate government services. In her effort to secure sufficient respite hours for her daughter Helen wrote numerous letters, and it took years for her to obtain approval for 40 hours of weekly care.

Although most of the comments parents made about the Janeway were positive and oriented them as partners in the child's care, parents also leveraged combative advocacy in the hospital where necessary.

> I know that clearly, if he was well enough to come out of ICU, he shouldn't need constant [care nursing]. [But] I can't be there 24/7. I just can't. And **I remember going up [to the Ward] one time, and he was sideways in the crib.** It takes Oliver like, oh my god, at this point, he wasn't even 2. It would take Oliver numerous, numerous minutes. Or maybe even an hour to get sideways in the crib. His head was pressed up against the [rungs]. They had just put in his port,[42] no—they had him accessed, but there was nothing running through it. So Dr. Jones was on. Of course, he had the bulldog clamp on him. My God, that thing was humongous. But that was like stuck into his side. **He was bawling, screeching. He had his oxygen out. He was down to like the 70s**. I'm like, 'What the actual fuck, b'ys?' Like seriously. And that's when Justine was the head nurse. So I called out to her, and I said, 'Get in here, and have a look at this and tell me what it is wrong with this picture.' She was like, 'Oh, someone was just in looking at him.' 'That's a lie. And you know it. That is a lie,' I said, 'Because you and I both know that it's going to take Oliver an awful long time to get sideways in that bed.' She was like, 'Oh, I assure you.' **'You know what, I don't believe you. So you know what's going to happen from now on? We're going to have constant care. I don't care who I gotta talk to, who I gotta call.' And she's like, 'Well, we just don't have the staff.' 'Guess what? It's not my problem—figure it out.** I cannot be here all the time.' 'Well, usually when children are in hospital.' Well, usually, they don't have three other children at home,

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[42] Port a Cath. A form of surgically implanted IV access.

> with a husband that works away. So guess what? Something got to give here.' She didn't like me after that. And I liked her a whole lot less, you know. And it was like it wasn't a big deal, you know, 'He's good now.' 'Is he, though? Is he really?' I hated it, Amie; oh my God, I hated it so much. Nobody should have like that kind of anxiety while in hospital. Knowing that he's not getting the care he needs. (Kathy)

Although Kathy has a long-standing relationship with Janeway nurses, when she felt that her son was not receiving adequate care, putting his health at risk, she voiced her objections to staff and ensured his care would be modified to suit his needs (Katzman, 2013; Woodgate et al., 2015). Taylor noted a similar situation,

> Then, at four, she got diagnosed with autism. Actually, **they weren't going to diagnose her because she already had two disabilities,** and they just figured, 'Ah, well, she's already going to have to live with these disabilities, so what's the point in diagnosing her with another one?' **So I fought for that diagnosis because I knew** regardless of the epilepsy and CP, I was a few years in educating myself at that time. **Autism was completely different**. (Taylor)

Taylor noted that she encountered substantial pushback from staff when she wanted her daughter tested for autism. But she fought for the testing to ensure her daughter was cared for and provided for adequately according to her needs.

My data and the literature reflect on parental advocacy as something parents feel they must undertake to ensure their child receives adequate service. When dealing with service providers, sometimes parental advocacy is a built-in requirement.

> So I don't know if you followed it or not—that there was **Human Rights Commission with the Churchill's.**[43] Yeah, so I was—James was like, 'You're gonna go blind watching this.' Like, I was super into it, but **one of the policies around access to services, one of the caveats was like**, you know, you need to meet the eligibility criteria. And the one that has like '**how well a parent is able to advocate for it.**' That was written in, yeah—that was written in the policy. Like, this is the eligibility criteria; and it could be based on, you know, your level of functioning, or blah blah, and how well your parents are able to advocate for you. I'm like, that's crazy. Like that's so unfair. (Debra*)

Debra notes that the parent's ability to advocate for their child's services effectively was part of the written eligibility criteria for providing government services within the

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[43] Kimberly and Todd Churchill filed a human rights complaint against the school board stating that the schools ongoing denial of appropriate ASL services violated the human rights of their son, Carter. The proceedings were live streamed online.

school district. Illustrating that parents were expected to undertake such advocacy, children would not receive and would not qualify for services without that advocacy. Through identity formation and the off-loading of medical work onto parents, medical parents become highly knowledgeable authorities in their child's care. With such a background, it follows that they must actively intervene when they see their child is not receiving adequate care and support.

4.6 Problem-Solving

Like all children, medically-fragile children experience enjoyment and pleasure. But they also feel fear. Because many of these children are non-verbal, emotional experiences are compounded as they struggle to communicate their emotions. Parents learn to read their child's cues, such as body language and vocalizations. Still, it can be challenging to connect the feeling the child is experiencing with the corresponding emotional trigger. Parents must work to connect and interpret their child's emotional presentation with the emotion and the stimuli which triggered the reaction (Woodgate et al., 2015). For example, my daughter was terrified of audience applause and laughter, and it took time and numerous episodes of exposure to connect her fear with those specific sounds. When I say she was afraid, what I mean is when she heard these sounds, her body would stiffen, her eyes would widen, the corners of her mouth would turn down, and taking a deep breath, she would exhale in a cry. With the exhale would come tears and a drop in oxygen concentration (noticeable by the bluish color her lips would turn). My interpretation of her presentation was that she was afraid. And over time, I connected the presentation I understood as fear with the sound of audience laughter and applause on television. The lack of verbal communication makes it difficult for parents to assess triggers. It hinders resolution, so medical parents must leverage their past experiences with their present situation to work towards better future understandings. Parents employ problem-solving strategies informed by their temporal engagement to find better future outcomes.

> **Willow would not let me lie on the floor and stretch or do exercises. She'd get really freaked out** like there's something wrong with mommy if you laid on the floor. This was like this for years. And I couldn't lie on the floor and like just stretch my legs or something. She'd like lose her mind. I mean, we didn't understand. It was like, 'Mommy's Ok; I'm just doing stretches. Like it's Ok.' She'd freak right out. And I didn't know what to do because I couldn't do anything in my house without her freaking out. Anyway, we discovered Yoga with Adrian on YouTube. And **so one day, I was like, fuck it, I got her [her] own mat. I had my yoga mat, and she had her own purple mat.** And so I made it like, 'OK, you don't want me doing it, but maybe you'll do it with me,' So, I put down the purple mat, 'Oh, Willow do exercises with mom.' **And it kind of started like that** 'cause I was trying to figure out how to deal with the situation. (Monica)

When Willow reacted adversely to her mom stretching on the floor, Monica first had to connect her daughter's response with her stretching activities. She then had to test different potential solutions to find one acceptable to her daughter. Notice how Monica says Willow is content with "Yoga with Adrien," this suggests that Monica unsuccessfully tried other yoga programs as well—this specific program is a part of their solution.

My daughter's only source of sound was through a cochlear implant. With no way to ascertain her brain function, I leveraged her adverse reactions to auditory stimuli to test her cognitive understanding. She became highly sensitized to the sound of audience laughter on the television. She still cried even when I set her processor to the lowest input level. I only watched one show with a laugh track, and it opened with the same screen for each episode. Occasionally, I would disconnect her implant and turn on the program to see how she reacted—she had the same response. Minxie had a deep enough understanding of the related events that she knew the visual input that coupled with the undesirable auditory stimuli even when that stimuli was absent. As I leveraged past experiences to inform the present situation, so did she.

Medical parents must understand and respond to their children's needs through a trial-and-error process, often without standard communication cues. These responses may relate to the child's emotional well-being or discomfort. Both require the same method of observing the child's signals, interpreting them, linking the child's distress to an identifiable stimulus, and resolving the situation. The process requires temporal engagement coupled with an intense level of active attention within the situation.

4.7 Making Medical Decisions

Through off-loading, medical parents become experts in their child's care (Page et al., 2020) as they are the only ones handling the child's care across all boundaries. School staff do not interact with hospital staff; hospital staff do not consult with respite workers, and so on. The medical parent bridges the gap between these different aspects of their child's care; they learn from hospital staff, then relay that information to the school and respite workers, and vice versa. Part of being the expert in their child's care means parents are tasked with making important and possibly detrimental medical decisions for their child. Treatment, procedure, and death decisions become the parent's responsibility (Pinto Taylor & Doolittle, 2019; Wilkinson, 2013).

> The [doctor]called me in the room**, he said, So, here's what we're going to have to do' I said, 'We? Ok, go ahead.'** It's not very often I bring someone to task, but when it comes to Richard—I have to. He said, 'So, we're going to do this, and this, and this. We're going to put him on this,' **I said, 'So, your approach is to drug him up until he doesn't know he's in the world?' He said, 'Unless you want him to keep having seizures.' I said, 'Well, I'd kinda rather have [him alive and awake and to enjoy what's going on around him]. We can go a little bit with this, but I'm not doing what you say.** I know you have to tell me, but I'm not doing what you said. (Olive)

Seizures are critical medical events; for Richard, each one carries the significant potential of death. When Olive and her son's neurologist discussed his condition, she first made a comment that established herself as the authority in her son's treatment. Then she countered the doctor's recommendation (based on controlling Richard's seizures) with the medical intervention she was willing to accept (based on her desire that her son be present enough to enjoy his life). The potential implications for exercising such agency are clear—Richard was at a significantly increased risk of death because of the low dosage of his seizure medications. Olive's decision carries a significant emotional parental burden,[44] and she initiated her decision, rather than complying with or agreeing to something else—she presented this course of action, insisted it would be enacted, and clearly stated her refusal to follow the doctor's orders.

Olive's situation highlights the medical decision-making parents engage with inside the medical setting, while Alison's refers to the same outside this setting.

> **John and I were kind of looking at each other like, 'Do you think he's sick enough to bring to the hospital now?'** (Alison)

Medical parents have access to advanced medical technology at home, which blurs the line between what requires home intervention and hospital care. For example, for children who need home oxygen, their parents have access to supplemental oxygen and a pulse oximeter, and have probably been trained in CPR (among other medical equipment and training). With such things at their disposal, parents decide what medical care is also at-home care and what medical care is in-hospital medical care. From my experience, my daughter's usual level of supplemental oxygen was 2lts, but we could provide her up to 7lts. If she were sick, I would consider it something we could treat at home if she were stable in 7lts of oxygen or less, even though this was elevated from her baseline. I would call for medical intervention if she required greater than 7lts. As Alison's comment illustrates, the line between home and hospital medical care is blurred; they are not trying

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[44] Though during our conversation she emphasized the quality of Richard's life was far more important to her than the quantity. I suspect she would counter that providing him with such high-doses of medication would be a significant emotional burden for her.

to assess whether their son is sick—they are trying to determine if he is sick *enough* to warrant a hospital visit.

With the advanced level of home medical care they can provide, medical parents often bring their children to the hospital when critically ill rather than just in-patient level of sick. Critical illness may deteriorate rapidly; medical parents face the potential consequence that their child's condition may deteriorate too quickly for life-saving measures every time they wrestle with the question of their child being sick *enough.*

Some parents noted similar ideas related to their child's seizures. If or when to administer rescue medication is a decision that rests within the parent's discretion. As does the seizure timing, which I noticed differed among parents. Some parents timed cluster seizures as one continuous episode running from the beginning of the first seizure to the end of the concluding seizure. In contrast, other parents considered the time of each seizure within the cluster as a self-contained time unit. How they calculated seizures influenced the level of medical intervention they deemed necessary.

These parental decisions over the child's medical care extend into plans of action and inaction for end-of-life processes.

> Wanda: **We're not going to do [chest] compressions**. It'll break her chest bone, you know. We have her registered with palliative care. **So we have the process in writing how we do it.** And there's a binder out there with that. So, if we have to call an ambulance, there's a card with a palliative care number on it, and they cover the charge of the ambulance, and you know, a few booklets. Like I told them, 'she will never go down there to have her final days. She's going to do it here [at home].' If we do compressions on her, it's going to break her. She's not going to come back from that, and that would be misery. **The best thing that could happen for her is to go in her sleep.** Do you mind if I ask how Minxie passed away?
> Me: In her sleep
> Wanda: At home?
> Me: At home
> Wanda: That was a gift. As horrible as it was.

In preparation for her daughter’s death, Wanda has a palliative care plan that outlines what interventions are acceptable and which are not, depending on her child’s condition. To develop such a detailed program, she actively engaged with the end-of-life possibilities her daughter may face and decided which ones she is willing to allow and which ones she is not.

On a personal note, I have reflected on occupying the position of the medical decision-maker for my daughter for a long time. Her underlying conditions, which drove her instability, could not be cured, only managed. And it seemed ironic to me that we would continue to repeat the same cycle (illness, hospitalization, return to wellness, transition to home, illness, and so on) over and over until her death. Reflecting on her death through the advantage of hindsight, as her medical decision-maker, I made the wrong choice, and that choice led to her death. I suspected she may have been in the beginning stages of respiratory distress, and I put her to bed rather than calling 911. I thought if she were in the beginning stages of distress, that would be a problem for tomorrow—not something that required intervention right now.

Medical parents occupy a contradictory and complicated position as the medical decision-maker in their child’s ongoing care. As a parent, they are expected to be the provider and protector of their child—to undertake things that benefit their child to the exclusion of all other options. But medical decisions also require a medical gaze (Foucault, 1973). Sometimes the decisions require striking a balance between the parental instinct of providing for the child and using the medical gaze to consider the consequences of ongoing medical interventions devoid of parental instinct. Among the tasks parents undertake and the situations they experience as part of medical parenting, making the advanced and potentially life-altering or ending decisions for their child is one of the heaviest burdens they face.

4.8 Having a Supervisory Position

This section relates directly to support and homecare services parents use. When they avail of such services, they are forced into a supervisory position over those workers. Having a supervisory medical parent position originates as part of the off-loading of medical work onto parents but also interacts with other ways of doing the medical parent; for example, parents who feel isolated may avail of homecare to alleviate some of their isolation.

Some parents are well-equipped for this enforced supervisory position, while others are not.

> I'm the boss. I direct them what to do. I tell them what to do—I'm their boss. I mean, like, when the respite workers come, I arrange their schedules. And like I said, **what's kept my workers with us is that we do treat them like family. But they also know not to overstep either. They have all been put in their place with that as well.** They know that I am, like, as their supervisor. And I am, I quote, the best boss. My workers know not to cross me. They know that you know. I am very; I have a line. I have a limit, you know. Don't go calling in every weekend—that kind of stuff. Now, they don't. But they also know that they can count on me beyond being their boss, as well. They know they can count on me as a friend, as well. Like, they call me 'other mom' because they can count on me for that stuff. And that's just something that is part of me—not something that I'm obligated to do. It's just something I would do for anyone, whether Charlotte has any issues or not. (Nancy)

Although she has a good rapport with her daughter's workers and has maintained the same ones for years, Nancy comments on this dual role (Kish et al., 2020); she is the boss, and their friend and mother figure. Having such positionality may cause internal conflict. If Nancy has to choose whether or not to fire the workers who refer to her as "second mother," she may have to choose which role is most important to her (Kish et al., 2020). When my daughter was young, we had a respite worker who repeatedly stole from me. She took small amounts of money from our church offerings, some of my makeup, and Scentsy products. But she never stole any possessions belonging to my children—she was terrific with them. In addition to her caregiving duties, she would paint the children's nails, engage them with art activities, and style their hair in new fashions. She was employed to care for Minxie but cared for all three children with the same zeal. Respite workers are also challenging to find and maintain. Because she was good with the children, I took no action except to lock my bedroom door to minimize theft. I allowed her to steal my possessions to ensure my children received good care. Allowing respite caregivers into your home results in a substantial loss of privacy, at the least. For me, that was coupled with a loss of possessions as well. But the exceptional level of care medical parents undertake requires help—they are forced to avail of homecare for their children.

Parents also have increased responsibility (Hewitt-Taylor, 2008) of training respite workers (Woodgate et al., 2015) to provide their child's specialized care.

> **We use an agency. But it took me a while to get them on my page.** So but they'd be like, 'Oh, you know, we're going to send this person in.' And I'm like, 'You can't really do that with Scarlett.' Right? Like I said, 'You can't, you know, just…switch them out, right.' **Like you can send one in, but I have to spend like three shifts to train them.** Because there's just so much to know, so you can't just willy-nilly send people in—she's not that type of kid. It's not like, well, 'If she has a seizure, then you do this. It's when she has a seizure.' I said, 'You need to know how to use the lift, need to know how to use the G-tube and all the oxygen. You need to know about seizures. You know she's got to how to move her—'cause she's got the stuff in her back. You need to know like everything. So you just can't willy-nilly send somebody in off the street. And she's nonverbal. She's totally blind. (Ursula)

Ursula's comment highlights the complexity of occupying this supervisory position. She uses the services of a home care agency for her daughter's respite workers, which generally means parents have an easier time finding people to work respite hours. However, when using an agency, parents may be provided with a different worker at any time and sometimes without notice. As Ursula comments, it took time for her to convince the agency that her daughter's care was complex enough that they needed to provide stable workers for this position. In addition to providing her daughter's care, Ursula was tasked with training respite workers, securing the services of a homecare agency, and communicating with them about her daughter's needs and how the agency would need to consider those needs. Ensuring a homecare agency understands and accepts those needs may be a struggle that rests solely on the parent's shoulders. Until parents and agencies reach a shared understanding of services (Hewitt-Taylor, 2008), they may provide parents with inadequate and ineffective respite workers. Even with an understanding between Ursula and the agency, the respite worker they provided is still sub-standard. The worker prefers one of Scarlett's parents be at home during her work hours, limiting the reprieve Scarlett's parents experience from this respite care.

As medical parents become tasked with ensuring ongoing care for their child, they engage with homecare services to offload some of the work that has been offloaded onto them. But this also requires seeking respite care approval, finding workers or an agency, training workers, and ensuring they provide adequate care for the child.

4.9 Feeling Policed

As part of being a medical parent, parents experience both empowerment and surveillance. To be entrusted with advanced medical knowledge to undertake medical care is empowering, but where parents may feel as though they are being surveilled, they may experience disempowerment and stigma.

Where parents feel surveilled, despite their powerful medical parent position, they may push back agentically with secondary adjustments (Goffman, 1961).

> **[They want] all of your bank statements.** So then Jarred said to them one time, **he wanted to take a couple of things out,** right? Like not the amount but like where he shopped. And this was just for badness. And they were like, 'No, you can't. You can't take where you shopped.' And he was like, 'But I shopped at Our Pleasure[45], and I don't want you to know that.' Another one, one time [another medical parent said to me] she said, 'Yeah, it's my month to do my assessment.' She said, '**We always eat good, so they don't know how bad we eats during the rest of the year.' S**he was like, 'Yeah because, you know, it's assessment month, and I can't have Mary Brown's cause they're going to know I eat out all the time.' (April)

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[45] A sexual adult store.

The parents are discussing the Special Child Welfare Allowance (SCWA) program. Which is the program that most medical parents rely on. It provides respite care, medical supplies, and medical equipment. The approval process consists of a home visit from a program social worker and a lengthy application form that assesses the applicant's financial means and expenses as well as family support the applicant can draw upon to lessen the care provided by the program. Parents are required to redo this process annually. As part of the documentation, they must provide bank statements for the previous 30 days, proof of income, 12 months of records for their primary heat source, and so on.

April mentions two different efforts at control here. First, she talks about her husband trying to control the information provided to the SCWA program by providing partial information, accentuating the power he is exercising. Blacking out information on a document draws attention to the removal, emphasizing that the recipient was barred from accessing it. It highlights the removal of the data. He could easily hide purchases using cash instead of a traceable payment method such as a debit card but chose a route to ensure the SCWA program was aware of his subversion actions. Second, the other medical parent she speaks of chooses the opposite path; she subverts the authority of the SCWA program by altering her behaviour during the month when they will have access to her bank records, exercising control over the situation without alerting them to that control.

While the medical parent is empowered in their child's medical care, and medical professionals affirm that trust, they are also not trusted in situations like this where they feel as though they are surveilled.

4.10 Experiencing Time

The experience of the medical parent is wrapped in temporality, so logically, the interaction between time and illness (Charmaz, 1991; Davis, 1956) emerged from my data as relevant. I noticed different facets of time work (Flaherty, 2003) among the parents I interviewed. These patterns and contradictions make categorizations difficult, but I have loosely sorted them into "unchanging time" and "changing time."

Unchanging time refers to ways parents expressed experiencing repetition as part of their everyday life (Charmez, 1991). A key aspect of illness management is repetition, which requires routines (Charmaz, 1991; Page et al., 2020). Chronic care and management require repetitive cycles. For example, suppose a medication must be administered every 12 hours and taken with food. In that case, proper management requires a schedule that ensures the drug is provided every 12 hours during waking time so it can be piggybacked with a meal. But such repetition may also lead to time that feels unchanging.

The repetition associated with illness management routines can make people feel stuck in place, as though they are repeating the same day (Charmaz, 1991), as life has to be fitted around caregiving and medical requirements (Page et al., 2020), as Shelley's comment confirms.

> Shelley: I don't know if you felt it, but **I feel like I'm living the same day over and over**
> Me: yep, I totally felt that way, like being stuck on groundhog day but like a whole lot less funny.
> Shelley: Right. You're living the same day over and over. **I just feel like there's no days that are different. There's days that are double time—like Christmas, right? Cause now you have all the extra work, and you got to fit around your regularly scheduled work**
> Me: exactly.

Complex illness management requires scheduling to ensure established blocks of time dedicated to specific illness-related purposes. For example, my daughter received five daily medications, each with a once to twice-daily repetition, and some required food administration. To ensure I met her needs, her g-tube feedings were completed on a schedule—8 a.m., 12 p.m., 4 p.m., and 8 p.m. Laying her down during her feed helped ensure a smooth process because gravity was the delivery method. She was also changed after her feeds. Lifting her from her chair to her bed, setting up and providing her feed, changing her diaper, and settling her back into her chair would take about an hour, so each feed required blocking off 1 hour, four times per day, which Shelley and I discussed above. Everything else has to be scheduled and completed around those pre-determined blocks of time, and while most parents seemed to follow similar patterns, there was a notable exception.

> Frances*: Our days are so weird 'cause you never know. If someone said, ‘Describe your typical day,’ just not gonna happen**. It's always different;** there might be some things that are the same, like **there's some things that we do every day, but yeah, most days are never the same, you know.** It's just, you know, some days, I do feel stagnant, like I'm just kind of treading water
> James: No two days are ever the same because we don't have a schedule. We can’t have a schedule. Mason tells us when we're gonna do this or when we are going somewhere, when we're not going somewhere; it all relies on Mason cause if he's having a bad day, we’re not going. If he has the sniffles, we’re not going. If he’s fussy, we’re not going, so we can’t have a schedule.

Frances referred to their days as different and unscheduled, even though she and Shelley both provide similar medical interventions (g-tube feeds and regular medication). But they both appear to focus on differing aspects. Shelley referred to a focus on the medical portions of caregiving (Page et al., 2020), which led her to feel time was repetitive. Frances highlighted the time in-between caregiving to conclude that each day was different. Through such a lens, days would be different because the complexity and instability of these children require flexibility to changing conditions, which the child dictates.

While a routine helps parents meet their complex child's medical and caregiving needs, it may also create time constraints for them (Page et al., 2020).

> There's times that I feel like, you know, I'm not giving my older children [voice cracks] what they need because I wasn't planning on doing it on my own I didn't have three kids because I wanted to do it on my own right. **That's probably the hardest because caring for her in like chunks of time is not difficult per se if I get space to myself, if I get that minute, if I can get to work. If I can get to work, I feel better because I'm doing something different than caring for her.** (Penny)

For Penny, the full schedule required for parenting her daughter is what she considers the most challenging thing about her daughter's condition. Penny works full-time and has two other children. Providing her daughter's care while working full-time only leaves small chunks of time for her other children and their activities, and, as she remarks, she feels like she does not have enough parenting to give them because of these constraints.

A previous comment by Zoey[46] talked about having her daughter at the same time her friends had children, and as their children grew and her daughter did not, those friends began to move on and disappear. This highlights an interesting aspect of time for these parents—the lack of change in their children; they are frozen in time.

> Linda: There's no normal for [children with this condition]; there's no typical behavior. My father said, 'Kids meet milestones, but not Carl. **Carl won't have milestones'. He said, 'Carl will have inch-stones.'**
> Me: Will have what?
> Linda: Inch-stones. He said a typical child will do this and this and this at this normal period of time. Carl may get there, but it may take five times the amount of time, or he may not, and that's OK because he will meet his inch-stones when he meets them, and it really struck me as, like, yeah, makes a lot of sense. But when we have gone to the hospital, or gone to our pediatrician, or gone to whoever, we always have to explain certain things about his condition. Nothing about Carl or his condition is going to be normal

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[46] In the Feeling Isolated section.

> James: what's normal this day and age anyway?
> Linda: but even the EEGs that he gets frequently there abnormal. So last when we were down [for appointments], Dr. Marshall said, 'Well, you know it's abnormal' I'm like, yes, but it'll always be abnormal, so **is it any different from his typical abnormal? And he's like, 'no,' then it's normal—that is his perfect.** If it's the same
> Me: yeah
> Linda: why don't we celebrate that? It's not going to be a typical EEG looking 'cause his brain waves are abnormal, we know that, but if it's his typical abnormal, hey, it's perfect, good to go
> Me: yeah, there is no adverse changes.
> Linda*: Yeah.

Linda's comment reflects this concept very well. Children typically develop along a milestone pathway where pre-determined skills emerge at pre-determined time intervals; her son will have inch-stones instead. If he develops skills, he will do them in his own way and on his own schedule. But also, the lack of change (such as the lack of change in Carl's EEG) represents a positive development because if it were to change, it would indicate a worsening condition. Olive noted similar about her son, who has now aged out of the Janeway but was "A child in all the ways that count" (Olive).

While Olive's son has continued to age, he has also remained a child—and in the ways she attributes as essential. Time has continued to pass around him, but for Olive, her son is outside the conventional time measurement. One mother pointed out that a positive part of her son's condition is that he will remain tiny and lightweight. So there is an accepted lack of change in these children. For these parents, the lack of change can be a positive for their children.

Finally, we encounter the unending day. Our general conception of time consists of periods of high intensity followed by periods of low intensity. For example, work time is high-intensity, while watching television after work would be viewed as low-intensity. But managing complex chronic illness is an intrusive experience (Charmaz, 1991) with a lack of “down-time” (McCann et al., 2012) or low-intensity periods for parents as they are required to always be “on” and alert for their child’s caregiving needs.

> So many of my friends' kids have passed away in their sleep, you know. But sometimes I'll be up with her during the night, and I’ll sleep in a chair in her room, and I'll be so tired, and **I will set my alarm clock for 15 minutes because you know you just you have to go to sleep, and I'm like OK I'll wake up in 15 minutes and check her, I’ll wake up in 15 minutes and check her, I'm going to wake up. And I just hit snooze continuously because then, if I doze off, I know that in 15 minutes, my eyes will open again. But that's really hard, really hard to do that**. Scarlett does have this thing about stopping breathing all the time, you know. And you know, cause she gets these mucus plugs that, and they’ve told us [doctors] their like you know there's going to be a time when you don't get the mucus plug. (Iris)

Iris works outside the home and has a husband and two children. On top of her other high-intensity duties, she also talked about timing her sleep to ensure she rested while overseeing her daughter’s overnight caregiving if she was unwell. This pattern creates a continuity of high-intensity time with little to no corresponding low-intensity time to offset this. With the idea of the typical day consisting of high-intensity and low-intensity intervals, the day may feel unending, like a band pulling tighter and tighter with no release of tension.

Medical parents engaged with elements of timework as part of their parenting, and while the ideas above illustrate how they experience time as unchanging (Charmez, 1991), they also talked about changing time; how they engaged with the concept of their child’s life expectancy, how they enacted agency over their temporal experience, and their experiences with continuity.

When I spoke with parents about their child’s potential life expectancy, they expressed different responses than above.

> I made him a promise when he was born. I said, ‘I will do every single thing I can for you to make your life a happy, good one.’ **I just didn’t think it would be this long [laughs], as horrible as that sounds.** It was only last year that I admitted that to myself. I thought he’d live a couple of months, a year, two years…. (Quinn)

The doctors told Quinn her son would not live long after birth as his condition was "not compatible with life," and they offered the option of leaving him in the hospital to pass away rather than taking him home and trying to care for him. But she promised to give him everything she could for his entire life, and how she framed her narratives illustrated that commitment. She focused on making memories for him and with him because she knew his life would be short (Charmaz, 1991; Knoll, 1989). With the understanding his life would be temporary, Quinn concentrated on filling that time with life. In comparison, the potential for an extended life influenced Shelley's choices.

> I asked Dr. Brooks. I asked a few doctors, and I never got a good straight answer cause you know, they just don't. And I asked Dr. Brooks about Mia's longevity, and I'm like, 'Ok, I'm ready. I'm ready for this.' he's like, 'Well, I can't predict past the age of 40.' What? 40? **What do you mean 40?** I was expecting 10, 15, 20,…40. And then I started thinking like 40 years of diapers, 40 years of lifting. **How the hell am I gonna lift her for 40 years**? So for me, the actual thought of her living that long…how the hell am I going to transition to the adult world? (Shelley)

The potential life extension beyond what Shelley had anticipated resulted in a realignment of her activities. When she started thinking of the possibility of 40 years of lifting her daughter, she began employing techniques to ensure her own continued abilities into the far future, such as asking her partner to do the lifting more often or using the mechanical lift. Shelley began to view her resources as finite and started considering how she should stretch those limited resources.

For Kathy, knowing a potential timeline was the cause for emotional preparation.

> Kathy: I think at first when they told me that….Dr. Mercer, I'll never forget it at this point [Dr. Mercer] was like, 'you know,' he might see 10, maybe.' But this was when he was in every couple of weeks, you know, all this sort of thing. It's always still there **every time he goes in [to the hospital]. I'm like thinking oh my God, is this the last time?** Is this the last time? So **it's always in the back of your mind**. Always, I dunno, I feel like [if] I don't think about it, it's not real. That's not healthy; I know that, right, but **how do you prepare yourself for something like that?** Really prepare yourself for that? Can you even prepare yourself for that?
> Me: you can think you have, but the reality of it is still not going to be anything near what you…thought it was going to be
> Kathy: No.

When Dr. Mercer provided Kathy with a potential life expectancy, she grappled with how she could prepare herself and her other children for the eventuality of her son’s death. Linda’s reaction was different;

> [The doctors] gave us the Google, you know [life] expectancy of, I think it was 2-5 years but well, a. I didn’t accept it ‘cause I was nah, that’s crap you can’t…he’s not a statistic, he is not a number, he’s a kid. He’s my kid. And **if that’s the way it’s going to be, so be it, but I’m not going to wait for a countdown**, so I went online, and Dr. Keller looked at us, and he said, ‘Listen, go online. Do your research. Ask your questions.’ but he said, ‘Just be [aware] what you’re going to find is not going to pertain all to Peter. (Linda*)

Linda’s response expresses a different sort of reaction. For Quinn, impending death meant filling her son’s life while she could; Shelley, however, had to consider her ability to undertake long-term care. And for Kathy, it meant considering how to prepare. But Linda’s response disengages with her son’s potential death, focusing on continuing things as though death was not an impending outcome. Each parent grappled with the same circumstance but customized their temporal experience (Flaherty, 2003) to reach differing understandings of that circumstance.

Parents also customized temporal experience (Flaherty, 2003) to reframe time.

> She’s after having, like, you know [so many seizures]. I called 811 one night, **‘So, she’s been seizing now for 14 minutes.’ And the lady on the other end of the phone goes, ‘14 minutes!’ I was like, ‘Yes, 14 minutes. Now, I gotta question.’ She was like, ‘Call 911—I’m gonna put you on hold,’ I’m like, ‘Relax, lady, it's only been 14 minutes. Like this child can seize for hours.’** (Alison)

Parents of medically-fragile children can access advanced medical care equipment inside their homes. As such, there is a blurred boundary between what care to provide at home and what problems require medical intervention from other sources, as discussed in section 4.7. Alison’s daughter has frequent seizures, and they have treatment options for her at home. If a child has a seizure, they should be taken to the hospital. If a child with a known seizure disorder has a seizure lasting longer than 5 minutes, they should be taken to the hospital. But suppose you have a child with an established history of long-lasting seizures and advanced treatment options at home. In that case, the line between standard home-based medical care and medical care that requires a medical setting becomes blurred, as Alison did when she called 811 about her daughter's situation. The pre-established understanding of her daughter's condition had led to a reframing of time for medical emergencies and interventions—5-minute seizures are not a cause for alarm. Nor are 15-minute seizures, even though they represent a break from commonly accepted medical standards and understandings of such events.

The last facet of changing time that emerged from my data was how parents experienced the continuity of the world during moments when their own world stopped.

They spoke of this continuity as an anchor point—their world was linked to the world that was still moving, and because they were connected, their world would continue to move, too; just not at this moment.

> Oh [the day of the diagnosis], **it seemed like everybody else's world kept going, and ours stopped. Traffic kept moving. We were at a standstill** and just kept looking around. And just we were, 'How are we going to pay the mortgage? How are we going to do this? Somebody has to quit their job.' How how how how. So many hows and no answers. **And I remember looking out the window [at the Janeway] and seeing the cars and people walking. And I remember going like, 'No,' like the world has stopped, the world is still. Why are you people moving?** It was like, no, no, no, like 'cause my world had literally just crumbled, and you guys are still going on living your life—what the heck. I was literally going like, 'This is not OK.' (Frances*)

At the life-changing moment of diagnosis, many parents talked about feeling as though their world had stopped while also seeing that the world was continuing for others, and many of them recalled the two events side-by-side. As Frances' comment above notes, her world stood still when her son was diagnosed, but she could observe the world was still moving for other people simultaneously. This became a theme throughout the data, especially during difficult times—a confirmation of continuity as an anchor point within the event.

Bonnie's upcoming comment[47] speaks of continuity from the other perspective. The PICU isolation rooms are designed to limit contact and interaction—if you are outside the room, you cannot see in, and if you are inside, you cannot see outside. They also muffle sound, making establishing an anchor point of continuity challenging. But Bonnie noted that one of the people in the room that morning spent a lot of time watching them have Christmas morning with their son, and I suspect it formed part of their anchor point to the continuity of the world during a time when their world stopped moving.

The experience of the medical parent is inherently enmeshed in time; they experience both the passage and unchangingness of time in various aspects of their everyday lives. Sometimes they feel ruled by time, and sometimes they enact agency to exert control over it; either way, they are constantly engulfed in time.

4.11 Feeling Like an Individual

Outside of medical parent, caregiver, provider, and so on, the parent also has wants, needs, and desires—just like others. The parent is an individual. Who are they in such a way that it does not connect to and originate from any obligation to other people? For example, "What do you like to do in your free time?" This question relates to the parent as an individual. Most identity sections in my thesis highlight a general recurring theme or idea throughout the interviews. This one is a notable exception; my interviewees highlighted two opposing views of their individual self.

> I love my kids. I do want to be [there]. But **I need to be something else besides 'mom.' I don't even know who Bonnie is anymore**—and that's scary. So I do; I just need to do something. I need to change something. (Bonnie)
>
> **I kinda forgot who Valerie is, even now**. (Valerie)

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[47] In the Faith and Time section.

Some parents discussed their loss of personal identity. Their role as a parent, spouse, advocate, and so on is so significant and encompassing that it has eclipsed their personal identity (Katzman, 2013; Woodgate et al., 2015) to the point that when they speak of this loss, they phrase it as though it is outside of themselves. Bonnie said, "I don't even know who Bonnie is anymore," rather than, "I don't know who I am." These parents have focused on their other roles to the exclusion of their personal identity (Katzman, 2013). They do not seem to consider their individual self as equally worthy of importance.

> **He's my life-I don't know who I am outside of him.** No clue. I was thinking about that a while ago. It's like the things I used to do—like paint and stuff like that. Like, I don't want to do that anymore, you know. I used to like to sew, but now, I'm like, 'Yeah, I gotta sew that, I gotta sew that, I gotta sew that.' It's all out in the bin. (Quinn)

Quinn's comment suggests that she is not interested in the same things she used to enjoy. Her child's life consumes so much of her identity that she does not know who she is outside that role (Katzman, 2013).

On the other hand, some parents expressed experiencing the opposite.

> One of the things my counselor said to me years ago was, '**You need to learn how to create space in between the moments that you have to care for her all the time**.' So, like, even if I'm sitting on the stool in the bathroom, waiting for her to do her poo. Like, just to breathe and **create some space for myself**. Just not to be so like, 'Fuck, I'm stuck here, watching her do her poo. Like I want to be doing this, and I want to be doing this, and I need to go wash the dishes. And I would rather go finish writing, and I'd like, you know.' Instead, just like—this is where I'm at right now; this is my jam. I'm sittin' on a stool waiting for her. You know, like, just that's life-saving. (Helen)

Even though the enormity of the role of the medical parent does not change, some parents talked about ensuring they do not lose themselves in that role. Helen's example highlights this well.[48] She talks about feeling pulled in different directions and across

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[48] This illustrates the same concept Taylor spoke about in section 4.3 about her relationship with her husband—what she refers to as "stolen moments."

differing responsibilities: she must care for her daughter, tend to household chores, and finish her files for work. The competing obligations lead to a temporal strain wherein she experiences pressure to do all these things when she can do none except sit and wait for her daughter. None of those responsibilities relate to her as an individual. But, she controls this frustration by using it as an opportunity to create space for her personal identity instead. Helen is sitting on a stool, and Helen can use this time to check in with herself and assess her needs, her emotions, and her very existence. At that moment, she is not Ava's mom sitting beside her daughter; she is Helen sitting beside her daughter, Ava. Most parents express having no time for themselves while caring for their child (Nygard & Clancy, 2018), but some of the parents spoke about techniques they use to actively work against that loss of self, such as Helen's technique.

4.12 Feeling Protective

Being a parent requires protecting your child. But when the child is medically-fragile, and the parent is responsible for them as their parent, caregiver, and medical-care provider, this feeling of protectivity is exponentially increased.

Some parents I spoke with said that they felt tired, many had experienced physical and mental health declines, most experienced significant financial struggles, and all chronically lacked sleep. Sometimes they lamented the simplicity of their life before their child was born. But every parent shared one simple sentiment that eclipsed everything else in their experiences—these parents love their children (Katzman, 2013).

> She's just; she's so happy. And you know that you're there to love her and cuddle her. **I look at her face, and I'm like, 'Oh my God, how am I so lucky to have you?**' We were blessed with these kids, and it's too bad society doesn't realize how to treat them. (Emma)

The medical parents I spoke to did not consider their child a burden, nor did they see parenting them as something they somehow had to endure (Knoll, 1989).

> Sometimes I think like, especially when I'm dealing with the school. These kids are loved; these kids are wanted. 'Cause I almost feel like people think, 'Well 'oh, poor you that you've got her. Or, you know. Or it's just Grace, and she doesn't know the difference anyway.' S**he's the sunshine of my world. Like, the sun doesn't shine till she wakes up,** right? But I almost think that there are people that think, 'Well, she's just a disabled child, so who cares.' (Iris)

And even in their most challenging and darkest moments, these parents frame their child as a gift they were given (Coffey, 2006).

> At the time, like, Aiden was literally like three weeks old. I'm still completely brand new yet. Like I was just—I was such a fucking mess. And I pulled the curtains across [in the NICU]. And I'm like. 'I know you need to see his monitor, but I'm really ugly crying. So I just—I need some time,' you know. So they put the curtain across, they put his monitor up on their monitor on the desk and all this stuff. **And I just sat there, and I cried and cried and cried. I was hyperventilating. I was just—I was a mess**. And Wilma comes in closes the curtains behind her. She's like, 'What are you doing?' 'Like, what does it look like I'm doing? Like I'm fucking falling apart—what do you think I'm doing?' She's like, 'You're going to get through this. You know how I know?' I said, 'How?' She said, 'You have no choice.' And all of a sudden, it hit me—oh my God, she's absolutely right. It's exactly what I needed to hear 'cause I was in that stage of like, 'Why me? Why me? I didn't deserve this. I didn't want any of this. Like, I can't do this.' And it was like, **'What is wrong with me? This is a gift—seriously.' And I do—I strongly believe this is a gift**. (Debra)

Having a medically fragile child made parents re-orient their lives and value systems (Knoll, 1989).

> He's an amazing little boy. He has taught me how to be a better person. You become a better person when you have a medical complex child because **you see the world differently.** (Linda*)

> I really just don't know who [I am] because all of those roles and titles come first, and it is overwhelming, but **I wouldn't trade them.** (Rees*)

> [The doctors] came and said, 'You know you can leave him here [until he dies]. I said, 'Look, **all that's getting me through now is getting him home**. I don't care if it's for an hour.' (Wanda)

> **Absolutely appreciate things more; we celebrate more.** We also are tired more. But, you know, we appreciate things a lot more. (Taylor)

Providing such an elevated level of intense and ongoing caregiving to their child results in deeply intense bonds between the parents and the child (Woodgate et al., 2015).

I would eat you alive for that child.[49] (Iris)

Above everything else medical parents experience, they are privy to the intensely rewarding and fulfilling experience of being the parents of extraordinary children and consider themselves better because of it.

4.13 Conclusion

The previous chapter detailed the behind-the-scenes processes which act as the filters medical parents use to view and interact with the world. These processes manifest through their interactions with the world—which is this chapter's content. Medical parents expressed bereavement, which relates to temporality; they feel supported and isolated, which connects to boundaries and how they view their position in the world. But life is messy and complicated. This chapter outlined aspects of doing medical parent, resulting in a thick, detailed conceptualization of the medical parent.

Using the juggling illustration from the beginning of the chapter, I posit that being the medical parent experiences continual interaction with constant hazards, and I identify and develop 13 such hazards which emerged from my data. I discussed how parents experience constant worry as part of their parenting, along with a temporal understanding of worry, and the interconnected matrix-like existence of worry. I also developed ideas around bereavement and grief related to how parents experience the ongoing loss of the child they thought they would have, how they interact with the knowledge of the impending death of their child, and how they discuss the possibility of their own death. From there, I detailed how parents experience isolation using the imagined idea of the “typical parent” as a frame of reference, as well as how parents used those experiences to

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[49] This comment was made by an interviewee I knew beforehand and someone I consider as a friend, but she said this with such conviction that I could feel the intensity behind her comment so much so that it was intimidating to be on the other end of her comment even though she was speaking hypothetically.

redefine and reconceptualize ideas of inclusion and exclusion; which informs the next area I developed—how parents feel supported as this also relates to feelings of inclusion and belonging. Next, I developed the idea of the medical parent being an advocate for their child using “non-combative” and “combative” advocacy experiences as the framework for the conversation. I also discussed the temporally-based trial-and-error process of problem-solving medical parents undertake as part of parenting their child. From there, I detailed how parents experience the role of being the medical decision-maker for their child, and how that relates to their parenting experiences and medical knowledge; which led to my development of how medical parents discussed and experienced having a supervisory position over homecare service workers. I also explored how parents discussed feeling policed or surveilled through their engagement with government services, and from there, I developed how they engage with and experience concepts of time as both “unchanging” and “changing.” Finally, I detailed how parents talked about themselves as individuals; and how they framed and conceptualized parenting their child.

As I previously noted, these are overlapping and intersecting ideas and concepts because life is messy, with intricate connections and intersections. I teased apart these ideas to develop each one in rich detail, but in reality, they exist together as active, intertwined experiences for medical parents.

Chapter 5: The Medical Parent in Relation to Others

Most of my data relates to the identity of medical parent, and how they perform that identity through parenting, but how they interact with others also emerged. This chapter expands my ideas on the medical parent by exploring their interactions with and related to their medically-complex child, the dad as a medical parent, their interactions with their other children, and their interactions with faith.

5.1 The Medical Parent and the Child

Being a medical parent requires having a child. However, we do not conceptualize of medically-complex children through the same frames as typical children. This section highlights aspects of how parents talked about the medically-complex child through three differing frames: the sub-human, human, and transhuman. Each child occupies space within each category simultaneously, through differing contexts.

Some parents detailed interactions where their child was conceptualized as being less-than or sub-human. Sometimes this dehumanization (Hewitt-Taylor, 2008) was inflicted on the child by other people.

> And then, of course, it came time for him to go to school. And we had the big meeting with the school and all this kind of stuff. And the community health nurse was like, 'Ummm, so just wondering, you know. 'Cause I mean, there would be adequate training. But, **would it be easier just to not, you know, feed him at school? Just so there's no like mix up?' I'm like, 'Sure, that's not a problem at all if you ask everybody in the class not to bring their lunch.**' Are you fucking kidding me? He's not going 9 hours without like food or water—fucking sick. She said, 'No, no, no, I mean, you know, I'm just saying, it would be easier.' 'Yeah, it would be easier, but you know what? Easier is not always best. So. No. We're going to do training, and people are going to know how to use a g-tube. It's not scary—fuck, anybody can do it!' Yeah, 'Can you not feed him?' Are people insane? (Shelley)

Shelley's comment highlights how the community health nurse viewed her son as sub-human. Her son is provided nutrition through a g-tube—the equivalent of his school lunch. But the nurse felt withholding his feed during the school day was reasonable until Shelley reframed the request without reference to her son's disability. This is how he receives his nutrition—that is his lunch. I am confident the nurse would never make such a suggestion to another kindergarten student. The nurse viewed Shelley's son as sub-human and did not correlate his experiences with other children's.

In some situations, this dehumanization of the child resulted from organizational bureaucracy.

> I know that clearly, if he was well enough to come out of ICU, he shouldn't need constant [care nursing]. [But] I can't be there 24/7. I just can't. And I remember going up [to the ward] one time, and he was sideways in the crib…His head was pressed up against the [rungs]. They had just put in his port, no—they had him accessed, but there was nothing running through it. So Dr. Jones was on. Of course, he had the bulldog clamp on him. My God, that thing was humongous. But that was like stuck into his side. He was bawling, screeching. He had his oxygen out. He was down to like the 70s. I'm like, 'What the actual fuck, b'ys?' Like seriously. And that's when Justine was the head nurse. So I called out to her, and I said, 'Get in here, and have a look at this and tell me what it is wrong with this picture.' She was like, 'Oh, someone was just in looking at him.' 'That's a lie. And you know it. That is a lie,' I said, 'Because you and I both know that it's going to take Oliver an awful long time to get sideways in that bed.' She was like, 'Oh, I assure you.' 'You know what, I don't believe you. **So you know what's going to happen from now on? We're going to have constant care. I don't care who I gotta talk to, who I gotta call.'…**And it was like it wasn't a big deal, you know, 'He's good now.' 'Is he, though? Is he really?' I hated it, Amie; oh my God, I hated it so much. **Nobody should have like that kind of anxiety while in hospital. Knowing that he's not getting the care he needs.** (Kathy)

The required level of nursing care in the ward during hospital admissions is determined based on specific criteria. For example, if increased nursing care is necessary when a child may fall out of the crib (the result of standing up and trying to climb out), then children who cannot stand or climb would be deemed low-risk. However, a medically-fragile child's lack of mobility increases their likelihood of becoming wedged or stuck in a painful position in the crib. Rather than assessing the child based on their specific circumstances, nurses assess the child and family compared to the "typical" child.

And where the “typical” and medically-fragile child differs, the medically-complex child is considered the lower risk.

Similarly, sometimes parents adopt a sub-human approach with their child as well.

> She had umpteen hospital admissions. And she was terrible for IV access. So, 7, 8 tries—and each try was like three times kinda thing before they would get an IV. And I'm holding her down the entire time. **Never dawned on me the sort of pain my child was experiencing. Ava needed an IV because Ava needs this medication. And I need to make sure she has an IV.** You turn off—that's what happens. You turn off that part of yourself that feels for your child. (Gemma)

Gemma’s comment illustrates this idea. During hospital admissions, she concentrated on the associated medical necessities—Ava needs medication administered through an IV. Therefore she needs an IV. Even if the process of establishing one is painful. During such procedures, Gemma positioned herself as the person charged with ensuring her daughter had IV access rather than as Ava’s parent, attempting to minimize her daughter’s discomfort.

The parents I spoke with recalled instances when they treated their medically-fragile child as sub-human and when others viewed their child as sub-human. In juxtaposition to this incomplete human persona is the human child, which parents also spoke of during our discussions.

Parenting a child with complex needs and medical conditions is just like parenting a “typical” child but also nothing like parenting a “typical” child. Someone once asked me how my daughter was capable of communicating while also being non-verbal and deaf. I did not know how to respond because her inability to verbalize did not represent an inability to communicate. She could communicate just like a “typical” child, except her communication was non-verbal, so it was also nothing like that of a “typical” child. Normalization is critical here (Carolan et al., 2014; Knafl & Deatrick, 2002; Murdoch &

Franck, 2011; Sallfors & Hallberg, 2003)—parents participate in normalization processes, consciously or unconsciously.

> [Dr. Andrews] came back in later, and he was sort of trying to convince me to just keep the continuous feeds, right? Like, 'No, no—**we want the tube. we want to be able to do the feeds—the belly emptying.' The normal-ish stuff.** (Rees)

Shelly's comment in the previous section and Rees' above refer to the normalization within abnormal instances. They talk about g-tube feeds using terms and concepts associated with oral feeding. As a parent, I had discussed this with one of my daughter's doctors. He said undertaking activities using similar patterns as "typical" children allows for the experience to have similar effects, even if the delivery method differs. In this situation, Rees was referring to g-tube feeds administered by gravity. Typically, such feeds are given 3-4 times daily around the same time other family members eat. This provides an opportunity for everyone to be nourished at the same time. The child is part of the dinner table experience and conversation. Maintaining the circumstances surrounding a meal (for example, smelling cooked food, seeing plates of food, and so on) and the internal mechanisms associated with eating (feeling filled afterward and empty beforehand) preserves all aspects of eating apart from the delivery method. Although the delivery method for her son's nourishment differs from most people's experience, maintaining the surrounding familiarities provides continuity within such typical experiences and reinforces the normality and humanness of the situation.

Scholars refer to parenting a medically fragile child as intense parenting (Woodgate et al., 2015) because it requires high intimacy between the child and parent (Hayes et al., 2009; Kendall et al., 2004).

> **I literally, like, I have this sixth sense about stuff. He sneezes more than three times in a day [snaps fingers] Pack your bags, man—we're done**. And sure enough, by the end of the night, he'll have a fever. And people, some of them don't like me telling them what you know and what to do. But again, I'm a parent, you know? You know what to do. (Christine)

> **It depends on the moon. It depends on the weather**; it depends on if he's sick. We have come to realize that the moon plays havoc with complex children. **Full moons are nasty, and a few months ago, we had that pink super moon—it was hell.** So I'm a part of a closed Facebook group for parents like us. And I stuck it up there one day. I'm like anybody else's youngsters just thrown off by the moon? And so many parents were like, 'Yes.' For Peter, it was just like he was cranky; he was grinding his teeth, he was awake, he wouldn't sleep. Just mad at the world. And as soon as that moon started to wean, he went back to his normal, happy self. (Valerie*)

> And then it's the unconditional love that comes from her. **Like, it doesn't matter; when I walk in the house, she laughs. Right, she knows it's me. They used to say at Easter Seals, they would say, 'You know, we're around all day, but the minute you walk in or Zachery, and the minute you guys say something, it's a total change in her**.' And even the Janeway nurses used to say—there's a couple times she was in the special care on the fourth floor, and they would say, 'You went home last night, and Lily wouldn't sleep.' They were like, 'She misses you.' (Ursula)

Christine and Ursula's comments both highlight this shared intimacy from differing perspectives. Christine talked about the intimacy of her connection with her son Leo, and her statement highlights how intense parenting connects to intimacy between parent and child. She has noticed that if Leo sneezes more than three times in one day, he is unwell and will soon require medical intervention. This conclusion required Christine to be physically present and actively aware during his caregiving, to notice a prior trend, a subsequent correlation, and a predictable outcome for future occurrences. Ursula's comment relates to a similar intimacy in the opposite direction—her daughter's intimacy towards her parents. When Ursula arrives, Lily's demeanour and behaviour change, reflecting her preference for her parents.

Both comments reflect similar normalization experiences but expressed through non-verbal communication (Hewitt-Taylor, 2008; Kendall et al., 2004). Leo's sneezes and Lily's elevated comfort with her mother become the non-verbal equivalent of "I don't feel well" and "I missed you" verbally expressed by "typical" children.

Valerie's comment also reflects the experience of intense parenting similar to Christine's but connects it to an organic existence within the world as well—how the phases of the moon affect her son.

Some parents discussed integrating their medically fragile child and related equipment into their lives.

> Nicole was 5 when Aiden was born. So when he came home, she was 7. **She [would] be skipping like his extensions[50] and stuff.** Like, have at her man, give'r. Like, what's the worst that could happen? Seriously. But like everything was—just that's our normal, you know. [His siblings] They love him, you know—Nicole especially, my God. **Nicole, the 15-year-old like, she takes him down on the floor. She's rolling around, you know.** If he's up on the couch, she'll push him over and whatever. I remember my mom was like, 'My god, you can't be doing that.' She's like, 'Why not? He's my brother—he's annoying me. He's getting on my nerves.' **She's the only one that really, truly treats him like a normal kid, you know.** (Kathy)

Kathy's comment highlights this integration of medical equipment into the rhythm of family life (Carolan et al., 2014; Rehm & Bradley, 2005). With it, her son has an established position as a "typical" child among his siblings—they do not see him as being different nor treat him as different.

But this normalization through the process of reconceptualization also highlights some of the ways these parents see their child's differences as well.

> We were pregnant at the same time—me and Megan. And the boys are two weeks, a little over two weeks apart. And so Louis is at the house all the time with Megan. Like **the boys are the exact same age, they well, they'll go to school at the same time, so it's kinda like seeing Louis doing things. It's like, would Jack be taller than Louis? Would he be climbing around like Louis?** Would he talk like, would they have good speech? What would he sound like? We know how he squeals, but, yeah. (Valerie*)

Parents can experience their child's personalities and intricacies, and normalize the processes and equipment associated with their medical conditions, but a disconnect

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[50] The home oxygen cord can be extended up to 50'. Kathy's daughter would use her brother's oxygen cord as a skipping rope.

remains. Valerie wonders what Jack's voice would sound like, how tall he would be, and if he would be a climbing toddler; as much as parents work to reconceptualize normal, holes remain.

Just as the sub-human child exists beside the human child, the transhuman child exists, illustrating how technology combines with the child, resulting in a child transcending the "typical" child and becoming more-than-human.

My daughter was profoundly deaf, meaning that she could not hear anything. Even at the maximum capacity measurable through the audiologist's equipment, there was no receptive response to auditory stimuli. We opted for cochlear implant surgery to bypass the broken auditory mechanics in her ear. With the cochlear implant, she was deaf and not deaf at the same time. She was non-verbal but could access a talker switch to speak for her. Modern technology stands in the gap for these children and forms a bridge between them and the world outside of themselves. But while technology provides them extended access, it also fuses with the child and becomes part of them; the child and technology become the transhuman child (Coenen, 2014).

> And he likes us to scare him every day. I said, 'Do you want to be scared?' 'Eh' [yes] 'Want to do it now? '…Eh' [yes]. So, we'll go out, and I'll sneak in, and I'll go to the head of the bed. And I'll go, 'Boo!' '[Gasp]' 'So was that a good scare? 'Eh' [yes]. He's got this eye gaze thing he can talk on. So he looks in the squares, and whatever square he looks at, it will say what's in it like, "I'm tired' if he looked at it, it will say, 'I'm tired' Well, we had "fuck off" on it, but he lost his privileges. We were going into Winners one day—I'm deaf in one ear, so I can't hear. So I had the door open, I was pushing him through, and there was a missus pushing past us. I was like, what are you doing? Anyway, she was looking at us, going [strange look]. What the fuck is her problem? Anyway, then my ear went right to Noah going, "Fuck off, fuck off, fuck off, fuck off, fuck off." You lost your privileges. Say that again in here, and I'm taking it off. "Fuck off." Well, **I waited til he was 21 the first time I heard, "Good morning, Mom, how are you?' I said, 'I'm good, thank you, how are you?' He said, 'I'm good, shut up.**' (Debra)

Debra's son found a voice through eye gaze technology, which allowed him unprecedented communication, limited only by the options within the system parameters.

Most parents I spoke with had children dependent on technology for survival (Hewitt-Taylor, 2008), and some also for communication. The section above also notes how the child and their accessories mesh together as part of a larger conceptualization of the child and aid the normalization process. However, this sometimes also leads to misconceptions or misunderstandings about the child.

> Thankfully, now I'm getting Aiden's stuff somewhat covered, you know. And then when you get things covered that way, you get that nice other side of it too. That you have to wait for those things. You don't have any other option but to wait for them, so if stores sends your supplies six weeks instead of four. Honestly, oh my god. I remember two years ago, I called in. Jessica gave me the number to Stores. She said, 'Just to have it on hand in case anything happens.' Perfect! I called in and explained, you know what happened—that I didn't have three cans of milk supplies left. Should have been here, you know, two weeks ago. Yeah, so, like, what's going on? **'Well, is there something else you can give him for the time being?' 'What exactly? Jigs dinner?'** Like, what are we talking about here? Like, you ignorant—I'll get right on that now. I'll blend up some fries, dressing, and gravy. What a douche! (Christine)

"Stores" provides the monthly supplies for these children. If their nutrition, diapers, and so on are covered through provincial government supply, they are controlled and shipped from "stores." When "stores" suggested Christine could provide something else to her son, she was upset with their lack of understanding about the mechanics of how g-tube feeding works. It is possible to give a blended diet instead of a pre-formulated liquid (such as Boost); however, doing so would require tremendous input from a dietician and possibly her son's surgeon on how to switch and precisely what should be provided to ensure her son receives the appropriate nutrition in a consistency that will not damage or block the feeding tube.

Technology meshes with the medically-fragile child to assist and support their lives. However, as the comment above illustrates, it may also create a lack of shared understanding and liminality (Kemmery & Compton, 2014). Since Christine's child receives nutrition, Stores thought an alternate form of food might be suitable.

As this section illustrates, parents related examples of how their child had been viewed as less-than-human, viewed as human, and viewed as more-than-human.

5.2 Dad as Medical Parent

Caregiving is a gendered undertaking (Hamilton, 1979; Kendall et al., 2004). Society provides a set scheme for parenting along gendered lines, and often (whether purposely or not), we align ourselves with those schemas (Hamilton, 1979). Because men and women are socialized differently as children (Kendall et al., 2004), fathers are likelier to play with their children. At the same time, mothers are more likely to feed and change them (Brekke & Nadim, 2017; Hamilton, 1979)—women do the "work" of parenting while men enjoy the "fun."

When parenting is complicated with a complex child, the mother traditionally bears the associated extra care burden (Brekke & Nadim, 2017). Therefore most of the existing literature on gender and parenting medically-fragile children focuses on mothers because they are expected to carry the disproportionate burden of care (Brekke & Nadim, 2017; Feeley, 2012; Gravdal Kvarme et al., 2016; Katzman, 2013; Knafl & Deatrick, 2002; Nygard & Clancy, 2018). This divide appears to extend into my research as well. I conducted nine interviews in total. Seven interviews were with the mother alone, while the other two I completed with both mom and dad present. Between those two interviews, there were apparent gendered parenting differences. In the first interview I conducted with a couple, the mother provided most of the information, and the father provided his affirmation of her answers. Sometimes he prompted her direction by saying, "Tell her about…" or something similar. Their combined interview reaffirmed gendered labour division among parents of medically-fragile children. However, the second couple I interviewed appeared to be an anomaly to this gendered division of labour, and it is that interview I wish to discuss[51].

The first thing I noticed about this interview was that they did not engage with me or each other as though one person was the authority and the other was the backup. Their nuanced interactions positioned them as two separate people, each with their own ideas, thoughts, and opinions.

> Andrea: Gabriel is two years old [to Spencer]. **Did you already cover this?**
> **Spencer: Yeah, but she wants to hear your side** [to Andrea]

Andrea stepped out to run an errand, so Spencer and I began the interview, and she arrived shortly after that. Spencer provided some information about Gabriel but also noted that Andrea had a better understanding than he did on some things, and she could fill those gaps when she returned. When she joined us, I asked her the same beginning question I had posed to Spencer—"Tell me about Gabriel." Spencer's reply highlights this differentiation between the parents. Even though he had answered the question, he reaffirms that that does not invalidate her answer, and his comment before her arrival affirms that their information compliments each other rather than mirrors one another.

While Andrea answered a question at another point, Spencer indicated his disagreement with "Umm" and a puzzled look. When she finished speaking, Andrea turned to him and said, "Spencer disagrees, though," prompting Spencer to provide his separate, dissenting answer as well. They made space for each other throughout the interview, and affirmed the value of each other's positions and opinions within the discussion.

This was a common theme throughout the interview. Neither parent was the primary interviewee. When I posed a question, sometimes Spencer answered, and

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[51] Andrea and Spencer's child is under the age of ten.

sometimes Andrea answered. Both of them answered many of my questions; however, their answers were not affirmations to one another—they were supplementary. If Andrea provided the initial comments on a question, Spencer often offered additional information.

> Andrea: And in that sense, [the birth] was more for Spencer than it was for me. 'Cause I didn't see anything, I didn't experience any of that. **That's not true—cause they did the, 'Here's your baby' [quickly shows the baby] but like it was a quick glance like.**
> **Spencer: It was literally, yeah, she's not exaggerating like, 'Here's your baby,' it was that quick.**
> Andrea: But the first time I seen him was down in NICU. And his color was good by then, and like they had him settled and that kind of thing right. Like I didn't experience all the stuff that Spencer did during that initial piece.

Their interactions supplement and confirm one another while also recognizing each other as individuals who have experienced and conceptualized their son's condition separately, as Andrea confirms when she says the birthing process was more traumatic for Spencer because he saw their son's condition, while she could not and therefore, has no continuing trauma from that event. This is also an interesting position for her to express because women are generally viewed as the primary caregiver, and she gave birth to their son—she has a valid claim to traumatized status for that experience, but she acknowledges the effect it had on Spencer and why it was so formative for him. Building on how they engaged with each other during the interview, their non-conformative work-sharing was also evident within their narratives and their interview approach.

Before each interview, I asked participants to think of something that represented the best and the worst things about parenting their child and bring those representations to the interview for discussion. Andrea and Spencer discussed this beforehand and divided the work; Andrea had to find, obtain, and discuss what was the best part, while Spencer had to do the same for the worst part.

Their answers also illustrated the depth of their supplementary parenting. Spencer noted that Andrea had a permanent, well-positioned occupation and lamented that they would like to find an option allowing him to stay home and care for the children while Andrea provided the household income. Spencer also stayed with Gabriel when he was admitted to the hospital following a seizure.

> Andrea: We were in emerg for his last seizure. So he ended up he was in the trauma room because he came in in statis. And we got there like 9:00 o'clock in the morning. He was there the entire day. They knew they were admitting him; they knew he was going up to the floor
> Spencer: **I went ahead and started doing stuff because I knew the nurses wouldn't have time to come in and see us, so like, I was taking off some of his leads and stuff.**
> Andrea: **That's when he was discharged**
> Spencer: **No, even in the middle of the night there also.**
> Andrea: **Oh, cause Spencer stayed overnight**
> Spencer: So he had an IV in and like, I disconnected it cause I was like, 'Their gonna be too long before they come in.' I was confident in what I was doing. It wasn't actually taking the actual needle out—it was just the connect thing on the end.

During Gabriel's admission, Spencer stayed in the emergency department and assumed the medical parent role overseeing his equipment for transfer to the floor. Their lack of acknowledgment of the circumstances adds to the normalization of their gender-non-conforming roles. Neither explains why Spencer stayed instead of Andrea. Their lack of explanation reaffirms this to be a routine undertaking—only those things viewed as outside the "ordinary" warrant an answer to an outsider.

They also both commented on their behaviour during medical crises;

> Andrea: I was thinking about Gabriel's diagnosis. Like a little bit after that 'cause you [to Spencer] had a really hard time.
> Spencer: Yeah, we're really like, **we do well. Where I'm good in an emergency moment, and then I fizzle out. And then you're [Andrea] really not great[52] in an**

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[52] Spencer's word choice here is also worth noting. He hesitated slightly before saying "not great." He seemed to be trying to balance conveying his message while ensuring his words were respectful towards Andrea. The phrasing is also awkward—it is not representative of common parlance you would expect within an informal setting such as this; "you suck in an emergency," is more representative of the language, or "you're bad in the moment." His hesitation combined with the awkward phrasing illustrate how he ensures his language is respectful towards her.

> **emergency, and then you pick up everything once I fizzle out, so things are always covered**.

Their complementary crisis styles allow them to work together to get through a situation without one person experiencing most of the accompanying stress and strain. They even directed many comments toward each other rather than me. Their approach to Gabriel's diagnosis highlights a similar path.

> Once we got the diagnosis, I was just kind of like I remember Googling it like the first thing, of course. What else do you do, right—Googling it and looking. The first video, we were looking at YouTube videos. I was like, **'I don't want anything to do with this.' I did not want to look at it. Spencer was the absolute complete opposite Spencer was like, 'I'm going to buy a laptop now, so I can do all the research and have everything in one place.' And I was like, 'Cool.' But that wasn't me. (**Andrea)

When Gabriel was first diagnosed, Andrea chose to shy away from information, whereas Spencer wanted access to all the information he could obtain. While this is a highly gendered reaction, their approaches reflect their shared respect for each other—they processed things the way that best suited their nature without forcing the other to do the same.

The last aspect I want to highlight is how their interactions illustrated that they are two individual people, but they are two individuals working together in this situation. They have a complementary, shared parenting style towards their medically-fragile son, but they also showcase a complementary style towards each other.

> Funny enough, actually, 'cause I've done most of the talking here. **But Spencer is actually the communicator of the family, and I'm more reserved. And Spencer's just more expressive. I guess he's able to express his emotions better, so he's kind of dragged me along, which is nice**. But we do have pretty open communication. And for the most part, we're able to verbalize our feelings pretty well. (Andrea)

Andrea identifies Spencer as the communicator of the family who emphasizes the need to verbalize and understand each other when they have disagreements, and she acknowledges that she follows his lead with communication.

The shared but separate nature of their relationship was evident throughout their interview. They talked to each other, provided additional information for one another, and created space for verbalizing when they disagreed with each other. They also offered grace and understanding to each other. For example, when Andrea voiced her disappointment with herself over past decisions, Spencer quickly reminded her that she was young when that happened, and everyone does such things when they are young.

Their interview indicates a shared approach to medical parenting and their relationship, with both occupying an equally essential and elevated position. And although there is still a high caregiver burden, it appears to be distributed between both parents. The gendered division of labour and role is beyond my research scope and expertise; however, it was so salient during this interview that it necessitated recording.

5.3 The Medical Parent and Their Other Children

The experience of growing up with a sibling with a complex medical condition is an underdeveloped area of research (Lowes, 2007) and was not something I sought to explore in my project. Where literature exists, the focus is on measurable outcomes, such as an increased likelihood of developing depression and anxiety (Kenney, 2010; Lowes, 2007) or a child’s conceptual understanding of death based on age categories (Hewitt-Taylor, 2008). But their other children was a topic for all the parents with whom I spoke who had more than one child, so I include some preliminary observations from my data.

Parents with multiple children spoke about two different elements here—how the combination of their children affects them and what they view as the effect on siblings. I begin by prefacing this section as I did previously—by drawing on Weber’s concept of ideal types (Weber, [1919] 2014) because I develop these ideas using categorizations for these concepts, but these categorizations are arbitrary because these ideas flow into one another—they are not separate or apart. Where one exists, they all exist. But categorization is necessary to allow for directed discussion.

First, parents engaged with the prospect of talking about the potential death of their child with their child's siblings. Parents experience an ongoing engagement with death, which adds an additional layer of questions for parents with multiple children.

> Shelley: Did you ever prepare the kids that Minxie might pass away sooner than later? I've never had that conversation
> Me: We've never had it as a conversation like that—never in a serious tone or like a big deal, but we did approach it like in passing—in offshoots of other conversations.
> Shelley: Right. **Yeah, I've never actually come out and said you know**. Like I feel like Alison might have an idea because of the amount of hospitalizations he's had. You know, things that have been going on, I don't know. **I would like to prepare them, but** then like for Bridget, for instance—she's nervous enough as it is. She'll just be like be afraid to be around him, watching his every move. So **I don't want to take what they have away from them now**, you know. 'Cause they have a really good relationship with him—they love him, you know. And she said one time before she said, 'I forget sometimes that Leo's not, you know—your typical. Like, 'I forget that he's, you know, got a g tube or whatever.' Which I love. I wouldn't want to take that away from her.

Shelly's commentary shows the complexity of talking about the potential death of their sibling. Her children are of different ages, with different personalities, behaviours, and ways of interacting with their brother, Leo. She also states she was afraid her children might resent her if Leo died, and she had not prepared them in advance, but she does not want to alter the relationship her other children have with Leo now. Parents must work on their personal acceptance of their child's eventual death but also grapple with the information they should share or withhold from siblings and how that information will affect them.

> I think that, like the third [seizure] for me, it was harder emotionally because Elizabeth was here and because she knew what was going on. And so we ushered her out to the neighbors. The neighbours came over and took her and got her, which is great. But she was very aware, right and I picked her up from daycare that day, and she got in the car. And she's a very creative kid too, like; she has a very good vocabulary like she's very expressive, and she said, 'Mommy, my heart today was sweaty.' I was like, 'What do you mean?' She was like, 'My heart felt really sweaty. I don't want Ethan to be sick.' That's how she described it. She was obviously feeling quite anxious. So I think that's very interesting. She's a very capable little girl. She's very bright. But she's seen stuff—**I was very adamant on getting her out**

> **of the house today before you came. I don't want her here for these conversations. She's almost had to mature in a way that I wouldn't necessarily want for her.** (Jackie*)

On the other hand, Jackie's children are much younger than Shelley's. Rather than potential discussions of death, she shields her daughter from the bulk of information about her brother's condition to protect her from the resultant emotional effects, such as forced maturity. She also notes that having her daughter present for one of her son's seizures made it more emotionally difficult for her.

From my experience, the healthcare professionals involved in my daughter's care did not ask for or provide direction in approaching this topic with my other children. Parents may be left directionless on how to proceed here.

Second, parents I spoke with talked about how attending to the needs of their medical-fragile child led to a decreased level of care for their other children.

> **My kids are missing out on medical appointments—so their health, it just doesn't seem to ever be as important as their brother's health**. **My baby was supposed to be out here the same day William was brought in for surgery to see the same doctor because she needs tubes in her ears**. And she could actually have major hearing issues because of it. And now she's not getting in until April—we've already canceled it three times because he's been out here. So it seems like everyone else's health is just put on the back burner all the time; I know I can only do so much—but breathing issues come before this. But how does that make them feel? (Eileen*)

Parents have a limited number of resources to draw from. Sometimes this means that two things are scheduled simultaneously, but resources will only allow for one. When that happens, parents are forced to triage care for their children (Hewitt-Taylor, 2008; Page et al., 2020). Eileen is correct; breathing problems must be considered before ear issues because one is potentially life-threatening while the other is not. She also notes that the situation poses an emotional dilemma for her children because they are not provided the care they need while seeing their brother receive extensive care (Hewitt-Taylor, 2008). Their needs are pushed aside while their brother's needs are provided for.

Parents also spoke of feeling guilty and worried when caring for their medically-fragile child interferes with parenting their other children.

> **I don't have time to be mom to the other kids**. Oh, that was hard. If we do start playing something, it probably has to be interrupted because of care for Kyle. I'm gone [to the hospital with him], and they never know when I'm coming back. (April*)

April said she always feels parental guilt, even though she recognizes there is only so much one person can do when caring for multiple children. She worries about the lack of support she can provide for her other children and feels guilty for not being able to give them that care. Guilt and worry are the bedfellows of parents trying to juggle the responsibility of parenting multiple children, including one with complex needs.

Some parents spoke of altering their parenting styles to alleviate these concerns to shelter the siblings from emotional upheaval and disappointment.

> **Like I never tell the kids anything in advance.** We're going to the mall. We're going to see a movie—nothing. And I mean even when we're on the way, 'Mom, where are we going?' 'We're going to military school..' They wouldn't know we were going to see a movie until we landed in the parking lot because that's the only time that I could pretty much guarantee we were going to get there, right. **But I been thinking about this lately that you know, that also means they never anticipate anything**. There's never anything for them to look forward to because they never know about it. **So this summer, when it dawned on me, we had tickets to the circus. I had tickets to the circus, of course. I wrote it on the calendar, and I told them we're going to the circus on this day—we have tickets to the circus.** And I was worried that something would happen. But I wanted to see what this was like, and a couple of times, two of them had gone to the calendar multiple times to check and see when it was 'cause they knew it was coming up, and they wanted to know when it was. They were excited, so they got the anticipation that they never had. (Laura)

Laura developed a strategy in response to her son's fragile condition; after disappointing her other children with plans that did not come to fruition, she opted to stop giving them advanced knowledge of events to ensure they were not disappointed if they were cancelled. She also actively worked against this knowledge when she considered it from the other angle; she tried a different approach by telling them about upcoming plans so they could experience the excitement of anticipation. These two approaches contradict each other but illustrate the continual cycle of adapting, re-evaluating, and moving forward for parents with complex children.

In addition to how the presence of siblings affected the parents, they also spoke of the effects their other children bear. A sibling relationship is complicated, especially during the formative years, but the research notes that the relationship between a complex child and their siblings differs (Kenney, 2010). Siblings have a closer emotional connection (Hewitt-Taylor, 2008), even when other siblings feel protective of their complex sibling (Faux, 1984). None of the parents I interviewed discussed any aggression between siblings. Helen mentioned the closest association with aggression when she said her youngest child would occasionally ask if they could drop her sister off to foster care, which Helen attributed to her young age and developmental stage.

> But I remember [the guest speaker] coming and saying things like that like, 'Don't be afraid of your family. Don't be afraid, **don't treat them any differently.' And all that sort of thing now in certain circumstances, you can't [treat them the same], but it was like, Oh my God, that was exactly his older sister right from the get-go**. (Christine)

Christine's other children engaged with Aiden as they would any other child, insofar as they could. Penny said her oldest daughter was writing about her sibling's condition for school assignments. Emma's youngest child always includes Scarlett when they go places or meet new people. Andrea described her older child as interested in caring for her younger brother, while her youngest child engaged with his older brother as two typical toddlers entertained with each other.

As the children grew older, some parents reported an increased caregiving burden for these siblings.

> I can see where it comes from because **Judy's probably the only one that does everything with Aiden.** Like she'll change his bum; she'll talk about it for days

> after, but she will do it most of the time. And she'll be 23 soon, right **Harriett is 15—she knows how to do the stuff. Like she'll set up his pump, she'll feed him, whatever. She won't change him**. Nor would I want her to, really. She's 15. **The 18-year-old downright refuses to do any** changing or anything like that like; just it's not happening. And again, I don't expect them to. But she's actually really nervous about his care. Like she's scared to death cause last year last July, we went out, and Judy was trying to take Aiden out of his chair. I just set up his feed and, 'cause normally he's in his chair, I got his tube like wrapped in and put up underneath the surgilast, or it's you know it's out. So Judy was like, Well, I'm going to take him out now and sit him down with us.' Best kind, wonderful. Anyway, she's like, 'What? what's going on?' Snag[53] so the g-j comes out balloon still intact. Like he didn't even flinch, I'm like, 'Do you have any sensations in your stomach at all?' Like, I mean, we're talking like the size of a quarter out through a hole that's like [smaller than a dime]. So, of course, Judy was like, 'I almost killed him!' I'm like laughing like, 'He's fine.' So now the 18-year-old is like, 'I'm not touching him. I'm afraid that something, or I'm going to do something.' So again, I get it. **But I think that ties to, you know, turmoil between the 3 of them. Like, well, Judy's almost expected to do it, right? So I mean it is a lot. So yeah, there are still times that they need to be the sitter, and they do it without any real complaining. But I wonder sometimes, though, are they bitter that way?** They're not telling me anyway. But I would hope that they would tell me. But every now and then, you know, they'll kind of say like, 'Ahhhh, you're going to the supermarket again?' 'Yeah, yeah, I am. It's been like a week since I went. (Kathy)

Kathy's older children are in their late teens-early twenties, and with Aiden's increased needs and a lack of outside support for caregiving, her older children have undertaken some of the work. Ursula's youngest child is too young to care for her older sister, but she is keenly attuned to her sister's needs.

> I remember taking her to—she might have been like 4, and she had to come with me to one of the appointments. And they were asking me her meds, and I was telling them, but I was giving them time to write it down. So it was like, Lamictal and Topamax. And anyway, she pipes up, and she was like, 'And don't forget about blah blah,' and rhymed off all the seizure meds pronouncing them all correctly. And the doctor went [gasp], right. But she's very empathetic, you know. **If she goes out and somebody asks her name, she'll go, 'My name is Adrienne, and this is my sister Scarlett**.' You know. If I had to pick between allowing this person to stay and watch Scarlett, or Adrienne, Adrienne could watch her. She's not legally allowed to watch her, but Adrienne [knows what to do]. I'll go in [Scarlett's bedroom], and Adrienne will go, 'You should videotape that, Mom.' And **she knows, like, she knows everything**. She'll say, 'What's her temp?' 'Oh, you know, it's 38.2.' 'Oh, that's high. We need to give her Advil now and blah blah blah.' **She knows all of it. 'Mom, Scarlett needs to be suctioned. Scarlett needs this. Scarlett is doing this.' Like she knows all of it**. (Ursula)

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[53] Judy did not notice Aiden's g-j tube was hooked up to his feed. Her tried to pull him out of the chair and inadvertently pulled the tube out of his stomach.

From a young age, Ursula's daughter exhibited a keen interest in her older sister's care, which has continued and blossomed even though she is still relatively young.

Most of the literature on siblings discussed the effect of having a medically complex sibling while adding negating qualifiers. For example, even though they are more likely to develop depression and anxiety, they also build altruism (Lowes, 2007). Researchers note the development of resiliency (Ashton & Ashton, 2018), acceptance of differences (Ashton & Ashton, 2018), increased sensitivity (Faux, 1984), and understanding (Ashton & Ashton, 2018) in the literature as positive outcomes for siblings. The parents I spoke with mentioned similar observations.

> **My oldest daughter…I'll be ok [tears up]. But she's she would be the picture of why having Mia is the best because the person she turned out to be, it's like amazing. Like she's so empathetic and compassionate**, and all her teachers are like love her. And she's got like a 98 average, and **she works really hard. And it's just like; she's a superhuman**, you know. And I think a lot of that has come from having to deal with a life that is totally out of your control, you know. She has had to help us a lot. She has sacrificed a lot, but she just, you know. And she does like—she's very happy kid. She's not resentful. She has a social life, and she does her thing like she owns her own car—she bought a car year ago. And she's just like the hardest worker on the planet. But I think a lot of who she is is because of Mia because we had to do with Mia, right? So and she knows it too, you know. She's written about it in school like. They got like writing assignments for English and stuff, and she said to me the other day joked she said, 'Mom, she said anytime I have to write about something like off top my head.' She said, 'I just write about Mia because then I get 100%.' I'm like, 'Oh my God, you're hilarious.' I said, 'Really? Are you using your sister to get good marks?' She's like, 'Yeah, gotta use her for something. She gotta be good for something [Laughs].' (Penny)

> **I think Amanda is a lot more empathetic than most of her like friends. I think she's wise beyond her years. I think it's been a very positive thing, like you know, she is mature.** And if anything goes wrong—like any kind of injustice, you know. She's right there to stand up and go, 'Oh hell no, that's not gonna happen.' She will, but she's good. And you know, she knows all the medical stuff. (Emma)

There is no denying that siblings of medically complex children develop additional strategies from the experience. They build empathy and understanding, but the corresponding price is largely unaddressed in the literature.

> **I just wonder how much weight siblings carry**. **We had a family friend who had a sibling with a significant disability. And you know, as he grew older and his**

> **parents passed, like, the care of that sibling really fell on our friend to the point where like, he never married, never had children.** Because he didn't have the time to be able to do that, but like, would his life have been different had he not had a sibling? You know—had not had to take over that caregiver role. He said he promised his father that he would look after his brother, and he took that to heart. And that was a lot of the reasons we decided on a third child because we didn't want to have that—not that we would ever expect Sara to—'cause we will have arrangements made long before if that ever came to pass and Ethan needed care, it would never be Sara. It's just visiting, you know, like. Yes, ok, you have a sibling who's in care somewhere like, and you're the only other family member. Like we want to have other children to split that responsibility. (Debra*)

Debra discusses the effect of having a complex sibling with a long-term view. She agrees that siblings may find the experience rewarding but also understands the additional long-term burden and makes a plan based on the potential outcomes she envisioned. Six of my interviewees had multiple children, and all of them discussed the effect their divided parenting had on the other children; most of them discussed the positive associations with having a complex sibling, but only Debra extended the discussion into the price siblings pay for this in the long term.

As I noted, the literature on siblings of medically-fragile children is grossly underdeveloped. In my experience, avenues for help and support are non-existent, making this a critical area for future research.

5.4 The Medical Parent and Their Interactions with Faith

Faith emerged as a theme during an interview, and after reflecting on it, I added it as a probe to subsequent discussions, where the opportunity arose. Although some of my interviewees expressed an explicit belief in God and Christian faith, I use the term faith here in the broader sense to refer to the belief in a higher power and an ordered universe.

From my personal experience, coping with a child's medical instability is daunting; without a higher belief system, it may feel impossible. Spirituality provides hope and purpose (Ashton & Ashton, 2018; Biaggi Leite et al., 2019), and some parents began their parenting journey without faith but developed it along the way.

> **It's weird how things happened. It's just really weird—it's funny how you had just what happened to you, and now we're meeting**. That's weird**. I'm pretty logical, pretty rational. But there's times where I'm after having, especially around Tommy, there's just been these things where I'm like, 'Man oh man,'** these weird little coincidences. [We met a doctor with a lot of experience with Tommy's condition, which is a very rare disease]. But it was one of those just serendipitous things and just something something around Tommy. Always said I'm more of an analytical person, but since all of our kids, I'm a little bit more willing to delve into the idea of spirituality and, well, this is interesting. (Michael*)

Michael and I realized that we shared an unexpected commonality between our children, which prompted him to talk about his budding spirituality. This comment reminded me to reflect on my path, which was similar. I would have described myself as agnostic-ish when my daughter was born, but I quickly developed a solid faith-based belief system. I also recalled a friend who had a similar transition. After the medical journey with his child, he changed careers and became a minister.

However, the experience may be different if someone has faith before becoming the parent of a medically-fragile child.

> I remember being in NICU, and at this point, we were, I don't know, we were probably in there a couple of months. And again, like, I'm still kind of, you know, like new to it all. Like, I'm still in just the twilight zone, you know. Nothing really makes sense. Anyway and there was one day where there was a baby, and I remember thinking like the baby was really dark—not not like skin colour but just like, just like they weren't well basically. And like the doctors were all in looking at him or her—I don't even know if it was a little boy or little girl. Anyways, I'm in at the bedside. And there were other people coming in and all this sort of thing. Then the next day, I come in, and the bed is empty. There's a rocking chair there in its place, and I'm like, 'Oh my God, they got to go home—they went home already.' But you know, and then the mother came in to pick up the last of the belongings and she's crying and the nurse is crying. **And all of a sudden, it hit me. It was like, 'Oh my God.' It was then that like—children die. My child could be one of them**. It just hit me like a ton of bricks. Up to this point, I thought, 'Well, they're all safe; this is all safe.' I mean, like they're gonna take care of him, and suddenly it was like; there's only so much even medicine can do. And I mean, like, I had to leave and go take a walk and all this kind of stuff. **But I really truly did not think that God would ever let that happen. And then I was angry for this other mother's loss**. (Shelley)

Spirituality is based on trust (Ashton & Ashton, 2018). For someone who believes in a higher power and an ordered world, death and disability may feel like a breach of trust (Ashton & Ashton, 2018), especially if the deceased is a baby just entering the world.

> I do remember like I remember, you know, being angry with people I didn't even know just because they had no idea [that babies die]. And it wasn't a case of like, 'Oh my God if you only knew what I was going through.' I gotta say, I was angry at the world**. I was very mad with God; we did not have a good relationship for quite some time, I'll be the first to admit. We're OK again now,** but I was just I was so angry. (Shelley)

As a parent, Shelley was exposed to loss during her son's NICU admission when he was diagnosed with his disability. The experience caused a lot of anger towards God which continued for a long time, but she has since come to terms with it.

If the pre-existence of faith leads to a potential breach of trust following the death of a child, then it seems logical that faith that developed during a child's illness may falter after the child dies. I cannot address this question with direct data from my interviews. But Bonnie's comment in the section below indicates the continuation of faith for that family. In my personal experience, people asked me what kind of God would let my child die. I would answer by providing them with my personal belief of the situation;

> When Minxie was young, she was granted a Wish trip to Florida. We flew from St. John's to Toronto, and Toronto to Orlando. I consider the question "How could she die?" to be as illogical as asking, "Why didn't you get off the plane in Toronto?" Toronto was never the destination—it was the necessary path to reach the final location. Just like this life is the required stop before moving on to heaven. **My daughter moved from here to a place where there are no hospitals and no wheelchairs. How could I be mad at God for providing her with such a place?** (Me)

Both comments place death within the continuity of existence, of life beyond death, with interpretations of what that life looks like; no hospitals, no wheelchairs, but birthdays are celebrated.[54]

Some parents talked about faith providing continuity through death.

> Wanda: He was three weeks in ICU [in the adult world] there about two years ago. But he was up in the floor, and he was desating and desating, and he was in 100% oxygen—he was 80. And I was just, I couldn't comprehend it—and that's not me. And they were like, 'We're going to have to bring him to ICU. He's going to have to be intubated.' I was like I said, 'Fuck, let's grab everything, go down.' And they wouldn't let us in 'cause they were doing stuff with him. I just about threw up in the corridor. So when we went in, I saw him, I was actually [sigh, relieved] cause he wasn't suffering anymore—he had like the tube in, and he was sedated, and he was [relaxed and calm]. So I was actually really relieved. So he was on that for a week until he stabilized cause he had pneumonia. And you know, but they said, 'Ok, we're going to have to start weaning him off.' And that was Friday, so I got up behind him I said, 'Now Leo, can you hear me?' I said, 'Just blink your eyes once for whatever, twice for whatever.'' [blinks yes] I said, **'Ok, I'm going to have a talk with you now. And, it's going to be a serious talk.' I said, 'Are you ready to go to heaven?' He went [blinked, indicating no]. I said, 'No? Ok, here's what's going to happen. You're going to have to smarten the fuck up** cause tomorrow this is what we are going to try, and then Sunday this is what we are going to try, and then Monday we are going back up on the floor. Is that good with you?' [blink indicating yes] I said, 'Ok, glad to hear it.' so anyway, you know Martha Janes?
> Me: I do
> Wanda: Love her. Anyway, I told her, and she told Dr. Jones, and he said, 'Never said that to that child?' I said, 'Yes, I did. He had to be told what was going on—it's his life, you know, it should be his choice.'

Wanda framed her question to her son as one of transition—"Are you ready to go to heaven?" Rather than finality, it provides continuity, allowing parents to engage with the concept of transition.

> Jack was in hospital for his first Christmas. He was in PICU, and what we done we had Christmas at home, we stayed at home, and then we came in after. We opened presents out there, we came in and had Christmas with Jack. Buzzed into the PICU, 'Jack's mom and dad are here,' 'OK, Dr. Reily is coming out to see you.' Dr. Reily came out, and she said, **'I realize it's Christmas, and I realize you wanna celebrate. But if you could please keep it to a minimum because the other child that was here just passed away a half hour ago, and the family's still in there**.' The kid and the family were in #5, right? It was the moment, and I can still literally fucking picture her in front of that door; it's so seared into my mind ten years later. It's the moment that I realized that this is where they die—that there is not

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[54] As per Bonnie's comment below.

> somewhere else that you go, you know. They are that sick. Until then, I just thought this is where they go until they get better; but they will get better. So anyway, I was telling that one to Roberta, actually, the physiotherapist, and this was a couple of years later—quite a few years later. She said, 'I know the family you're talking about.' **She told me that they were big believers in God, and they took a lot of comfort in the fact that or the idea that their son went home to be with Jesus on his birthday.** (Bonnie)

As Bonnie's comment indicates, this continuity of life beyond death also provides contentment for parents after their child's death. If someone believes in such continuity, they may experience it in other areas.

> Oh yeah, well, I'm spiritual. I'm not religious. That [cross] actually was a gift I gave to **my grandmother** in England—my mom's British, and I gave to her many, many years ago, like maybe 30 years ago. When she passed away, I got it back. So it actually represents my nan more than [anything]. **She's always in the kitchen with me, I'm always smelling her kitchen, and I'm always like she's always in the kitchen**. That's one of the other ways that has helped me survive is having some faith in spirituality that, like, 'Jesus, some things,'—no offense to Jesus. I didn't mean it—that was ironic [laughs]. But 'cause I'm sort of moved away from more of the religion than just the spirituality. **My grandmother has come to me many times, and when I've been really, really down, like really, really dark times. She's yeah it's, it's wild, and she was always a very spiritual person,** and she's just she's a bit of a force like she's like she was huge in the community she was like this amazing person. (Helen)

Helen said she often smells her grandmother while in her kitchen. Coupled with her belief in the continuity of life beyond death, she interprets this as an indication that her grandmother is present with her in the kitchen.

Belief in a higher power allowed some parents an outlet for frustration.

> **I get it that I'm sure people are uncomfortable when Aiden is around. And that's fine, but like, I'll pray for them**. That's good too, but like, I don't know—don't make it obvious that you're like, you know. (Kathy)

Many parents have experienced negative interactions with others when their complex children are publicly ostracized. Kathy notes having such experiences, but her belief in a higher power provides an outlet for her frustration and a route toward change. She can pray that these people will develop an understanding of medically-fragile children, and knowing that this may happen through prayer, provides her hope.

In addition to hope, belief also provides reassurance.

> **But this is our role. This is what we're supposed to do**, I guess, right, Carl? [to Carl] Supposed to be your mother. (Valerie*)

For Valerie, belief in an ordered world reassures her that she was meant to be the parent of a complex child. If you believe you are doing what you are meant to, you can feel reassured that you are equipped to handle it, regardless of how things progress and develop.

Considering the small number of parents I interviewed, and the declining societal belief in a higher power, faith was a vital part of my research findings, even though it constitutes only a tiny portion of my thesis.

5.5 Conclusion

As I noted at the beginning of this chapter, this portion of my thesis expands on the previous two sections by developing my ideas surrounding the medical parent in relation to others. First, I explored the medical parent in relation to the medically-fragile child using the conceptualizations of the sub-human, human, and transhuman child as the framework for discussion. From there, I detailed the ideas of gender and gendered roles that emerged from my data by exploring dad as the medical parent. Next, I considered the experience of siblings of a medically-fragile child, as detailed and conceptualized through their parents; lastly, I explored the interactions between medical parents and faith within my data.

Chapter 6: In Closing

I began this research project with the idea that I wanted to develop the existing scholarly literature by expanding on the experiences of parents of medically-fragile children using a symbolic interactionist lens. My initial literature review highlighted a plethora of information from the US, but substantially less from Canada, which has a very different healthcare system. With that knowledge, the focus of my research narrowed: how do parents of medically-fragile children describe and conceptualize their experiences here, in Newfoundland and Labrador where there is one location which provides services to these children, and public medical-care coverage?

After compiling my data, I realized my findings contributed to the current literature on the subject but also provided an understanding of the novel idea of the medical parent. I set out to explore how the differences between the US and Canadian systems translated to differences for medical parents instead, I discovered how my experiences as a parent shaped the information parents provided to me and how that interaction revealed medical parent as an identity. The medical parent is a novel idea requiring someone with a researcher's gaze and an insider status to uncover it. I started this research to highlight the voice of other medical parents to the exclusion of my parental voice. But they cannot be separated. My status shaped our interactions, which shaped how parents responded to me and influenced the depth of the information they disclosed. These findings would not have emerged without my dual role in this research. I set out to explore the differences between the healthcare systems; instead, I discovered how different the outcome can be when research is conducted within a population rather than on a people.

The overarching idea from my data is the identity of the medical parent, which stems from the concepts of medical professional, caregiver, and parent. Because this is an identity, social interactions are prerequisites of development, making the interconnectedness of my participants with each other, with me, and with the same healthcare providers and services crucial for finding and developing this portion of my findings.

I began the discussion of the identity of the medical parent by detailing how this identity is formed and confirmed through interactions with others. From there, I described how parents engage with boundary-work through interactions based on how they position themselves and those they interact with during these shared meaning-making processes. From there, I developed the concept of temporality through engagement with the past, present, and future; then discussed the intertwined ideas of normalization and medical knowledge. While I found the concepts of temporality, identity formation, and normalization in the literature before my research, my work brings them together as interrelated ideas through my novel medical parent identity framework.

Following this, I used the identity of the medical parent as the behind-the-scenes process these parents use as the filter through which they interact with the world as developed through the 13 hazards which emerged from my data. This is another point where my research ties into prior scholarly works. Each concept has been explored already, but my work draws them together as related, overlapping, co-existing ideas rather than disconnected experiences. My work expands the existing literature by developing these ideas as interrelations and then showcasing how they relate to the identity of the medical parent.

Lastly, I use the identity of the medical parent as the framework to develop and discuss how parents interact with others through the concepts which emerged from my data. Specifically, I detail their interactions with their medically-fragile child, how they talk about their child in relation to their other children, and their interactions with faith. I also discuss the father as a medical parent within my data.

Together, these ideas represent the findings from my research: that the parents I spoke with are medical parents; that medical parent is an identity; that parents interact with others based on their conceptualization of the boundaries around that identity and where they position themselves relative to that identity; and that having this identity shapes and informs how these parents interact and understand processes in the world and within their relationships with others.

6.1 Hindsight Reflections

I stand between two worlds writing my thesis; the medical parent and the sociological researcher. While holding both identities helped inform and develop some of my findings, it also made some concepts challenging to access. My supervisor noted normalization as a concept that ran throughout the quotes in my first draft of this paper, and when I read her comment, I thought to myself, "What is she talking about? This is normal." Ventilators, g-tubes, suction—it is all normal. I approached this research as both a medical parent and sociologist, and that orientation was vital for my findings, but there were also instances where I felt blinded by that dual positionality rather than empowered by it.

Looking at my data through the lens of hindsight, I suspect focus groups rather than individual interviews would have led to very different findings. During some interviews, I noticed that my interviewee and I interacted and reacted to each other because of our shared positionality as medical parents. A focus group setting would have allowed a more profound development of those nuances.

Recruiting participants for interviews was more difficult than I had anticipated. I knew my focus was on a small population of extremely busy and often overwhelmed parents. Still, I felt my insider status would help counter-balance those drawbacks and hoped recruitment would be straightforward. It was not. I also suspect the language I used in advertising may have led to some confusion about my research topic. One participant pointed out several things to me that she had found during her child's life (such as obscure cures for skin breakdown or places to purchase disability-friendly toys), while another participant commented that she had seen my post on prior occasions but felt she would not qualify because her family had not had harmful or detrimental experiences while dealing with government organizations. I suspect using the term "lived experience" caused this confusion, and in hindsight, I would have opted for something with no academic jargon.

6.2 Limitations

My research engaged with a tiny population. As a further complication, they are also an extremely busy and overwhelmed population whose lives are in a perpetual uncertain state. It is difficult for such parents to find the time to answer interview questions. Even where they have the time, they may not be in the right state of mind for the process either. To sit with someone and discuss your fears and concerns about your child's life and death requires courage, a comprehensive understanding of the situation, and an acceptance of the circumstances. Taken together, this further narrows the potential population represented in this data. I began with a small potential research population and interviewed eleven people from that pool. I had aimed for twenty, leaving me short of my goal. I made the right decision by restricting the population under study in this way, but I am sure that if I had allotted additional time for this research, I would have recruited more participants. I do not feel the volume of my data suffered; however, the small number of interviews did result in a minimal amount of repeated illustrations and quotes in my thesis. I would have preferred to use different quotes for each idea and concept throughout, but sometimes there was only one quote that effectively conveyed the picture I wanted to illustrate while maintaining the confidentiality of my participants.

My interview data provided me with thick, rich descriptions of the concept of the medical parent, but some ideas developed here emerged unexpectedly in the latter part of my data collection, such as the role faith plays for these parents. As such, these ideas warrant further development and exploration, which is beyond my scope for this thesis.

While my insider status may have helped with recruitment, it may have also worked against recruitment. Potential participants I knew as fellow medical parents may have been disinclined to speak with me because they knew me in a parental context.

6.3 Future Research

One of the critical aspects of this research is the structure and functional approach of the Janeway Hospital. The shared space allows parents to interact with each other and medical staff. But not all hospitals are structured this way. When my daughter was admitted to the ICU in Florida, she had a private room, and the nursing ratio was 2:1, so she shared a nurse with another patient, and both patients were housed in their own rooms. There was no access to staff outside of their hands-on caregiving. I suspect this decreased access would hamper the identity formation of the medical parent. The off-loading of care may also be exceptionally different in countries with private medical care because that process would lead to less monetarily backed healthcare for such families.

Future research in both countries would develop the similarities and differences parents experience and further inform how this connects with the health care professionals they interact with.

This research is intimately connected with the Janeway Hospital. Parents talked about how they experienced and understood their positionality and relationship with healthcare workers. Considering similar ideas from the perspective of Janeway medical professionals would be an informative next step. For example, how do doctors view medical parents? How do they frame parents as competent or incompetent as their child's caregiver?

My research provided me with the thick descriptions and details I have developed here, but other ideas developed from this data that I did not have room to unpack and explore, but they would serve as frames for future research analysis. The role of gender in this research warrants a deeper exploration. Both how the division of labour is gendered and how the responses from the mothers I interviewed represent traditional gender roles in our society. This could also be expanded to include the interaction between the mother, as the caregiver of her child, and doctors, as overseers of medical knowledge.

I spoke with parents of medically-fragile children for this research, but future research may also explore the lived experience of other populations—parents of children with chronic but stable disabilities, for example, or parents of children who have battled cancer in Newfoundland and Labrador. Undertaking such tangential research directions may provide insight into how different groups of parents discuss their experiences and how they frame their interactions with health care workers.

Beyond population ideas, additional research would also develop some ideas that were unexpected findings in my data. For example, I had not expected faith to play such an important role for my participants. Further research may explore this link at a more in-depth level.

Whatever the future lines of inquiry that stem from my research, if they are future developments in the concept of the medical parent, they will require researchers with insider status. Each researcher brings themselves to the interview, and interactions between the interviewer and interviewee are shaped by the researcher's responses to the interviewee. Medical parents are not easily surprised or emotionally upset, which provides an opening for parents to reveal their situations without someone feeling sympathy for them. I responded to them with empathy devoid of sympathy, which my interviewees responded to and embraced—evidenced by my findings. Further research that seeks to expand on the medical parent will require a similar orientation provided by a researcher with insider status.

My thesis marks a point of departure from previous research on the experiences of parents of medically-fragile children, which means these ideas can be considered, expanded, and re-developed along various lines of inquiry within and beyond this geographic location.

Lastly, though not related to future research, I am developing a white paper to the government based on the data I compiled for this thesis. The frustration parents expressed about accessing support services from the government was widespread and detrimental to their situations. My white paper will concentrate on the SCWA program to inform the government on how it is received by parents, where some of the more significant issues exist, and provide recommendations for policy changes to improve service delivery for these families.

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Appendix A: Interview Recruitment Documents
Social Media Post For Interviews

My name is Amie Richards, and I am a student in the Sociology Department at Memorial University of Newfoundland. I am conducting a research project called Impossible Circumstances: the lived experience and community building among parents of medically fragile children in Newfoundland and Labrador for my master's degree under the supervision of Dr. Lisa-Jo van den Scott. The purpose of the study is to gain a deeper understanding of the lived experience of and community building among parents of medically fragile children in Newfoundland and Labrador. For parents, it will provide a venue to discuss their experiences and allow their voices to be heard.

If you are the parent of a medically fragile child, I would like to invite you to participate in an interview in which you will be asked to talk about your experiences parenting your medically fragile child and where you turn for help and support along your journey. Participation will require approximately 90 minutes of your time of your time and will be held at a location of your choosing.

For the purposes of this study, eligibility is determined as parents of those whose children are:

1. medically fragile and/or severely disabled
2. Have experienced frequent and/or prolonged admissions in the Janeway PICU within the last 4 years.

If you are interested in participating in this study, please private message me. Please DO NOT respond to this post publicly.

If you have any questions about me or my project, please contact me by email at z99afr@mun.ca or by phone at 709-222-9302.

If you know anyone who may be interested in participating in this study, please send give them a copy of this information.

Thank-you in advance for considering my request,

Amie Richards

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as your rights as a participant, you may contact the Chairperson of the ICEHR at icehr.chair@mun.ca or by telephone at 709-864-2861.

Recruitment Poster

DO YOU WANT TO HAVE YOUR VOICE HEARD?

My name is Amie Richards, and I am a student in the Sociology Department at Memorial University of Newfoundland. I am conducting a research project called Impossible Circumstances: the lived experience and community building among parents of medically fragile children in Newfoundland and Labrador for my master's degree under the supervision of Dr. Lisa-Jo van den Scott. The purpose of the study is to gain a deeper understanding of the lived experience of and community building among parents of medically fragile children in Newfoundland and Labrador. For parents, it will provide a venue to discuss their experiences and allow their voices to be heard. For health care professionals it will provide an opportunity to reflect on your role in the lives of these families.

If you are the parent of a medically fragile child or a health care professional who provides on-going care to medically fragile children, I would like to invite you to participate in an interview in which you will be asked to talk about your experiences. Participation will require approximately 90 minutes of your time and will be held at a location of your choosing.

For the purposes of this study, medically fragile is determined as children who:

1. Experience long-term health repercussions due to one or more medical conditions.
2. Have experienced frequent and/or prolonged admissions in the Janeway PICU within the last 4 years.

If you are interested in participating in this study or have any questions about me or my project, please contact me via telephone at 709-222-9302 or email at z99afr@mun.ca

If you know anyone who may be interested in participating in this study, please provide them with this information.

Thank-you in advance for considering my request,

Amie Richards

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as your rights as a participant, you may contact the Chairperson of the ICEHR at icehr.chair@mun.ca or by telephone at 709-864-2861.

Appendix B: Informed Consent Form

Title:	Impossible Circumstances: The Lived Experience and Community Building Among Parents of Medically Fragile Children in Newfoundland and Labrador
Researcher(s):	Amie Richards, Masters Student, Sociology Department, Memorial University of Newfoundland, (709) 222-9302, z99afr@mun.ca
Supervisor(s):	Dr. Lisa-Jo van den Scott, Department of Sociology, Memorial University of Newfoundland, lvandenscott@mun.ca

You are invited to take part in a research project entitled "Impossible Circumstances: the lived experience and community building among parents of medically fragile children in Newfoundland and Labrador."

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Amie Richards, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Introduction:

My name is Amie Richards, and I am a Masters student in the Sociology Department at Memorial University of Newfoundland. I was also the parent of a medically fragile child and, as such, I understand some of the things parents of medically fragile parents are faced with. As part of my Masters thesis, I am conducting research under the supervision of Dr. Lisa-Jo van den Scott to explore the lived experience of such parents.

Purpose of Study:

The purpose of this study is to gain a deeper understanding of the lived experience of and community building among parents of medically fragile children in Newfoundland and Labrador. For parents, it will provide a venue to discuss their experiences and allow their voices to be heard.

What You Will Do in this Study:

Parents of medically fragile children who express an interest in participating will first be provided with this form and an opportunity to ask any questions they may have. They will then be asked if they would like to participate. Should they agree, we will set up an interview time together. Interviews will be one-on-one and conducted in the venue most comfortable for the participant. Interviews will consist of open-ended questions and are expected to last 90-120 minutes. Please note that you may skip any questions that you do not wish to answer and no explanation for skipping a question is required.

Participants will be asked to bring along 2 items for discussion to the interview. One item that visualizes something positive about parenting their medically fragile child and one that visualizes something negative. The representation can be a personal photo, a memento, a cartoon, a social media meme or any other thing that the interviewee considers appropriate.

Length of Time:

Interviews are expected to last 90-120 minutes. There are no further time commitments beyond the interview process.

When all interviews are completed, I will conduct 2 gift cards draws both in the amount of $50 as an honorarium for participation. All those who participated in the interviews will be included in the gift card draws.

Withdrawal from the Study:

The participant may stop or end their participation **at any point during the interview process** by informing the interviewer of their desire to withdraw. At which point, the participant will be asked if they wish for the data collected up to the point to be included in the data collection process or removed. Participants will not be coerced or enticed to continue once they have expressed their desire to stop.

If the participant wishes to withdraw from the study **after** the data collection process has been completed, they must contact the interviewer **within 30 days of the interview** to express their desire. Participants will be provided with a card containing the interviewers contact information and cut-off date for data removal at the time of interview.

Possible Benefits:

a) Participants will have a venue to share their stories and concerns.
b) Discussing these situations may help participants articulate them and provide a deeper understanding of them.
c) Discussing these circumstances may help to identify ineffective service delivery methods among parents and community partners.
d) Having a deeper understanding of the relationship between parents and community partners may facilitate developing more positive relationships.

e) Documenting and disseminating the experiences of these parents may help others understand the challenges such parents face.

Possible Risks:

There is a potential risk of the interviewer spreading Covid-19 through the data collection process. To reduce this risk, I will be implementing a testing regime on myself during the collection process. I will administer (either at home or through on-site PCR testing, such as that available through MUN campus) a Covid test 3 days prior to any scheduled data collection, again on the day of collection, and 3 days post collection for each interview. Additionally, I will perform a Covid self-assessment once a day every day starting 3 days prior to collection and ending 3 days post collection. Results from each self-assessment and Covid test will be recorded in a notebook, including date and time of testing. If at any time during that process I begin to exhibit symptoms or test positive, I will reschedule the interview, and any potentially affected parties will be notified immediately. Participants are welcome to view the entries and results pertaining to their interview, if they so choose.

Participants may become upset, as this is an emotional topic. If this happens, they will be asked if they would like to take a break. If the participant becomes extremely upset, the interviewer may conclude the interview early. Please note that mental and emotional help is available, should you need to speak with someone, please contact one of the following services:

1. Community counsellors: this program is available through the government of Newfoundland and Labrador and provides counselling related to grief, loss, depression, and anxiety (among other things) and may be accessed through www.bridgethegapp.ca or by calling 811.
2. DoorWays: this program provides single-session drop-in counselling services with no requirement for a referral or appointment and may be accessed by calling 811.
3. Mental Health and Addictions System Navigator: This service provides information on available resources to individuals and may be accessed by calling 709-752-3916 or 1-877-999-7589.
4. Additional supports can be found online at https://www.canada.ca/en/public-health/topics/mental-health-wellness.html and https://www.gov.nl.ca/hcs/mentalhealth-committee/mentalhealth/
5. Emergency mental health resources may be accessed by contacting 911 or 811.

There is a loss of privacy between the participant and interviewer as they will be providing information that is personal and previously unknown to the interviewer. The interviewer will ensure that participants are fully aware that answering any question is voluntary-they are under no obligation to answer anything. Additionally, while the interviewer will take all possible steps to ensure confidentiality, given that this is a small community, there may be a loss of privacy/reputation between a participant and someone reading the results who is familiar with the topic being discussed. For example, if a parent is providing information about their son’s surgery and points out that this surgery was the first of its kind in Newfoundland, it may be possible that the surgeon or some of the nurses involved in that patient’s care would be able to discern who the patient was and, thus who the interviewee was. To combat such things, the researcher will cover the identity of the participant insofar as possible without compromising the data. For example, if the child was 10 at the time and female, the researcher may change the sex to male and the age to 15, if such changes do not affect the data.

Confidentiality:

The ethical duty of confidentiality includes safeguarding participants’ identities, personal information, and data from unauthorized access, use, or disclosure.

The data from this research project will form the basis of the researchers Masters thesis and may be published and presented at conferences; however, your identity will be kept confidential. Although I may report direct quotations from the interview, you will be given a pseudonym, and all identifying information (such as name, location, age, etc.) will be removed from the report or edited to ensure confidentiality.

Because the participants for this research project have been selected from a small group of people, all of whom may be known to each other (directly or indirectly), it is possible that you may be identifiable to other people based on what you have said. As noted above, the researcher will try to cover all potentially identifying characteristics without compromising the integrity of the data collected and while I am confident this will protect your confidentiality in general, I cannot guarantee that those most closely and intimately familiar with your child and family will not be able to discern your identity.

Anonymity:

Anonymity refers to protecting participants’ identifying characteristics, such as name or description of physical appearance.

Participants’ city and location of interview will be recorded in my forms (e.g. Tim Horton’s, Gander). Your name will only appear on the consent forms, which will be stored separately from the data. I will not be collecting personally identifiable information such as birthdates, addresses, etc. Interviews will be transcribed verbatim so, everything you say will form the written record of the conversation. However, identifying characteristics of both participants and their children will be protected in any and every format. As I transcribe, I will anonymize the data. Ex.: [my child] instead of typing the child’s name. Another example: if a parent is talking about a surgery that their child underwent that was the first of its kind at the Janeway, then the fact that it was the first of its kind is important and that part needs to be preserved. However, the sex of the child, the year of the procedure, and the age of the child at the time are all details that may be changed to ensure anonymity of the parties while preserving the pertinent details. Participants and their children will also be provided with pseudonyms and all written information (besides the Informed Consent Form) will contain only their pseudonyms.

Every reasonable effort will be made to ensure your anonymity. You will not be identified in publications without your explicit permission.

Although every reasonable effort will be made to protect your identity to others, participation in this researcher is not anonymous as you are identifiable to the researcher

Recording of Data:

Interviews will be audio recorded by the interviewer and transcribed verbatim into a word processing program.

If participants use mass media visual representations as part of the interview process, they will be asked if they consent to the representation being included in the data collection as well. If they use personal representations, they will not be asked about including such representations in the data and they will not be recorded.

Use, Access, Ownership, and Storage of Data:

The researcher will be the only person with access and/or ownership over the data.

All electronic data will be stored on the researcher's personal password protected computer until data analysis is complete at which time, it will be transferred to a password-protected USB drive and stored in a combination lockbox which will be placed inside the researcher's locked file cabinet.

All hardcopy data will already be anonymized and will also be placed in a file folder inside the researcher's locked file cabinet.

Data will be kept for a minimum of five years, as required by Memorial University's policy on Integrity in Scholarly Research.

Reporting of Results:

Upon completion, my thesis will be available at Memorial University's Queen Elizabeth II library, and can be accessed online at: http://collections.mun.ca/cdm/search/collection/theses.

Data from the findings may also be published in a journal article, reported to an agency, and/or presented at a conference.

Data may include direct quotations, which will be anonymized, as discussed above.

Sharing of Results with Participants:

Participants may access full project results at the website noted above or the researcher will provide a hard copy, upon request.

Questions:

You are welcome to ask questions before, during, or after your participation in this research. If you would like more information about this study, please contact: Amie

Richards (Researcher), 709-222-9302, z99afr@mun.ca, or Dr. Lisa-Jo van den Scott (Supervisor), lvandenscott@mun.ca

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.
- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to withdraw participation in the study without having to give a reason, and that doing so will not affect you now or in the future.
- You understand that if you choose to end participation **during** data collection, any data collected from you up to that **point will be retained by the researcher, unless you indicate otherwise**.
- You understand that if you choose to withdraw **after** data collection has ended, your data can be removed from the study up to 30 days from the date of interview.

I agree to have my photovoice representations included in data collection (mass media representations ONLY. Personal representations will NOT be included. ☐ Yes ☐ No
I agree to the use of direct quotations ☐ Yes ☐ No
I allow my pseudonym to be identified in any publications resulting from this study ☐ Yes ☐ No

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your Signature Confirms:

☐ I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

☐ I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

☐ A copy of this Informed Consent Form has been given to me for my records.

Signature of Participant Date

Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of Principal Investigator Date

Appendix C: Interview Guide

Opening reminder: Skip any questions you are not comfortable with

Child
-Tell me about *(child)*
-When/how did you first know your child had medical issues? Take me through that
-Do you remember when (first big event/hospitalization/etc. happened)? Take me through that
-Progression since then: how things have changed over time
-How are things expected to progress in the future?

Experience
-Photovoice representation of worst moment/experience
-Photovoice representation of best moment/experience

Personally
-Tell me about your role in *child's* life when it comes to dealing with health care workers?
    -School staff
    -Respite workers
    -Friends
    -Strangers
    -Other organizations
-How do you feel about being in these roles?
-How do you think other people feel about your roles in these positions?
-What do you say when you call into the PICU?
-Has your health changed since you've had *child?*
-If you were to describe parenting your child/a medically-fragile child to someone who had no idea what this parenting entails, what would you say to them?

Community
-Where do you turn for help/who do you rely on?
-Tell me about the help you get there?
-Do you get enough support there?
-Where else do you get support?
-Do you have people in your life that you feel understand what its like to be a parent of a medically-fragile child? Tell me about them.
-Are there health care providers that you rely on?
-Are there other organizations that you get support from?
-Do you get support from other medically fragile families?

Closing
-Is there anything else you want to tell me about
-Is there anything you think I should have asked you, but I did not
-Do you have any questions for me?