MEANING-MAKING AND RESILIENCE IN PARENTS OF CHILDREN WITH COMPLEX CARE NEEDS

BY

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Abstract

This study explored: (1) the ways and extent to which parents of children with complex care needs (CCCN) find and create meaning in their caregiving experiences; and (2) parents' perceptions of the relationship between resilience and meaning-making. The sample included seven parents who were recruited through online support groups, NaviCare/SoinsNavi (NB patient navigation centre's family advisory council, and word of mouth. They participated in semi-structured qualitative phone interviews, which were eventually analyzed using thematic analysis (Braun & Clarke, 2012). Overall, this study found that parents of CCCN made several meanings of their caregiving experiences, including but not limited to acceptance, growth, resilience, and finding purpose. As a conclusion of this study, the findings suggest that meaning-making in parents of CCCN likely follows an iterative and ongoing process. Furthermore, perceived parental meaning-making seems to be instrumental in their ability to cope with caregiving's difficulties.

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Meaning-making and Resilience in Parents of Children with Complex Care Needs

In *Man's Search for Meaning*, psychiatrist Viktor Frank (1992) chronicles his experiences in Nazi concentration camps. In reflecting upon the psychology of a concentration camp prisoner, he explores the darkest depths of human existence. As a prisoner, Frankl noticed that some prisoners, despite enduring the absolute limits of suffering, destitution, and squalor, found an enduring meaning in their lives. The meaning they found in their suffering served as a bulwark for their survival. As Frankl (1992) notes, the quest for meaning is central to the human condition. Finding purpose, significance and comprehensibility in our lives is necessary. The lack of meaning can create confusion and anxiety. This can be most true when seemingly meaningless pain and suffering is bestowed upon ourselves or our family. The diagnosis of a child's life-threatening or chronic illness may cause parents to consider the meaning and purpose of their child's condition. It may also lead them to consider the meanings of parenthood, a career, or their own health. As Frankl (1992) recognized, the meanings we find in our experiences can have a fundamental connection to our resilience, as they can mean the difference between life and death.

Focusing on parents of children with complex care needs (CCCN), this thesis investigated the processes of meaning-making and its relationship to resilience. The literature review for this thesis begins with an overview of the CCCN literature, exploring definitions of CCCN, the prevalence of CCCN, and the experiences and consequences of caring for CCCN. Then, the resilience literature is reviewed, including several definitions of resilience and the role of resilience in stress research, with specific reference to caregivers of CCCN. From this, the review transitions to discuss the role of meaning-

making in resilience, explores the definitions of meaning and meaning-making, and presents Park's (2010) meaning-making model. The latter was the conceptual framework guiding this study. Finally, the review highlights the current gaps in the meaning-making literature as they relate to parents of CCCN.

Literature Review

Children with Complex Care Needs (CCCN)

Being a parent can be a stressful experience. Beyond worries about their child's health and safety, parents may be concerned about their child's behaviour, education, social environment, or developmental milestones. Ensuring these needs are met often necessitates a substantial burden for parents, and may affect their finances, time, career or social life. However, when a child has complex care needs, parents must fulfill a host of other health, social, or educational needs on top of the typical demands of parenthood. Fulfilling these extra complex needs may compound the stress associated with caring for a child.

Definitions and prevalence of CCCN. "Children with complex care needs" (CCCN) refers to children with "multidimensional health and social care needs, in the presence of a recognized medical condition or where there is no unifying diagnosis" (Brenner et al., 2018, p. 1647). CCCN is a hypernym that encompasses all children whose mental, physical, medical, technological, pharmacological, social, or educational care needs exceed beyond what is necessary for the general population of children (Brenner et al., 2018; McPherson et al., 1998). CCCN usually require healthcare and other services (e.g., social, educational) from multiple care providers (e.g., physicians, therapists), often in multiple locations (e.g., hospitals, clinics) (Cohen et al., 2011).

Therefore, as an all-encompassing term, CCCN can refer to children with congenital abnormalities, cancer, physical or mental disabilities, mental disorders, or children without a recognized diagnosis, but whose needs exceed beyond what is generally required.

Prevalence estimates of CCCN are difficult to ascertain because these children are defined differently throughout the literature (Cohen et al., 2011). There are many variations of "complex care needs" due the interdisciplinary nature of its research (Brenner et al., 2018). Variations may include "complex health care needs" (Kirk, 2001), "complex needs" (McCann, Bull, & Winzenberg, 2012), "complex health conditions" (Azar et al., 2016), and many others (Cohen & Friedman, 2012). However, in a systematic review of prevalence estimates for children with chronic health conditions, Van Der Lee, Mokkink, Grootenhuis, Heymans, and Offringa (2007) found a substantial range in prevalence estimates, from 0.22% to 44%, depending on the operational definition of "children with chronic health conditions". Nevertheless, in the United States, the prevalence of children with complex medical needs in hospitals is increasing (Burns et al., 2010), due in part to medical, technological, and nutritional advances that have increased the survival rate of children born with complex needs (Dewan & Cohen, 2013; Edelstein, Schippke, Sheffe, & Kingsnorth, 2016), such as those with low birth weight (Kaiser, Tilford, Simpson, Salhab, & Rosenfeld, 2004), cerebral palsy (Vincer et al., 2006) or congenital anomalies (Orford, Cass, & Glasson, 2004; Wong & Paulozzi, 2001).

Attributes of CCCN. Despite the variations in definitions, CCCN share similar attributes across conditions. In their systematic concept analysis of CCCN, Brenner et al.

(2018) identified three main attributes of children's complex care needs. First, their needs are heterogenous and substantial. The authors (Brenner et al., 2018) found a significant diversity in the needs of CCCN, including but not limited to nutritional, pharmacological, respiratory, palliative care, and personal hygiene needs. In addition, these needs are substantial in that the children often require near-constant supervision and care in most situations, whether from home, in the community, or in school. Second, their needs are individual and contextualized. There are substantial differences in the children's individual characteristics and family environment, such that differences in developmental milestones, illness severity, age, and family structure contextualize their needs to make each situation unique (Brenner et al., 2018). The third and final attribute is that their care needs are continuing and dynamic. Children's complex care needs changed as their condition worsened or improved, and as children matured physically and psychologically (Brenner et al, 2018). In sum, CCCN are a definitive population marked by the heterogeneity and intensity of their needs, the uniqueness of every child's situation, and the ongoing and changing nature of their needs and circumstances.

The impact of complex care needs. One critical theme of CCCN was the impact of their needs on the family. In reviewing the consequences of meeting their child's needs, Brenner et al. (2018) found that caregiving is integral to the family routine and affects the entire family unit. Meeting their child's needs often strained many aspects of parent's lives, including their physical and mental health, finances, career, time, social life, and identity (Brenner et al., 2018). Thus, it is not surprising that parents of CCCN often experience considerable stress and burden. (Caicedo, 2014; Cousino & Hazen, 2013; Dumas, Wolf, Fisman, & Culligan, 1991; Uzark & Jones, 2003).

In a systematic review of 96 studies, Cousino and Hazen (2013) found that parents of children with chronic illnesses (i.e., cancer, athsma, type 1 diabetes, sickle cell disease, cystic fibrosis, juvenile rheumatoid arthritis, epilepsy) experienced significantly more parenting stress than parents who cared for healthy children, where a significant portion of this stress derived from increased parenting demands and responsibilities. In parents of children with type 1 diabetes, for example, parents who reported greater caregiving responsibilities and lower self efficacy with treatment regimens reported more frequent parenting stress (Streisand, Swift, Wickmark, Chen, & Holmes, 2005). Unsurprisingly, parents may also experience significant disease-related stress, which may stem from worries about their child's wellbeing (Woodgate, Edwards, Ripat, Borton, & Rempel, 2015) or when their child expereinces pain episodes (Anthony, Bromberg, Gil, & Schanberg, 2011; Barakat, Patterson, Daniel, & Dampier, 2008).

High parenting stress when caring for CCCN has negative consequences for both parents and children. In one study, approximately 33% of parents of children with cystic fibrosis or type 1 diabetes had depressive symptoms higher than the clinical cutoff (Driscoll et al., 2010). Another study found that mothers of children with chronic illneses had significantly higher levels of anxiety than the control group, and were more likely to meet the clinical threshold for anxiety (Van Oers et al., 2014). Moreover, in yet another systematic review, the prevalence of post-traumatic stress disorder (PTSD) in parents of children with chronic illnesses was approximately 23% (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009).

Beyond mental health consequences, caring for CCCN can impact parents' physical health. Rosenberg et al. (2014) found that parents of children with cancer were

more likely to binge drink, and in parents with lower resilience, were more likely to report sleep difficulties and lower health satisfaction. In a Canadian population-based survey, Brehaut et al. (2011) found that parents' reports of their own health were associated with the complexity of their child's needs: parents reported poorer health when their child had more complexity, and better health when they had less complexity (Brehaut et al., 2011). Finally, Raina et al. (2005) found that parents with lower caregiving demands experienced better overall physical and mental health. Therefore, on top of the psychological strain of caring for CCCN, the physical health of parents may be at risk. Presumably, worries about their own health may further contribute to their chronic stress.

In turn, parental strain can have a significant impact on the health outcomes of the children. For example, in children with sickle cell disease, higher disease related stress in the parents at baseline was associated with higher disease severity one year later (Barakat et al., 2007). Although higher parenting stress may not contribute to the child's disease severity in all conditions, as was found in a study involving children with heart disease (Uzark & Jones, 2003), parenting stress may contribute to poorer sociocognitive development (Guajardo, Snyder, & Petersen, 2009), and may make children more stressed themselves (Robinson, Gerhardt, Vannatta, & Noll, 2007). For example, parenting stress was a significant predictor of depressive symptoms in adolescents with inflamatory bowel disease during a six-month follow-up (Guilfoyle, Gray, Herzer-Maddux, & Hommela, 2014). In addition, one study found that poor parental support was associated with anti-inflamatory resistance in children with athsma (Miller, Gaudin, Zysk, & Chen, 2009).

In summary, the intensity and multidimensionality of a child's complex care needs put a significant strain and burden on parents. This strain may have consequences for the physical and mental health of both parents and children. Therefore, identifying protective factors is imperative. One protective factor that has received significant attention in the pediatric literature is resilence, or the ability to maintain psychogical wellbeing in the face of adversity (Masten & Powell, 2003). As an integral part of the present investigation, the construct of resilience will be reviewed at present.

Resilience

Definitions. Resilience is the ability to maintain positive or better-than-average wellbeing despite difficult or demanding circumstances (Masten & Powell, 2003). It has also been characterized as the ability to cope well with stress, "bounce back" from adversity, and avoid maladaptive adjustment to stressors (Cabib, Campus, & Colelli, 2012; Shrivastava & Desousa, 2016; Tugade, M., and Fredrickson, 2011). However, definitions and conceptualizations of resilience have sparked considerable debate (Zolkoski & Bullock, 2012), and may differ between disciplines and researchers (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014).

Process versus personality trait. A main area of confusion in the literature surrounds the difference between "resilience" and "resiliency". The former refers to a "dynamic process of positive adaptation" (Luthar, Cicchetti, & Becker, 2000) where an individual's resilience is determined by a multitude of protective factors (Zolkoski & Bullock, 2012), including but not limited to coping skills, social support, community involvement, and temperment (Benzies & Mychasiuk, 2009). Importantly, these protective factors can be the target of interventions and are part of a process that

enhances resilience. In contrast, resiliency, or ego resiliency (Block & Block, 1980), is a stable personality trait that reflects "general resourcefulness and sturdiness of character, and flexibility of functioning in response to varying environmental circumstances" (Luthar et al., 2000, p. 5). As Luthar et al. (2000) noted, the main differences between resilience and resiliency is that resiliency is a personality trait, whereas reslience is a process, in which personality characteristics may be involved. While resilience as a personality trait has received some support, namely through Wagnild and Young's (1993) resilience instrument, resilience as a process is more common (Allen, Haley, Harris, Fowler, & Pruthi, 2011) and is preferred when investigating "competence despite adversity" (Luthar et al., 2000, p. 5).

Resilient outcomes. In the pediatric literature, resilience has been defined in terms of outcomes. Hilliard, McQuaid, Nabors, and Hood (2015) defined resilience as "the demonstration of emotional, behavioral, or health outcomes that match or surpass normative developmental

milestones, behavioral functioning, or emotional well-being, despite exposure to the substantial challenges of living with and managing a medical or developmental condition." (p. 837). According to this definition, an individual is resilient if they have resilient outcomes. For Hilliard et al. (2015), these resilient outcomes may include positive experiences, maintaining a typical developmental trajectory, or the absence of negative experiences. However, as Rosenberg and Yi-Frazier (2016) argued in a commentary to Hilliard et al. (2015), defining resilience in terms of outcomes is problematic. Identifying resilence may be difficult when, for example, a study finds one positive and one negative outcome in the same individual, such as positive psychogical

wellbeing despite higher disease severity. Additionally, since outcomes are defined differently for each population (e.g., blood glucose levels for people with diabetes, depressive symptoms for people with depression), identifying resilence across studies and populations may be challenging (Rosenberg & Yi-Frazier, 2016). A final criticism from Rosenberg and Yi-Frazier (2016) is that positive or better-than-average outcomes (i.e., resilient outcomes) are indicative of (or provide evidence for) resilience, but are not resilience as such.

Resilience resources. In contrast to Hilliard et al.'s (2015) defintion of resilience, Rosenberg and Yi-Frazier (2016) proposed a new definition that emphasized resilience resources. First, they argued that resilience involves both static and dynamic processes. The former highlights the role of resilient dispositions (e.g., stable personality traits) and the latter highlights the role of dynamical protective factors that enhance resilience. Second, they argued that resilience should be defined as a set of resources individuals harness in order to cope with adversity and achieve positive outcomes. The authors further noted that, in the literature, these resources have been characterized as internal, external, and existential resources (Rosenberg & Yi-Frazier, 2016). Internal resources may include a resilient disposition or learned coping skills, such as mindfulness. External resources may include intimate relationships and other social or community supports. Finally, an individual's existential resources may include their spirituality or meaning-making efforts. Therefore, according to this definition, enhancing an individual's internal, external, and existential resources will enhance their overall resilience.

Resilience as a protective factor. Despite the myriad of definitions of resilience, it has been recognized as a protective factor against adversity's negative consequences in

the general population. Indeed, a systematic review of resilience in adult patients with chronic illneses found an association between higher resilience scores and lower anxiety and depression scores, improved physical and mental health, and improved health-promoting behaviors (Cal, Sá, Glustak, & Santiago, 2015). Higher resilience may also contribute to longer life expectancy (Zeng & Shen, 2010) and lower disease severity (Denisco, 2011).

More specifically, resilience has received significant attention as a protective factor for caregivers of CCCN (Hilliard et al., 2015). For example, some research has focused on the factors of resilience for parents of CCCN (Peer & Hillman, 2014), the effectiveness of resilience interventions in parents of CCCN (Pandya, 2019; Yi-frazier et al., 2018), and the effect of resilience on parents' health outcomes (Rosenberg et al., 2014). In a systematic review of resilience factors for parents of children with developmental and intellectual disabilities, Peer and Hillman (2014) found that a problem-focused coping style, dispositional optimism, and social support were significant contributors to parent's resilience across studies. They also recommend that practitioners explore and support parents' coping, optimism, and social support when ameliorating parental stress (Peer & Hillman, 2014). Resilience-promoting interventions, such as those that promote spirituality and mindfullness (Pandya, 2018), or that teach stress management and problem solving (Yi-frazier et al., 2018), have demonstrated moderate effectiveness in parents of children with autism, cancer, and with type 1 diabetes (Pandya, 2018; Yi-Frazier et al., 2018). Importantly, however, resilience has implications for the physical and mental health outcomes of the parents: in a study involving parents of children with cancer, parents who lacked resilience resources were more likely to

experience high psychological distress, sleep difficulties, and lower health satisfaction (Rosenberg et al., 2014). Moreover, in parents of children with autism spectrum disorder, resilience was found to reduce the likelihood of anxiety and depression symptoms, regardless of the degree of stress the parents expereinced. The results of all these studies suggest that the construct of resilience may be crucial when investigating the lives of parents of CCCN. Thus, research should continue to explore the resilience resources that buffer against the negative consequences of parental stress.

Resilience and meaning-making. One resilience resource highlighted by Rosenberg and Yi-Frazier (2016) is meaning-making, which is the process by which people create and recreate meaning out of their situational experiences and global beliefs about the world (Park, 2013). Meaning-making can be an influential factor for individuals who experience trauma such as serious illneses, natural disasters and war, as the ways in which these experiences are appraised can have a significant impact on psychological outcomes. (Park, 2010; Park, 2016). In general, people are more resilient when they perceive traumatic events as "less threatening and more controllable" (Park, 2016, p. 165). For example, in adults who were exposed to similar trauma, the prevalence of PTSD was significantly lower when they did not blame themselves for the event (Cox, Resnick, & Kilpatrick, 2014). Meaning-making is also an important resource for parents of CCCN, particularly after the death of their child (Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013; Waugh, Kiemle, & Slade, 2018). Only until recently, empirical studies have begun to explore meaning-making as an important component of resilience among parents of living children with complex care needs (Basalik, 2017; Bekker, Deacon, &

Segal, 2019). As the third major component of this thesis, the theoretical background related to meaning-making will now be reviewed.

Meaning-making

"Meaning" as defined by Baumeister (1991) is a "mental representation of possible relationships among things, events, and relationships. Thus, meaning *connects* things" (p. 15). The need to find meaning and significance in our life derives from our need for comprehensibility, control, identity, and agency (Park, 2017). Therefore, in general, meaning-making refers to the process of assigning meaning to our experiences.

The meaning-making model. A significant contributor to the constructs of meaning and meaning-making has been Crystal L. Park, who together with Susan Folkman, first introduced the meaning-making model (Park & Folkman, 1997). Building off of the theoretical work of Lazarus and Folkman's (1984) stress and coping model, which emphasized cognitive appraisals of potentially stressful situations, the meaning-making model describes the process of meaning-making, in which individuals appraise stressful situations, compare their appraisals with their global meaning systems, and create new meaning (see Figure 1). The model consists of two major meaning systems: global meaning and situational meaning.

Global Meaning. First and foremost, global meaning is an individual's general orienting system that helps them navigate and make sense of the world (Park, 2010). Global meaning consists of their global beliefs, their global goals, and their life's meaningfulness (Park, 2010). An individual's global beliefs are their overarching beliefs about the world, and may involve their beliefs about the controllability, benvolence, or predictability of the world. Global goals are an individual's desired outcomes or states

that they would like to achieve or maintain. This may include goals related to their knowledge, career, or relationships (Park, 2010). Last but not least, the concept of "life's meaningfulness" recognizes individuals' subjective feeling that their life is meaningful, that it has a purpose or a goal (Park 2010).

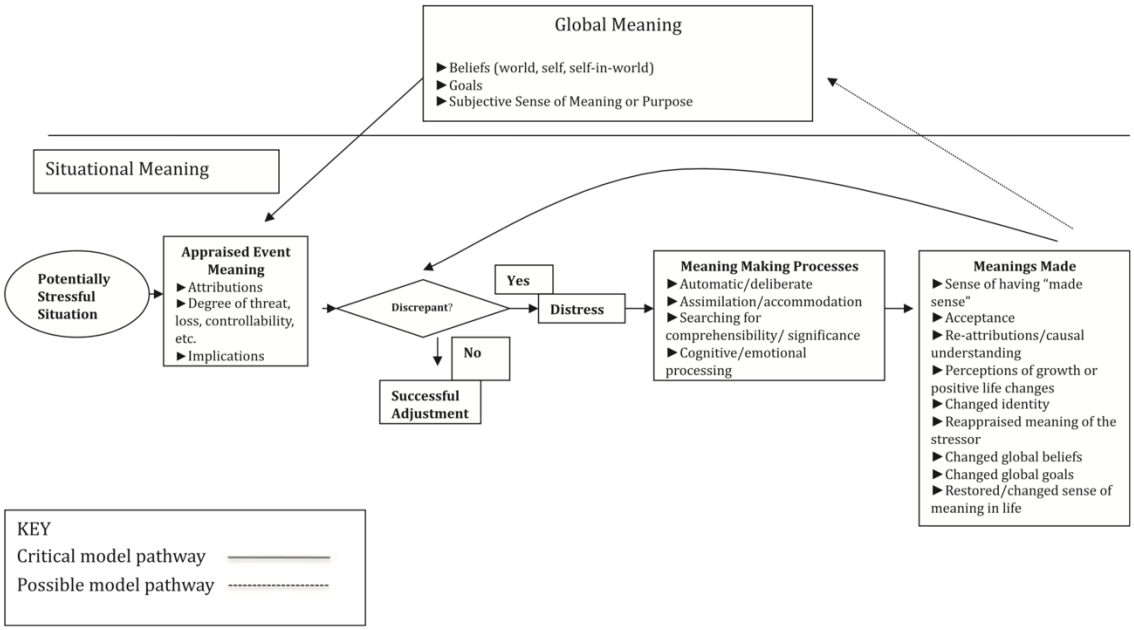

Figure 1: Park's (2010) Meaning-Making Model

Situational Meaning. Situational meaning is the "meaning in the context of a particular environmental encounter" (Park, 2010, p. 258). It is created and recreated through several processes: First, when individuals encounter a potentially stressful situation, they first appraise the meaning of the experience or situation. In other words, individuals determine the "implicit meaning" (Thompson and Janigian, 1988) of their experience, which may involve their appraisals of why the event occurred, whether the event is positive or negative, or whether the event has consequences for their future (Park, 2010). Following the initial appraisals described above, individuals, consciously or unconsicuously, determine the extent to which the appraised meaning lines up with their

global meaning. Depending on how these meanings match up with (or are discrepant with) their global meanings, individuals may experience distress (Park, 2010). For example, certain experiences or situations may "shatter" individuals' beliefs or goals, causing them to experience distress. This may be the case when parents suddenly learn about their child's life-limiting illness, which may conflict with their previous beliefs in the benevolence or predictability of the world, or may cause them to change their life goals.

To quell the distress, individuals go through a process of meaning-making to reduce the discrepancy between their situational and global meanings. As Park (2010) noted, this is accomplished through four main processes that co-occur with each other. First, meaning-making may be accomplished unconsciously or consciously, such as through unconscious avoidance of the situation or through deliberate positive reappraisals. Second, meaning-making may occur through assimilation, where individuals attempt to change their appraised meaning to fit within their global meaning, or through assimilation, where they attempt to change their global meaning to accommodate their appraised meanings. Third, individuals may attempt to find understanding and comprehensibility in their experience or determine its significance. Finally, meaning-making may occur through cognitive processes, such as through reappraisals or thoughtful reflection, and through emotional processes, such as through exposure and habituation to the stressful stimuli (Park 2010). To be clear, meaning-making processes often act in conjuction with one another.

The end results of meaning-making are new "meanings made", or the "changes derived from attempts to reduce discrepancies or violations between appraised and global

meaning" (Park, 2010, p. 260). This can include a newfound meaning or purpose in life, a reattribution of the causal event, acceptance of the event, changed global beliefs or goals, or a feeling of having made sense of the causal event (Park, 2010). Theoretically, these newly made meanings have the potential to influence individuals' global beliefs, which in turn affect how they will respond to the next potentially stressful sitution.

Evidence of the model. In reviewing the literature, Park (2010) found that meaning-making attempts after stressful life events are mostly ubiquitous and that meanings made are common, but not guaranteed. While some aspects have received limited empirical attention, there is moderate empirical support for most aspects of the model, including the assumptions that distress follows from global and appraised meaning discrepancies, that meanings made following meaning-making attempts tend to lead to better adjustment, and that finding meaning or making sense of traumatic experiences yields better outcomes than if no meaning or comprehensibility is found (Park, 2010). Beyond quantitative studies, the meaning-making model has been successfully used in qualitative designs to explore the meaning-makingprocesses of parents of migrant mothers in China (To, So, & Kwok, 2018), and in exploring the written narratives of parents of children with leukemia (Freda & Martino, 2015). However, there exists gaps in the meaning-making literature as it relates to parents of CCCN. This thesis intended to fill these research gaps.

Rationale

Most studies on resilence and meaning-making have studied populations who have experienced acute trauma, such as natural disasters or the sudden death of a loved one (Park, 2016). These experiences can have long-lasting effects, but meaning-making

and resilience have received little attention in parents of CCCN, whose difficulties result from the burden of prolonged parental stress. There is considerable research into the meaning-makingprocesses of parents of deceased CCCN (Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Rosenberg et al., 2013), but investigation into the meaning-making processes of parents with living CCCN is limited. Basalik (2018) and Freda and Martino (2015) investigated meaning-making processes in parents of childen with autism spectrum disorder and leukemia, respectively, and Bekker et al (2019), explored the meaning in life of parents of children with type 1 diabetes. However, neither of these studies incorportated an examination of parents' resilience, or did not explore whether parents percieve meaning-making as instrumental to their resilience. Furthermore, there is a paucity of published research investigating the relationship between meaning-making and resilience in diverse samples, that is, across diagnoses, health conditions, or disabilities.

Since parents of CCCN take on a significant burden and experience considerable adversity, becoming a caregiver of CCCN is likely a transformative experience: to fulfill their child's needs, parents may need to reformulate their financial or career goals; seeing their child suffer may cause parents to doubt the benevolence of the world; or, parents may find a new purpose or identity in being a caregiver. Moreover, as has been demonstrated in other populations, the meanings that individuals make out of their expereinces can have a significant impact on their resilience. Therefore, to investigate the meaning-making processes in parents of CCCN, this study explored parents' experiences with meaning-making since learning about their child's condition. From this, the study explored how parents' meaning-making has influenced their resilience.

Thus, using a sample of parents with CCCN, this study aimed to investigate: (1) the ways and extent to which parents of CCCN find meaning and purpose in their caregiving and; (2) the extent to which parents perceived a relationship between meaning-making and their own resilience. To so, this study addressed the following research questions: (1) in what ways, and to what extent, do parents of CCCN create meaning when caring for and living with their child's complex care needs?; and (2) in what ways, and to what extent, do parents of CCCN consider that meaning-making has influenced or currently influences their resilience?

Method

Design

A qualitative descriptive design was used, which seeks to create a holistic picture of the resilience and meaning-making experiences of parents of CCCN. In other words, this design does not quantify into numbers and search for statistical significance (Braun & Clarke, 2012). A qualitative descriptive design relies on low-inference descriptions (Milne & Oberle, 2005; Sandelowski, 2000). This means that researchers remain close to the data, which is not possible with other approaches that use a more interpretive lens (Milne & Oberle, 2005; Sandelowski, 2000).

Participants

Eligible participants met three criteria: they (1) were a parent of a child/youth with complex care needs, adhering to the following definition: infants, children, and youth who have one or more undiagnosed or diagnosed condition, and who have medical, pharmacological, technological, psychological, emotional, social, or educational needs that exceed beyond the general population of children; (2) consented to a recorded

telephone interview; and (3) spoke English or French. Biological, adoptive, foster, step-parents, or legal guardians were all eligible. CCCN included infants, children, and youth from 0 to 25 years of age, who had one or more undiagnosed or diagnosed condition(s), and who had medical, pharmacological, technological, psychological, emotional, social, or educational needs that exceeded beyond the general population of children.

The original target sample size was 10-12 participants. Participants were recruited through online forums, support groups on Facebook, snowball recruiting through NaviCare/SoinsNavi's Family Advisory Council (FAC), and word of mouth. For online recruitment, online Facebook support groups for parents of CCCN (i.e., support groups for parents of children with cancer, autism, diabetes, etc.) were sought out through Facebook searches. Permission was given from the moderators to post a recruitment notice. For snowball recruitment, the researcher presented the study to NaviCare/SoinsNavi's FAC, which comprised of six parents of CCCN and one young adult who grew up with complex care needs. The FAC is a key component of NaviCare/SoinsNavi's organizational structure, providing clinical advice to patient navigators as well as input on projects (e.g., surveys), and participating in workshops for the community. We invited the parents on the FAC to "spread the word" about this study to other parents. In addition, these parents were also invited to participate themselves, if they wished. FAC members interested in sharing the study with other parents were provided with an information slip containing information about the study to distribute to other parents in their community. For recruitment through word of mouth, any parents who heard about the study through other means were welcome to participate in the study.

Materials

The interview script for the semi-structured interview (see Appendix) was developed for this study in accordance with the meaning-making model (Park, 2010). The questions were open-ended and intended to capture each research objective. Supplemental questions were available for the researcher to continue conversation topics when necessary. The interview first gathered demographic information, followed by participants' goals and beliefs about parenting (global parental meaning), initial thoughts after their child's diagnosis (appraised meaning), and emotional reactions to their child's diagnosis (discrepancy between global and appraised meanings). Then, the interview asked participants to describe their caregiving experiences in general, along with notable positive or challenging experiences. Next, the interview gathered participants' meanings of those experiences, corresponding to the "meanings made" of the meaning-making model (Park, 2010). In this study, "meanings made" was defined as the reappraised meaning of their caregiving experiences. After exploring their meanings made, the interview explored the degree to which participants felt that their meanings made have contributed to their resilience (e.g., "To what extent has the meaning you found in that experience influenced your ability to cope?").

Procedure

Participants who expressed an interest in participating in the study contacted the researcher through email, and an interview time was coordinated. The researcher provided participants with a consent form that was reviewed prior to the interview. At the beginning of the interview, to ensure participants were fully informed before data collection, the researcher reviewed the consent form. He reminded participants that their

participation was voluntary and that, if they wish, they could withdraw at any time without consequences. Additionally, participants were reminded that the interview was to be recorded for accuracy (as per the consent form). They then provided verbal consent over the phone. After receiving consent, the audiotaped semi-structured phone interview was conducted, lasting approximately 30-60 minutes, where the researcher followed the interview script that was developed for this study (see Appendix). The interview took place in a private office room, and the researcher took notes on participants' apparent emotions, tone of voice, and other non-verbal cues. After the interview concluded, participants received a debriefing email.

Data Analysis

Telephone interviews were manually transcribed, and themes were extracted and analyzed using thematic analysis (Braun & Clarke, 2012). This qualitative analysis method involved the following steps: (1) familiarizing self with data, (2) generating initial codes, (3) searching for themes, (4) reviewing potential themes, (5) defining and naming themes, and (6) producing the report. The researcher managed data in a word processing document and themes were colour coded.

Results

Demographics

The final sample included seven participants, and were all residents of New Brunswick (NB), Canada. Participant demographics are presented in Table 1. Although a cut-off was set a priori at 25 years old for the age of the parents' children, the age of three participants' children exceeded the age limit. However, the developmental needs of these children did not match their chronological age.

Table 1

Participant Demographics

Participant (Pseudonym)	Gender of parent	Age of parent	Age of Child	Gender of child	Age at diagnosis	Number of siblings (age)
Anna	Female	49	12	Female	0	2 (23, 8 years)
Candice	Female	33	5	Male	3	1 (2 years)
Andy	Male	61	37	Female	13	1 (33 years)
Kevin	Male	56	27	Male	0	2 (30, 31 years)
Beth	Female	48	10	Female	1.6	2 (20, 8 years)
Stacy	Female	57	27	Male	4	2 (30, 23 years)
Olivia	Female	27	5	Male	2	0
M		47.28	17.57		3.37	2.43
SD		12.76	12.65		4.49	11.12

As the interview questions were designed to elicit participants' processes of meaning-making, the following paragraphs present the findings for the two research questions in accordance with the phases of the meaning-making model.

The "overarching themes" were as follows: global parental meaning, appraised meaning of the diagnosis, discrepancies between global and appraised meaning, and meanings made. Each overarching themes has "main themes", and some main themes have subthemes. A summary of the overarching themes and main themes are presented in Table 2.

Global Parental Meaning

In this study, global parental meaning was what parents expressed about parenting overall, in an everyday sense. This included their reported beliefs about parenting in general, the goals of parenting, and the values they think a parent should have. It also included their expectations of parenthood, such as their expectations surrounding their child's needs. Three themes characterized participants' global parental meanings: (1)

seeking to guide and promote growth, (2) *perceiving difficulty and benefit*, and *(3) expecting "typical" developmental needs*.

Seeking to guide and promote growth. This theme characterizes parents' global parental meaning at the time of the interview. In general, parents reported that they wanted to be a patient guide for their children's growth by teaching them to be virtuous and leading them to their fullest potential. They reported that they wanted to provide their children with opportunities and wanted them to reach their full potential, regardless of their abilities. Furthermore, they reported that they seek to raise strong, competent, productive people who would have important life experiences. When asked what values a parent should have, Candice explained the importance of raising good, virtuous children, who could be resilient in the face of difficulty:

> "Being kind is one of the top values I want to instill in my children, and to be resilient despite some of the challenges they might face. I don't want to do everything for them. I want them to learn, and make mistakes on their own, and figure out how to overcome them without us, you know, making it easy for them. That's the way you learn and become a better person."

In addition to raising strong and confident children, parents reported wanting their children to reach their fullest potential, regardless of their child's abilities, or the challenges they might face.

Beth described this below:

> "Being a parent means to raise your children to be in a way where they can reach their greatest potential, no matter what they're like, what their strengths are, what their weaknesses are, and just making sure that they get everything they need."

Table 2

Research Question 1: Overarching Interview Themes, Main Themes, and Subthemes

Overarching Themes	Main Themes and Subthemes (italicized)
Global parental meaning	Seeking to guide and promote growth Perceiving challenges and benefits Expecting "typical" developmental needs
Appraised meaning	Seeing the order and chaos *Reevaluating global meaning* *Bargaining with the future* *Confronting needs* *Coming to understand their child's behavior*
Discrepancy between global and appraised meanings	Feeling a rollercoaster of emotions *Feeling negative* *Feeling positive*
Meanings made	Acknowledging pervasiveness *Identifying with full-time caregiving* *Managing the system* *Acknowledging the effects on relationships* *Planning ahead* Growing as a person *Having compassion* *Changing perspectives* *Learning resilience* Maintaining progress *Staying positive* *Using coping and self-care strategies* *Utilizing knowledge* Searching for meaning *Getting involved* *Finding meaning*

Perceiving challenges and benefits. The second theme, p*erceiving challenges and benefits,* captures parents' beliefs that being a parent was both a gift and a challenge. Participants reported that parenting brought them happiness and fulfillment, as well as stress, worry and burden. This dichotomy is best exemplified by the following quote from Stacy, the 58-year-old mother of a 27-year-old with developmental disabilities, when she was asked what parenting meant to her:

> "It's wonderful, wonderful. It comes with lots of challenges, of course. And as a parent with children without any difficulties and with special needs, it comes with a lot of challenges, but a lot of important events that come along for each of them."

Andy, the parent of a child with severe mental health issues, listed off the words that came to mind when he was asked about the meaning of parenting:

> "Proud…work….stress…fear…frustration sometimes…worry. Those are all words that come to mind when I think of parent."

Importantly, however, one parent of a child with severe autism, Beth, expressed how she did not see their child's suffering as a gift, or something to cherish:

> "I know we're the ones getting left behind with this whole 'autism is a gift'. It is not a gift. My child is not—this is not a gift. This is the worst thing that she has to deal with every single day, and I know she is unhappy being autistic, and I know she doesn't think it's a gift. There is no way."

Expecting "typical" developmental needs. Parents' global parental beliefs were not assessed in this interview, but two parents reported their expectations of parenting and beliefs about complex care needs prior to receiving their child's diagnosis. The third

theme, therefore, captures the passages where parents discussed their beliefs and expectations of parenting prior to their child's diagnosis. Like most parents, Kevin and Olivia expected to have "healthy", non-disabled, neurotypical children. Kevin, the parent of a 27-year-old with multiple disabilities and highly complex needs, demonstrated this in his interview:

> "You expect nothing but a perfect baby to be born, and you find out that none of that is true, or at least in the moment you think none of that is true."

Olivia, the single parent of a five-year old with autism, echoed these expectations of typicality:

> "It's not really the experience of parenting that I had pictured while I was pregnant."

In addition to their prior expectations of parenting a "typical" child, Kevin described his previous beliefs about children with complex care needs before his son was born. For him, having a child with complex care needs was undesirable and unconquerable:

> "I guess to have a child born with complex needs was my worst nightmare. I didn't want to have that happen. You know when growing up you would see other families and other kids with a disability or some other health condition and you thought, 'oh well I can't deal with that', 'I hope that never happens'. And then lo and behold, when my child was born, it's not just one health condition, its multiple."

Appraised Meaning

Appraised meaning refers to the initial appraisals of their child's diagnosis when they first received their child's diagnosis, either right after they were born, or when their

child was assessed by a medical professional. In other words, appraised meaning refers to the thoughts that were going through parents' heads immediately after their child received their diagnosis. One main theme was found for parents' appraised meaning of the diagnosis: *Seeing the order and chaos*.

Seeing the order and chaos. On one hand, parents reported that the diagnosis caused them to reevaluate their knowledge and beliefs of parenting and to question life itself. It was also reported that it led them to bargain with the future by questioning the possibility of certain developmental milestones, doubting their own parenting abilities, and anticipating the social implications of the diagnosis. At the same time, however, they added that the diagnosis created thoughts of order: some parents reported having an understanding and a reason behind their child's atypical development. Furthermore, most parents reported that the diagnosis laid out a path to confront their child's needs. The subthemes for this theme are (1) *reevaluating global meaning*, (2) *bargaining with the future*, (3) *confronting needs*, and (4) *coming to understand their child's behavior.* This theme is best exemplified by the following quote from Olivia, when her suspicions of an atypical development were confirmed by a pediatrician:

> "It was like this kind of 'oh' (sighs)—this relief. It wasn't just a suspicion, I was right. But at the same time, it closed the door on a lot of opportunities for my son."

Reevaluating global meaning. The first subtheme refers to the passages where some parents discussed how learning about their child's diagnosis caused them to rethink and reevaluate their knowledge, expectations, and goals, and caused existential doubts of life itself. This theme is best exemplified in Kevin's interview, where he described how

his knowledge, expectations and goals needed to be adjusted, and how the diagnosis caused him to ask existential questions. When asked what his initial thoughts were after his son's birth, Kevin described how learning about his son's disabilities caused him to reevaluate his expectations in life:

> "That I would have this burden to carry for the rest of my life, and that any enjoyment that I would have, or would have thought of having, and a life I would have had was completely erased."

Beyond thinking about his life expectations, Kevin also reported thinking about how his previous knowledge of parenting would be "thrown out the window":

> "Well, I guess it meant that my view of what parenting would be was completely thrown out the window, and all the quote 'experiences' I had with raising two other ones, would be of little value. It was almost like you were starting over and you didn't know where to start and there was no guidance. So you were kind of thrown into, I guess, a place where you weren't sure if you were gonna be able to handle it or not."

Candice echoed this experience of "throwing out" parenting knowledge when she recalled back to when her child was diagnosed with autism:

> "It was difficult the first couple years of his diagnosis, we really didn't know what we were doing. Both kids were very young too, so most parents with young children are in a floundering survival mode, but we were especially in survival mode because most of the parenting techniques that you would sort of normally know of weren't quite the same for us."

Kevin and Stacy reported that they asked themselves existential questions when they received their child's diagnosis:

> "But after he was born you begin to think that, well maybe…maybe there is no God. 'Why have we been given this?', 'Have we been abandoned?' and things like that." (Kevin)
>
> "I was upset, I was distraught I was…maybe because 'why is this poor child getting it all?', and that sort of thing. And now… well, now what? Where do we go from here?" (Stacy)

However, at least one parent reported not experiencing these existential thoughts, as evidenced by the following statement from Beth:

> "I don't know if it was necessarily 'why me?', but more so 'how can I do this?', 'how can I raise a child with special needs?'"

Bargaining with the future. This subtheme refers to passages where parents reported that their initial appraisals of their child's diagnosis involved thoughts about the future. These reported thoughts included worries about their child's milestones, the social implications of their child's diagnosis, or the parents' ability to provide care for their child. Below, Olivia described some of these thoughts, after her child was diagnosed with autism.

> "I just remember standing there and thinking to myself well he's probably never going to be able to talk and he's probably never going to be able to go to school…because, at the time, I only had my experience with autistic children that I grew up with in school, and at the time, where I grew up, they weren't in the

> classroom, so it was like…I was very worried about how the world would react to my son now, and I had to protect him a lot. A lot more than before."

Confronting needs. This subtheme refers to the passages where parents reported that their initial thoughts about their child's diagnosis involved dealing with and confronting their child's needs by organizing all the supports and services their child would be eligible for. Indeed, many parents described how receiving their child's diagnosis opened up an orderly path to aid their child, guided by therapists, specialists, physicians and other professionals. For these parents, their initial appraisals of their child's diagnosis were reported to focus on what was in their control. In other words, they described "doing everything that needed to be done" so that their child could get the supports and services they needed. Below, Beth described her attitude as she confronted her child's needs:

> "When I received a formal diagnosis of autism, I had already done a lot of research and I was ready for it. And it was just basically 'okay, so what do we do now?' And the only thing on my mind was: I need to take charge and I needed to do whatever I had to do to make sure, you know, either make her journey easier, maybe even get her to a point where she can function independently."

Anna reported a similar attitude toward her child's complex care needs, as evidenced by the passage below:

> "I think we kinda recognized it from the get-go, and probably dealt with it, y'know, in a big slam, rather than just a gradual type deal."

Similarly, Kevin reported "following the steps" to aid his child:

> "Well, I guess there was this underlying hope that things would get a whole lot better, that if you follow these steps and waited long enough things wouldn't be as bad as you thought they might be."

However, one parent, Stacy, recognized that "the big slam" could not go on forever:

> "So we wanted to be able to help him, but we also…we couldn't rush too much…we had to slow down because we were doing physio and speech and wearing our self out."

Coming to understand their child's behaviours. This subtheme refers to the passages where several parents reported that their initial appraisal of their child's diagnosis was relief. For Candice, Beth, Stacy, and Olivia, they reported noticing or suspecting that their child was functioning or developing in an atypical fashion. They all reported that, when a professional revealed to them their child's diagnosis, they felt relief. Below, Candice explains her experience of relief:

> "It was almost a relief to get the diagnosis, for sure, because it confirmed that I wasn't crazy seeing the behaviours that didn't seem typical. So, it was nice to get that confirmation that, yes, he is displaying some atypical behaviours, and we'll do what we can to get him help."

Whereas she reported feeling confused about her child's development prior to the diagnosis, Candice described how she received some comprehensibility and sense along with the diagnosis. In the following passage, Beth echoed Candice's relief:

> "It was a relief for me because I knew there was something wrong, like you know its…I had a doctor who didn't listen, and you know even though I kept saying there's something, there's something. And to finally have somebody say to me

> you know, 'have you ever heard of autism?' I mean that one person, that one professional, who basically verified what I felt."

Discrepancy Between Global and Appraised Meaning

In this study, the theme that encompasses parents' emotional reactions to their appraisals is "*experiencing a rollercoaster of emotions*".

Experiencing a rollercoaster of emotions. This theme illustrates: (1) reports from parents that receiving the diagnosis was overwhelming and; (2) the up-and-down experience that included both negative and positive emotions. This theme is best characterized by the following statements from Candice:

> "There was a ton—(laughs) a ton of emotions, it really was a rollercoaster, for sure. It still continues today."

Just as a rollercoaster goes up and down on its track, so too were the emotions of Candice and many other parents. Like Candice, when Stacy was asked to describe the emotions she experienced after experiencing her child's diagnosis, Stacy reported the overwhelming nature of the emotions:

> "Oh, I was all over the place and of course, that meeting I went without my husband. I don't know, he must have been working or something. It was devastating. It was—yeah, yeah, it was not easy to digest."
>
> "When you hear the words, you feel—yeah, you're in shock and you're—you're angry—you know you're—every emotion that I can think of would come out. I was upset, I was distraught."

The subthemes for this theme*, "feeling negative"* and *"feeling positive",* are presented below.

Feeling Negative. This subtheme captures the negative emotions that parents experienced following their appraisals of their child's diagnosis. Major emotions that parents reported experiencing were as follows: anger, frustration, grief, sadness, depression, anxiety and fear. Most parents stated that they experienced anger or frustration following their child's diagnosis. The following quote from Olivia describes some of the anger and resentment she experienced:

> "I have a lot of resentment, which, it sounds very bizarre, but I resented people at the time with neurotypical children, because I knew there was going to come a time when my child's behavior wouldn't pass for neurotypical and everyone would notice. So, I felt resentment and anger."

Many parents also reported feelings of grief, sadness, or depression. Andy described his feelings of grief as follows:

> "You grieve. The fact that your child is not like other girls, like other children. You know, you grieve that process."

Grieving the loss of parents' prior expectations for their child was echoed by other parents, such as Candice:

> "There was grief, because y'know, it's almost not that you've lost a child but you've lost the thought of what your child was going to be like, which is kind of hard to say, but there is a little bit of that in it".

Another major component of parents' negative emotion was anxiety and fear. Stacy described learning about her child's diagnosis as "terrifying". Related to this, Anna reported the following:

> "My biggest worry was connecting with her, because I think that when a parent can't connect with a child, and you can't know that they know you…that would be really difficult, so that was one of my big fears."

Both Kevin and Olivia reported feeling anxiety and uncertainty about the future:

> "You're lost and directionless. You don't know what the next day is gonna bring. A lot of uncertainty." (Kevin)
>
> "Yeah a lot—it was the fear—what are people gonna think, like how am I gonna cope…just a lot of anxiety around the future." (Olivia)

Feeling positive. The second subtheme captures the positive emotions that parents reported having experienced following their child's diagnosis. In addition to the host of negative feelings, some parents reported feelings of relief, excitement, confidence, and hope. As was discussed previously, receiving a diagnosis was a relief that provided comprehensibility. As a feeling, relief was a positive emotion that resulted from this comprehensibility. Beth describes these feelings of relief below:

> "I have to keep saying relief because I knew what it was. I knew there were things we could do. You know, I didn't worry a lot at first. It was just—it was just "this needs to be done", and the feeling was: okay, this is what we have to do."

Beth went on to list other positive emotions she experienced after her child's diagnosis, and discussed her feelings of hope:

> "Curiosity, umm, confidence, like in the sense that okay I can do this."
>
> "At the time—a lot of hope. I really believed that there was a way to ensure—you know, I heard there's a lot of worry in where she might end up going, because you hear of the adults, and some kids never talk and some kids, you know, become

> very aggressive and—and you know I just—I just—at the time, had a lot of…I know she's smart, I can tell, she was very, very intelligent, I could tell she was trying her best to communicate—it was just do whatever you have to do to make sure she reaches that full potential.

For Candice, there was also excitement that their child would be getting all the help they could:

> "There was some excitement to see that we're going to get help, there's experts that are gonna work with us to show us, the best ways to help him, the best ways to navigate this new life that we weren't expecting".

Meanings Made

After reporting their initial experience of receiving the diagnosis, parents discussed what living with CCCN is like now. This overarching theme, therefore, describes parents' reports of the meaning, purpose and significance of being a parent of CCCN. The following quote from Kevin is an example of parents' new meanings made:

> "It has opened my mind to so many things, and I guess it's something that I thought I was fulfilled about before but now I realize that I had no idea. It is truly something that the opportunity and the ability to be able to care for my son makes me more whole, if I can say it that way."

In this study, four themes characterize parents' meanings made, and are as follows: (1) *acknowledging pervasiveness*, (2) *growing as a person*, (3) *maintaining progress* and (4) *searching for meaning*. Each theme and its associated subthemes are presented below.

Acknowledging pervasiveness. This theme captures the passages where participants discussed and acknowledged the pervasive and multidimensional aspects of

caregiving. As Olivia stated in her interview, “there’s isn’t a part of your life that isn’t affected by your child’s needs.” For many parents, caring is a full-time job, and navigating NB’s complex care needs system pervades their life. In addition, parents acknowledged how their child’s needs affected their relationships and their plans for the future. As such, the four subthemes of this theme are (1) *identifying with full-time caring*, (2) *managing the system*, (3) *acknowledging the effect on relationships*, and (4) *planning ahead*.

Identifying with full-time caring. This subtheme captures the passages where parents identified caring for their child as a “full-time job”. For many parents, caring for their child was a constant burden that was a major component of their life. Anna reported this in the passage below:

> “I often tell people that she’s like running a business. I mean there’s just so much full-time stuff”.

In her interview, Anna described the immense amount of paperwork and “fighting” that was involved in organizing various programs, therapies and services to care for her child, Below, she describes how the burden of her full-time duties can be mountainous:

> “Back to the paperwork, and just fighting for everything—that’s probably been the worst. Most of that has rested on my shoulders, and its mountains, and again its added to your plate. And there so much to her day, and structure, and feeding tubes, and making sure everything goes right, and you’re playing doctor half the time.”

Olivia also described the challenges of full-time caregiving. For Olivia, caring for her child with autism meant sacrificing work and school for several hours of therapy:

> "It changed everything because especially when you have a child with autism, that specifically means you're going to be doing the four hours BI therapy that needs to be in your home, every day. There was no ability to go to school there was no ability to get a job"

Managing the system. This subtheme captures the many passages where parents expressed their dealings with the current complex care needs "system" in NB. All parents discussed their dealings with a multitude of specialists, physicians, therapists, respite services, mental health supports, and community outreach program and support groups within NB. Managing these services was a job in itself, and nearly all participants expressed frustration with NB's "system". For Anna, her initial hope in the system changed:

> "I mean you think you're gonna get the social worker from the special needs program… and you think: 'oh that's my answer, they're really gonna help me'. They don't. I mean they just hold purse strings—I mean they don't really…so, I learned that very quickly too. There was this constant fight. There was this constant fight for everything."

Furthermore, Anna added:

> "I wish that there was a better respite system. I wish that we could have a weekend. But they're truly isn't… there's no place for her to go. So, there's a lot of issues that way around respite."

Many parents, like Andy, expressed frustration with NB's system throughout the interview:

> "Even though I'm trying to change things from the inside out, and from the outside—change it from the outside in…that frustration that they still don't have appropriate services for people in the community—or even in the hospital."

Olivia mentioned how there were not enough supports for parents of children with autism in NB. As a result, she needed to travel out of province to meet these needs:

> "Unfortunately, I haven't been able to find a lot of supports within our area, there isn't that much for parents of autistic children. I have seen efforts in the last little while to create more, but there's definitely not anything in New Brunswick, I have to travel out of province to get anything, and it's been a consistent problem I've sort of run into."

A few parents talked about their appreciation for the system, however. For Candice, it was a relief to know that the province's system would provide her child with support. Beth recognized that her daughter's school was trying to provide her daughter with support, even while her frustration lingered:

> "That was a big relief to know that yes, in this province, in New Brunswick, we are able to get some help because I know that that that's not the case in a lot of other provinces." (Candice)
>
> "Well, since she started school, the support disappeared. And, you know the school's trying, right?" (Beth)

Acknowledging the effect on relationships. This subtheme refers to the passages where parents reported how caring for their child has had implications for relationships, both familial and intimate. In addition to managing their child's needs, parents often

reported having to manage the expectations and beliefs of other people, including friends and family members. Anna described having to "teach others" after her child was born:

> "But what I found was, is that we almost had to deal with everyone else in denial. So, you know, like, so everybody else, maybe, was like "well she seems to be normal"… "well I think she's okay". So, I found there was a lot of, kind of, teaching others.

Kevin also discussed having to manage the expectations of other people, particularly his extended family. He reported that his extended family could not yet see beyond his son's disabilities:

> "To my siblings and extended family, it—they've—they had and continue to have a tough time seeing beyond those deficits that I talked about. They don't see a person, when they look at my son. They see a series of disabilities. So, you know, despite having him part of our family for so many years, they can't get their mind around it. So, it has changed that relationship".

Other parents reported how their child's complex care needs affected their intimate relationships. In contrast, some other parents described how their intimate relationship was strengthened as a result of their journey, such as Anna and her husband:

> "My husband and I wouldn't have the relationship… either you depend on each other and you work together or you crumble and fall apart. You resent because one's doing one thing and one's not pulling weight… so, we went to the together stage, I guess. So, I feel that we're functioning on a level that we wouldn't have dreamed of."

On the other hand, Stacy described how managing her child's needs took a toll on her marriage:

> "Of course, and you probably find this in a lot of studies, is that marriages—it takes a take a toll on your marriages. And so, when my son would have been four our first marriage broke up. So, it's a lot of stress."

Olivia, the only single parent in the sample, described the challenges associated with finding an intimate partner whilst caring for a child with complex care needs, as evidenced by these two passages:

> "Umm, well, it has significantly complicated finding a partner. That for certain has been the case. I've had people come outright and say to me that they wouldn't date me because of my child, because he has needs, and because being with me potentially, if I pass away, needing to take on his care, for the rest of their lives. And that's a lot to ask people, so it can be difficult to not only find partners, but friends, because I will often be told we would love you to be able to come out, but we know we won't be able to find someone to watch your child."
>
> "And so, although I am in my twenties, I'm not experiencing anything that a twenty-year-old does because I'm either too frightened to kinda reach out to be people because I don't relate, or people don't wanna reach out to me because they're uncomfortable with my situation.

Planning ahead. This theme captures the passages where parents tried to make sense of their future through planning. Whether planning for the next emergency, or for the next phase of their child's life, many parents tried to prepare and plan for the future,

both logistically and emotionally. In the passage below, Kevin describes the importance of planning ahead:

> "And now, there's probably, I guess, maybe bigger picture and more strategic. And there are still, you know—there is a tactical part to caregiving, that goes on day in and day out. You tend to step back a little more and say 'okay, well how's this gonna look?'. What do we need to do in the next six months or six years? Or when I'm seventy-six as opposed to fifty-six?' Well then what, right? I mean my mind might still want to do everything but, as I say, my body won't let me so… you can't just blindly, you know, keep going every day without figuring out what's coming."

The "tactical" component of caregiving was still present for many parents. Beth reported that she felt the need to always anticipate the next emergency:

> "Back to juggling and staying one step ahead. What's the plan? You're always waiting for the shoe to fall."

Other parents echoed these feelings and felt the need to stay prepared in the event of a crisis, such as having bags packed that could aid them on trips to the hospital:

> "My husband and I learned very quickly to cope. You learn quickly to have a backpack in your vehicle because you don't know when there is a hospital stay."

Beyond immediate emergencies, many parents discussed their planning for the long-term future. In her interview, Anna discussed "the after": the possibility of her child's death:

> "So, I think you don't like to think about the after. But I think it's one of those things where I feel like I'm starting to think about that now…y'know, is there going to be an end to her life before mine, what's that gonna look like, is she

gonna get to adulthood, what's that gonna look like…so those are more my thoughts now."

Similarly, Andy described the tragic nature of thinking about "the after".

"The thing with having this kind of illness is that you grieve it until they die, or until you die. And they can outlive you. You know one of my biggest fears is dying before she does because I don't trust the system to look after her."

Growing as a person. This theme captures how parents reported finding personal growth as a result of their child's needs. Specifically, they reported feeling the following: First, their sense of empathy had changed. Second, caregiving has changed their perspective on life. Third, they reported feeling stronger than they thought they could be whilst learning to never give up. Accordingly, the subthemes for this theme are (1) *having compassion*, (2) *changing perspectives*, (3) *learning resilience*.

Having compassion. This subtheme captures the passages where parents reported that caregiving had affected their compassion and empathy for others. Indeed, some parents reported that their experiences left them feeling less empathy for others, especially when others' problems seemed trivial. In general, however, many parents reported that they felt they had more compassion and empathy for others. In other words, they understood what it was like to go through difficulty. Many parents, such as Andy, reported feeling that their compassion and empathy had grown:

"My knowledge, understanding, empathy and compassion has amplified."

Olivia describes this growth further:

"That every human being has a whole story behind them that I might not even know because I certainly don't expect that everyone, upon first glance, is seeing

> me as a single mom with an autistic child whose father is out of the picture completely who passed away…so as a result I try to treat people more decently, to give people the benefit of the doubt when they are giving me a hard time or, struggling themselves. They're not meaning to give me a hard time."

However, some parents reported impatience as well:

> "Sometimes, it's hard to have empathy for other people when they're complaining about things when I'm thinking—you don't know half of it darlin' (laughs)" (Stacy)
>
> "I find people are—they don't have patience today. I see people blowing horns at people for—they may cut out two cars ahead of them, and they think it's slowing them down for two seconds, so they blow the horn. That's not the real stuff in life, y'know. The real stuff in life can reach out and bite you pretty quick. If you save your energies for that kind of stuff. Fighting over pettiness or being angry because somebody did something two cars up, y'know, or a burnt bagel at Tim Hortons. You just don't waste time on that stuff in life. Its precious, right? And that's how I look at it." (Andy)

Changing Perspectives. This subtheme refers to the passages where parents reported feeling they had developed completely new perspectives on life as a result of caring for their child's needs. Many parents stated that they had a new perspective on life in general whilst others mentioned how they had new perspectives on disability or special needs. To illustrate this, Candice, mentioned her new perspectives several times. Two examples are below:

> "Oh, it completely changes your perspective on the things that are important in life, like it becomes the most important thing. Being a parent, it has become—especially with my son that does have the complex care needs, our family life right now. It has become the most important focus."
>
> "Both my husband and I talk about it all the time. We feel very fortunate that we have a new perspective about the things that are important in life".

Beyond their perspectives on life in general, many parents expressed how their beliefs and knowledge about disabilities and special needs has changed. The following quote from Candice illustrates this change:

> "Before, I wouldn't have thought about how difficult it might be for a person with a disability to enter a grocery store, or someone with a disability to walk up a set of stairs, or anything really. Like it's just—and I'm at that point where I feel embarrassed that I didn't have that understanding before."

For Kevin, the birth of his son introduced him to a new world of understanding:

> "The whole world of disability and inclusion—those things would not be a part of my vocabulary before. I guess I see the injustice, prejudice, and lack of understanding that a lot of the population just don't see."

Learning Resilience. This refers to the passages where parents expressed growth and resilience following their child's diagnosis. Specifically, parents talked about how they felt that they are stronger than they thought they could be. They reported that they learned to never give up. First, when asked if their parenting experiences had taught them anything, many parents responded that they learned they were stronger than they thought they could be. For example, Stacy said the following in her interview:

> "I think I'm stronger than I thought I was. And to go through as a family…it's been a lot on my shoulders and, I think I'm better for it, but—wish it would get a little easier! (laughs)".

In a similar, way, Anna expressed her perceptions of resilience, when asked if caregiving taught her anything:

> "Oh definitely. All about the heart, y'know, I mean you can survive anything. That's the other thing, I mean I've certainly learned my strengths."

In addition, many parents expressed how they would "never give up". They would not give up on their child, their needs, nor on themselves. Andy, who had health issues of his own stated:

> "My daughter taught me not to give up. She hasn't given up, so why should I give up? So, don't give up. I could. I could say: okay, I don't want any more treatments…I don't want this no more. I could die. I would die. I could do that but I'm not gonna do that."

Furthermore, several parents also mentioned how parenting mistakes or past challenges were learning moments. For example, Kevin described this as using failure as feedback:

> "You know sometimes there are—often there are setbacks. You think, geeze, I'm worse off this week than I was last. So now what? But we kind of always look at—we try to anyways—It's hard to do, on some days, but you look at failure as feedback, not that you've done something wrong but that it's not this way, it's got to be some other way. That's why it failed."

Maintaining progress. The third theme of parents' meanings made corresponds to the passages where parents recognized that they needed to perform regular

maintenance on themselves and their perspectives on life, in order to cope and deal with the challenges of caring for a child with complex care needs. As such, parents made active efforts to maintain their own coping and caring. That is, parents aimed at acknowledging the positive aspects of caregiving and the joy from reaching milestones. They also found many ways of coping, from respite and social support to physical exercise and meditation. Furthermore, they were adamant about gaining and sharing knowledge and research that would help themselves and others on their respective journey. This theme has three subthemes as follows: (1) *staying positive*, (2) *using coping and self-care strategies*, and (3) *utilizing knowledge.*

Staying positive. This subtheme refers to the passages where parents reported that they utilized and recognized the importance of positivity. Indeed, they expressed how they exercised positivity with regards to their child's trajectory, past accomplishments, milestones, and/or just "the little things in life". Moreover, parents reported that they came to appreciate the "little wins" and "little gains" in their child, which they reported, would be insignificant or trivial for other parents. As for optimism and positivity, the following quote from Candice best exemplifies this theme:

> "We are super proud of him too, like we want him to use his strengths to his advantage. He has a lot of challenges, but he has some pretty incredible abilities too. So, we're gonna take those and hope that he can do something with his abilities."

Candice stressed the importance of optimism for her own well-being:

> "Like I said I try to keep a more optimistic, more positive point of view—I won't dwell on the negative aspects, because it's no help to anyone. I can get there sometimes, but I'm not gonna stay there."

Many parents described their elation when their child reached milestones. Below, Olivia expresses this joy:

> "When he does hit those milestones it's fantastic. When he did say 'mom' for the first time, and you know, just when he learned to take his shirt off for the first time…Anything that he has managed to learn how to do has been really great."

For Beth, for example, reaching milestones was not only significant for their child's wellbeing, but served to reward the efforts that parents had invested. The passage below illustrates Beth's satisfaction, when a professional reassessed her daughter's functioning:

> "She came back three months later and she was absolutely floored and amazed at the progress she had made, because she had pretty much—she admitted it to me, several months later, when she had first met her, you know, she never thought that—she said there isn't much that we can do. So, for me and my daughter that was important because people really saw the potential then. And it was important for me because I was adjusting her diet and making sure she is part of the interactions at home. So, it made me feel that we were really going in the right direction. It just created more hope."

Many parents also expressed appreciating "the little things in life", after having been a caregiver of a child with complex care needs. For example, Anna and Olivia stated the following:

> "I mean you learn to appreciate the little things the miracles in everyday stuff." (Anna)
>
> "You have to change your thinking so that every small thing is something that you celebrate." (Olivia)

Using coping and self-care strategies. This theme refers to the passages where parents mentioned their coping and self-care strategies when dealing with the difficulties of child care. Some coping strategies mentioned by parents are as follows: using respite, cutting back on work, seeing a therapist or counsellor, using complimentary or alternative medicine, taking anti-depressants, using faith, engaging in physical exercise, meditating, and more. For example, after Andy reported that he and his family experienced a particularly traumatizing experience with their daughter, he insisted on seeing a counsellor:

> "I pretty much insisted on everybody going to family counselling. And we did counselling as a group but also as individuals because my son needed to be able to talk about his feelings too, you know?"

One parent, Anna, started using reiki as a coping strategy:

> "Also, I started on a path with reiki. I've been taking Sophie for all kind of treatments and massage therapists. So, I started on that path—that spiritual path, has probably really helped me, today."

Related to spirituality, for Kevin, their church community has been important to his family:

> "Well, our faith is a big contributor. That there is, I guess, everything that you see isn't everything that there is. So, we rely on that in the end overall. You know, I

> guess we would say that we haven't been led this far for it to all end horribly, so, there's I guess a bigger drawing that you know at some point things will work out."

However, as some parents reported adopting appropriate coping strategies has a learning curve.

When asked about the effect of parenting on her physical and mental health, Stacy made the following comment:

> "You have to work on it. Definitely do and you have to make time for yourself for sure."

Candice also reported:

> "It's kind of been a learning curve really, to be honest…It definitely hasn't been easy, and I haven't had as much of an ability to cope."

Utilizing knowledge. This theme captures the passages where parents reported that knowledge, research, and education were vital components of their caregiving. Many parents expressed their beliefs about the value of knowledge and education, and some reported staying up to date with the latest research on their child's diagnosis. Below, Candice describes her attempts to find research that may help her child with autism:

> "I've always thought that—just like having, like, knowledge about things, is comforting and helpful. So, I'm always looking at things like research or professionals that would be in the field that I can speak to about things, like asking questions and getting help. I think that just speaking out that education and knowledge about his disability is helpful, to me, and to him I think."

Andy described the importance of education in the following ways, with these two quotes:

> "You have to understand your kids. So, if there's a little extra education, it wouldn't hurt. Not everyone is cut out to be a parent, so you almost should take a few courses when you first become a parent."
>
> "Y'know, with education you become stronger. With learning you become wiser".

When knowledge from others is not immediately available, Olivia reported how she utilizes the internet to gain valuable experiences and perspectives from others:

> "To cope, I find that, a lot of times, I'm having to turn to google. I'm having to turn to the internet, I'm having to turn to just, you know, anything I can find, any story of someone with maybe an adult with autism…and just learn from their experiences".

Searching for meaning. This theme captures the passages where parents explained their active attempts to find meaning and purpose in their caregiving experiences. Many parents reported being involved in organizations that help families with complex care needs. Many parents reported finding meaning in life by sharing knowledge and reported making career changes in light of their caregiving experiences. Many parents said that through their caregiving experiences, their life had taken on a new meaning, and that caring for their child is an end in itself. This theme has two subthemes: (1) *getting involved*, and (2) *finding meaning*.

Getting involved. This subtheme refers to passages where parents reported how they found meaning through becoming involved in the complex care needs community.

Some of the ways parents reported being involved were as follows: a changing of careers, sitting on advisory boards and committees, writing a book about their experiences, being part of an autism resource center, raising awareness for their child's diagnosis, participating in fundraising, sharing knowledge with others, and of course, participating in research. Olivia, for example, describes how she made career changes in light of her child's needs:

> "It changed the whole line of work I was planning to go into. Prior to having my son I was interested in becoming a paralegal, umm, but after I had him, and I experienced the sort of like change of heart, I ended up going to school to become a continuing care assistant, and hope to continue with that in nursing. I want to care for more people".

Anna made similar career changes. Now a reiki business owner, she considers herself a "heart healer" for others:

> "I mean I wouldn't have gone down this path, again back to the reiki, and I mean I have a little business that I'm helping clients with that, and I'm able to help… I often say to people, I'm a heart healer. And I've healed my own heart, but in many ways my heart is broken everyday, so a lot of the time the people that are coming to me, their heart is broken as well. And in some way, I'm able to help heal that as well."

Andy explained how he has a newfound duty to help others like his daughter:

> "I no longer just see my daughter as an individual who is sick. She has taught me to not only keep a look out for herself but for others like her. I feel other people's issues, heavily. If I can help somebody in any way I can, get through it, I will."

As for Kevin, he added:

> "I wrote a book about my son. Those are things that I would have never envisioned ever doing, or why would I do that, and so it's taking me down a completely different path from what I thought it'd be."

Finding meaning. This theme corresponds to the passages where parents reported the meaning or purpose they found in caregiving. When asked if they found meaning in their caregiving experiences, all but one parent agreed that they had. Many parents reported that they had found a new meaning or purpose in life. Others gave examples of feelings of fulfillment. For instance, Kevin describes this below:

> "It has opened my mind to so many things, and I guess it's something that I thought I was fulfilled before but now I realize that I had no idea, and that, it's truly something that the opportunity and the ability to be able to do that makes me more of a—whole, if I can say it that way."

For many parents, caregiving was reported as a duty. For them, they perceived their child as their purpose. For example, this was brought forward by Beth and Anna in their interviews:

> "The meaning is I'm her parent. I have to do this. I have to. Because the meaning is the values that I hold and this is it. I need to make sure she reaches her potential, somehow." (Beth)

> "I would have to say that she probably is our purpose." (Anna)

One parent did not find meaning or significance in their caregiving. When asked if she found meaning in her caregiving experiences, Beth responded with this:"

> "Meaning (pause) umm, no. You know, part of the reason I wanted to [participate in the study] is because I wanted to make sure that it's not all roses and rainbows. I don't find any meaning in this, at this point. Before, when she was progressing, and before the aggression, before the crisis situation—you know, I could see my flower blooming. And now its dying."

Meaning-Making and Resilience

Most parents reported that the meaning they found in their caregiving did play a role in their resilience, or their ability to cope. Therefore, the theme that illustrates this result is "*Perceiving meaning as a bulwark*". This theme describes how parents reported feeling that the meaning they found was a bulwark (i.e., a defense) against the challenges of caring for their child. Overall, parents reported that their outlook on life, their hope for the future, their determination, and their strategies to finding meaning (such as being involved in the community) impacted their ability to cope. For example, Anna describes how her outlook impacted her and her family:

> "I guess at the end of the day we could have looked at it differently. We could have stayed in the 'woe is me' stage. Maybe part of that is my daughter. Maybe part of that has been seeing her being so resilient. How could we be any other way? So again, back to her being a teacher, that's what I often think, you know."

Candice reported that staying positive and envisioning a path for growth has been instrumental:

> "I'll continue to help my son and educate myself and others, of our situation. When I get back to work, I'll continue to try to help other people who are in the same situation. I guess my kind of my field of thought is to take this experience

and to take the positive things from it and move forward. I guess that's how I cope."

As reported by some parents, such as Stacy, duty is what kept them going:

"I'm not sure—meaning—you don't have a choice. This is your family. This is what you're gonna do for your child and you—it certainly has influenced me. There are days, certainly, where I feel 'oh I can't do this'. But you do."

Finally, Beth reported that her duty as a mother kept her going. According to her, her sense of hope and seeing the potential in her child was "everything". She added:

"The meaning is I'm her parent. I have to do this. I have to. Because the meaning is the values that I hold and this is—I need to make sure she reaches her potential, somehow."

"Like I don't think I need meaning because it's my daughter. If there's any meaning it's because she is my flesh and blood… If I didn't think that she could be more, then I'd be doing all this for nothing, right? She could be more. And I know she can, and I know she wants to be. I don't care what anybody says. I know."

Discussion

To explore the ways and extent to which parents of CCCN find and create meaning in their caregiving experiences, seven parents of CCCN participated in qualitative interviews that explored their meaning-making processes. In addition to investigating these processes, the interview explored parents' perceptions of the relationship between the meaning they found in caregiving and their own resilience. To the best knowledge of the researcher, this study was the first to explore meaning-making

and the relationship between meaning-making and resilience in a sample of parent-caregivers with diagnostically diverse children. The themes for each research question are discussed below, followed by strengths and limitations of the study as well as suggestions for future studies.

Research Question 1

The first research question asked: "In what ways, and to what extent, do parents of CCCN create meaning when caring for and living with their child's complex care needs?" In addressing this research question, the interview questions were designed to elicit the entire process of meaning-making. This included parents' overarching beliefs and expectations of parenting, their initial appraisals of their child's diagnosis, their reactions to those appraisals, and their resolutions to the reactions in the form of new meanings made. Thematic analysis of the interviews found that parents' responses seemed to form a coherent pattern of themes that aligned well with the meaning-making model. As a result, several ways of parental meaning-making emerged from the data. Interestingly, all parents in this study found at least one "meaning made". Below, each theme is discussed in detail.

According to the meaning-making model (Park, 2010), individuals have a global meaning system that consists of their life goals, beliefs about the world, and their perceptions of life's meaningfulness. In this study, it was expected that parents would have a specific global meaning system for parenting, termed global parental meaning. This consists of their beliefs about the meaning of parenting, their expectations of parenting, and their goals and values as parents. This information was gathered from participants to explore whether their global parental meaning systems changed after

having learned about their child's diagnosis. Three questions, at the beginning of the interview, were designed to capture global parental meaning. Overall, at the time of the interview, parents wished to promote their child's growth and offer guidance whilst being mindful of the challenges and benefits of parenting children with complex care needs. This study's findings seem to suggest that parenting's main tasks consisted of guiding and facilitating their child's growth. As a guide, parents may wish to raise children to be virtuous, resilient, and independent. Indeed, in this sample, parents clearly expressed their wishes for their children to reach their fullest potential, regardless of their health or developmental challenges. Moreover, participants saw parenting as both deeply challenging and rewarding at the same time: parenting was stressful and burdensome, whilst providing joy and fulfillment. Since these beliefs and goals represent participants' global parental meaning at the time of the interview, they can be considered as parents' final, changed global parental meaning that resulted from the meaning-making process (Park 2010). In other words, the meaning-making process is thought to be capable of influencing individuals' global meaning systems. Because of this, it is possible that participants' global meaning had been modified since their children's diagnosis and is a product of the meaning-making process, as a result of the continuous challenges in caring for a child with complex care needs.

Thus, one can argue that participants' current parental beliefs may not be representative of participants' goals and beliefs that existed prior to their child's diagnosis. Despite this possibility, and although this study did not address parents' global meanings at the time of diagnosis, the findings also suggest that most parents simply expected to have a healthy child. Indeed, parental global beliefs were in line with what

parenting would “normally” be like. Such parental beliefs do not seem to be independent from sometimes negative perceptions of CCCN before any diagnosis. Related to this, the literature suggests that the valence of parenting beliefs is related to parental stress (Respler-Herman, Mowder, Yasik, & Shamah, 2012). Specifically, holding more positive perceptions of various parenting behaviours, such as bonding, protection, and education, were shown to be associated with lower parenting stress, whereas negative perceptions of those behaviours were associated with higher parenting stress (Respler-Herman et al., 2012). Similarly, one study found that the parents’ expectations of their child’s autism spectrum disorder (ASD) outcomes were associated with ASD severity and parental psychopathology. Moreover, a qualitative study by Ayres (2000) found that caregivers of spouses, parents, and children with complex care needs used a combination of expectations, strategies, and explanations to find sense and significance in their caregiving. Specifically, global expectations helped caregivers in orienting their interpretation of events and in evaluating caregiving efficacy. Thus, global meaning may be a necessary orienting framework for parents of children with complex care needs. In turn, this may affect parental distress level following their child’s diagnosis.

According to the meaning-making model (Park, 2010), a stressful encounter, such as learning about a diagnosis of complex care needs, results in an initial appraisal of the situation. This appraised meaning, also known as implicit meaning, may take place immediately or very shortly after a traumatic event (Park, 2010). In this study, to further explore parents’ initial implicit meanings of their child’s diagnosis, parents were invited to describe their first thoughts after learning about their child’s complex care needs, if any. As suggested by the findings, parental initial appraisal of child diagnosis seems to

have included thoughts of uncertainty and a reconsideration of parenting beliefs and expectations, as well as thoughts of comprehensibility and controllability. Based on these findings, one can argue that parents may assess their stressful encounter as being both disruptive and orderly at the same time.

Of note, Park (2010) highlighted the types of appraisals that can arise from traumatic situations: these include, but are not limited to, evaluations about the future implications of the event, the controllability of the event, and the reasons for why the event occurred. Interestingly, the findings reflect these appraisal-types. For example, upon receiving their child's diagnosis, many parents raised uncertainties about the future, questioned their own parenting abilities and knowledge, and questioned how the diagnosis would impact their lives. Moreover, some parents questioned the reason behind their child's health condition, asking themselves existential questions such as "why me?" or "why has my child been given this?" Asking the question "why me" is a prevalent cognition following a trauma in general (Park, 2010). Additionally, and more specifically, thoughts of uncertainty following a child's diagnosis are usually commonplace as well (Santacroce, 2003).

In addition to the initial "why me?" question for many parents in this study, caring for a CCCN seemed to have been appraised as being controllable. For instance, there was a pre-determined path of needed services, involving health professionals, therapists, and other practitioners. While parents in this study saw controllability in this predetermined path, loss of control was a common cognitive appraisal from one sample of parents of children with epilepsy, following their child's diagnosis (Nguyen, Pertini, & Kettler, 2015). However perceived feelings of relief and comprehensibility in parents of

children with ASD are common in the literature upon receiving their child's diagnosis (Avdi, Griffin, & Brough, 2000; Mansell & Morris, 2004; Midence & O'Neill, 1999; Osborne & Reed, 2008).

The meaning-making model (Park, 2010) proposes that after individuals appraise the initial meaning of a traumatic experience, a discrepancy between their global meaning systems and the appraised meaning may lead to distress. This study seems to indicate that there was a discrepancy between global and appraised meaning, as evidenced by the emotional reactions that were reported. Indeed, parents experienced a rollercoaster of emotions, especially at the time of diagnosis. Learning about their child's diagnosis seems to have unleashed a torrent of mixed emotions, mostly negative and some positive. Importantly, these mixed emotions seem to be present several years after the initial diagnosis or diagnoses. Negative emotions included anger, fear, anxiety, and sadness, whereas positive emotions included relief, excitement, confidence and hope.

From a theoretical perspective (Park, 2010), parents' emotional reactions can be considered as being partly derived from the discrepancy between their global parental meaning and the appraised meaning of their CCCN's diagnosis. From this perspective, parents' expectations, goals, and knowledge may have conflicted with their appraisals of their child's diagnosis and generated distress as a result. In addition, it could be argued that parents' positive emotions resulted from a lack of contrast between appraised and global meanings. One study found that positive and negative emotions are commonly experienced by parents following a child's diagnosis of intellectual disability (Boström, Broberg, & Hwang, 2010). However, Mansell and Morris (2004) reported that, after parents learned about their child's diagnosis of ASD, their most common emotions were

shock, anger, hopelessness, denial, and confusion. Similarly, in parents of children with bladder exstrophy-epispadias complex, parents reported feeling fear, anxiety, and anger (Di Grazia, Pellizzoni, Tonegatti, & Rigamonti, 2017). Bearing this in mind, the present study corroborates findings related to parents of children with down syndrome, who experienced overwhelming emotions, namely feeling "every emotion at once" (Goff et al., 2013).

In the present study, parents of children with neonatal diagnoses (i.e., at birth) had less relief than parents who received a diagnosis postnatally, from months to years after. In addition, the majority of positive emotions following a diagnosis was felt almost exclusively by parents of CCCN with postnatal diagnoses. Indeed, reactions to a child's diagnosis may be affected by the timing of the diagnosis, as was seen in parents of newborns with severe disabilities (Graungaard & Skov, 2007). One may argue that this could also generalize to other conditions. Ultimately, the nature of positive emotions experienced after a child's diagnosis may be related to numerous factors beyond the timing of the diagnosis. Examples of such factors may be the access to social support, the quality of an intimate relationship, the temperament of the child, the severity of their child's needs, or their access to medical care, as needed.

In order to resolve the discrepancy between global and appraised meaning, parents in this sample seemed to have engaged in a process of meaning-making, with new meanings made as end products. Some meanings made included acceptance, perceptions of personal growth, a change in the stressor's meaning, and a new meaning in life; all of these "end products" could have reduced the discrepancy between appraised and global

meaning. Based on our findings, these meanings made consisted of four factors, as discussed below:

First, acknowledging the pervasiveness of complex care needs may have allowed parents of this sample to accept their child's diagnosis in the form of full-time, exhausting caregiving. This may have allowed them to forge new global meanings through new identities, goals, and beliefs about the world. Thus, and based on our findings, parents may have succeeded in perceiving caregiving as a significant burden or, at least, a challenge. Related to the latter, most parents seemed to complain about difficulties associated with coordinating care, services, and support, especially with regards to services in New Brunswick (NB). Indeed, frustration with NB's complex care needs services was commonly reported, even if it was beyond the scope of this study. Parents also reported how their futures and close relationships were affected by their child's complex care needs. Therefore, it is possible that through the recognition of the pervasive nature of their child's needs, parents were able to accept their child's diagnosis and integrate it into their global meaning systems (Freda & Martino, 2015; Park, 2010). Freda and Martino (2015), for example, in exploring written narratives of parents of children with leukemia, found that parents often discussed acceptance of their child's needs. They also discussed how caring for their child's needs occupied their future (Freda & Martino, 2015). Moreover, Brenner et al., (2018) also found that caring for children with complex care needs pervades caregivers' lives, including their intimate and familial relationships.

Second, parents in this sample seem to have found personal growth in the form of changed compassion, a new perspective on life, and a newfound strength and

determination. As suggested by Park (2010), personal growth could allow individuals to perceive a stressor as less distressing and more positive. Therefore, perceptions of personal growth are new meanings made that may reduce the discrepancy between the appraised and global meaning system. Many studies have found that post-traumatic growth can occur after parents' learn about their child's diagnosis (Picoraro, Womer, Kazak, & Feudtner, 2014). In a study with Australian parents of children with developmental disabilities, post-traumatic growth was found to be significantly more prevalent than compared to other samples of adults, such as cancer survivors or victims of motor vehicle accidents (Strecker, Hazelwood, & Shakespeare-Finch, 2014). As such, post-traumatic growth may co-occur with distress in this population (Strecker et al. 2014). Bayat (2007) found that parents of children with autism perceived themselves as being stronger than they were before caring for their child. Although post-traumatic growth was not explored quantitatively in the current study, the interviews suggested that post-traumatic growth was present in some if not many participants. Perceptions of increased strength, at least, were reported by many parents in the current study. Pakenham, Sofronoff, Samios (2004) found that many parents of children with Asperger's syndrome perceived positive personality change, personal growth, new perspectives on life, and a greater understanding of disability post-diagnosis. In line with earlier research (Pakenham, Sofronoff, Samios, 2004), many parents in the present study reported changes in personality and perspective.

Third, by maintaining coping progress (e.g., staying positive, finding coping strategies, and gaining knowledge, etc.), one may argue that parents seem to have been active in their attempts to reduce the discrepancy between their appraised meaning of

diagnosis and their global meanings. Through the use of optimism and hope, and by appreciating the significance of milestones, parents clearly reframed the meaning of the diagnosis into something more positive and less discrepant with their global meanings. Through searching for knowledge and research, parents gained comprehensibility and made sense of their child's diagnosis. By utilizing active coping resources such as social support, exercise, and psychotherapy, parents may have been able to gain mastery and control over their environment. Therefore, through sustained efforts to cope with their child's needs, parents made new meanings of their child's diagnosis by reframing the appraised meaning of the diagnosis, and by finding comprehensibility and control. Similar to the present study, Twoy, Connolly, and Novak, (2007) found that parents of children with autism utilized social support, reframing, and knowledge gathering as coping strategies. Another study found that, in comparison to parents of children without a disability, parents of children with disabilities were more likely to seek out social support and use positive reappraisal (Paster, Brandwein, & Walsh, 2009). In addition, attempts to harness control may be beneficial, as locus of control may be an important factor in parental well-being for parents of CCCN (Lloyd & Hastings, 2009). With regards to knowledge searching and use, Feinstein (2014) found that parents of children with ASD seek out scientific research and knowledge from experts (e.g., autism researchers). However, gathering "near-science" knowledge such as that from pediatricians and educational assistants, or from personal accounts forms a more common form of information gathering. Related to this, parents of the current study sought out both scientific and near/non-scientific information when learning about their CCCN's diagnosis. Pushing the interpretation of these findings further, we could perhaps

hypothesize that these parental coping efforts (i.e., through positivity, active coping strategies, and knowledge gathering) may have aided in reducing the discrepancy between appraised and global meaning.

Fourth and finally, parents in this sample seemed to find meaning and purpose in caring for their child. In addition, they found meaning in participating in their child's complex care needs community. Specifically, some ways in which parents became involved was through changing careers, spreading awareness of their child's diagnosis, or taking part in complex care needs boards and committees. By being involved in these ways, one can interpret this as participants' attempts to search for meaning beyond their own child in order to develop larger global goals and purpose in life. According to Park's (2010) meaning-making model, this would help reduce parental distress by reducing the discrepancy between appraised meaning and global meaning.

Interestingly, many parents from the current study considered that it was their duty to care for their CCCN because their children were their purpose. It is possible that parents found new meaning in life through caregiving. As a result, this may have altered their global sense of life meaning and may have contributed to reducing any discrepancy between their appraised meanings and global meanings.

Finding meaning in caregiving is essential for adjustment and well-being in parents of CCCN (Rosenberg et al., 2013; Whiting, 2013). This may significantly predict family satisfaction (Lightsey & Sweeney, 2008). Additionally, meaning in life can be related to higher perceived physical health in parents of CCCN (Bekenkamp, Groothof, Bloemers, & Tomic, 2014) whilst contributing to a sense of life coherence (Sivberg, 2002). Despite these positive benefits, one must bear in mind that meaning is not always

present (or at least self-reported) after exposure to a trauma (Park, 2010). Related to the latter, earlier research (Pakenham et al., 2004) indicated that most, but not all parents of children with Asperger's syndrome reported finding caregiving-related meaning (i.e., 75 percent of the total sample). In the present study, only one participant, Beth, reported not having found meaning in her caregiving. This parent, who explained that her family was in the middle of a crisis, described how she had initially made sense of her child's needs by confronting them. However, now she did not find meaning in caregiving.

In this way, based on the latter finding, it could be argued that the meaning-making processes of some parents of CCCN may not be linear. Indeed, caring for CCCN is not a singular trauma from which the parent recovers over time. It is rather a series of continuous, distressing, or grief-inducing events in their child's life. Thus, parents may be able to search for (and find) meaning at certain times but not others. Clearly then, for parents of CCCN, meaning-making is a unique, ongoing, and likely complex experience, with different possible trajectories during the family's journey. During periods of crisis, caregiving may appear as senseless. During these times, finding meaning may become more challenging.

Research Question 2

The second research question was: "In what ways, and to what extent, do parents of CCCN consider that meaning-making has influenced or currently influences their resilience?" In this sample, most if not all parents perceived that the meaning they found in caregiving was instrumental in their ability to cope. In other words, meaning served as a bulwark—a strong defense—against the difficulties of parenting. Examples of this "bulwark" may be the involvement in one's community, experiencing growth, and

utilizing coping resources. Parents also expressed how their duties and obligations as a parent contributed to their resilience, even when meaning in caregiving was not found. Indeed, one parent, Beth, saw finding meaning in their caregiving as unnecessary, since they already had a duty to care for their child. In this way, while meaning-making may be a resilience resource for parents of CCCN, it may not be a necessary resource when duty or obligation allow parents to persist.

Strengths

This study had many strengths. First, the qualitative interview script used for this study was able to engage participants and draw out a detailed narrative. Second, by using Braun and Clarke (2012)'s thematic analysis, this study generated a rich description of the data. This rigorous yet flexible method helped capture all the components of the meaning-making model (Park, 2010). A third possible strength of this study was to organize the themes that emerged from the data according to the components of meaning-making model (Park, 2010). This study used an interview script inspired by this model, which was carefully adapted to the context of this study. This conceptual framework has likely provided further depth to the analysis of the data, despite a possible bias, as described further below.

Limitations

This study had several limitations. First, although the sample size is acceptable for such a qualitative study, the initial planned target sample (10-12 participants) was not reached. This may have limited the generalizability of the findings. However, the inclusion of both mothers and fathers and all types of complex needs of children may have slightly mitigated this limitation. Due to recruitment challenges, four out of seven

participants were recruited from the family advisory council of NaviCare/SoinsNavi's (NB virtual navigation centre for CCCN, their families, and care teams). These participants are thus highly involved in the CCCN's community. Thus, they may have specifically skewed the "*getting involved*" subtheme, presented in the results. Second, despite the strength of organizing the data themes according to the components of meaning-makingmodel (Park, 2010), this may have perhaps introduced an unwanted interviewer bias. This limitation may have been perhaps mitigated by resorting to a mock interview prior to data collection. Third, the present study assessed global parental meaning at the time of the interview and did not directly explore parents' global meaning prior to learning about their child's diagnosis. As such, definitive conclusions about any prior global parental meaning cannot be made here.

Future Studies

To address the limitations described above, future research should incorporate the following changes: First, future studies should use larger sample sizes. Second, resorting to mixed-method designs along with large and ideally more diverse samples may be more informative. For the quantitative component of mixed-method designs, reliable and valid ad-hoc measures of meaning-making and resilience would be better than self-reports, as has been suggested by researchers in both areas (Luthar, Sawyer, & Brown, 2006; Park, 2010). Third, future research may benefit from comparing meaning-making between parents of children with neonatal diagnoses and parents of children with postnatal diagnoses. The results of this study seem to perhaps suggest possible differences. Fourth, and perhaps ideally, longitudinal studies (i.e., prospective) are needed to fully explore global and situational meanings before, during, and after parents learn about their child's

complex care needs. Only longitudinal designs may accurately assess if, and how, global meaning changes over time. Furthermore, through a prospective approach, the initial appraisal of the diagnosis and subsequent emotional reactions could be assessed, followed by the extent to which distress is lessened as a result of meanings made. Fifth, and finally, since the topic of NB's complex care needs system was raised multiple times in nearly every interview, parents' frustration and recognition of gaps in services in this province should be explored in future studies.

Conclusions

This study investigated: (1) the ways and extent to which parents of CCCN find meaning and purpose in their caregiving and (2) the extent to which parents perceived a relationship between meaning-making and their own resilience. Overall, this study found that parents of CCCN made an array of meanings of their caregiving experiences, including but not limited to acceptance, growth, resilience, and finding purpose. In sum, meaning-making in parents of CCCN is likely an iterative, ongoing, and complex process. It may also be instrumental in parents' resilience. In conclusion, this study can be considered the first step in exploring meaning-making in parents of CCCN. Further investigations are needed to better inform research and practice about parental resilience. This would allow the development of refinement of tools that could facilitate parental resilience when caring for their CCCN.

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Appendix

Telephone Interview Script

Introduction
Hello, my name is Luke Mungall. I am the student researcher conducting the study on finding meaning and purpose when caring for children with complex care needs.

I would like to thank you for agreeing to participate in this interview. Before we start, I would like to review the consent form with you. If you have any questions, please do not hesitate to ask. (*Go through the form and answer any questions).*

Do you have no further questions before we begin?

(When all questions are answered): I am now turning on the recording device. *(Start device).*

Demographic questions:
What is your age?
Where do you reside?
How old is your child with complex care needs? And how old was he/she at the time of diagnosis?
If you have other children, if so how old are they?

Global Parental Meaning

1. For you, what does it mean to be a parent?

    Supplementary Questions
    What are your goals as a parent?
    What do you think are the goals of parenting?
    What values do you think a parent should have?

Assignment of Meaning

2. Recall back to when you were first learning about your child's complex care needs. Could you describe what that experience was like?

    Supplementary Questions
    What were you thinking at that time?
    What was that experience like?
    Could you describe an experience with your child's needs that was particularly important?

Reactions Derived from Discrepancies

3. Could you describe the emotions you experienced when you were learning about your child's needs?

   Supplementary Questions
   What were you feeling when you were learning about your child's needs?
   What were some emotions you were experiencing?
   What did learning about your child's complex care needs mean for you?
   What did it mean your life
   As a parent?
   For your career?
   For your finances?
   How did you react to those feelings/emotions/meanings?

Meanings Made

4. What is it like to be a parent of a child with complex care needs?

   Supplementary Questions
   What is it like to be a parent of a child with _____ (condition)?
   Could you describe one experience that was very important for you and your child?
   Could you describe any significant challenges while caring for your child?
   Could you describe any significantly positive experiences while caring for your child?
   Have you experienced any significant difficulties or challenges while caring for your child?
   If so, in what ways have you coped?
   If so, how have you coped with those difficulties or challenges?
   If not, how were you able to avoid or overcome any significant challenges?

5. (Either in general or in reference to a particular experience) What did that(those) experience(s) mean to you?

6. How have you found meaning/purpose/ in those experiences?
   a. What meaning have you made out of those experiences?
   b. IF NOT: Have you tried to find meaning out of that(those) experience(s)?

7. What did these experiences mean for your life in general?
   a. For your family and/or relationships?
   b. For your career?
   c. For your own health?
   d. For your mental health?

8. Did those experiences teach you anything?
   a. Anything about yourself?

b. About the world?
c.

Supplementary Questions

To what extent have your thoughts about those experiences changed over time?
Have those experiences changed the way you think about life?
Did you always interpret those experiences in the same way?
Have you always felt the same way about these experiences?
Have these experiences always meant the same thing to you, or have they changed over time? If so, how have they changed?
Have those meanings/feelings/interpretations changed since the time of your child's diagnosis? If so, how have they changed?

Resilience
Could you describe how the meaning you found in that experience has influenced your ability to cope?

Supplementary Questions
To what extent has the meaning you found in those experiences helped or hindered your resilience?
You mentioned [the meaning they found in an experience]. How has that meaning influenced your resilience?
To what extent has the meaning you found in that experience influence your coping efforts/influenced your ability to cope?
Could you describe how the meaning you found influenced you coping efforts

General concluding question.

My questions are finished. Is there anything else you would like to mention, or anything that you think was forgotten in this interview that should have been discussed? Do you have any questions or comments?

This concludes the interview. Would you like to receive a copy of the findings after the conclusion of the study? Once again, I would like to thank you for your time and participation in this study.