Giving Dad the Spotlight:
Paternal Experiences of Raising a Child with Cerebral Palsy: How Does This Influence Fatherhood Trajectory and the Meaning of Fatherhood?

By

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Abstract

For approximately the last 45 years, researchers have examined a standardized pathway for an individual's life course, involving leaving the parents' home, building a stable career, getting married, having children, followed by retirement and death. Contrary to what was been previously discovered, the life course is no longer considered as linear as it was once thought to be. This statement has been further investigated and proven more specifically among families of children with special needs. This Master's thesis reviews the perspective of 11 (eleven) fathers of children with cerebral palsy located in Canada and in the United States. Fathers voluntarily participated in a qualitative 90-minute qualitative structured interview, followed by the construction of a historical timeline of key events pertaining to their journey to becoming a father. Qualitative analyses consisted of a content analysis to investigate how fatherhood is constructed and the experiences of being a father to a child with cerebral palsy consist of. In essence, becoming a father to a child with cerebral palsy is an extremely emotional experience as complex and continuous feelings emerge in those transitioning into fatherhood.

"It's not about what we can't do, it's about what we can do" – Fathers of children with cerebral palsy.

Keywords: *Cerebral Palsy, Fatherhood, Life Course, Sociology, Qualitative, Critical Disability Studies, Kinship Imaginaries.*

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Kelsey Seguin, Ottawa, 2023

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Introduction

Numerous research articles have placed in-depth significance on examining the life-course transition of individuals (e.g., leaving home, attending post-secondary education, stable employment, marriage, starting a family, and retirement: Mitchell, 2006). Since its conception, this traditional pathway has shifted as a repercussion of multiple transitions occurring among individuals and changing societal norms. Families are central to the life course because their internal and external dynamics characterize the modern life span emphasizing the sequence, timing, meaning, and implication of the various social roles one may have during their life course (MacMillan & Copher, 2005). *Roles* can be defined as "positions that individuals occupy within social institutions and family" (MacMillan & Copher, 2005, p. 859). *Roles* are most often conceptualized as *role trajectory* (a situation from start to finish, ending with a transition) and *role transition* (short duration, from one role to another) (MacMillan & Copher, 2005, p. 859). Likewise, roles can be defined as schemas providing a blueprint for roles and behaviors (MacMillan & Copher, 2005). The way a role shapes itself is predominantly influenced by factors that are part of everyday lives that include but are not limited to culture, social factors, and the environment. In turn, because the life course is characterized by the interlock of multiple transitions that occur over the biological process of aging, the life course perspective has the necessary elements available to comprehend the variety of transitions that an individual may experience in a continuously changing society.

The life course perspective states that once the transition to parenthood occurs, permanent changes are set in place for both mother and father (Deave & Johnson, 2008). Not only are permanent changes implemented, but parents and their children also transition together as they each enter a new stage of life. Thus, being a parent brings more change than any other

developmental stage in the life course because this change results in an adapted lifestyle. In other words, parenthood forces individuals to change their roles, as their expectations may be associated with what they envision to happen in the future (Roy 2014, p. 319). Furthermore, the process of becoming a father not only shifts over time, but parenting roles also change as their child's needs shift as they grow older. Thus, it remains necessary to examine fatherhood over an extended period, rather than examine it solely one point in time.

This project will concentrate on the transition of couples expecting a new addition to their family, more specifically, the experiences of fathers' caregiving for a newborn diagnosed with cerebral palsy. For every family, the birth of a child indicates a new transition with adaptation periods ranging from but not limited to creating new daily routines and adjusting to new roles within the household (Kazak & Marvin, 1984). Future experiences for parents are inspired by the arrival of a newborn child, such as teaching your child how to ride a bike or teaching your child how to swim. However, normative expectations of parenting are challenged when a family welcomes a child with developmental difficulties. According to the World Health Organization (WHO), a *developmental difficulty* is described as a group of conditions due to an impairment in physical, learning, language, or behavior usually beginning in the developmental period (2012). As a repercussion, parents of children with developmental difficulties are faced with long-term uncertainty and encounter daily challenges that other families may not experience (Kazak & Marvin, 1984). Regarding a child diagnosed with cerebral palsy, it has been discovered that families may experience a variety of challenges, including extensive daily caregiving demands, frequent trips to healthcare facilities, advocating upon their child's behalf, and long-term concerns about their child's health (Palisano et al., 2009). In turn, these additional factors create different daily routines from families with children without developmental disabilities, but these

differences are currently neglected within the scholarship on parenting and the life course. Thus, additional research is required to better understand the unique challenges that parents of children with cerebral palsy may encounter during their transition to parenthood and for the rest of their lives.

What is Cerebral Palsy?

Cerebral palsy is one of the most common disabilities diagnosed in childhood, affecting one in every four hundred (1/400) children. *Cerebral* means brain, while *palsy* signifies paralysis or inability to move (Cheschire, Barlow, & Powell, 2010). Most definitions describe cerebral palsy as a neuromuscular disorder where a "group of permanent movement disorders affecting the individual's overall motor ability causing activity limitations" (Cheschire, Barlow, & Powell, 2010, p. 1673). Cerebral palsy can also be described as "a static lesion occurring in the immature brain that leaves children with permanent motor impairment" (Miller 2005, p. 27). These limitations are generally caused by complications occurring within the fetus or a lack of oxygen exposure at birth, creating brain injury before complete development of the cerebrum (Krigger, 2006). Eighty percent of cases are acquired prenatally, but cerebral palsy can also occur perinatally and postnatally, as brain development remains continuous for the first two years of life (Krigger, 2006). Cerebral palsy can be categorized into the following types: athetoid, ataxic, atonia, rigidity, spastic, and tremor (Palmer, 2004). These categorizations are based on what limb(s) are affected and the distribution of motor impairment(s) (Cheschire, Barlow, & Powell, 2010). Cerebral palsy can also be distinguished by the degree of severity with a chart ranging from Class I (no limitations) to Class IV (unable to do any physical activity) (Palmer, 2004).

A diagnosis resulting in cerebral palsy is based on two primary factors (1) etiology and (2) anatomic classification. *Etiology (cause of the disability)* can be congenital, neonatal, or

postnatal while *anatomic classification (what area on the body)* is based on what location of the body is affected (e.g., hemiplegia, diplegia, double hemiplegia, etc.). (Miller, 2015). In this circumstance, etiology may be known but it is not required as it does not aid treatment in comparison to a disease that is curable (Palmer, 2004). As such, the cause of cerebral palsy is not of primary concern. It is the diagnosis that remains essential while the etiology is utilized to keep track of the infant's maturation and developmental milestones (Miller, 2015). Health complications premature infants may experience in the hospital include but are not limited to affected suck-swallow-breathe coordination, underdeveloped lungs, and lack of body temperature regulation (Golish & Powell 2003, p. 311). Nonetheless, the premature newborns' organs have not reached the required level of maturity to function independently, and development must be completed with an incubator for an average 14-16 week stay that may include ventilators, monitors, and tube feeding (Golish & Powell, 2013). In most severe cases, cerebral palsy can be accompanied by a variety of secondary disorders, such as but not limited to epilepsy (25-38%), swallowing difficulties, and sensory processing disorders such as textures, lights, and sounds (Cheschire, Barlow, & Powell, 2010; Jaynes-Nicewander, 1988).

It is crucial to reiterate that cerebral palsy is not a degenerative condition; at the same time, it is permanent with no cure. However, early intervention can provide greater tonal and reflexive movements, helping overall posture and independence (Cheschire, Barlow, & Powell, 2010). Hence, parents of children with cerebral palsy must make permanent adjustments within their family lives, ranging from a greater level of caregiving, treatment regimens such as but not limited to neurodevelopmental therapy, botulinum toxin (Botox), physiotherapy, occupational therapy, surgery (rhizotomy, heel cord lengthening) and orthopedic devices (Cheschire, Barlow & Powell, 2010; Brehault, et al., 2004).

Diagnosing Cerebral Palsy

Research suggests that an infant who does not reach motor developmental milestones at the appropriate age is a standard predictor of cerebral palsy (Palmer, 2004). Examples include abnormal muscle tone, feeling stiff, development of Moro reflex after 6 months, and signs of hand preference before one year of age (Krigger, 2006). Diagnostic tools are vast but the most recognized tools for diagnosing cerebral palsy include the Child Health Questionnaire, Pediatric Evaluation of Disability Inventory, and Gross Motor Classification System for Cerebral Palsy (Krigger, 2006). Receiving a diagnosis is not only essential for identification but serves additional purposes such as determining the specificity of the diagnosis, long-term prognosis, and possible secondary conditions that may develop over time (Palmer, 2004).

Parents' reactions to their infant's diagnosis have not been examined in-depth (Schuengel et al., 2009). However, research shows that parents of newly diagnosed infants may feel a sense of ambiguity regarding their child's level of impairment and functioning. In turn, this ambiguity may create a sense of uncertainty and parents may grieve a normative life course pathway.

Premature Gestational Labour: Neonatal Intensive Care Unit (NICU)

Statistically, two percent (2%) of newborns are born before thirty-two weeks and are considered extreme preemies, while those born before thirty-seven weeks are known as preemies. Ten percent (10%) of preemies and extreme preemies are diagnosed with a severe disability (Whittingham et al., 2014). Primary concerns and expectations tend to be influenced by their experiences and interactions with others along with the fact that before their child's birth, most individuals have limited social encounters with an individual diagnosed with a disability (Seligman & Darling 2007, p. 99).

Having a premature infant in the NICU appears to be more traumatic for fathers than mothers as they are not capable of being in control of the current situation (Stefana et al., 2018). For example, a lack of control can be viewed in the NICU as many new fathers often felt they were living in a separate reality due to losing track of time. Not only do fathers lose their sense of time, but the incubator is also perceived as a barrier, making it difficult to sense they had become a father (Lundqust et al., 2017). Lastly, the incubator may trigger in fathers a sense of anxiety because of their newborn's small physical appearance, and a fear of hurting their infant.

What is a Father?

F*athers can be* defined as a "biological, foster, stepfathers, and other male caregivers living in the household and caring for the child at least twenty hours a week for at least one year" (Ahmann 2006, p. 88). It has been estimated that eighty percent of men will become a father in their lifetime (Deave & Johnson, 2008). Children that grow up having a close relationship with their father foster a happier and healthier life regardless of the strength of the mother-child relationship (Broger & Zeni, 2011). Moreover, children who do have a good father-child relationship demonstrate higher levels of cognitive competence, empathy, language, economic skills, and independence, along with less delinquency and emotional distress (Mullan Harris, Furstenberg, & Marmer, 1998) (Quinn, 1999). Aside from the amount of time spent together, children will form an attachment to their father within the first six to eight months of life (Hornby, 1994). This evidence illustrates that father involvement is significant for fostering healthy child socialization, contrary to academic literature indicating that fatherhood simply entails being the family breadwinner. Despite absences in previous decades, fathers are now more physically present within their children's lives due to changes surrounding parenting norms (Broger & Zeni, 2011). However, there is little to no discussion of transitioning to fatherhood

(Palkowitz & Palm, 2009, p. 3). Previous research has examined short-term changes, such as the diagnosis process following at-home adaptation, without taking into consideration long-term changes. The disproportionality of these experiences further remains present among intellectual, developmental, and chronic disabilities, providing substantial evidence for additional research. Additional research should examine the events that fathers of children with cerebral palsy may experience differently than mothers do (Seligman & Darling, 2007).

Moreover, authors Davis et al. (2009) Navalkar (2004), Appelbaum & Smolowitz (2012), Broger & Zeni (2011) emphasize a substantial lack of literature on fathers' transition to parenthood and how fathers perceive the caregiving demands of a child with cerebral palsy, as most studies have emphasized mothers' experiences. Thus, current research does not examine how the child's cerebral palsy has an impact on men's transition to fatherhood because of a disproportionate emphasis on mothers. Out of the ten articles found through the University of Ottawa online library and Google Scholar via my own literature review, only two articles focused on the father's perspective when researching parenting experiences of children with cerebral palsy. In other words, academic literature does not adequately take into consideration fathers' experiences, especially for fathers of children with developmental disabilities such as cerebral palsy. Furthermore, despite growing interest within the social sciences in the last two decades regarding parent adaptation of families who have children with cerebral palsy (Guillamon et al., 2013), researchers Cheschire, Barlow, & Powell (2010), state that analyses have been conducted worldwide ranging from the United States, Europe, and Australia, with only one study having been conducted among Canadian communities (Brehault et al., 2004).

Thus, minimal attention has been given toward examining the role of fatherhood. One sociological study explored the following elements regarding fatherhood involvement: level of

engagement, accessibility, and responsibility. Research is now considering the social role of fatherhood (Lamb, 2000). This new factor creates variability, and opportunity for new outcomes. These new situations may be numerous, frequent, and subsequently most central to the life course because they tend to occur in response to challenging circumstances. Reasons for paternal marginalization include but are not limited to the assumption that fathers are difficult to recruit for research because of work schedules, outdated theories that still perceive the mother as a primary caregiver, or beliefs that researchers can receive the father's perspective indirectly through their partner (Jordan, 1996). Not only have mothers been perceived as the parenting blueprint, but research on fathers also remained limited when examining fatherhood involvement by studying the effect of fatherhood presence and absence in children's lives (Mitchell et al., 2007). Literature on fatherhood has also been criticized for using cross-sectional analyses and lacking consideration of external factors (i.e., education, finances, social status, etc.). that may influence the decisions individuals may choose to make as parents.

As the life course emphasizes heterogeneity, examining the diversity of parenthood is essential to gain a more accurate and descriptive picture of the challenges fathers of children with cerebral palsy may experience (Young, 1999) as parenthood is an on-going process (Jordan, 1996).

Thesis Statement

For this thesis, studying fathers of children with cerebral palsy will shed light on how becoming a father is a journey involving a cascade of continuous emotion. Not only do fathers experience a variety of intense emotions, but this thesis will also emphasize the concept of linked lives to shed light on how having a child with a developmental disability becomes intrinsically linked to their own life as the child ages. Hence, by incorporating the life course approach as my

conceptual framework and refocusing what is already known about being a parent to a child with cerebral palsy, I aspire to shed light on the accounts of men on becoming a father to a child diagnosed with cerebral palsy.

My research seeks to answer the following questions:

1. **What are the key experiences of fathers raising a child with cerebral palsy?**
2. **How do fathers describe parenting children with cerebral palsy at different moments in their child's life?**

Thesis Structure Overview

My research begins with a critical but not exhaustive overview of current literature discussing the history of the life course literature and the essential elements of the life course approach while demonstrating the paradox present in the five milestones of adulthood of the life course. This will allow for a critique of the normative sequence of milestones as fathers of children with disabilities are torn between the normative and non-normative life course. Lastly, I will use concepts of fatherhood and child milestones to enhance the life course literature by emphasizing that a normative sequence for fathers is essential as it demonstrates that their child is going to be okay. In turn, I will provide evidence that fatherhood and children are intrinsically linked when it comes to achieving both their milestones.

This study is theoretically grounded in critical disability studies and kinship imaginaries, discussed in further detail in Chapter 2. Incorporating a critical disability studies approach will allow for exploring disability as a social construct while challenging the concept of normativity and paradox of life course milestones in an ableist society. A kinship imaginaries approach will demonstrate how fathers not only re-write their narrative of fatherhood but additionally re-shape their expectations and norms based on what is compatible for their family.

The methodology for this study consists of a semi-structured qualitative interview and the creation of a historical timeline, described in Chapter 3. The analysis measure used in this study is content analysis which will be used to demonstrate themes that are essential in differentiating the transition to fatherhood from the standardized life course. This will also demonstrate how being a father to a child with cerebral palsy is talked about, not only by fathers' but from members within their immediate social circle and community. In turn, this will shed light on the activities that a father and a child with cerebral palsy experience at different moments in their lives.

Findings have been separated by theme and their accompanying subthemes, such as the key experiences of fathering a child with cerebral palsy followed by a discussion of what is unique about the transition to fathering a child with cerebral palsy, a summary of key findings, and discussion of implications with directions for future research, found in Chapters 4, 5 and 6.

Chapter 1

Literature Review

History of the Life Course Approach

The life course approach can be defined as the study of biological, psychological, and social trajectories that occur within the life course embedded in socio-historical and bio-cultural contexts (Kok 2007, p. 204), allowing for the exploration of historical events and social interaction, inside and outside the individual's biological and psychological state (Giele & Elder, 2013). In the 1960s, sociologists examined human behavior through two methods of inquiry. The first method involved observing social relations and the impact of immediate surroundings on the individual. The second method emphasized examining lives over a lengthy time, known as a longitudinal approach (Giele & Elder, 2013). One of the first studies to flourish in life course academia was conducted by Thomas and Znaniecki (1918) titled, "*The Polish Peasant in Europe & America"* who investigated the transition of Polish peasants transitioning from their rural home to urban cities. Through analysis of social surveys, Thomas and Znaniecki examined the ethnographic and historical means of an immigrant village in Poland to determine how individuals adapted to their new environment. The first hallmark study to emerge was conducted by Glen H. Elder titled *"The Children of the Great Depression"* during the 1920s and 1930s at the University of Berkeley which sought to examine how an age cohort can influence a person's life course trajectory (Shanahan et al., 2016). Elder concluded that individual lives are influenced not only by previous historical contexts but also influenced by current events as everything in a person's life remains interconnected. With a helping hand from several disciplines such as social history and developmental psychology, by 1950 the life course approach obtained the

appropriate tools to examine ecology, age, and the multiple roles individuals may occupy over their lifetime (Giele & Elder, 2013) creating a surge in the approach's popularity by 1970 (Roy, 2014 & Hutchison, 2011). With the creation of new survey techniques, longitudinal measures, and vast societal changes such as population composition, the life course emerged as a distinct field of study approximately forty-five years ago with the aid of foundational life course theorists Heinz & Kruger (2001). Early studies of the life course examined families and their roles over time within specific contexts. Four types of empirical study benefited the life course approach: historical demography (observing patterns of birth, death, and fertility in pre-industrial villages to demonstrate how location shapes individual lives) sociology of aging (cohort studies) life history (how individuals adapted human agency to face social constraints) and longitudinal surveys (demonstrate the variety of how individuals timed their life events) (Giele & Elder, 2013).

As time progressed, the life course originated as a new approach used to study the interaction between individual lives and social change occurring from birth to death (Kok, 2007). Unlike approaches that examine the predictable and universal, the life course examines the passage of time and how a variety of factors shape individuals at each stage of their life (Shanahan, et al., 2016). By examining the sequence of positions, a person has throughout their lifetime, along with the frequency and timing of these positions (Kok, 2007), this allows researchers to examine how individuals may change or may stay the same during their journey and how they may become influenced by social institutions (Hutchinson, 2011). Additionally, this approach provides an understanding of individual stories while simultaneously unveiling how their lives across time interact with correlated factors that may influence the outcome of their transition (Worth & Hardill, 2015). To summarize, the life course approach is a

multidisciplinary concept to study the sociology of change occurring through Glen Elder's five primary concepts of the life course. These concepts will be discussed below.

Five Core Principles of the Life Course Approach

The life course consists of five principles created by Elder (1998): (1) socio-historical and geographical location, (2) the timing of lives, (3) heterogeneity, (4) linked lives, and (5) human agency. These five elements are crucial in constructing the life course of the individual and providing essential context for comprehending life experiences (Heller & Harris, 2012). (1) An individual's socio-historical and geographical location will influence how they come to perceive certain life events, which may influence their future choices and future behaviors. For example, individuals born during the Great Depression or World War II may have experienced significant economic deprivation creating hardship in raising a family, rising health concerns, and lack of labor success (Elder, 1998). Concerning the (2) timing of lives, Elder (1998) distinguishes between three types of time. There is *individual time* consisting of chronological age, *generational time* consisting of age groups and cohorts, and lastly, *historical timing* consisting of societal large-scale events. Not only did Glen Elder elaborate on three types of timing, Elder elaborated further by establishing the distinction between the concept of a transition and a trajectory. A *transition* is a discrete life change that may include a change in social status, social role, or identity (Elder, 1998). A transition can also be described as a social context in which individuals' choices may influence their behaviors and making decisions toward what they see as best fit for their present time pathway (Mortimer & Shanahan, 2003). On the other hand, a *trajectory* encompasses long-term change creating stability through a sequence of stages that are intrinsically linked together. It is not a straight line, but instead, continuous (Hutchinson, 2018). Elder (1998) additionally describes the concept of *"turning point".* A

turning point can be described as “an abrupt and substantial change from one state to another” (Black, 2009, p. 42). An example of a turning point is having an infant discharged from the NICU. A turning point has also been described as an “event” where a “moment in a time and place have specific feelings, actions, and thoughts, (Levy et al., 2005, p. 17).

The element of (3) *heterogeneity* is essential as the life course perspective emphasizes the occurrence of diversity regarding individual pathways. Hence, it is essential to consider the fact that not all individuals will follow the same life course providing a connection to the concept of *reciprocity*. *Reciprocity* can be described as the idea that every person will have an impact on other persons and in turn be impacted by others during their lifetime (Elder, 1998). For example, the relationship a father or mother has with their child will have an influence on the relationship the child has with their mother or father, creating a reciprocal interaction. Heterogeneity and reciprocity can further be tied to a concept known as (4) “*linked lives*”. The concept of linked lives consists of reactions and reciprocal influences from connections ranging on broad social/individual levels but can also be examined on a wide level such as the family where for example, the level of social support may or may not constrain behavior during their lives (Portier-LeCoqc, 2017, p. 165). The final principle of the life course is known as the principle of *agency (5)*. The life course describes individuals as active agents of their own lives who make their own choices and take responsibility for the choices they make (Kok 2007, p. 2). In turn, the choices and decisions individuals make may impact their future transitions and upcoming opportunities, in turn, potentially creating constraints (Mortimer & Shanahan, 2003).

The Concept of Linked Lives

“Social relations are essential to our emotional, social, physical, and economic well-being at every stage of the life course” (Alwin et al., 2018, p. 41). For Elder (1994), we as individuals

are embedded in social relationships, kin, and friendships throughout the course of our lives. We live in social relations, with many social circles where changes in one circle will influence another. Rather we are intimately linked to the decisions and needs of those surrounding us in which we are in a continuous negotiation and adjustments in our relationships (Carpentier & White, 2013). In other words, an individual's social ties create constraint along with social control for their actions and decisions (Elder, 1998). Due to interdependence, individuals' lives can only be understood through these interconnections because they are intimately bound to the lives of others (Djundeva, 2015, p. 230). Hence, individuals are embedded within interconnections that are intertwined, naturally affecting each other. Thus, the concept of linked lives can help us comprehend family dynamics. As such, the concept of linked lives will be a key concept in the following analysis, regarding the complexity of the relational aspect of parenting a child with a developmental disability, more specifically the impact of social relationships of fathers of children with cerebral palsy.

Adulthood Milestones & Connection to Linked Lives

Inglis (2022) & Clark (2001, p. 14) discuss what are considered as the five traditional milestones occurring in adulthood: (leaving school, leaving home, steady full-time work, conjugal union, and parenting). These "*existential milestones*" are also known as "milestones where individuals organize their lives around a limited set of socially induced milestones" (Inglis, 2022, p. 31). Life course milestones are relational at the societal level and individual level. They are considered as a "existential ladder" where feelings of urgency may present themselves if an individual has not completed that specific milestone in a certain time frame (Inglis, 2022). However, the milestones in adulthood are now not only elongated due to social norm changes, such as attending post-secondary education for a longer length of time, but there

is also a more nuanced analysis of delay due to attention to inequalities ranging from socio-economic status, race, specific societal norms, physical, and biological factors (Inglis, 2022). For example, some individuals may not have the possibility to pursue post-secondary education due to a lack of financial resources. In turn, this power inequality may lead to discrepancies of expectations and the normative of "completing them on time" may force individuals to re-think their milestones to fit their own timeframe or create their own milestones (Inglis, 2022).

DePaulo & Morris (2005) further the concept of life course milestones by discussing the assumptions and stereotypes single individuals experience compared to married couples. Popular discourse tends to shape the normativity of our lives where milestones become embedded and habitual, and often go unquestioned. Thus, there is an assumption that every individual wants to marry and have children. In contrast, individuals who do not marry are considered "lonely or missing out on one of the most important social relationships" and prone to stereotyping (p. 60). DePaulo & Morris (2005) additionally discovered individuals who remained single versus divorced individuals were perceived by society as less favourable due to singlism not demonstrating potential of achieving other adulthood milestones compared to someone who was previously married. Individuals remaining single were perceived as less favorable than the divorced individuals because experiences of singlism do not illustrate potential of reaching additional adulthood milestones.

Authors Kefalas et al. (2011) add to DePaulo & Morris's (2005) argument by examining how marriage has changed over time through normative and non-normative notions of timing. Kefalas et al. (2011) make the distinction between naturalists and marriage planners where naturalists feel as though marriage is the "right thing" to do and have a "schedule to follow" while planners elongate the transition to marriage through co-habitation and realizing personal

goals. This study exemplifies how normative structures and values have become so strongly embedded within everyday lives that individuals are often not consciously aware of how these invisible rules influence the choices they make. Even though we make our own choices, these choices are made in a continuously changing environment (Kok, 2007), where the the *notion* of the *"right time"* is based on a social system that constraints future decision-making. Even though we make our own choices, these choices are made in a continuously changing environment (Kok, 2007). What may be considered as a scheduled sequence for one individual may not be realistic for another, whether it is resultant of their life experiences or a repercussion of biological and social inequalities.

Each of the five-adulthood milestone are the product of the linked lives of an individual's experiences - whether this be graduating from post-secondary education, new employment, or retirement - which occur alongside or with contribution from other individuals connected to not only the individual in question but the social environment as well (Alwin et al., 2018). In other words, we are all in relationships. As relationships change with the passage of time, so do social roles. Often, individuals may experience a "*counter transition*" where the actions of others are required before one completes the transition into that social role (e.g., in-law relationships, widow). The life course considered a personal transition is ultimately intra-personal, a social experience continuously impacted by others (Alwin et al., 2018). The lived experience may transcend the status: having an emotional connection to a child or spouse post-death. Similarly, emotional connections extend beyond divorce for co-parents. Therefore, relationships are characterized by complex combinations of permanence, impermanence, and context-driven outcomes. (Settersten, 2015).

Life Course Sequence & Normativity

According to scholars, there are social pressures around timing of life decisions or milestones (Kok, 2007). Examples include graduating from high school, moving out of your parents' home, and attending college by certain ages. Authors such as Inglis (2022) & Clark (2001) argue that politicians and others raise alarm bells when there is a demographic shift in the timing of these milestones. Patt & Fiese (2004) discuss how market time and domestic time have become more integrated and simultaneous in the life course (p. 85) as the work environment and home environment became intertwined rather than separated. Since gender and age segregation have decreased, parent life tends to be co-occurring as parents now tend to allocate equal shares of employment and housework. Additionally, because individuals tend to multiply roles over time, this variability in role change creates diversity in life course schedules. Due to these differences in timetables, this creates a difference in sequence. Thus, what is not in sequence can be potentially perceived as "off sequence". However, because of different timetables in roles, individuals are not considered off sequence but are simply asynchronous with the normative life course rather than normativity based on age or institutions. As an example, Rindfuss et al. (1987) describes the sequence regarding parenthood. For some couples, having children is something that is thought about prior to conceiving, while for other couples it is unexpected. Thus, whether parenthood is discussed or not, sequence is not essential as it becomes irrelevant to the order of activities pertaining to becoming or not becoming a parent.

The major life course milestones tend to be viewed through the lens of "norms" and normative patterns. The structures of social institutions reflect these patterns (Hogan, 1978, p. 574). Norms tend to assume and govern the order of events, where it is used to explain some behaviors and not others. Thus, transitions are not only a product of social institutions but also of

expectations in relation to institutional roles and norms and expectations (Ecclestone et al., 2009). Viewing norms and expectations in this context does not perceive them as "flexible", such as becoming and unbecoming, challenging normativity. Rather, the sequence of normative milestones is assumed to exist based on the observed aggregate order of events in the transition to adulthood (Hogan, 1978; Marini, 1984, p. 232). Life course research thus makes use of a 'normative concept of social time' which specifies 'an appropriate age for transitions' and thus makes it possible to say that individual transitions occur as relatively 'early' and 'late' transitions (Ecclestone, et al., 2009, 5-6).

Moreover, Evans & Baxter (2013) discuss the complexities of sequence when analyzing the emergence of the second demographic transition where the sequence of and timing of having children has shifted because of ideological and cultural changes such as personal and economic decisions influencing individuals' decision about having children. More specifically, while globalization and diversity of society created new opportunities for individuals, individuals are now left with feelings of uncertainty when trying to make a vital life course decision, thus potentially elongating a milestone. As a result, "life states, events, and their sequence can become experiences which either characterize an increasingly smaller part of the population or may occur at more dispersed age with more dispersed durations" (Neyer et al., 2013, p. 100).

The Transition to Fatherhood

The transition to parenthood is described as stressful for three following reasons: delivery and post-partum, energy expense, and personal adjustment (Belsky, & Rovine, 1994, p. 455). A study conducted with approximately 3,000 participants aged 21-64 stated that the birth of a child was considered the sixth most stressful life event among a list of the 102 most stressful life events (Belsky & Rovine, 1994, p. 455).

The transition to fatherhood begins when a couple anticipates bringing an infant into the world. During this time, men begin forming a paternal identity within the first trimester of their partners' pregnancy, idealizing the type of father they want to be (Genesoni, 2009). Parents may fantasize about the physical and personality characteristics of their unborn infants (Seligman & Darling, 2007). Their level of knowledge is most often gained by their interactions with other individuals within their social circle. Additionally, men are socialized as fixers, where they emphasize “what can I do?”, rather than viewing the situation through an emotional lens (Doucet, 2006). Hence, fathers may experience immense difficulty when they are not capable of fixing their child’s troubles (Doucet, 2006, p. 115). This may result in fathers distancing themselves from roles such as father and spouse. In turn, this distancing may impact the household as a whole and ultimately set a particular tone for the household (Seligman & Darling 2007, p. 224). Although long-term emotional impacts remain unknown, it has been found that fathers experience emotional disturbances when pregnancy is first announced and experience these feelings once again, three months postnatal (Codon, 2004).

Men and women are required to incorporate multiple roles, making their transition multi-faceted (Crespi 2015, p. 355), such as integrating parenthood into their self-concept, lifestyle, and overall identity. As the child ages, parents adapt their parenting abilities in parallel to their child’s changing needs. The mental images they make tend to guide their parenting behavior by adjusting their construct of what being a parent signifies to them (Golinsky, 1987). Hence, not only is parenthood continuouly bringing changes to all facets of an individual’s life, but these changes further become more prominent when welcoming a child with a developmental disability such as cerebral palsy.

The Experience of a Premature Newborn on Fatherhood

Parents of preterm infants may experience the following secondary stressors on top of primary stressors of becoming a first-time parent: parents may have not had the opportunity to have a baby shower to celebrate the new addition or may not have had time to read parenting books or finish building the nursery because the baby arrived before the expected arrival date, thus creating an overall lack of parental preparation (Whittingham et al., 2014). Parents may feel a sense of grief from having to experience the NICU and not being able to hold their infant immediately after giving birth. Being discharged from the hospital can be a shock because the hospital is perceived as a safety net for new parents. Not only do parents face parenthood with a medically fragile infant and a rigid regimen for maintaining their newborn's health, but parents also experience the challenge of early home life by learning new parenting skills and creating a new routine while balancing their new role as a parent (Kokanovic et al., 2018). For example, Simmons (2019) discussed fathers' experiences of parenting their newborn as encompassing what is known as "*parallel spaces*" of the NICU/baby and home/work. This could also be referred to as a "*revolving door*" (p. 127) where fathers are a part of two distinct spaces, one with the baby and one without, while committing to both. Fathers may feel a sense of disconnect with their overall environment; what occurs at home or in the NICU will go on whether or not the father is present, perhaps making the transition to fatherhood difficult (Simmons, 2019).

In addition to having a preterm infant, some early infants become diagnosed with disabilities and various researchers have examined the chronological process of the reactions to a child being diagnosed with a disability by researching the initial stages of this diagnosis (e.g., diagnosis, shock, acceptance) (Avieli & Band-Winterstein, 2017). While initial stages have been explored, researchers have failed to view emotional reactions as an ongoing process as children

face subsequent developmental milestones following the initial diagnosis. Having a child with a disability may result in parents learning to parent in unexpected ways (Seligman & Darling 2007, p. 212). Parents may also experience a shift in the way they perceive parenting (Davis, 2004). In other words, parents may challenge previous expectations of what they thought becoming a parent was supposed to be like, perhaps being left feeling "cheated" (Davis, 2004).

Long-term emotional reactions have not been considered in scholarship and more exploration is required of fathers' emotional experiences of welcoming a premature infant, more specifically an infant with cerebral palsy.

Caregiving for a Child with Cerebral Palsy

Providing care for any child requires a large level of involvement. However, caring for a child with cerebral palsy can be in need of an extra level of hands-on parenting.

Involved fatherhood can be described as applying the following characteristics when caregiving for their child: accessibility, engagement, responsibility, and 'warmth' (Macht, 2020, p. 5). These characteristics were coined by Esther Dermott who described intimate fathering as "having and maintaining a close bond with their children (Macht, 2020, p. 5). Further O'Brien and Wall (2017) describe Andrea Doucet's three characteristics of involved fathering as: emotional (knowledge and attentiveness to children's needs), community (institutional and societal elements interconnecting between inside and outside household relations required for caregiving) and responsibility (meeting children's needs short-term and long-term).

The authors further describe caregiving responsibilities as a nested concept that includes a direct process of taking care of another and an indirect process in making sure that they have access to sufficient resources (p. 15). Thus, emotional responsibility includes caring for unmet needs to ensure critical needs are met through ensuring an appropriate access to resources. To do

so, Dermott examined what she referred to as *"emotional bordering"* where males express closeness or distance in their relationships. She indicates that emotional expressivity is embedded in the practices of fatherhood, challenging previous models of masculinity. In turn, fathers' emotions in caregiving change the maneuvers when thinking about caregiving practices (Ranson 2015, p. 17).

Adding to Dermott's concept of bordering is Andrea Doucet's concept of "*bordering*" for fathers, wherein caregiving for their child involves "doing something": performing an action means their child feels loved. For example, as fathers are not recovering from pregnancy, they may be responsible for carrying in the car seat and lifting heavy objects. As discussed above, fathers are not able to experience direct embodiment with their infant is born in contrast to the mother who experiences immediate embodiment beginning in pregnancy. Hence, fathers tend to experience a strong shift when it comes to embodiment with their child, otherwise described as a "*slow burn*" when it comes to caregiving practices.

Many fathers described parenting as being "all about mom" until their infant began to flourish into their own person. Hence, as the infant grows, fathers enjoy a greater embodiment presence that involves fun activities and physical aspects such as carrying or picking up their child because they may have more strength and stamina than their partner. As time passes, fathers learn the rhythms of daily caregiving, adapting to spatial and social contexts. In her book *"Do men mother? Fathering, care, and paternal responsibility (2006),* Andrea Doucet discusses how fathers push their children to take more risks and be more independent. When comparing fathers to mothers, fathers provided their children with more independence and let their children take risks. For example, when children were climbing a tree, fathers were more actively engaged if their child went up the tree too high; fathers were "right there" to help their child down while

mothers sat back and would simply tell their child “That is too high”, demonstrating more protectiveness than fathers who promote more independence (Ranson 2015, p. 3).

Keating et al. (2019) suggest that the life course of family care transitions and trajectories create structure and rhythm in individual lives. In turn, they describe the life course of care as activities and responsibilities toward a family member with a long-term illness or disability. Authors Keating et al. (2019) incorporate the concept of career care trajectory (CCT) to examine the life of the caregiver through their caregiving tasks and life course trajectory changes regarding general caregiving. As mentioned previously, taking care of someone involves making sure that all daily needs are met throughout each life cycle (Uribe-Morales et al., 2021). Tough caregiving tasks for children with disabilities may not be different in the beginning of the infant’s life, as the child ages, caregiving tasks may intensify and lengthen in duration, which will be discussed below.

Macht (2020) provided insight on the differences in caregiving for fathers of children with developmental difficulties. She discusses fathers experience of what she described as “*wear and tear*” regarding their attire and other personal belongings as caregiving demands progress as the child ages. However, for fathers of a child with a developmental disability, this “wear and tear” was found not to change over time but was instead continuous. For a parent to a child with a disability, the concept of wear and tear can be described as “*grunt work*”. Grunt work is more than getting a child a new pair of shoes for a parent of a child with a disability. Grunt work involves a lot more physical labor and general toll on the body than parents of children who do not have a developmental disability (Ranson 2015, p. 115).

Grunt work was additionally elaborated as “intra-caring” or “intra-active becoming” where both the father and child are physically growing together (Macht, 2020). Hence, for these

fathers, the physical aspect of caregiving is expressed multiple times a day whether through carrying their child to the washroom or lifting them into the car. Moreover, Macht (2020) mentioned how one father had to learn to provide for his son by understanding his sons bodily and facial cues as his son was non-verbal. This father stated that their daily routine is one that is made of very tiny details, is mundane, and order of tasks are crucial otherwise described as "*programmed caregiving"* (Ranson 2015, p. 112) as it is heavily regimented routine along with "*advocating caregiving*" where parents are continuously advocating on behalf of their children.

Additionally, the congruence of involvement, expectations, support, and overall care will vary at each child's transition stage (Quinn, 1999, p. 445). For example, Ytterhus et al. (2008) discuss how by the time one's child(ren) is 9 years old, caregiving tasks should begin to shift from "doing to being" as the child can accomplish and organize more independently (e.g., maintaining relationships with grandparents, maintaining self-hygiene and participating in home division of labor by doing house chores) However, for parents of children with disabilities, the parental shift from "doing to being" may not as clear cut as described above. Rather, instead of decreasing, practical caregiving workloads tend to increase as the child grows bigger for parents of children with developmental disabilities (Ytterhus et al., 2008).

Parents of children with developmental disabilities described feeling better equipped to take care of their children than hospital staff due to the fact they do the caregiving tasks at home best unless an emergency presents itself (Hobson & Noyes, 2011). In turn, parents may experience role strain in terms of over-extending their caregiving tasks as their child ages. For example, Ytterhus et al. (2008) discuss closeness vs. distance (helping their child with general hygiene during puberty) and care vs. control (being overprotecting and doing everything for their child rather than helping their child take control in situations, such as speaking up when someone

does something they do not like without asking). Parents feel accomplished when their child succeeds, as they describe doing a lot of trial and error in helping their child learn the appropriate milestones and reach their full potential. The primary difference in this circumstance is the caregiving of an infant is not different: it is the level of engagement and intensity that increases as the child ages (Ranson, 2015). Hence, not only do parents have a more watchful eye, but their caregiving labor becomes intensified rather than diminished (Ranson, 2015).

Implications on Life Course Sequence

The birth of a premature infant may lead to a disrupted, discontinuous relationship, and may influence the link that is formed between the parent and child as for many, infants spend time growing in the incubator, creating a potential delay the parent and child bond. For some parents, it took longer for their bond to form where parents had to learn to know their child, grow to love their child, then finally bond; the love for the infant was withheld until the infant's survival was more likely. Similarly, returning home from the hospital provides the opportunity for creating larger social world links and bonds (Black et al., 2009, p. 10). It has been found that families who have children with a chronic illness tend to have a smaller social network, a more rigid household, less supportive extended family, more stress, and fewer opportunities for personal activities (Kazak et al., 1988). Authors Nalder et al. (2012) examined the transition from home to hospital for parents of children diagnosed with a traumatic brain injury (TBI) to determine not only how their role as a parent shifted but how it influenced their future. When they first returned home, parents felt an increase in the weight of their responsibilities along with a heightened sense of protectiveness of their child. Instead of celebrating and creating social ties outside of the hospital, parents limit ties to protect the health of their child, reinforcing how families with children with disabilities have smaller social networks.

Hence, general stressors and emotions are interconnected and affect fatherhood. Thus, what occurs during one transition may follow to the next, leading to what Settersten & Hendricks (2003) described as a "*domino effect*". As a result, this interdependency may not only create instability between family members but reverberate for parents of children with long-term injuries. In essence, the concept of linked lives is key for comprehending family relations. Thus, familial social relationships and the ways they are linked can demonstrate the complexities that not only occur within the household but also those that occur outside the household with the social institutions connected to that family.

Experiences of parenthood can be affected by the achievement of a child's developmental milestones. Reaching milestones signal healthy growth. Developmental milestones can be defined as a set of behaviours, skills, and abilities demonstrated by specific ages during infancy (Singh et al., 2019, p. 183). They are considered as definite predictors and patterns in growth and development, known as principles, that are universal and basic to all human beings (Singh et al., 2019, p. 182). Infant developmental milestones are sequenced as followed: two months (2): hold head up with support, four months (4): roll over, hold head up unsupported, six months (6): begin to sit and stand with no support, nine months (9): crawling, twelve months (12): few steps, standing alone, eighteen months (18): walk, eat/drink cup/spoon, twenty-four months (24): run, climbing, up/downstairs). (Singh et al., 2019). This sequence plays a role regarding expectations, such as what is normative versus diverse within the life course. Parent trajectories are linked to their child's trajectories. Both trajectories are interdependent and generationally supportive (e.g., taking care of a terminally ill child, a parent may consider early retirement). It is not the fact that fathers have been "thrown off" sequence. Rather their circumstances demonstrate that what they "anticipated" becoming a father would entail went off-script. Thus, parent and child trajectories

are interdependent when the child has a disability because seeing their child reach developmental milestones on time indicates that their child is going to be okay.

Hence, incorporating a life course perspective reveals the power of normative notions of milestone sequence and the experience of fathers of children with disabilities highlights this power. Additionally, studying changes over time can provide a new perspective of parenthood by unveiling hidden complexities that occur over time while ultimately seeking to comprehend the influence society has on individual decision-making and the overall sequence of their life course transition.

Conclusion

This chapter provided the foundation for this research study as it demonstrates how academic literature is limited regarding the topic of men's transition to parenthood, particularly on the subject of parenting children with disabilities. The review of literature offers a glimpse of how having a child with developmental difficulties challenges sequence and normativity in milestones. This is because fathers wrestle with the thought of having a normative sequence in terms of having their child reach their developmental milestones while having their lives simultaneously linked, and fathers require an adjustment of not only their overall lives/expectations but an adjustment of their expectations for their child as well.

Chapter 2

Theoretical Frameworks

Parenting a child with a disability reveals a paradox concerning milestones and the sociology of the life course. In this chapter I explore sociological theories of disability to argue that disability is a social construct resulting from an ableist society. As a repercussion, having a disability is considered "hard" as parenting has become embedded in this ableist world that emphasizes normative child milestones (e.g., school, social peers, aging expectations). However, for fathers of children with disabilities, their "normative" may appear different than what society views as the normative sequence of these milestones.

Scholarship on the treatment of people with disabilities remained scarce until institutions were built for educating and housing people with disabilities. Following institutionalization, individuals with disabilities acquired worldwide recognition during the disability rights movement (Albrecht et al., 2001). Disability as a construct is considered a social category in terms of its significance, origins, and boundaries. It is primarily concerned with the elements of normative embodiment and non-normative embodiment experiences (Coleman-Fountain & McLaughlin, 2013). For the discipline of sociology, the concept of disability offers an opportunity to challenge how the body is represented on a personal level, in different social environments. For sociologists, disability is constructed as a "determined empirical fact" (Shuttleworth & Meekosha 2012, p. 351). However, physical differences tend to be sociologically and politically produced (Vehmas & Watson 2014, p. 640) although individual differences are biologically rooted, providing the appearance that they are a "naturally caused". Society provides evidence that all bodies are socially constructed because attitudes from human

beings influence how disability is perceived rather than being solely the biological rooting of the impairment (Siebers, 2001). As a repercussion, how disability is viewed and discussed in daily conversation becomes further influenced by political and social institutions (Barton 2001, p. 555). Thus, it is evident that the dominant discourse substantially influences societal perceptions between the majority and marginalized members of society. Current theory emphasizes what occurs around disability rather than theorizing about the actual experiences of persons with disabilities. The disconnect in disability research surrounding academic versus lived experience creates a variety of social misrepresentations (Mauldin & Lewis Brown, 2021). In turn, a lack of in-depth meaning creates an ineffective solution of the problem regarding disability rather than seeking to unveil the root cause of the persisting divide between the able-bodied and non-able bodied.

History of Sociological Approaches to Disability

For the purposes of this thesis, disability is understood as a social construct rather than an empirical fact. According to Jones (1996), "disability is not viewed as an individual or medical experience but as a socially constructed phenomenon that incorporates the experience of those living with disabilities in interaction with their environment" (p. 348). Disability is less rooted in empirical practice as it is in the margins of social institutions that create disabilities out of individual characteristics ranging from physical and social that include but are not limited to mobility and learning behaviours. To support this claim, Lachowitz (1989) provides an example of men living with blindness to demonstrate disability as a social construct indicating that disabilities are made, and individuals are taught to behave in accordance with those expectations for those possessing that disability. Thus, disabled people's behaviors are not inherent to their condition but are inherent to social learning. Rather, disability is a socially constructed condition

because it demonstrates a deviation from a socially valued norm (Lachowitz 1989, p. 3-5) due to an individual's characteristics. Thus, for individuals with a disability, their nature of personal functioning is to strive for characteristics that are as culturally normative as possible. In essence, recognizing disability as a social construct and incorporating critical disability studies critiques social norms and structures that pathologize individual experiences.

The topic of disability has often been ignored within the field of sociology (Albrecht et al., 2001). Only in 2010 did the American Sociological Association (ASA) incorporate a section on disability in society because members were slowly moving beyond the medical and biological aspects of disability (Green & Barnartt, 2016). Before this, few sociologists explored disability as a sociological concept, with the exceptions of Irving Zola, Harriet Martineau, and George Simmel who examined the deaf and the blind. Although illnesses were examined, sociologists did not examine disability as a characteristic but rather as a category where persons were categorized as efficient and non-efficient (Green & Barnartt, 2016). The concept of disability was first theorized by the medical model, followed by the social model where each approach had its own focus: the medical model on the individual, the social model on the environment. The differences in these approaches created the separation of disability and impairment as their separate constructs. This separation led to the development of critical disability studies, which emphasizes construction and experience of disability through a critical approach. Each approach (the medical model, the social model and critical disability studies) will be discussed below.

The Medical Model

The medical model emphasizes the pathological and biological functions of the individual body. For the medical model, disability is perceived as a medical tragedy because the body does not have the proper abilities to meet normal standards (Butler & Parr, 1999).

Disability lives strictly within the body (Dobbs 2012, p. 9) and the cause was perceived to be linked between the body and the impairment, resulting from personal tragedy, biological deficiency, or psychological trauma (Goodley, 2013: Reddy 2011, p. 290). Due to emphasizing pathology, treatment was solely based on medical intervention (Butler & Parr, 1999), giving doctors eligibility to only provide treatment and rehabilitation for members of the elite class (Titchkosky & Michalko, 2009). Within the medical model, healthy individuals were perceived as "having the greatest value and acceptance within society, while their less-abled counterparts were perceived as a degenerative population and lacking social value" (Malhotra & Isitt, 2017, p. 7). In contrast to their “healthy counterparts," individuals with a disability were perceived not only as “sick” but as deviant members of society. These individuals were labeled as deviant because they failed to overcome their impairments. Many scholars including Green & Barnartt (2016) indicate that the medical model is another name for Talcott Parsons’ “sick role”. For Parsons (1951), when an individual occupies the social status of the “sick role,” they are expected to have child-like behaviors because they are socially exempted from being a productive citizen of society. The difference between the medical model and the sick role model consists of being labeled as deviant and responsible for their impairment within the medical model, while persons occupying the sick role are not viewed as responsible for being sick. Instead, individuals are described as being "unlucky" (Green & Barnartt 2016, p. 18). Fortunately, as technology advanced, this led to moving beyond examining simple physical elements and God-like comparisons (Green & Barnartt, 2016). Instead, it became time to reverse the “tragic discourse” and change representations of persons with disabilities, moving toward neutral terms (Okrzynska & Wieczorek, 2020).

The medical model overlooked the self because of reductionist thinking of the body being a non-social entity. The model neglects individual experience, giving power to medical professionals (Albrecht et al., 2001). In essence, the medical model is rooted in the clinical diagnosis. It does not encompass the understanding of disability as a holistic experience because living with a disability is more than having a medical label (Butler & Parr, 1999).

The Social Model

The social model was founded by British sociologist Mike Oliver in 1983 following the "Union of the Physically Impaired Against Segregation in 1976" (Watson & Vehmas, 2020). Mike Oliver partnered with disability activist Vic Finkelstein who created an all-accessible village utopia to demonstrate a realistic perspective as to how disability was represented within society (Watson & Vehmas, 2020). As both researchers quickly discovered, vast changes were required for disability to no longer be perceived as a tragedy. For Oliver & Finkelstein, individuals should be liberated from this negative label and live their day-to-day lives without experiencing stigmatization and discrimination. To move forward with our understanding of disability, they believed that research should shift analysis away from physiological elements and explore how disability is conceptualized in society to gain a holistic perspective of the disability experience (Butler & Parr, 1999). In essence, the goal of the social model is to identify what can be changed collectively and politically and bring back agency back to those with disabilities by diverging away from medical cures (Schillmeier, 2010). In other words, the model seeks to address the social oppression surrounding the concept of disability, while also addressing the debate surrounding an impairment and a disability (Butler & Parr, 1999). In this model, impairment is imposed on top of disability (Davis, 2016). Disability as a construct is public and structural, placing emphasis on social exclusion, while impairment is an individual

and private matter emphasizing physical limitation (Davis, 2016). It can also be described as a social creation versus an individual deficit. Unlike the medical model that focuses on the cure, prevention, and rehabilitation, the social model places focus on barrier removal and anti-discrimination measures (Davis, 2016). For the social model, an individual's disability only becomes relevant when interpreted during a social situation. In this case, disability is on top of impairment due to the ways that society involuntarily isolates these individuals from normative societal participation (Thomas, 2004). It is the community that disables individuals because they are subjected to barriers and exclusions. As Mauldin & Lewis Brown state (2021, p. 480). "[It] goes beyond the personal limitations that impaired individuals may face to social restrictions imposed by an unthinking society. Disability is understood as a social and political issue rather than a medical one". Unfortunately, this discrimination will only be understood if individual restrictions are examined simultaneously with societal elements (Thomas, 2004) as impairments become an element of prejudice through the construction of social norms (Coleman-Fountain & McLaughlin, 2013). Georges Canguilhem (1991) states that normal, in the most usual sense of the word, is that which is met with in the majority of cases of a determined kind, or that which constitutes either the average or standard of a measurable characteristic. (p. 125). Thus, the normal man is not a mean correlative to a social concept or judgement of reality but rather a judgment of value, perhaps otherwise limiting their full physical capacity (Canguilhem 1991, p. 118).

While the social model is the most successful tool in promoting global disability activism, the model also has its own set of limitations (Reddy, 2011). One of the main weaknesses of the social model is trying to obtain "a barrier-free economy" is not possible due to various reasons, such as a lack of financial resources and lack of policies and regulations

surrounding ableist perceptions of the environment and social institutions (Watson & Vehmas, 2020, p. 377). Furthermore, the social model takes away from the individual experience by creating a mainstream response. Instead, disability is perceived as a group experience (Albrecht et al., 2001), dismissing the recognition that disability is also an individual experience, where everyone has their own version of what a disability may be (Butler & Parr, 1999). Therefore, if the social model seeks to remove all barriers, all members of society should collaborate to create a barrier-free society for all as "ableism is not only relevant to the disabled" (Flynn 2021, p. 687). It is necessary to seek a new understanding of the construct of disability to determine how individuals may benefit from a restructured understanding of disability in their day-to-day lives. One should identify all levels of embodiment and shift our knowledge regarding ableism for all of society, and not simply for those who experience barriers.

Critical Disability Studies

Critical disability studies as a theoretical approach were pioneered in the United States by advocates and academics personally living with disabilities. One primary founder was Irving Zola. who was diagnosed with polio at the age of 16. Zola became the chair of medical sociology, establishing the academic journal *"The Disability Studies Quarterly"* (Watson & Vehmas, 2020). Following suit, critical disability studies gained worldwide attention during the movement of International Year of the Disabled People in 1981, making disability a part of global human rights discourse (Meekosha & Shuttleworth, 2009). The central argument of critical disability theory surrounds expanding on the deficits of both the medical model and social model. Both models are thought to be too one-dimensional for capturing the diversity of living with a disability (Davis, 2016). As such, disability studies seek to engage with a variety of disciplines when approaching disability to remove the existing binary between impairment and

disability (Meekosha & Shuttleworth, 2009). In other words, “it is a means to think critically about disability, a juncture that can serve both academic discourse and social change” (Mauldin & Lewis Brown, 2021, p. 479). Critical disabilities studies emphasize moving away from hegemonic thinking, shifting boundaries, and incorporating new strategies for inquiry (Flynn, 2021 & Flynn, 2021). Thus, if one is to continue investigating new areas of a discipline, it is necessary to “change the structures that have created boundaries, such as the existing boundary between ableism and non-ableism” (Johannsdottir et al., 2021, p. 344).

Critical disability studies do not deny the idea of intervention or disability. Rather, the premise of this approach is to create a more complex understanding of disability. Not only does this approach challenge the existing nature of the disability, enables researchers to question additional factors that may go unnoticed, such as embodiment and identity factors while encouraging researchers to rethink the current relationship between the disabled and non-disabled (Watson & Vehmas, 2020). To summarize, critical disability studies aim to demonstrate how disabled bodies are perceived against the idealized body (Flynn, 2021) with the end goal of removing the persistent link between the material world and the interactions that exist between the physical body and social encounters (Schillmeier, 2010). Unlike the medical and social model, critical disability studies can acknowledge that the barriers individuals experience are not always physical. So, to enhance our understanding of the concept of disability, we must pay attention to the body and the experiences of daily living. (Schillmeier, 2010).

Critical disability studies creates the opportunity to challenge what not only exists about the nature of disability but allows for further questioning about how embodiment, agency, and identity are influenced by social structures (Watson & Vehmas, 2020). Authors Mauldin &

Lewis Brown (2021) emphasize that ableism is more than a preference for the non-disabled. It is a set of values, institutionalized and codified into systems and structures, that privileges certain bodies, minds, and features over others (p. 481). In other words, ableism socially consists of constructed ideas of body and mind preferences. These preferences are an example of social norms, which regulates and validates social life (Vehmas & Watson, 2016, p. 3). Post-modernism has added to the confusion of the term ableism leading to additional confusion and oppression of people with disabilities. Norms play a role in what is enabled and constrained (Chapman & Saltmarsh, 2013, p. 3). Thus, these differences in normativity arise because of these regulatory systems constructed through a power discourse that prioritize normativity, resulting in the marginalization, exclusion, and oppressions of persons with disabilities (Vehmas & Watson, 2016). While this normative lens circulates most of the scholarly literature, normativity offers no stance on the daily life of living with an impairment nor how this may impact individuals in one's immediate social circle. "It is the societal perception of normalcy that creates additional difficulties for individuals with disabilities" (Vehmas & Watson 2014, p. 641). Thus, because the normative judgement is persistent, one needs to examine this judgement to shed light on what requires change in the social world (Vehmas & Watson, 2016).

Rather than emphasizing what is valued and not valued by an ableist society, critical disability studies challenge the persistent oppression and marginalization existing between able and non-abled individuals while additionally examining ableism, disability, and normativity in a critical manner (Mauldin & Lewis Brown, 2021, p. 481). Paying attention to disparities present regarding what is medicalized versus not medicalized and how this brings differences in individuals' daily experiences with disability will unveil how the binary between both groups influences societal relations (Watson & Vehmas, 2020). It has been suggested by Minich (2016)

that instead of emphasizing the pathological elements of a disability, one should scrutinize social norms and how these norms attribute to disabled individuals' daily life challenges. Going beyond the medical aspects, this could unveil additional contexts that are crucial, although not immediately recognized as influencing, experiences related to parenthood. This would include parents of children with disabilities who challenge the standards and expectations of their community toward a social understanding that is more flexible about social norms (Waldboth et al., 20220, p. 1927).

As discussed by Kelly & Orsini (2021), through their work of disability activism and art, they have discovered that it is necessary to promote a safe space for having conversations about individuals' experiences and their embodiment. Society and academia should no longer emphasize what is "normal" or a condition requiring a "cure". Instead, both should examine and comprehend experiences on a social level rather than a physical level. Doing so will allow the fathers in my study to tell their stories and challenge the pervasive feelings that surround the concept of disability. It is not often discussed what parents of children with cerebral palsy may go through on a day-to-day basis, more specifically, the emotional aspects of parenting a child with special needs. Feelings and affects directly influence all individuals, not just the individual with a disability. Not only do the fathers in my study need to be comfortable with the activity, their comfort in the location itself is just as important (Kelly & Orsini, 2021). Thus, with the help of critical disability studies, I hope to shed light on the emotional aspect of fathering a child with cerebral palsy as the influence of affect is not heavily explored in an ableist society.

Disability Worlds: Kinship Imaginaries

We live in a social world of interacting with others: based on proximity, those closest are the most important and experience the greatest impact (Albrecht et al., 2001). Regarding families,

families are considered as a relational environment encompassing of organized parts interacting with one another continuously, meaning they are reciprocal in nature (Cummings et al., 2002, p. 15). Thus, relations and more specifically family relations are interdependent, a chain connecting us to others (Ketokivi, 2012). Not only are relations interdependent but familial roles also becoming interdependent with extra-familial roles, such as employment and education (Macmillan & Copher, 2005, p. 860). Hence, we cannot understand familial influences by only examining one family member as each member, is linked to the larger family unit (Cummings et al., 2002). Hence, it remains important to examine multiple family members rather than solely relying on one – notably, mothers - to explain a family dynamic as each family member has a unique role in family functioning.

Welcoming a child with developmental disabilities creates a sequence shift when parents realize their current experiences do not match with their pre-existing life models (Rapp & Ginsburg, 2011). For example, “when children's education is "stretched out" to accommodate differences in developmental time, so too is the time of parenting and the shape of the domestic cycle. When a child's developmental narrative is re-written by a medical diagnosis, so, is the family's sense of its history refashioned” (Rapp & Ginsburg, 2011, p. 381). During the process of incorporating their child’s disability into their daily lives, parents find new ways of transforming their spatial, temporal, and caregiving plans. These new arrangements are known as “Worlding” or “Kinship Imaginaries” where individuals transform their discourse to find unique methods in navigating their child’s bodily differences through an ever-changing environment (Ginsburg & Rapp, 2017). Through a “Life World” we can have a better understanding of personal experiences and community responses, as individuals live in a social world and continuously interact with others (Albrecht et al., 2001).

For Rapp & Ginsburg (2011), “kinship imaginaries can be described as the building block for transforming the social narrative surrounding disability” (p. 384). This approach demonstrates that taking care of one’s kin involves micro and macro influences of social structures, and the family can be considered essential for building theory on disability and on the reciprocity of social relations (Lewis, 2016). When a biographical disruption occurs, the acquired life-world knowledge of everyday life is used to relate to the disruptive phenomenon and form a solution (Lupton, 2012). In other words, by paying crucial attention to the material conditions and the impact of infrastructures during their day-to-day lives, parents reimagine their ways of life by reframing the implicit norms and expectations of life course milestone sequence by living daily life at their own pace. As this occurs, parents may feel a sense of alienation from their extended family and friends who are frustrated that child-rearing a child with special needs requires more extensive caregiving than traditional child-rearing (Rapp & Ginsburg, 2011). As a repercussion of these differences, parents re-evaluate their generational differences and reframe their child's expectations to provide their child with the best life possible. For example, photojournalist Dan Habib, a father of a child with cerebral palsy took the opportunity to advocate on behalf of his child through photography and filmed a documentary with four other children to shed light on the difficulties that may present themselves within inclusive education for these children. Thus, by incorporating a new *“Kinship Imaginary.”* Dan and his family gained the ability to re-write their life course (Rapp & Ginsburg, 2011).

Another example provided by Nelly-Barnes et al. (2010) involves parents of children with disabilities who state that “as a parent and family member, it is their « job » to help their child interact with the community and gain more access and support”. Participants further elaborate how as a parent they tend to do these jobs in response to a lack of support, exclusion,

and discrimination as a way empower in an ableist society, as well as promoting advocacy and information regarding diagnoses (p. 9). Additionally, Waldboth et al. (2020) discuss how empowering others and how trying to follow community standards and norms have helped them as a family come to terms with the situation and reactions from other individuals. Thus, not only does the child's lifecycle experience change, but the entire family lifecycle simultaneously changes with the child's lifecycle (Rapp & Ginsburg, 2011). For example, becoming a parent to a child with a developmental disability, such as cerebral palsy, may create difficulty for families in establishing social connections and community support, leading to the parent feeling isolated (Lewis, 2016). Due to these changes, kinship imaginaries can influence the life course by shedding light on boundaries that may present themselves in different social contexts.

In essence, the concept of kinship imaginaries can help us to reframe the implicit norms, expectations, and sequence of the life course, such as those present when welcoming a child with a disability into the family. When a developmental milestone for a child does not occur in the specified time frame, family members become aware that their current experiences may or may not be congruent with what they previously envisioned or have personally experienced. What is considered non-normative for others, may be considered normative and part of everyday life for that family. Moreover, providing parents with the ability to renavigate their world will allow for the concept of disability to be perceived as more than a social construct in an ableist world. All members, regardless of their capabilities, are a part of society, creating a more inclusive discourse (Rapp & Ginsburg, 2001). Lastly, incorporating a kinship imaginaries perspective will complement critical disability studies in providing a "critical perspective on everyday life with a difference" (Ginsburg & Rapp, 2020, p. 5).

Application to Current Study

To reiterate, disability has rarely been researched within the field of sociology of the life course. The research on disability is now largely conducted under a critical disability studies framework where the meaning of a social construct is not static but remains dynamic and contingent (Watson & Vehmas, 2020): Constructs vary based on socio-historical and geopolitical factors making the life course too divergent for one single theory and thus requiring a multidisciplinary approach (Mortimer & Shanahan, 2003). For this thesis, the theoretical models chosen are used to explain disability as a social construct because the notion of "the other" has been socially created as a repercussion to ableism. Individuals experience life at their rhythm, making disruptions impact that everyone in their social sphere based on their level of interdependency (Albrecht et al., 2001). Hence, one cannot generalize life experiences as universally the same for all.

Throughout this chapter, the history of disability studies has been explained to indicate the changes made within the field and the creation of critical disability studies as a theoretical approach. Critical disability studies have the necessary elements to expand existing information and challenge normative expectations of parenthood. As disability is a key concept in my research, this theoretical framework becomes essential in demonstrating how parenting a child with a disability is perceived as difficult due to social ableism and changes in normative discourses regarding child milestones. In turn, these changes lead to increased relational dynamics and interdependencies, particularly between the parent and child. In essence, critical disability studies can provide an interdisciplinary approach toward everyday life changes while simultaneously challenging the notion of "normative". Society plays an important role in the

concept of disability and life course. Societal norms and discourse influence how individuals not only view their world but how they view others.

In addition to critical disability studies, I have also incorporated the theoretical perspective of kinship imaginaries. This approach will aid my research by demonstrating how fathers have not only become an advocate for their child but have also adapted their overall lifestyle to the sequence of events that present themselves. Fathers' adaptation to their life world will further demonstrate the emotional interdependencies that occur between parent and child as fathers navigate an ableist society. Kinship imaginaries will compliment critical disability studies by providing support in demonstrating that not all child-rearing experiences are standard and should not be considered linear as life events do not occur at the same temporality for each family member. Rather, to gain a holistic comprehension of "normative", it is required to examine the paradoxes present in life course milestones and childhood milestones as fathers become intertwined with wanting a proper sequence of life events while wanting their child to reach milestones, providing reassurance that their child is going to be okay.

Chapter 3

Methodology

The decision to conduct this qualitative study is based on the dearth of qualitative data on families with children diagnosed with cerebral palsy. More specifically, past, and present research emphasizes the quantitative elements of what it means to be a father, such as the amount of time the father and child spend together (Phares, 1999). Not only has academic literature highlighted some of the quantitative aspects of fatherhood, but recruitment processes for family studies are also informed by outdated ideas. For example, fathers are rarely asked to participate in research studies due to the assumption that they may not want to participate or are not available to participate because of a non-flexible employment schedule (Phares, 1999). Hence, I sought to offset these factors and utilize a more inclusive perspective when it comes to the experiences of becoming a father and raising a child with developmental difficulties.

Therefore, this paper aims to build on the limited existing research by querying and analyzing some of the experiences of fatherhood. As a result, this paper sheds light on the ongoing journey of the participants in this research. This study addresses the following research questions:

RQ1: What are the key experiences of fathers raising a child with cerebral palsy?

RQ2: How do fathers describe parenting children with cerebral palsy at different moments in their child's life?

Sample

In total, eleven fathers of children with cerebral palsy participated in this study. The study included eight fathers from Canada and three fathers from the United States. Their children

comprised three daughters and nine sons, ranging in age from infancy to adulthood. *(Participant Characteristic Table can be accessed in Appendix G).*

Due to the worldwide pandemic of the novel coronavirus (COVID-19), I could not physically recruit fathers of children with cerebral palsy within social institutions such as a hospital or school. Instead, participants were recruited by word of mouth from family, friends, co-workers, and colleagues, and via the social media platform Facebook. Various online support groups exist on Facebook for parents of children of cerebral palsy to provide a safe space to seek support and advice. Recruiting from these online platforms gave me greater access to possible participants. I did not place restrictions on participants beyond being a father of a child with cerebral palsy, so the father's age, child's age and location were not restricted. Additionally, the severity of the child's cerebral palsy was not restricted; all cerebral palsy types and severities were welcome.

To recruit participants, I joined the following Facebook support groups: *"Canada Rocking CP", "Alberta Support Group",* and *"CP Worldwide".* These groups are "closed" to protect the privacy of current members. Thus, if an individual wanted to be a part of the group, they needed to gain access by answering a short screening questionnaire to ensure they meet group criteria. For these reasons, I disclosed at the group screening questionnaire that I intended to recruit research participants for my Master's thesis. My answers were reviewed and approved by the group administrator. Once I was approved as a member of the group, I took initiative to monitor group posts and members and made note of potential participants. Additionally, to acquire interested participants I included a recruitment poster with my initial recruitment message to the administrator and group with the core details of my study and contact information if they wanted to participate. As far as recruitment processes, I anticipated challenges due to

recruitment being conducted online and participants potentially expressing weariness of my researcher authenticity. However, after providing a brief description of my study with additional information upon request, I successfully managed to recruit more than my anticipated goal of 8 participants and ended up with a total of 11 participants.

Research Design

1. Semi-Structured Interviews

For this study, I utilized two measures of fatherhood experiences. The first measure I incorporated into my research design was semi-structured interview. The interviews were audio-recorded, and notes were written in a notebook to track initial impressions. Due to the coronavirus, interviews were conducted via video conference platforms FaceTime and Zoom. Participant confidentiality has been obtained by signing the participant consent form. Father and children names have been changed to pseudonyms to ensure anonymity of my participants *(The Consent Form can be accessed in Appendix D).*

Since interviews were virtual, I focused on their body language and tone of voice to the extent that was possible although this was challenging. Studies conducted by Day & Lamb (2004) indicate that conducting in-depth interviews is the most suitable method to holistically capture the complex interpersonal reflective processes of fathering, as people make sense of themselves through the stories they tell. Thus, not having a proximate perspective of body language proved to be a difficulty. On the other hand, these methods proved to my advantage as it allowed more flexibility for the parents regarding their work schedule and time spent and caregiving for their children, along with flexibility of participating in the interview from the comfort of their home rather than having to schedule a location to meet which can prove challenging for parents of children with cerebral palsy.

A narrative perspective allows fathers to tell their individual experiences of what it means to become a father by describing how they identify and view themselves. Moreover, a narrative approach is considered interdisciplinary, having multiple branches of knowledge that enable the researcher to gain insight into fathers' unique experiences (Atkinson, 1998). Thus, having heard fathers' stories allowed me to unveil a more in-depth understanding of their experiences.

Questions and responses were open-ended, allowing the participant to freely express themselves on the topic, providing a holistic perspective. Interviews varied in length, the shortest being approximately 35 minutes, the longest being approximately 1 hour and 30 minutes. On average, the interviews were approximately an hour in length. Data were analyzed based on how the participant constructed fatherhood, allowing me to understand their parenting struggles. Lastly, this approach provided me with the ability to consider how historical and cultural settings influence the transition to becoming a father to a child with cerebral palsy. *(Interview Schedule can be accessed in appendix A).*

2. Historical Timeline

The second measure I incorporated in this study is the creation of a historical timeline highlighting key events in becoming a father to a child with cerebral palsy. A historical timeline can be described as a participatory visual communication measure enabling the agency and empowerment of the participant by providing an opportunity to channel their inner voice (Literat 2013, p. 87). A historical timeline captures retrospective data in the context of time and place while revealing how these spatial variables influenced fathers' key experiences (Woodgate & Ateah, 2008). Including visuals with historical timelines creates an alternative mode of production by challenging the notion that metaphors exist materially by unveiling individual experiences (Kelly & Orsini, 2016).

The primary strength of constructing a historical timeline is that this approach emphasizes the internal point of view of participants. This biographical material is considered the perfect sociological material to broaden the overall understanding of an individual's personal history (Goodley, 1996). Not only does the biographical content aid in constructing their reality, but these biographical events are how individuals make sense of every situation new or old during their lifetime (Smith & Sparkes, 2008). As an individual's life progresses, experiences are accumulated. When a new situation arises, individuals have what is known as a *"ready stock"* to help make the appropriate decision. In turn, this *"ready stock"* influences the following elements concerning the life course: embodiment, agency, and structure (Smith & Sparkes, 2008). More specifically, incorporating a historical timeline "facilitates the expression of perspectives and narratives that may be silenced, overlooked, or rejected" (Literat 2013, p. 85). As a result, this measure provided an opportunity to acquire a subjective meaning of the studied phenomena a (Goodley, 1996). Thus, incorporating a timeline extended my findings beyond instrumental and strategic maneuvers of perceiving disability and normative parenthood. Lastly, a historical timeline enhanced my recognition of individual lived experiences that occur beyond traditional norms, emphasizing that not every person's experience should be generalized as a universal experience (Kelly & Orsini, 2016).

Timeline measure may also assist with the discussion of sensitive topics. Participants have the opportunity to reflect on their responses and create the timeline of events at their own pace, as I provided prompt questions to guide the process (Literat, 2013). Not only do timelines alleviate researcher and participant tension, but this approach can also be referred to as *"free time"* regarding the creation and reconstructing of daily life. Having the participant narrow in on the critical events can shed light on encounters that may have not been remembered otherwise

because of *"daily routinization"* (Kelly & Orsini 2016, p. 64). Likewise, text representation is bound by a temporal logical sequence while an image is non-linear, providing a holistic representation of each interconnecting concept. Hence, drawings provide the ability to demonstrate the relationship between visual elements that may not be accurately captured through the written or spoken word (Literat, 2013). Thus, for participants, having the opportunity to provide a *"visual"* of their experience can alleviate the stress that may be present during the face-to-face interviews.

Constructing the Historical Timeline

Adriensen (2012) suggested the following methodological technique for the construction of a timeline interview that was most fitting for my thesis. I began the process of constructing the historical timeline with my participants by instructing them to have a blank piece of paper and colored markers because these two materials are required for creating a well-constructed timeline. I asked participants to draw a line in the middle of the page, leaving space for pertinent information in the margins. As information is based on recall of events, this gave participants a chance to correct themselves if they found themselves accidentally making an error. Moreover, not only did margins help with correction of time frame errors, having extra space enabled my participants to reflect on the order of events on their own terms, allowing for enhanced reflection of how the sequence may have had an impact on their transition to fatherhood.

Adriensen (2012) stated it is up to the researcher in making the decision where the timeline should begin and end. For the purposes of my study, participants began the construction of their historical timeline once pregnancy was confirmed to discuss the preliminary transition to fatherhood, flowing to present time. More specifically, key questions asked were based on recall: what do fathers remember most vividly and what event they considered to be key to their

transition to fatherhood? In turn, this layout helped me demonstrate fathers' different perspectives, how they unfolded, and whether or not they impacted or coincided with one another. Lastly, constructing a historical timeline with my participants provided balance between me as the interviewer and the participants as they claimed ownership of constructing the timeline while I provided general guidance and recall cues. As a result, the interview became more of a conversation between me and my participants, which is of crucial importance when discussing a sensitive topic. Due to analysis structure, the timeline has been used as a secondary source of data because publishing the timelines would give away my participants' identities and providing the timelines does not provide my readers with sufficient detail to comprehend participants' fatherhood experiences. To ensure validation of my participants experiences, I asked participants for any clarification once the timeline was complete. Hence, having included a timeline as a secondary measure provided a visual picture of key transitional events that were impactful to fathers raising children with cerebral palsy. The timeline visually demonstrated and supported the importance of key events fathers emphasized during the semi-structured interviews.

Data Analysis: Content Analysis

I will use a content analysis perspective to analyze the data in my thesis study (Talja, 1999). The rationale for using content analysis as a methodology is because content analysis unveils information that cannot be observed directly Talja 1999, p.10). Content analysis is used to reveal inferences from all data types, such as, but not limited to, verbal, pictorial, and symbolic (Krippendorf, 2004). It is most often used to describe the experiences, trends, and patterns of a specific group of individuals. For this thesis, the focus was placed on fathers of children with cerebral palsy (Stemler, 2000). Content analysis compensates for data that may not be directly observable and for events that may have already happened, as well as those that may

happen in the future. Content analysis can provide new insights and enhance the understanding of fathering a child with cerebral palsy for both the researcher and the reader. Messages do not speak for themselves, and their intent may not always be correctly interpreted, as context is always constructed by someone, and is ultimately influenced by the environment and situation. Lastly, content analysis has more probability to succeed when addressing linguistic social realities that are rooted in conversations produced by what is being analyzed (Krippendorf, 2004). Thus, having fathers speak about their day-to-day lives created a more in-depth understanding of which language is used most often and how this language influences conversations between fathers, their social circle, and members in their community.

The goal of this content analysis is to deconstruct the key experiences of being a father to a child with cerebral palsy while describing key events of parenthood at different moments in their child's life. To aid with the validity of multiple meanings and interpretations, I have included participant quotes, which have been incorporated in my Findings chapters (Chapters 4 and 5). As I obtained data from two different measures, a semi-structured interview, and a historical timeline, both measures have enhanced the validity and reliability of hidden inferences by creating an extra dimension to my findings. In this study I use content analysis to classify the language and unveil the way fathers talk about their transition to fatherhood while a historical timeline has been incorporated to aid the recall of key events and emotions during their transition (Talja, 1999).

For my semi-structured interviews, I used the content analysis to conduct a word frequency count regarding words that fathers have mentioned most frequently, indicating the crucial importance of what they tried to convey. I then created categories and themes based on events fathers shared about their transition to fatherhood *(Word Frequency Count and Table of*

Common Themes can be found in Appendix F) (Stemler, 2000). Categories can be described as a group of words with similar meanings (Stemler 2000, p. 2), while a theme can be described as the essence that runs through the data (Granaheim 2017, p. 32). During my analysis, I examined concepts related to parenthood, pregnancy, cerebral palsy, diagnosis, routine, activities, advocacy, and accessibility, among others, to unveil how these concepts emerged in the interviews. Not only did content analysis enable me to discover the essential factors that encompass the transition to fatherhood and the key experiences of parenting a child with cerebral palsy, but content analysis also allowed me to dive further toward comprehending the role of language, such as how and when words are used and how non-verbal language is used to describe a father's reality when parenting a child with a developmental disability.

Lastly, analyzing data through a content analysis approach allowed me to give participants' perspective priority and give participants the opportunity to advocate for their experiences by not only highlighting fatherhood differences but also investigating their ongoing emotions. In essence, the goal of my content analysis is to uncover a broad description of the phenomena of becoming a father to a child with cerebral palsy and what emotions were central to that experience.

Analytical Tool: Nvivo

To get the most in-depth information out of the data collected, I used the qualitative software Nvivo to conduct my content analysis. With Nvivo, I was able to organize and categorize my findings by theme (nodes), which would be daunting if I had attempted to sort through the qualitative data manually. By utilizing an editing approach, I have reviewed, identified, and organized my findings by primary themes and sub-themes (DiCicco-Bloom & Crabtree, 2006). Nvivo also facilitated the process of interview transcribing because the software

has the tools equipped to modify voice pitch and spoken word. In turn, this simplified the process of critically analyzing what participants were seeking to convey about their experiences. It has been suggested by authors McLellan et al. (2003) that the level of my transcription should match the level of analysis I am seeking to uncover. Thus, I made sure that both my transcription and analysis levels matched for the conceptualization of the experience of fathering a child with cerebral palsy. To do this, I reviewed each of my transcripts as having the same standard features, rather than being examined individually as each having their own set of data to analyze. This facilitated categorizing and allowed me to view the overall picture, rather than examining one participant's perspective at a time (McLellan et al., 2003).

When coding, the first step was to become familiar with the data to gain a sense of the study. This familiarization aided in acquiring findings, identifying main themes, and creating in-depth structured descriptions of each theme and their subtheme (Drisko, 2015). As for creating themes, I found that it is best to draw upon the material that best captures the essence of the original data. An example of this includes creating a code in Nvivo that consists of a short phrase of the original content to describe the primary meaning. I then used a hierarchal system, discarding codes that were rarely used, and reorganizing and reordering codes to ensure coherence when summarizing my key findings (Drisko, 2015). I present my findings in a narrative format by having two major themes, 1) The Life Course of Fathering a Child with Cerebral Palsy, and 2) The Responsibilities of Fathering a Child with Cerebral Palsy, followed by their subthemes, highlighting participants' experiences by incorporating their quotes. The goal is to reveal the meaning of the text and symbolic expressions and go beyond describing the surface of what has been found (Drisko, 2015). This allowed for the exploration of new territory, but also describes a phenomenon rarely discussed: fathering a child with cerebral palsy.

Research Design Limitations

Two different sets of data allowed me to cross-reference findings creating more validity while balancing the methodological limitations of each. The semi-structured interview worked with the objective of the study while the historical timeline emphasized the subjective elements in helping fathers describe their transition in becoming a father to a child with cerebral palsy.

Positionality

When conducting qualitative research, or any research for that matter, it is important that the researcher reflect on the positionality the project. Positionality can be described as the world view and position a researcher in a social and political context (Holmes, 2020). Positionality becomes integral to comprehending in an empirical manner how I carried out my research and exposing how I have understood the world around me and constructed my perception of the concept of disability (Cassell, Cunliffe, & Grandy, 2017). In the writing of this thesis, having cerebral palsy myself, I wanted to research an area that is extremely close to my heart and be given the chance to inspire and give a sense of hope to parents of children with cerebral palsy. More specifically, I wanted to allow fathers to be brave and use their voices to express the potential misunderstandings that surround families of children with cerebral palsy. I anticipated ahead of time that this project was going to be very fruitful, not only for my own growth as an individual, but also for other individuals who may be currently experiencing similar situations. However, I did not anticipate for the emotional challenges and in-depth reflection of my own experiences growing up with cerebral palsy that came up when conducting this study.

In this study, positionality was crucial as I am part of the community of people with cerebral palsy. Having the same disability as the children of my research participants posed its

advantages and disadvantages. In terms of advantage, it became easier to gain the trust of my participants in discussing a sensitive topic. While I did not disclose prior to the interview that I have cerebral palsy, disclosing I had cerebral palsy during the interview and sharing my experiences provided my participants a sense of comfort for the future of their children. Shaw et al. (2020) discuss how conducting research among vulnerable groups may create a power imbalance between myself the researcher and the population being researched (p. 279). Thus, by disclosing I had cerebral palsy, participants felt more comfortable as I was empathetic and ensured that my identity did not overshadow their experiences. However, sharing my experiences demonstrated a difficult side. Discussing my experiences with my participants posed feelings of unease within myself. As I heard my participants discussed their emotions, it made me understand more clearly what my parents may have felt while raising me, which in turn trigged my own emotions.

Chapter 4

Findings:

Part 1 – The Life Course and Fathering a Child with Cerebral Palsy

For logistical purposes the analyses and findings of my thesis will be divided into two chapters, each consisting of one major theme followed by their appropriate subthemes: 1) *"The Life Course of Fathering a Child with Cerebral Palsy"* will examine the following sub-themes: feelings of anticipation, parenthood includes embodiment, feelings of fear and anxiety, navigating living with these emotions as a father to a child with cerebral palsy, a day in the life of a father of a child with cerebral palsy, and feelings of grief. 2) *"The Responsibilities of Fathering a Child with Cerebral Palsy* will include the following sub-themes: advocating for your child, prepping the environment, prepping the child, becoming the most knowledgeable, community exhaustion, being hyper-vigilant of surroundings, social circle misunderstandings, and changing the activity to suit the child. Theme One will take an approach that is seldom examined in the literature of the life course by unveiling how the transition to fathering a child with cerebral palsy is not only an emotional journey, but also challenges the notion of sequence and paradox occurring between life course milestones and childhood milestones. Theme Two will examine how fathers not only become advocates for their children but how fathers adapt to the role of being their children's health care providers.

A variety of themes presented themselves when exploring the data collected. For the eleven fathers in my study, the prominent finding of this thesis includes how parents of children with cerebral palsy not only advocate for their children but simultaneously become full-time caregivers for every aspect of their children's lives.

1. The Transition

Transitioning to parenthood is considered a discrete event, bringing changes to roles and statuses with a distinct departure from those previously acquired (Roy et al., 2014, p. 35). This transition can also be described as a sequence of events that have become socially constructed, where parenthood is perceived by individuals in society to occur in a particular fashion. For example, experiencing a lack of sleep from feeding, diaper changing, and simply an overall lifestyle changes where parenthood becomes about the baby and no longer about oneself. (LaRossa & Sinha, 2006). When respondents were asked what they understood about the transition to parenthood, they described their new experiences. As Simon stated:

"Everyone at work said you're never going to sleep again. Like probably that's true. Having now been a parent there is no way that I can describe the change in your life that you're going to have becoming a parent. […] I think that's what people struggle with. Okay, well people say you don't sleep, that doesn't sum it up. It's true but it's not it - doesn't accurately describe the change in your life. Your life will never be the same again. It is a profound change. I struggle to describe it to people now. You have an entire new set of responsibilities that you've never had before. I had a dog like I had a dog for 8 years before our daughter was born and it's not the same. It's not even close to the same. Its responsibilities you've never had before or anything like it. And now there's no training for this, there's no practice." - Simon

For Simon, a prolonged sense of worry and extra level of care characterized his transition to fatherhood. Malcolm describes feeling blindsided:

"The whole illusion of becoming a dad prior to having those pregnancy experiences was that it was something that just is a natural progression as people get older right. Just you get married, have a kid, everything's easy, you don't think about anything that potentially could happen medical-wise. […] But that wasn't our story. It was very difficult, very emotional, very traumatic […] "You were always promised some sort of regular experience, and when that didn't happen. So, it's a natural feeling to have thoughts and doubts why that didn't happen." -Malcolm

Malcolm mourns the "what could have been". Victor expressed the opposite indicating difficulty in having lost his sense of self:

"Any parent has their personal pursuits by large on the back burner. But when you're the dad of a special needs child um. It's just that those things are um. They're out of the kitchen and boxed up presumably to never be seen again. There is a real palpable loss. For me, there is a real palpable loss of self in being the parent of a special needs child." -Victor

Parenthood can be considered a key organizer of the life course regarding how life events should sequence (Dykstra, 2007). Becoming a father to a child with cerebral palsy demonstrates a paradox of life course milestones and child development milestones as well as a flux of continuous emotions. Results in my study have shed light on how fathers wrestled with thoughts of what they anticipated in their transition to fatherhood in contrast to what they actually experienced. Fathers describe feeling "*cheated on*" a life experience that should be considered normative for every individual, wondering what a normative life course sequence would be like for them. As the fathers within this study discuss their anticipation being thrown off sequence, they stressed childhood developmental milestones as essential because having children achieving their milestones provides indication that their child is going to be okay.

Fathers also felt nervous. Samuel said: "*With my firstborn, I was really young. I think I was 20 when my son was born so I was really young. Dealing with pregnancy being young it was scary and exciting at the same time because you know I'm going to be a dad."* Samuel was grateful for having his parents' guidance through his new learning curve into fatherhood. Hence, becoming a father to a child with cerebral palsy not only emphasizes a range of different emotions but highlights the notion of sequence and paradox surrounding the life course approach.

1.1 Feelings of Anticipation

For most of the fathers in my study, the announcement of pregnancy came as no surprise as fathers previously discussed with their partners about extending their family. Fathers expressed their *"expectations"* and *"anticipations"* whether this was their first child, second, or third

anticipating a healthy newborn and smooth delivery with no medical complications. For example, Jake elaborated his expectations regarding pregnancy when asked about his preliminary emotions after learning he was going to become a father *"I figured it would be basically the average, you know have the baby, be home a couple days later and then you're getting up in the middle of the night with the feeds and all that."* In most instances, pregnancy was described as a learning curve, some having no experience with children, reading books, and hearing stories from their friends while other fathers such as Austin described pregnancy as letting his wife be the primary decision-maker, following her lead and taking things as they come, while Samuel described pregnancy as an on-going learning experience.

"My experience with pregnancy was me taking a back seat. I didn't really know what to expect. You hear horror stories and everything and I just said okay I'm going to go along with this and everything that was happening as my wife is a midwife. […] She knew what she was looking for and what she was doing so I said okay I'll be here, and I will follow your lead through the whole thing. So, my only impressions are I didn't really know what to expect and you know I've heard the whole range of things. So, I figured I'd just see what happens". -Austin

"It's true those commercials you see, firstborn you have like 600 bags with you, have this and this and make sure everything is scheduled. But by your third, you're like yeah, one bag is enough. You don't know, you're learning, you're still learning what's extreme, what's needed." - Samuel

An early arrival for almost of the fathers resulted in an extended stay in the neonatal intensive care unit (NICU) lasting approximately 130 days. Four fathers whose partners had full-term deliveries experienced complications post-delivery resulting in shorter time spent in the NICU (7 days) before being able to come home, Among the eleven participants in the study, they had an average of a 6 to 12-week stay in the NICU. Fathers who experienced complications during their partner's pregnancy felt a heightened sense of weariness regarding whether they would receive more bad news or potentially have their infant arrive early. When asked about these feelings of weariness, Simon stated: *"The meetings with the doctor just kind of got more*

dreary and more dreary and the news got kind of worse and um more scary. They were just throwing out ideas about what it could be… it was just a very scary time. A lot of fear and uncertainty." Malcolm described the experience of early delivery as frightening and not enjoyable. *"Where a lot of couples have that glow and joy, we were on edge the entire time. […] It was not enjoyable; it was very frightening. Every morning, every minute was just like oh my god".*

Experiencing an early birth meant that three fathers in my study missed the birth of their newborn. Not only did these fathers miss the birth of their child but this abrupt end to pregnancy created a race against time for both the mother and newborn's health. For example, Jake discussed his experience of a sudden end to pregnancy: *"When her water broke early, the rollercoaster kind of started"*. As this quote illustrates, early labor created a heightened sense of stress from not only being a first-time parent and anticipating a normal delivery but the fear of missing crucial events such as the birth of their infant. For example, when Austin realized that his wife's pregnancy was no longer going *"perfectly"* the realization hit that the expectation of having a home birth was no longer a possibility. In turn, details such as the gender of their newborn or details of having a home birth were no longer of importance compared to both the mother and baby remaining well. As the fathers in my study reflected on being a parent to a child with cerebral palsy, it was evident that fatherhood is not considered as a single event because fathers described parenthood as a continuous flux of emotions. The event of becoming a father consisted of the arrival of the child, relationship changes, role changes and ensuring the child's healthy development. Fathers have expressed feelings of trauma, loss, fear, uncertainty, and helplessness not only during pregnancy and birth but weeks, months, and years after the arrival of their child. Not only do these men experience the transition to fatherhood, but they are also

simultaneously experiencing an ever-lasting shift of continuous emotions. Bringing a child with cerebral palsy into the world brought an everlasting change for the rest of their transition to fatherhood and presented everlasting emotional changes.

1.2 Parenthood Includes Embodiment

For any parent, the phenomenon of embodiment is essential in raising a child. However, for the fathers in my study, embodiment as a parent to a child with cerebral palsy exemplified unique differences. Meeting your newborn for the first time in the NICU is not an experience any parent envisions. As Austin stated: *"You start the process of being a parent in a setting that no one ever wants to be in".* One of the key experience's fathers discussed when having to spend time in the NICU was not being able to immediately hold their newborn. Not only did these fathers feel a sense of helplessness, but not being able to hold their newborn immediately after birth enhanced the fathers' feelings of not immediately having become a father. Specifically, for Malcolm and Victor:

"What I would say is unique and different is that your child is so young and fragile and um that it just, you don't get those immediate feelings of this is your child. […] I got to hold her about two weeks in. Um, she was at a point where she was able to be moved out of the uh, I guess the little crib almost incubator thing. Um, and so we were able to hold her for about 20 minutes or so. And that was nice, that was really the first time I had ever actually touched her. It just didn't feel real. I knew that that was my child, but having like never actually touched her, um or held her or anything, it's kind of just felt like an extension of me but as soon as I got to hold her it was like okay this is real. My wife said the experience was a little different for her cause she actually carried Julia you know for the time, pregnant with her, she felt the kicks and all that stuff but uh, for me I was always just an outside observer, haha but until I got to hold her, I was like okay this is real." -Malcolm

"You expect to be able to you know hold your child. You expect to start interacting and begin that bonding process but um, it was very uh, very surreal. You know seeing your child there but not being able to be a parent." -Victor

As the fathers in my study illustrate, early experiences of embodiment are different from their partner. Unlike mothers, fathers are not able to experience direct embodiment until their

infant is born. Fathers discuss how mothers have an immediate bond due to having carried the infant for 9 months, while fathers first experience of embodiment is when the infant is welcomed in the world. Thus, unlike mothers, fathers experience a stronger shift, which can be described as a *"slow burn"* when it comes to parenthood embodiment (Ranson, 2015), requiring extra time.

1.3 Feelings of Fear and Anxiety

As the spectrum for cerebral palsy is vast, the process of waiting for the diagnosis was considered more troubling than receiving confirmation. Whether complications were determined during pregnancy or shortly after birth, most scenarios appeared to be a *"waiting game"* where doctors told parents that they saw abnormalities in their infants' medical scans but were not able to accurately confirm what impact it would have on their infant's development until further tests were administered. When asking the fathers in my study about receiving the diagnosis, respondents recalled the moment it occurred. However, what was particularly significant for these fathers were the detrimental events leading up to the diagnosis, instead of the confirmed diagnosis, it was the unknown, the waiting, and these events prior to the diagnosis that were most challenging. As stated by Victor:

"The diagnosis was simply words to describe what his life was going to be like. It helps fill the lines, not a shock or any diagnosis. The fact that his brain bled and 50% is dead is the shock. Seeing your child being given fentanyl for the pain is a shock. Calling it cerebral palsy is not the shock. The shocking part is the experience, not the words. The diagnosis describes the situation." -Victor

Receiving the diagnosis presented another shift in their transition to parenthood as fathers expressed a variety of mixed emotions. Earl felt relief, Austin felt anger, while Malcolm was in denial, thinking his daughter's cerebral palsy would be cured with an extensive amount of therapy. Conversely, Samuel and Jake were not surprised to receive the diagnosis as they had already speculated that cerebral palsy was a possibility. Despite mixed emotions, having the

diagnosis written on paper became essential for their child to receive proper treatments for their well-being. As *Malcolm* explained*: "The diagnosis is a catalyst to get a lot of the additional services […] The importance of the diagnosis was confirmation and then also key to get the ball rolling for all the therapies and stuff she would need".* Hence, the diagnosis not only provided confirmation but was a starting point for navigating their new life as parents to a child with cerebral palsy. As Samuel stated: *"We had a starting point on how to approach everything in our life. It kind of opened the door to a lot of other critical thinking, different ways of thinking, adaptations, modifications, all those different components. At the same time, it gave us a little peace of mind, you know we know what's going on and now we can move forward".*

Victor had a different outlook regarding his son's diagnosis. He discussed that receiving the diagnosis was the easiest part and the challenges increase as his child continues to grow. Rather, navigating his son's needs has become more and more difficult, requiring more adaptations as he ages. In turn, while parents have aid in navigating therapies and other medical treatments in the beginning, things remain difficult day to day as the child ages. *"Every week has gotten harder since the week before. You know with a special needs baby there are, um, you know the clothes are appropriate you know, the car seat works, the crib works there are things available that you can kind of navigate your life I guess for a better word."* While there are certain tools to help parents of children with cerebral palsy navigate their new life as parents, these generally become the first steps toward a large learning curve of navigating the world of being a parent to a child with a developmental disability. Moreover, these quotes illustrate a paradox. It is a common notion that parenting tasks are to get easier as the child ages. However, for these fathers, tasks become more difficult, challenging the normative sequence.

1.4 Navigating Living with these Emotions as a Father to a Child with Cerebral Palsy

Malcolm expressed feelings of jealousy as he felt he missed out on something that is supposed to happen for everyone when bringing a baby into the world.

> *"I watched most of them, have the one or two traditional two-day stay in the hospital and bring home a 7 or 8 pound little pink baby ha, and then it was the struggle of diapers and not sleeping and you know transitioning to solid food and all that stuff. You know haha here we are at the hospital for 4 months, transitioning home and you know going to a liquid diet and not knowing what to expect and you know I was very jealous and I was very I was like almost angry for a while that um, you know they got to experience something that I thought I would experience and so I think that's what probably distanced us from a lot of our existing friendships." -Malcolm*

Fathers felt their expectations were *"being thrown out the window"*. In contrast to Malcolm, Earl and Simon discussed feeling worried as to whether they would be able to bring their child home, while Jackson just wanted to go home to regain a sense of *"normalcy"* into his life. As parents are learning new parenting skills, parents may also have to maintain a strict regimen to ensure their newborn's health, such as monitoring oxygen levels or intravenous feedings depending on the severity of the diagnosis. Mixed emotions were present for two reasons: happiness for being able to bring their newborn home but also nervousness that they were leaving a safe environment that provided professional 24/7 care and would be required to complete all caregiving tasks on their own. Austin described this shift as *"the true parenting experience"*. Malcolm shared his experience by indicating that he and his partner were used to having trained professionals taking care of everything then suddenly, it was all their responsibility. *"You get used to having trained professionals with you 24/7 and all of a sudden it's your responsibility to take care of this tiny, tiny baby"*.

In essence, bringing the baby home can be described as *"exciting but extremely anxiety-inducing"*. Staying in the NICU with a team of medical professionals continuously looking after

the baby makes the transition to returning home more of a learning curve. Fathers say it was a shock as there was no longer any professionals to help and they didn't have monitors to indicate that something was happening to the infant. In essence, once discharged from the NICU, parents were left astray, having to do all caregiving tasks on their own. Not only do parents transition to parenthood, but parents are also simultaneously transitioning to becoming their child's health care provider. Thus, fathers in my study reflected on feelings of trauma, fear and uncertainty when transitioning to parenthood.

1.5 A Day in the Life of a Father to a Child with Cerebral Palsy

At the beginning of their transition to fatherhood, the fathers in my study primarily described the relationship with their newborn as more "mother-based", as there was not much they as a father could do in terms of caregiving until their child's personality began to flourish. As Malcolm noted:

"The first stage when she was a newborn, all the way to an infant I'd say I spent 99% of my time just scared haha, right nervous. Um, not enjoying fatherhood at all, thinking of it more as a chore, thinking of it as like constantly having to be on edge, and uh not `enjoying all the things that it would be typical for a newborn. Uh, luckily that stage probably after about a year transitioned to her being a toddler. And that's when I started to see her personality come through. She wasn't just a little blob sitting there anymore. She had emotions, words and feelings and stuff that's when I really started to connect with her more… […] While I'm still her caretaker in the sense that I take care of a lot of her physical needs, um she and I can have a long hour conversation about what she likes in school and all that other stuff so. I'm just so much happier now. And you know I would imagine that is probably the same with most parent experience but since mine didn't start off typical, I've transitioned from scared too proud." - Malcolm.

As this quote illustrates, the transition to fatherhood for Malcolm at first was worrisome, leaving most of the caregiving tasks to mom. Once his daughter transitioned to toddlerhood and developed her own personality, Malcolm built up the courage to build a relationship with his daughter as she had the capability to express her feelings and to enjoy the things she likes. Simon provided a similar statement stating that when things were less about mom, he was better able to

continue his transition to fatherhood alongside his children. Once both of his children developed their personalities, although he was still their caretaker, he realized that everything about parenthood and parenting roles changed as their children grow older. *"When it's less about mom, it just became a lot more fun. […] Now it seems like it's more of a teaching role for our kids as they are 3 and 5. Now it all evolves. Other friends, have kids, teenage kids, and develop that friendship. It's cool. It's neat on how it just keeps evolving."*

When asking fathers in my study to discuss acquiring new paternal responsibilities, the responsibility addressed most frequently was becoming primarily responsible for the physical involvement of their infant. Unlike their partner, fathers tend to have the strength and stamina to hold, carry, or lift their children for a longer period. For that reason, fathers tended to help with physical tasks involved in daily caregiving such as bathing, changing, and toileting. As described by Earl, *"most involvement with the child is physical".* Similarly, Victor states: *"I feel a lot on me being the physically strong one in the house […] You know my wife can still carry our son around but not for nearly as long can. And I can see that being a further thing of what one another can and cannot do".*

Following responsibilities, when asked about the primary difference between parenting a child with a disability versus without a disability during their daily routines in parenting, fathers in my study mentioned the child's daily routine of physical and occupational therapies. Due to these routines, parents of children with cerebral palsy's day-to-day lives feel more regimented than other families. Not only do parents experience a heavily regulated day-to-day lifestyle, but my fathers also discussed that, unlike other families, they relished doing other things that were therapy-related, such as spending time on family activities instead. Spending "*off-the-clock time*" with their children is fathers' favorite part of the day. As exemplified by Austin: *"We'll just*

cuddle up and do a little bit of stretching, nothing super serious or difficult, play with some things and it's just sort of off-the-clock time, I guess. You know because we feel like so much of her life and her awake time is so regimented in that we have to do this and this and this". Thus, spending time with their children that is not regimented by routine or therapy was most cherished by the fathers in my study. Another element of difference in their daily routine includes is having to keep a watchful eye on their child and remain in *"shelter mode,*" feeling more compelled to protect their child because they are medically fragile. Austin and Bob both discussed this:

"They can put their kid down at some point. Our daughter doesn't like being put down. She doesn't like being left alone. Like we'll go to my friend's house when we try to visit them sometimes and they'll have the playpen set up, little fences and everything, the toys and kind of just park them in there and you know they might be in the kitchen, you know you can see the kids from the kitchen, they can just leave the kid and the kid will go do whatever they want. They'll crawl over to things and play with things and that kind of stuff. You can never do that with our daughter. As soon as you leave, she'll lose her mind and she's up until recently has not been able to move around. So, wherever you leave her, that's where she is going to be". -Austin

"I think more of a worry. Making sure that he's okay. You know anything that he does you know I sort of saw him if he was at the playground or anything like that that I sort of advocate a more watchful eye on him, making sure that he doesn't get bumped because he'll definitely fall over a lot easier you know or you know just having to be in the playground with him or anything that he was playing on kinda had to be closer and making sure that he was uh, able to that he was in arms reach whereas other parents would just sort of where other dads would just sort of all they would have to do is watch their kid and not have to be so close to them to make sure that they are okay. They can sort of just sit and watch." -Bob

Hence, parenting a child with cerebral palsy not only involves spending time together that does not involve therapy, but also involves protecting and helping their child navigate their environment. Rather than having their child explore on their own, fathers kept a watchful eye on their children. On the other side of the spectrum, by doing their daily routine at their own pace, this adaptation provides evidence of a different normativity among families. As the realization set in that their lives were going to experience a permanent change, fathers in my study took initiative to not only change their perception of life but adapt their daily routines and long-term

goals for the well-being of their children. In turn, this new developed "normative" also led to a shift in the meaning of their child's medical diagnosis. For most fathers, their child's initial diagnosis was something foreign, something scary because necessary information and resources were lacking. However, once their child grows older and receives the appropriate medical services for an improved quality of life, fathers no longer worry about the diagnosis. What was once foreign, is now learned knowledge applied to receiving the appropriate resources for their child. In essence, fathers of children diagnosed with cerebral palsy are able to shift boundaries and expectations by living at their own pace.

1.6 Feelings of Grief

Welcoming a child with a developmental disability into a family creates a different sequence for everyone involved. Of particular interest to this study, the word *"grief"* was used to describe a change in expectations, while a sense of "*loss*" was recognized when welcoming a child with cerebral palsy to their family. As discussed earlier, Malcolm stated how people expect some sort of standard life course sequence. Since he was not given that, Malcolm felt it was a natural feeling to grieve this loss of experience. More interestingly, Austin and Samuel described how they followed *"the rules"* for a healthy pregnancy and delivery, such as not drinking or smoking before conception up until delivery. Even by following the rules, both fathers experienced a complicated pregnancy and birth. To emphasize this, both fathers spoke about parents who were aware they were expecting but still chose to abuse their bodies during their pregnancy and still welcomed a healthy baby. As Samuel explained: *"People abuse their bodies in horrible ways and have perfectly fine kids and she's seen people do the opposite and have all these complications. Neither of us drank for a month before our daughter was conceived, everything was done perfectly, we followed all the rules and did all the things we were supposed to do."* In

turn, Austin and Samuel felt a sense of confusion, as they did everything right and still did not get to have the standard pregnancy experience. This quote exemplifies that regardless of unspoken norms, things do not always proceed as they are *"supposed to be".*

Elaborating on the topic of grief Jackson discussed how he looked forward to doing certain activities with his child. *"You think you're going to be a father; you got a young boy who's going to carry on your name. It's almost like any father who's got a child and has expectations of what you're going to do. You know you're going to go fishing; you're going to do this, you're going to go hunting, you're going to cut wood, you're going to do whatever".* However, when welcoming a child with cerebral palsy, certain activities are not possible. Out of the eleven fathers in my study, Earl expressed the most grief.

> *"When it turned out that our son had problems, it brought to mind that we had a fellow at our church that spoke to a men's group that had a son with um, down syndrome. And he said as a dad, waiting for his wife to give birth he envisioned a son as what he was going to see as a child. And then he said, when his son was born, it was like a death because the child that they envisioned didn't show up. A different child showed up. A child that was obviously going to need a lot of care. Our situation was similar to that because we felt that to a certain degree after was born and not immediately but when we saw later on that he was going to have limitations. That he wasn't going to be out in the backyard playing catch our other son, then we saw that the child we were anticipating was not born." - Earl*

As a repercussion of experiencing a different trajectory and potential delay in developmental milestones, a couple of participants were actively preparing for their future and the future of their children. Specifically, Jackson and Victor have begun to prepare long-term to take care of their sons long-term differing from other family's children who tend to leave the nest after high school. Instead, both fathers will be taking care of their sons long-term, indicating that they will not only have to work beyond the age of retirement to compensate for their child's medical expenses, but they will further alternate their post-retirement plans due to long-term caregiving of their child.

"*The biggest challenge I have is just not knowing what the future holds right and you know when the roosters let the nest or whatever the little chickadees leave, they go and live their life, that's not going to happen with Nate. You know I left home when I was 18 or 19 or 20 and whatever, you don't go back but my parents don't have a room for me waiting. They get on with their lives, but my life is going to be taking care of my boy." -Jackson*

"I need to be prepared to be physically and financially and emotionally be a primary caregiver for him into adulthood. You know I think there's a realization that my wife and I will... retirement looks a lot different for us now. We're probably going to have to work a whole heck of a lot longer than before for the thousands and thousands of additional dollars in costs per year, and then knowing he's not ever going to be able to take care of himself. He will get through school and stuff but will never be able to do university or some sort of path and personal fulfillment in that regard." -Victor

Both fathers were aware that their future and child's future will be different than they previously envisioned. Daniel explains that most people do not understand what it means to take care of someone for an extended period unless it is an elderly member of the family. Daniel illustrates similarities between taking care of an elderly relative versus taking care of his son long-term.

"I think they don't understand the level of care until one of the members is older and there's a care issue for you know a grandmother or a grandfather than they may have a sense of what their care issues are. I think that's one of the other things for family members for parents for these children, you're a constant caregiver so a lot of people don't think you're caregiving until their parents grow old and you either have to take care of them in your home or go to a home or facility and you're there to kind of monitor what's going on make sure that the care is sufficient. It's hard for them to understand the care that is necessary for your child, they don't understand that it's kind of the same thing, but they haven't done it." -Daniel

In essence, the fathers in my study not only experienced a cascade of emotions, but they also experienced the paradox of life course milestones and childhood milestones. In this circumstance, it is not the fact that fathers of children with cerebral palsy were thrown off the normative sequence of the life course. Instead, the expectations and anticipations of becoming a father were the two primary elements perceived as "off sequence", rather than the overall sequence of the life course. In turn, as the paradox of life course milestones remained present, it was evident that the fathers in my study wrestled with their emotions surrounding this normative

sequence for their children. They felt that milestones provide confirmation that their child is going to be okay, regardless of what the life course approach indicates. Thus, fatherhood for children with cerebral palsy consists of a continuous wave of emotions while returning to a sense of normalcy that is consistent with their sequence of milestones.

Chapter 5

Findings: Part 2: The Responsibilities of Fathering a Child with Cerebral Palsy

2. Advocating for Your Child

Several of the fathers in this study discussed their role as advocates for their children. The term *advocacy* can be defined as "to advocate for another person is to speak up for them, to give them a voice (Isaacs 2015, p. 747). Advocacy can also be described as advocating on behalf of individuals who are part of a specific group to prevent societal disadvantages. The fathers in my study discuss having become an advocate to ensure that their children are given the necessary medical treatment and have access to important programs and activities. Hence, this theme will include two sections: one describing how fathers advocate for an accessible environment, followed by another describing how fathers prepare their children for the environment in question. By knowing their children, fathers have been able to take their knowledge and address the barriers faced by their children. Fathers in my study further expressed that barriers are not always physical, and that their children sometimes require additional protection in various situations.

2.1 Prepping the Environment

Fathers described having to advocate for their children within the school environment. Daniel provided the example where his son had attended a class trip and the caregiver in charge had not given his son any food or drink for entire 8-hour duration of the trip. Thus, Daniel took the initiative to be on the school board's parent committee to ensure that his son was properly taken

care of during school hours outside of his supervision. From his perspective, the school was transferring responsibility to Daniel and his partner:

> *"They wanted us to take him in our van separate from the rest of the kids. It means one of the parents has to take off to drive to the trip but also 2, um, he's separated and it's more expensive to get the accessible buses. So, my response was you can't have the school trip because our son has to be on the same bus as everyone else. The administrators or the teachers or some of the other parents would set it up as well we can't do this because your child has a disability so they try to separate, the reason why we can't do these things, it's your fault." -Daniel*

Daniel had to go to extraordinary lengths to ensure that his son was included in school activities *"School trips and things like that where most dads would just be a chaperone or send in a cheque while I had to have discussions with the school administration about whether the bus was accessible and making sure the trip was accessible"*. Further on the subject of school, Eric indicated that his son was being bullied by his classmates. As his son could not defend himself, Eric told his daughters to keep an eye out for their brother and protect him from children who were bullying other children. As a result, the principal told Eric that he couldn't tell his children to bully other children and Eric replied, *"if they're beating up my son, his sisters are going to protect him"*.

Jackson's son has a food texture issue often causing his gag reflex to act up, resulting in vomiting. *"He has a pretty bad gag reflex. So, he has been known to throw up at school and the norm is that if you throw up at school then you're sick. So, if you throw up, then you got to leave and you're not allowed to come back for 24 hours later after you stopped throwing up. It's like no you don't understand".* This quote exemplifies how he as a father is trying to aid the staff at school in comprehending his son's unique health circumstances and the need to have policies and exceptions due to chronic circumstances.

The Education Act (1990) & the IDEA (Individuals with Disabilities Education Act: 1990) are legislations put in place by both the Canadian and American governments ensuring that each child, regardless of their abilities, has access to free public education. However, for the fathers in my study, they reported having to demand accommodations. Earl described how his son struggled in school as a result of the physical challenges (e.g., stairs, crutches, carrying books). According to Kervick (2017), communication between families and schools is crucial in situations such as those described above. However, rather than having their input solicited or consulted on accommodations, these fathers felt that a) problems presented themselves and persisted until they stepped in, and b) their children suffered because of this.

Earl elaborates: "The challenges are different because when you realize what his limitations and you cannot communicate that to the school, principals, and teachers, then you're butting heads." This is a paradox: as a parent, they need to provide specific details their child's unique requirements, but when they do, they create problems for the school staff.

2.2 Prepping the Child

Advocating on behalf of their child required fathers to not only prepare the environment, but also navigate the complexities of preparing their child. These involved fathers discussing the tensions that exist between accessibility and ability by first understanding their child's limitations and confronting the barriers that their child encounters. As Earl describes:

"We wanted him to be as normal as possible and trying to make sure he overcome, that he was able to overcome normal living conditions cause at the time we're going back to the mid-70s late 70s, there wasn't much attention given to access, handicap accessibility. Like there were very few stores that had um doors that automatically opened and very few stores had ramps. So we knew if he was going to exist in a modern world at that point, even with crutches, we knew he would need to be able to deal with stairs and getting in and out of cars" -Earl

Fathers became advocates for their children to help their child achieve an independent life and to incorporate their knowledge and raise awareness of inaccessibility within their

community. By understanding their child's limitations, fathers were able to prepare the environment, then prepare their child based on their child's abilities. Hence, the fathers describe introducing methods and ideas to help their children and help others by *"trailblazing".* For example, Daniel worked to make his local community school more accessible and has also been working with airports to increase accessibility. Daniel's airport campaign revolves around expanding accessibility on air travel, such as increasing the number of change tables in airports and airplane restrooms. He explains he has had to change his son on the bathroom floor:

"When some of the people at school talk about how accessible the school is, we have to remind them that part of what our son did was make it easier for everybody else […] such as people in wheelchairs who came in after our son, remarking how accessible the buildings were and how the programs were set up. […] Having to travel and having to lay your adult child, and you have to use a toilet, and you have to lay him on the ground in the toilet because there are not enough adult changing tables in the bathrooms. So, imagine young people having to put their babies on the floor in a bathroom to change them. This is one of the things that uh we've been talking to some of the local airports about. So that when you travel, you know and forget about traveling in an airplane. All of those things, one, they require a great deal of extra planning, and two people don't realize how difficult they are for a parent with a child with a disability"

The fathers also reflected on their own process of realization; fathers in my study described realizing that people with disabilities encounter multiple barriers and people are not aware of how inaccessible the world is until they are put into that situation. For example, Daniel and Jackson both spoke about community misunderstandings regarding accessible parking spots:

"We've had times when we would pull into the parking lot and there would be people in the handicap spot because they were dropping off or moving things and they look at us like we're crazy because we're yelling at them. And they say we're only here for a minute is that a problem? And people just don't understand." -Daniel

"That it's like me complaining to people that take up a handicap spot and I'm so sick and tired of fighting with people, so I don't say anything anymore. It's like people that say that in front of me and I just like you know what I can't educate the world. I've done my share; I'm not going to get into this with everybody." -Jackson

Fathers also noted that their child's intelligence is sometimes dismissed by individuals in the community, caregivers, or teachers. Jackson and Daniel emphasized that just because their body

does not fully cooperate, it is not an indication that their brain isn't functional as well. They describe feeling a need to protect their children from people who may try to put limitations on them:

"I mean he's a very smart boy, and I think, that's what pisses me off with life, in general, is that people don't understand that people with disabilities, just because they are not able to communicate as well as you would think, their brain and maybe not in all cases but their brain, they understand it. Everything that's going on, they know everything. How do you look at people like Steven Hawking? He should be the definition of a disabled person. You're a brilliant mind, just because your body doesn't want to cooperate." -Jackson

"We talk to him about the fact that has to take charge of those things and make sure he's letting them know that it's not acceptable because take advantage of people with his disability and it's easy to ignore him or dismiss his intelligence. […] The world might try to pigeonhole him to certain categories of this what he can do, or this is what his intelligence is."-Daniel

While the world is still incorporating to accessibility and accommodation measures, fathers do wish that their community would be more understanding. Malcolm describes what he wishes he could tell more parents: *"My wife and I are definitely her advocate […] I realize that even though things are getting better the world is not made for people with disabilities. It's still very inconvenient. Just being kind of like extra patient or empathetic in arranging special transportation to get to school or you know rearranging your vehicle to be able to carry additional stuff.* In these portions of the interview, fathers expressed exhaustion and frustration with institutions (schools) and other people.

2.3 Becoming the Most Knowledgeable: Parents Challenging Experts

Children with cerebral palsy require a multitude of treatment regimens, including physical therapies, occupational therapies, and sometimes surgical procedures. In their experience, participants noted that becoming a father included learning about medical procedures. In certain circumstances, parents must make decisions for their child's health, sometimes with little to no knowledge, having a limited amount of time to decide, or experiencing feelings of discomfort

with what has been recommended by physicians. This theme will provide insight into how fathers learned to make decisions based on being in proximity to their child and their child's overall behaviors.

Austin, Eric, and Jackson discussed that as parents they occasionally felt that doctors do not always recommend the right approach for their child. They said that each child has their own unique quirks, and some treatments may or may not work with their daily routine, whether this involved medical or physical equipment. For example, Daniel stated that hospitals do not have the proper adaptive equipment for their son to have a comfortable hospital stay. *"We're at the point where now you know, we know we can take better care of our son than the ER folks can take care of him."* Daniel followed up this statement by providing examples of the equipment they have in their home that the hospital does not offer, such as a rift seat for the toilet, a bed free of railing holes, and anti-seizure foam pads, coupled with the fact that the medical staff does not have the appropriate skills to feed his son other than through an IV. As for medical treatments, Daniel and Jackson mentioned that they always take doctors' advice, but additionally consider their knowledge when it comes to certain situations.

When examining academic literature, it is clear that it is not uncommon for parents of children with developmental disabilities to challenge medical professionals when determining what is best for their child's health. However, parents' opinions were not met without some resistance. Authors Richardson et al (2021) discuss incidents where parents felt as though their children were not reaching developmental milestones as quickly as their other peers and siblings. Due to doctors' resistance, parents had to push for additional testing for their children as doctors insisted their child was only playing "catch-up" (p. 214). This scenario occurred for some of the fathers in my study who similarly had to push for additional testing and believed their child was

experiencing something more than a simple developmental delay that the child would outgrow. After pushing for this additional testing, they found that their children did have more than a developmental delay. As such, fathers in my study discuss that professionals do not always have answers, let alone the right answers. To elaborate, Kervick (2017), discusses how parents learn and adapt while caring for their children to ensure their child's needs are met. For parents with children with developmental difficulties, parents are described as a constant (Kervick, 2017, p. 66) or a case manager as they take responsibility for managing all facets of their children's life. Parents bridge the home environment with the school environment, watch their child grow, watch their symptoms vigilantly, and recognize when their child is not themselves. As a result of being on constant watch, parents utilize their insights and know what may be best for their child's health. In essence, academic literature illustrates how parents seek to establish some balance in being oriented toward their child as a parent and oriented toward doctors and others as an advocate. The fathers in my study confirm this point:

"Three days after he was born, the doctors wanted to do a tracheotomy. My wife did some research on the fact that there's a 50% mortality rate at the time for those that underwent the procedure and the vast majority after 6 months um basically it heals itself so what we did was we decided to not have the surgery based on her research and uh, the vocal cords eventually healed themselves." -Jackson

"I think is because of his speech, um, you know a lot of people were pushing the augmentative speech devices and the soundboards and all that. And that wasn't a route I wanted to go because I felt that I think if he used that he wouldn't try to speak as much. And I said you can disagree with me all you want; this is my son, and this is the way I see it. And you know what, he labors a bit when he talks, but he loves to talk, and he tries, and a lot of people can understand him. The more he does that, the more that he actually practices speaking compared to pushing him pushing a button here, pushing a button here, and then have a computerized voice say what he's going to say. I don't understand how that's going to make him you know learn how to speak better."-Jackson

Daniel and Jackson were able to advance their children's development within a safe margin by using their own acquired research and knowledge. By using their observations, Daniel,

Jackson, and Malcolm were able to push their children past the peak ability levels pre-determined by doctors. *"We've always took the advice of the doctors and the experts and all that stuff, but we also listened to our instincts, and we were able to push our daughter a little bit further than they were comfortable with, within a safe margin of course".*

Another area where fathers acted upon their observations came when their children were not reaching their developmental milestones. As a delay in not reaching milestones is one of the first indicators of cerebral palsy, fathers such as Earl thought that something was not quite right: *"The doctors refused to believe it was anything other than slowness. He was just a slow developer."* As a result, Earl took the initiative to find a second opinion and his son was diagnosed with cerebral palsy. Samuel described a scenario where he thought perhaps his daughter's shunt was malfunctioning due to his daughter's lethargic state, so he contacted the doctor, and if they discovered that the shunt was completely malfunctioning:[1] *"I contacted her neurosurgeon and I said I want to get a CT scan. I want a CT scan to see what we got to do. I'm going to take her to the ER there and let's get her in you know. Let's do all the testing we need to do, there's something that's not right. There was actually a full malfunction with the shunt, and she had to do surgery."* These fathers had to make decisions with little to no knowledge of anatomy and medicine. Daniel expressed sadness for the discovery that his son was experiencing a tremendous amount of pain before the medical cause was discovered. Similarly, Jackson felt regret in terms of wondering whether he should have pushed for more therapy so that his son would walk rather

[1] Samuel's daughter was born with hydrocephalus. To avoid blockage and implement continuous flow, a shunt is inserted. Per the participant's discussion of this event, a shunt has a life expectancy of 10 to 15 years before requiring replacement. His daughter had complications with her replacement. She was experiencing symptoms of nausea and feeling lethargic. In turn, Samuel contacted her neurosurgeon, insisting his daughter receive a CT scan to ensure the shunt was functioning properly as she was demonstrating symptoms of a malfunctioning shunt. As a result, his daughter required a full replacement and insertion of a new shunt.

than use a wheelchair full time. Hence, some of the fathers in my study spent time reflecting and questioning their previous decisions.

Another pattern that came up in the interviews involved fathers asking medical professionals whether their child will be able or not be able to achieve their developmental milestones, and if what is determined by professionals should be taken at "*face value".* For example, Jackson stated that because cerebral palsy has such a wide spectrum, a child with any diagnosis should not be categorized automatically in being able to do or not do certain things based on the diagnostic level determined. *"When the professionals tell you that this is it then you kind of take it at face value. The problem I have now is realizing that not everyone knows what they're talking about because everything is so different. People's kids' cases and severity are so different that you can't lump everything into one."* Daniel shared a similar point of view:

> *"I think the one thing is don't rely upon a predictive nature of diagnoses. I think that's the big thing. We're involved in a lot of support groups. And um everybody has said that what the doctors predicted that their child, their child turns out different. I mean, some better, some worse but it's never the same as the doctors predict. They can't predict that even though sometimes they make it seem as though they can. I think that is the important thing. You just kind of have to assume that they can do certain things, don't let other people put the limitations on them. Keep fighting for them." -Daniel*

Thus, fathers had to resist the categorization of their children, but Jake elaborated further that this principle can also be applied when doctors talk about statistical rates. Jake said that he does not believe in statistical rates and that one should not compare their situation to another as things always turn out different than what is predicted. Thus, one should not say for certain that their child is going to or not going to do something until it happens. As Jake states: *"I don't believe in statistics, that's the one thing I don't like and the one thing I didn't like about the hospital is that everything was based off statistics. They're basing it on all these statistics or whatever but who's*

to say they will, or they won't". Therefore, they made the distinction between medical reporting and their interpretation of outcomes.

2.4 Community Exhaustion: Being Hypervigilant of Surroundings

Attentiveness to the language used around their children came up in interviews where fathers discussed an increased awareness of everything around them. Becoming a parent to a child with cerebral palsy made fathers develop a heightened sense of awareness for their surroundings and the way society not only perceives them as well as their children. Not only are their perceptions different, but the fathers in my study have become more sensitized to the type of language that individuals use during daily conversations. Austin stated:

"You definitely pick up way more on things people are doing that they shouldn't be doing. You know I'm not here to police people's language and that kind of stuff and I know generally what people mean when they say things that they're not using the terms out of spite, but I think the second someone does use it out of spite, I will lose my mind". -Austin

While most fathers in my study know these *"terms"* are not used maliciously, fathers are not out to *"police"* or make *a "fuss"* about the language people are using. However, fathers still feel a sense of having to correct people, when misconceptions regarding their child's abilities and level of intelligence arise. As Jackson explained:

*"Nowadays when people talk about riding the short bus or he's retarded, and that's an everyday thing and that stuff pisses me off because then I'll tell them that the language you are using is not acceptable. […] when people say well the short bus, I say well what bus do you think Nate takes to school. Oh, I don't know. I say yeah, he takes the small one that the wheelchair fits on so when you're saying that he rides the short bus you mean r*t*rd*d and they're like oh my god I'm so sorry I didn't realize." -Jackson*

Samuel explained how he used to get upset at people staring at his daughter in her wheelchair. Now that he has accepted this when staring occurs, he takes the situation as an opportunity to tell others about the circumstance: *"I feel like when someone asks questions it's because they just don't understand but I don't think it's a negative thing. If they have the balls*

enough to come up and be like hey what's up with your daughter, I think hey you have the balls to talk to me and ask that question then I'll answer that question and educate you what's going on." On the contrary, Jake displayed a more negative side of having conversations with others. He mentioned that rather than focusing on the positive (e.g., that his children are happy and healthy) people emphasized the negative, such as the length of children's treatments and milestones they have not reached. He wished that people would simply offer a helping hand instead of awkwardly staring at what he or his child was trying to accomplish. Hence, fathers have transitioned to being more cautious and selective when engaging in social interactions.

2.5 Social Circle Misunderstandings

When I asked the fathers in my study to describe if becoming a parent to a child with cerebral palsy had an impact on other members of their social circle, answers varied. The highlight of this theme is fathers feeling alienated when visiting their friends and loved ones. This setting created the opportunity for a direct comparison of the pace of their child's development with that of other children. Emotions of feeling misunderstood presented themselves. More specifically for Victor:

"There's a certain, not sense of but persistent alienation that develops between um, myself especially and friend group who are parents as well. As much as I hate to say it, I don't have nearly as much in common now, as I did before. I can't relate to their lives anymore nor can they relate to mine. My friends are all people that have been in my life for you know 20-30-35 years, you know childhood friends that uh. I was the best man at 6 of their weddings. […] I have trouble connecting in any meaningful way because um, you know. Probably a lot of it is on me but there is an um, a bitterness that I feel when I hear about vacations or extracurricular activities or family outings. Those are just things that we don't get to do that anyone outside of our family really understand… […] It just changes the trajectory of everybody's life." -Victor

Victor elaborated on his statement by discussing how he no longer felt a connection to the friends he used to have because not only were their daily routines different, but they did not share the same trajectory when it came to being a parent. Victor no longer felt as though there

was a mutual level of understanding with his friends. Earl and Daniel expressed similar feelings, stating that parenting a child with cerebral palsy means that there is a lack of understanding and a lack of awareness from family and friends. For example, when talking to other parents from their children's class, many parents talk about their child being nominated for a scholarship or being drafted for a sports team. In contrast, the fathers in my study discuss not being able to relate to those types of experiences and parents.

"A lot of times where I hear some of my friends complain about certain things, that oh you know my kid is just bothering me they won't stop or leave me alone and it's like I want to tell them I would give anything for my kid to be able to run around and bother me and run away and do that stuff. But you just don't get into that kind of stuff unless they're really close friends". - Malcolm

Simon said: *"they just don't get it."* He describes that people can say all the right supportive things but at the end day, that is the extent of the conversation, creating a disconnect from his friends. On the other side of the spectrum, despite a lack of in-depth understanding, Eric discussed a positive change in their social circles. However, most of these examples demonstrate that an individual's life trajectory is not only influenced by social factors but is also shared and reciprocated between those of closest proximity. In this circumstance, the fathers in my study discussed how their lives are no longer in sync with their friends' lives, often creating disconnect and feelings of alienation.

2.6 Changing the Activity to Suit the Child

As a parent to a child with cerebral palsy, fathers *"adjust along the way"* when participating in family activities. The fathers in my study found ways to adjust their daily activities whether this involved a rugged wheelchair for hikes, a floating wheelchair for the beach, or tying a hockey stick to their child's arm so their child can play sledge hockey. These examples provided by Malcolm, Samuel, and Jackson demonstrate that fathers can find ways to enjoy activities

together with their children. A phrase that was most used was *"it's not about what we can't do, it's about what we can do."* exemplifying that the activities these fathers may have envisioned doing with their children, whether to have a soccer or a running buddy were no longer important. Instead, fathers described activities they could enjoy with their child, even if the activity required modification, such as the example given by Victor:

> *"Adjusting along the way. When the weather cooperates, I exercise an awful lot, and you know. That is one thing I pictured doing with my kid as he got older. You know my running partner, my exercise buddy. Well just because my son can't do that on his own, doesn't mean I can't push him in a special wheelchair or go snowshoeing and tie the toboggan to me and include him that way. […] It's not what we can't do, it's what we can do." -Victor*

This also applies to family outings. More specifically, Malcolm expressed that they do not like to leave one child behind if it is something that they cannot do. They would rather do something altogether. *"I don't like leaving our daughter with my mom or anybody just because we want to go off and do something that she couldn't do […] We make accommodations where all of us can go".* Therefore, the fathers learned to adapt activities for their children, especially if this involved a family outing. In summary, this chapter illustrates that fathers of children with cerebral palsy adapted their overall lives to father a child with a developmental disability, including family outings, caregiving, advocating, or getting to know their child. Fathers acquire the tools to shift their transition to parenthood. Fathers acquire the tools as they parent children with cerebral palsy.

Discussion

My research findings illustrate the tensions that exist between normative expectations of child development milestones, normative expectations of parenting and the unique challenges of raising a child with cerebral palsy for my fathers. My thesis findings raise two (2) key issues surrounding the life course literature: 1) how pivotal the stress of a premature birth and alarming diagnoses is toward being a parent and how this influences the overall experience of transitioning

to parenthood: 2) while caregiving tasks may resemble those of other parents in the beginning, physical caregiving tasks may in fact become more demanding. As such, the child's transition to adulthood may not mean independence, but rather continuous parental caregiving.

Specifically, pre-term birth affects how fathers experience *becoming* parents (Stefana et al., 2018). The range of responses went from feeling a *lack* all the way to an experience of "trauma". Building on Andrea Doucet's (2006) research on fathering, this project thus adds texture to her work outlining this range from lack to trauma by looking at the birth of children with cerebral palsy as an important fathering event.

Additionally, pre-term births as they pertain to cerebral palsy highlight an important paradox that is a contribution to the life course literature on milestones and sequence. As Rindfuss et al. (1987) and Pat & Fiese (2004) argue regarding the unpredictability of the timing of life events, pre-term births are characterized by periods of hospitalization, health uncertainty, and later paid employment beyond retirement ages for parents, and the open-endedness of parenting children with extensive and complex health needs. "Expected" trajectories and sequences in parenting (Inglis, 2022) get thrown out the window.

Also, this research builds on the embodied aspects of fathering (Doucet, 2006) including those caring activities such as carrying the child up and down the stairs, having a wheelchair in and out of vehicles, etc., and helping the child go to the washroom (Ranson, 2015). As such, the embodied trajectory of the child and father are inextricably linked as each faces the need to get stronger and the uncertainties and nonlinearity of those demands.

The experiences of fathers in this study also highlight the importance of critical disability studies – individuals, institutional systems and structures need to be challenged in order to address ableism and other barriers to include. The fathers in this study thus reinforce Kelly & Orsini's (2021) stance that it is important that research challenge an emphasis on the physical dimensions of some disabilities and understand biases and barriers within a social context.

Finally, my findings advance Rapp & Ginsburg's (2011) theory of kinship imaginaries. As fathers in my study demonstrate, parents and children must navigate environments,

institutions, and care systems together. These fathers also describe the ways in which kinship is emotional: including fear, grief, excitement, and frustration with injustice.

Hence, these findings confirm that life trajectories are not linear, but for these fathers that happens in particular ways: the intensity of (physical) caregiving may not ease up as the child ages, the need for advocacy may arise continuously, and the consequences of ableism may present unexpected challenges in places like school. In other words, if children were not developing their own mobility, independence, and/or self-advocacy, these fathers had to step in. The emotional intensity of pre-term birth and diagnosis events, as described by these fathers, contributes to the literature on kinship imaginaries and fathering in particular, highlighting how unexpected biographical events such as becoming a parent to a child with cerebral palsy may result in long-term interrelated care, concern, and uncertainty.

Chapter 6

Conclusion

The purpose of this thesis is to address notions of normative parenting by giving voice to fathers' experiences of parenting a child with cerebral palsy. In this thesis, not only did I explore the key challenges reported by the participants, but I also examined the various emotions fathers experienced during their transition to fatherhood. At the beginning of their transition, fathers felt "knocked off" sequence as they did not experience the traditional steps to parenthood, beginning with what was frequently a traumatic birth. From that point onwards, fathers reported that their responsibilities included protecting their child, learning about, and meeting medical and accessibility needs while simultaneously confronting barriers. The fathers in this study were learning while doing they discovered the extent to which environments and institutions were inaccessible, as well as the continuous demands of advocating for their kids. Parenting was also described as scary and worrisome in the beginning of their child's life, but was also rewarding, as the fathers described learning to connect with their child on their own terms.

Two crucial and unique elements to being a father to a child with cerebral palsy arose during my analysis. The first element pertains to fathers having to take on an intense responsibility in caregiving for their child within the home and outside the home environment while simultaneously acting as an advocate for their child to ensure safety and equal opportunities for their child. Not was caregiving intense for these fathers, but their role as a father also consisted of vast physical care, continuing beyond the age where society considers children old enough to begin to live independently. As such, caregiving tasks may not lessen, but *persist* as the child ages, leading to additional feelings of personal strain and extended worry about their child's future well-being. In turn, fathers' lives become heavily interdependent with their child's.

As for the second element, fathers in my study struggled with the prospect that a normative sequence of development would be a frame of reference for their family and child. Some fathers reported feeling cheated out of a "taken for granted experience" regarding standard child growth. Reassurance is expected when a child reaches milestones and when a child does not meet the normative milestones, "goal posts" of parenting and child development are unclear: do parents accept, accommodate, or push harder? Thus, due to a lack of clarity, fathers faced the reality that parenting challenges were often surprising and unpredictable; as fathers learned to adapt, many were faced with a wide variety of emotions including from happiness, sadness, anxiety, and grief.

As existing literature illustrates 'disability' is a social construct that places emphasis on the negative aspects of parenting a child with a developmental challenge. 'Disability' highlights the personal failures rather than the social and contextual failures. By using life course literature, family studies, and critical disability studies, this thesis brings a new perspective to the construct of disability by shedding light on the impact of parenting, becoming a father and being a father. These findings demonstrate that accessibility and inclusion extend beyond questions that address a child's participation, but question whether social and physical environments are inclusive in their design and intent. The fathers in my study demonstrate that despite how society perceives families of children with special needs, families *develop* the tools required to navigate inaccessible environments and social institutions within their community. This study illustrates how ableism can exclude children with cerebral palsy. Kinship imaginaries reveal the complexities and multiplicities of parenting roles that include caregiving, advocacy, medical expertise, medical care, and transportation expertise to overcome that exclusion.

Regarding implications and further research, readers should be aware of the following limitations. Firstly, it was difficult to determine details about the specific life course experiences of these fathers. The ages of the children in my study were wide ranging: from early infancy to mid-adulthood. Similarly, the spectrum of cerebral palsy makes it difficult to establish a singular argument about how this influences fatherhood challenges. For example, some fathers were taking care of their adult children, other fathers were preparing to care for their children long-term, and one father stated that it was too early to determine the full impact of his child's diagnosis. Future research should continue to examine if the life course trajectories are more circular than directional or progressive. Thus, I suggest the possibility of conducting a similar study but on a longitudinal level.

Lastly, future research should shed light on events occurring behind the scenes for fathers of children with disabilities, as evidence has shown there is a lot more than meets the eye. In essence, becoming a father to a child with cerebral palsy is not a one-time occurring event but a series of cascading emotions.

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Appendix A

Interview Guide

For Semi-Structured Interviews

I. **Opening**
II. **Interview Schedule for Participants**
III. (Establish Rapport) My name is Kelsey Seguin, and I am a student at the University of Ottawa completing a Master's in Sociology. I am currently working on data collection for my thesis research study. I am interested in understanding the everyday experiences of fathers raising kids with cerebral palsy: what are the challenges and what are some of the great things that you in particular have experienced along the way. I think that we all need to know more about what being a dad in 2020 is like, especially raising a child with special needs.
IV. (Purpose) I would like to ask you a few questions about your background as well as your experiences in raising a child with cerebral palsy.
V. (TimeLine) The interview should take approximately between 60-90 minutes. Is that okay? If something comes up while we are talking and me you need to go, please don't hesitate to let me know.

Ice Breaker
On a scale of 1-10 one being terrible and 10 being awesome, how are you feeling right now?

II Body
Introduction of Participant Characteristics
→ Location of participant? (As I had participants from Canada and The United States)

- Please tell me about an average day around your house.
- What are some parenting activities that you do?
- Please tell me a little about your child (e.g., age, CP type, severity)

Pregnancy

Now take me back to the beginning. I would like to understand more about some of the highs and some of the lows. What did you imagine being a dad would be like when you found out that your partner was pregnant?

- Can you tell me what you were thinking, feeling, anticipating?
- What did you anticipate in contrast to your current reality?
- Do you have a favorite memory during pregnancy?
- What were you feeling during the time of your partners pregnancy?
- Were you made aware by doctors that your partner may not carry to full term? (if applicable).
- How was the birthing process? Did you have any worries? Was anything confusing? Were you present?

Imagining being a Dad

- In what ways did you anticipate having a child would change your life?
- Did you do any preparing on how to be a dad?
- What currently influences your view on being a father?
- How were your childhood experiences growing up with your dad? If you can describe to me the most important experience that helped shaped, you into the person you are today?
- Additionally, does this experience have an influence on how you currently view being a dad?
- Did certain experiences/situations play a role on the kind of dad you wanted to be?

Receiving Medical Diagnosis

- Were there any early signs that your child had cerebral palsy?
- Tell me how you discovered your child had a disability?
- What was your reaction to the diagnosis? Were you familiar with cerebral palsy prior to your child's diagnosis?
- Can you walk me through your experience regarding hospital stays such as being in the NICU following birth (I myself having cerebral palsy have spent 16 weeks before I was able to arrive home)?
- Did you feel included? Were medical staff supportive in answering your worries?
- What changes were made in your family life following diagnosis?
- When it was clear that your child had cerebral palsy, how did you feel? What were you thinking about as a dad? What is the first thing you did?
- Did you have any expectations as to how having a child with cerebral palsy may be like?
- What is the most important thing in receiving a diagnosis?

Welcoming a Child with Cerebral Palsy to the Family

Can you walk me through your first few days at home with your newborn? What were they like?

- Did you experience any worry before and after being discharged from the hospital?
- What progress have you seen in your child since initial diagnosis?
- What came naturally during parenting? When did you seek advice?

Transitioning to Fatherhood

- How would you describe your transition to fatherhood? To you, what is the meaning of being a dad.
- What did you anticipate? Versus your current day to day life?
- Did you have a vision of what you wanted your future life to be like?
- What events were essential for you, during the process of becoming a dad? In other words, what events shaped your transition in being a dad?

Using examples out of a frame of reference, in pop culture we often see the dad teaching the child how to ride a bike. Having cerebral palsy, myself, you, and I both know that these types of experiences may not be possible for every family. I know personally for me having my dad teach me how to ride a bike did not go so well.

That being said, how did you come to the realization that you may not be able to teach your child things that society demonstrate as an essential experience between a dad and child such as riding a bike?

Do you grieve the loss of any experiences you dreamed to do with your child?

- Did any of your child's developmental milestones create a personal change in defining who you are as a person?
- Has your spouse, family and friends notice any changes in your overall self since becoming a father?
- Has becoming a dad changed your relationship with others? If so, can you describe these changes for me?
- Has becoming a dad impacted your work life?
- How do you think you changed as a person? (e.g., your biggest personal change).
- To you, what was the biggest help in your transition?
- How did your child help your transition?
- Do you think becoming a dad to a child with cerebral palsy makes your transition different from your peers and others in your social circle? If so, can you describe differences for me?
- How would you describe yourself as a parent to someone else?

The Relationship Between a Dad with a Child with Cerebral Palsy

I want you to think about your child's different life stages (e.g., newborn, toddler, child etc.). Can you describe how each life stage has influenced your transition and meaning of being a dad? What was your main role at each stage?

- Can you describe the relationship dynamic between you and your child?
- Does your child come to you regarding things they are dealing with? If yes, how do you handle this? (If applicable).
- Would you consider yourself to have a parenting style?
- How much time do you typically spend with your child during the week?
- Have you ever talked to your child about their cerebral palsy?
- Can you talk to me about your child's general accomplishments? What accomplishment are you most proud of that makes you feel that you are a good dad and shows you doing the right thing?
- What do you like most of being a parent to a child with cerebral palsy? What is the most rewarding?
- What activities do you and your child enjoy doing together?
- What is your favorite memory with your child?
- Most important thing about having a child with cerebral palsy has taught you.
- What are your hopes and dreams for your child?
- Do you have any worry? (e.g., my dad worries daily that I do not fall).

A Day in the Life of a Dad with a Child with Cerebral Palsy

I originally wanted to do participant observation of a father with their child during one activity such as going to the park in order to view the relationship and interaction occurring between both the dad and child. However due to Covid-19 this is not possible. That being said, would you be comfortable describing a typical day that occurs in the household? (e.g., morning, afternoon, evening).

- What care giving activities do you participate in?
- What is the most rewarding time of your daily routine?
- What activity or time of day do you feel the most connected to your child?
- Is there any activity you do differently during your daily routine with your child that differs from your friends and others within your social circle? In what ways does having a child with cerebral palsy make this different?
- Has welcoming a child with cerebral palsy have an impact on your relationship with your other children (if applicable). Has this affected the way you respond and interact with your other children?

Personal Challenges in Being a Dad to a Child with Cerebral Palsy

- What is unique in being the dad of a premature child?
- Have you experienced any emotional challenges in raising a child with cerebral palsy?
- How have other people reacted to your child having cerebral palsy? How did their reactions make you feel as a dad?
- How has your life changed after having a child with a disability? What is the biggest change?
- Has your perception of life changed after having a child with cerebral palsy?
- How does having a child with cerebral palsy impact your social norm view? (e.g., dad is most often perceived as being the "stronger" one).
- What types of challenges do you face as a dad of a child with cerebral palsy that other dads may not have to face?
- When you think of important decisions you have made regarding your child's well-being, what comes to mind? Is there anything you would have done differently?
- What is something you wish you could tell others, but usually do not get the chance to?

Most important piece of advice to other parents?
Is there anything else you would like for me to know about yourself or your child?
Something that I may have missed.

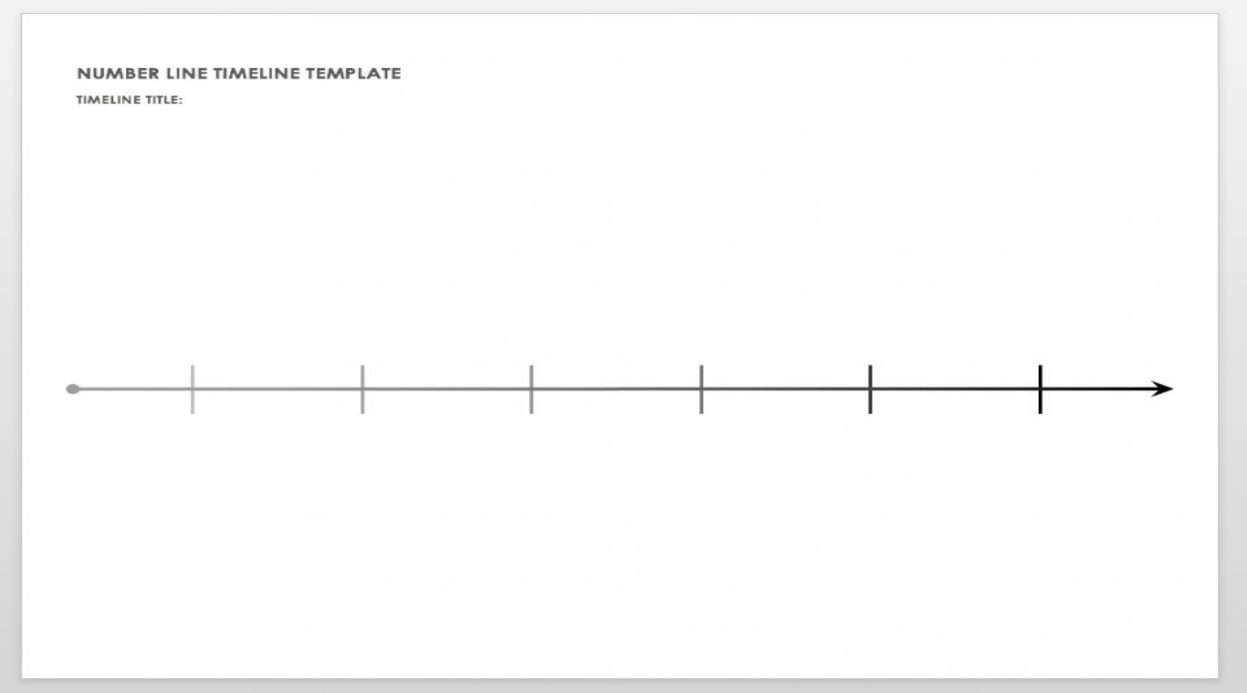
III Closing

I appreciate the time you took for this interview. I should have all the information I need, and I thank you again for your answers and willingness to participate. I look forward to sharing the results with you.

Appendix B

Timeline Template

Creation of a Historical Timeline



Appendix C

Participant Recruitment Poster For Facebook Groups

Department of Social Sciences
University of Ottawa
PARTICIPANTS
NEEDED FOR
RESEARCH IN THE GRADUATE DEPARTMENT OF SOCIOLOGY
We are looking for volunteers to take part in a study
of

uOttawa

Giving Dad the Spotlight:
Paternal Experiences of Raising a Child with Cerebral Palsy: How Does This Influence Fatherhood Trajectory and the Meaning of Fatherhood?

As a participant in this study, you would be asked to:
answer questions from a
semi-structured interview and
create a historical timeline of main events.

Your participation would involve one session lasting approximately 135 minutes for the interview and timeline.

For more information about this study, or to volunteer for this study,
please contact:
Kelsey Seguin
Master's Candidate

This study has been reviewed by and received ethics approval through a University of Ottawa Research Ethics Committee.

University of Ottawa
Office of Research Ethics and Integrity

Ethics File Number S-02-20-5451

Appendix D

Participant Consent Form

uOttawa

Faculté des sciences sociales
Faculty of Social Sciences

École d'études sociologiques et anthropologiques / School of Sociological and Anthropological Studies

Title of the study: Giving Dad the Spotlight: Paternal Experiences of Raising a child with Cerebral Palsy: How Does This Influence Fatherhood Trajectory and the Meaning of Fatherhood?

Kelsey Seguin, Master's Candidate
Department of Sociology, University of Ottawa

Dr. Willow Scobie
Department of Sociology, University of Ottawa

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Ms. Kelsey Seguin as part of her Master's Thesis under the supervision of her supervisor Professor Willow Scobie.

Purpose of the Study: The purpose of the study is to describe my experiences of being a father to a child with cerebral palsy. The goal is to describe how having a child with cerebral palsy has an influence on my personal view of fatherhood and the meaning of being a father.

Participation: My participation will consist of one session lasting approximately 60 to 90 minutes. It will entail responding to semi-structured interview questions and drawing a historical timeline of events occurring during my transition to fatherhood. Interviews will take place virtually through Skype, Zoom, FaceTime or by telephone. Once a verbatim electronic version of a transcript of the interview is complete, I will have the opportunity to review its accuracy. If changes are to be made, I will communicate that with Ms. Seguin within 5 business days of receiving the document.

Risks: My participation in this study will involve sharing personal information and may cause me to feel emotional, psychological, or social stress. I have received assurance from the researcher that every effort will be made to minimize these risks and that I will have the ability to decline to answer questions that make me feel uncomfortable, and that I may opt out of the study at any point.

Benefits: My participation in this study will contribute to the literature on fathering children with cerebral palsy, particularly within the life course literature within the field of sociology. I may, in the course of participating in

this research, draw some personal benefits including reflecting on my experiences as a parent.

Confidentiality and Anonymity I have received assurance from the researcher that the information that I share will remain strictly confidential. I understand that the contents will be used strictly for the purposes of the researcher's masters' dissertation and that my confidentiality will be protected through the use of participant number or changed named (based on my preference) in order to remain anonymous and to protect my personal identity. I have also been assured that Ms. Seguin will use standard safety measures such as signing out of any online accounts, closing her browser, and locking her device when it is no longer being used.

Conservation of Data: The data collected (both hard copy and electronic data, where necessary) will be kept in a secure, password protected manner at the University of Ottawa in a locked cabinet within the researcher's supervisor's office. The only individuals who will have access to this information is the researcher and her supervisor for the length of this study and five years following completion. Once the five-year mark has been reached, all information will be deleted and properly shredded.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and / or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be discarded and not included in the dissertation.

Acceptance I _____ agree to participate in the above research study conducted by Ms. Kelsey Seguin of the department of the School of Sociological and Anthropological Studies at the University of Ottawa under the supervision of Professor Willow Scobie.

If I have any questions about the study, I can contact the researcher, or her supervisor know.

If I have any questions regarding the ethical conduct of this study, I can contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550, Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Phone.: (613) 562-5387
Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

Participant Signature: _____ Date:

Researcher's Signature_____ Date :

Appendix E

Participant Recruitment Text For Facebook Groups

Hello, *(Insert social media group name)*

My name is Kelsey Seguin. I am currently a Master's student in the School of Sociological and Anthropological Studies at the University of Ottawa. My research is on the impact of having a child with cerebral palsy on the transition to and experience of fatherhood. This research contributes to the field of sociology by examining the ways in which men undertake fatherhood over the course of time.

I am recruiting fathers of children (infancy to adulthood) for interviews about their insights and experiences with raising a child with cerebral palsy, how this has influenced their role in becoming a father, and how this may resonate or differ from their expectations. In this respect, I am most interested in discovering the key moments that have had an impact on their understanding of becoming fathers, particularly as it pertains to fathering children with cerebral palsy. The interview will follow prepared questions but be flexible enough to address the interests and focus of participants and will include a timeline of parenthood experiences. Interviews will examine the following themes:

- The process of becoming a father (particularly the first few months).
- The activities, responsibilities, joys, and challenges of fatherhood.
- A discussion of how having a child with cerebral palsy has influenced your experience of being a father.

If you have any questions or concerns regarding this study or your participation, do not hesitate to get in touch with me or my research supervisor Professor Willow Scobie. If this information has been passed on to you by a friend or colleague who thinks you may be interested, please contact either of us to express your interest. Contact information is listed below.

To participate you must have a child diagnosed with cerebral palsy. Age of the child is not restricted.

Preference is welcome to English speaking residents living in Canada. However, English speaking residents from another country are welcome to participate. Interviews will be conducted virtually via Skype, Zoom, FaceTime or by telephone.

Thank you for your interest in this research project.

Kelsey Seguin, Master's Candidate
Supervisor: Dr. Willow Scobie
School of Sociological and Anthropological Studies, University of Ottawa

Appendix F

Nvivo Analyses

A) Word Frequency Count Table

Time: 314	Dad: 279	Child: 222	Different: 168	Life: 165
Born: 109	Home: 131	Family: 102	Relationship: 58	Together: 53
Worry: 48	Doctors: 45	Change: 42	Special: 37	Realize: 36
Pregnancy: 34	Disability: 32	Medical: 26	Expectations: 23	Situation: 23
Learning: 21	Typical: 21	Scared: 20	Difference: 17	Amazing: 16
Preparing: 16	Compared: 15	Concerned: 14	Incubator: 12	Hospital: 100
School: 96	Diagnosis: 70	Understand: 55	Transition: 50	Early: 44
Surgery: 37	Happy: 42	Therapy: 33	Rewarding: 24	Milestones: 20
Help: 70	Friends: 68	NICU: 66	Wheelchair: 40	Challenges: 34
Walk: 63	Question: 62	Experience: 61	Care: 59	Surgery: 37

Word Frequency Count from NVIVO of 50 words most mentioned by fathers during semi-structured interviews.

B) Common Themes Table

Meaning of Being a Dad	***Transitioning to Fatherhood***	***Life Course Differences***
• Being more attentive to their surroundings	• Not having the same experiences, one has anticipated.	• Not experiencing the traditional bringing home the baby immediately after birth.
• Learning to be more patient	• Waiting for the unknown.	• Long-Term Caregiving.
• Celebrating milestones and appreciating the little things.	• Life in the NICU and learning with medical professionals	• Early birth, some fathers almost/did miss the birth of their child.
• Advocating for their child	• Learning their child's limitations	• Spending more time together as a family
• Educating themselves and others	• Being more attentive to language individuals use.	• Loss of overall experience.
• Worrying about the future	• Lack of understanding and alienation from friend group.	• Daily routine differences such as therapy appointments.
• Becoming more understanding	• Learning more responsibilities	
• Including and adapting activities and daily routine for their child.	• Coming to terms with the diagnosis.	
• Feeling proud and rewarded for their child's accomplishments		

Appendix G

Participant Characteristic Table

Name of Participant	Age of Father	Demographic Area	Age of Child	Child Gender
Earl	**Early 70s**	**Canada**	**42 years old**	**Male**
Daniel	**50s**	**USA**	**25 years old**	**Male**
Malcolm	**Early 40s**	**USA**	**5 years old**	**Female**
Jackson	**Late 40s**	**Canada**	**15 years old**	**Male**
Eric	**Mid 50s**	**Canada**	**31 years old**	**Male**
Austin	**Early 30s**	**Canada**	**17 Months**	**Female**
Samuel	**Early 30s**	**USA**	**8 years old**	**Female**
Bob	**Late 40s**	**Canada**	**12 years old**	**Male**
Jake	**Early 30s**	**Canada**	**5 years old**	**Male**
Victor	**30s**	**Canada**	**3 years old**	**Male**
Simon	**30s**	**Canada**	**3 years old**	**Male**