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Characterizing Coping Among Parents of Children with Medical Complexity

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CHARACTERIZING COPING AMONG PARENTS
OF CHILDREN WITH MEDICAL COMPLEXITY

by

Julia B. Tager

A Thesis Submitted in
Partial Fulfillment of the
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ABSTRACT

CHARACTERIZING COPING AMONG PARENTS OF CHILDREN WITH MEDICAL COMPLEXITY

by

Julia B. Tager

The University of Wisconsin—Milwaukee, 2022

Under the Supervision of Professor W. Hobart Davies

Children with medical complexity (CMC) are characterized by intensive healthcare needs. Given the centrality of the relationship between parent and child well-being, an investigation of the experiences of parents who care for CMC is warranted. Parents of CMC experience significant challenges relating to practical matters and their own well-being, but there is a dearth of research examining parental coping strategies used in response to these challenges. Informed by the revised Transactional Model of Coping, the current study aimed to characterize coping among a sample of parents of CMC. Twenty parental caregivers of CMC served by the Complex Care Program at Children’s Wisconsin participated in one-hour semi-structured qualitative interviews regarding stress and coping. Findings suggest the use of a multitude of coping strategies which are primarily emotion-focused and meaning making in nature. Future research is needed to investigate coping strategies more systematically with representative samples to enable the development of culturally informed interventions to support parent and family well-being among those who care for CMC.

Keywords: children with medical complexity, parent coping

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CHARACTERIZING COPING AMONG PARENTS OF CHILDREN WITH MEDICAL COMPLEXITY

Children with medical complexity (CMC) are characterized by substantial health care service needs, medical fragility, functional limitations, and high health care resource utilization (Cohen et al., 2011, 2018). The Social Ecological Model posits that children with chronic illnesses are part of an interrelated sociocultural system in which family, community, and societal factors relate to the child's well-being and vice versa (Kazak, 1989). As such, the well-being of parental caregivers is likely strongly associated with CMC well-being. Parents of CMC experience substantial challenges, including practical and financial difficulties (Ghandour et al., 2017; Goudie et al., 2005; Kuo, Cohen, et al., 2011; Romley et al., 2017; Thyen et al., 1999), physical health problems (Brehaut et al., 2009; Gallagher et al., 2009; Keilty et al., 2018; Kuster & Merkle, 2004; McCann et al., 2015; Meltzer & Mindell, 2006) and psychosocial concerns (Carnevale et al., 2006; Chan et al., 2019; Cousino & Hazen, 2013; Goudie et al., 2005; Murphy et al., 2007; Thomson et al., 2016; Thyen et al., 1999; Verma et al., 2020). Although the difficulties of caregiving are well-documented among parents of CMC, little research has examined coping in this population. A revised version of the Transactional Model of Coping suggests that coping strategies can be categorized as problem-focused, emotion-focused, and meaning making in nature (Folkman, 1997; Folkman & Moskowitz, 2000; Lazarus & Folkman, 1984; Park & Folkman, 1997). Informed by this model, the current study sought to characterize coping among a sample of parents of CMC. Findings suggest that parents cope in a multitude of ways, most of which are emotion-focused or meaning making strategies. Results can be used clinically to inform patient care efforts and the development and implementation of psychosocial interventions for parents. Advocacy efforts are also needed to increase the availability of

supports (e.g., accessible respite care) to allow parents opportunities to develop effective coping skills. Future research directions include replication and expansion of results with more demographically diverse samples and the development and implementation of population-specific psychotherapeutic interventions.

Characterizing Children with Medical Complexity

As pediatric medicine advances, more children are surviving complex childhood conditions and living into adulthood (Blum et al., 1993; Child Trends, 2019; Perrin et al., 2007). This has caused a growth in the population of children living with chronic health conditions, including an expanding cohort of children in need of intensive medical involvement (Burns et al., 2010; Cohen et al., 2011). A subset of these patients, known as children with medical complexity (CMC), comprise less than 1% of children but account for one-third of child health spending (Cohen, Berry, et al., 2012; Kuo, Cohen, et al., 2011; Neff et al., 2004). The American Academy of Pediatrics differentiates CMC as a subpopulation of Children and Youth with Special Health Care Needs (CYSHCN; Kuo et al., 2016). Whereas CYSHCN generally require more services than are typically required for pediatric patients (McPherson et al., 1998), CMC require the most intensive health care utilization and highest cost (Kuo et al., 2016). CMC typically receive care from multiple pediatric subspecialists, require outpatient or home-based services, and utilize durable medical equipment (Cohen, Berry, et al., 2012; Kuo et al., 2016). Additionally, many CMC are dependent on technology (e.g., ventilators, dialysis) to maintain life-sustaining bodily functions and/or require technology assistance (e.g., wheelchair, communication device; Kuo et al., 2016). Compared to other CYSHCN, CMC experience the highest prevalence of developmental problems, such as speech or learning disabilities, and require the most frequent

medical involvement. Families of CMC experience higher demands placed on family members' time and financial resources compared to families of other CYSHCN (Bramlett et al., 2009).

Furthermore, CMC generally require intensive medical care both at home and in the healthcare setting. Despite representing a very small proportion of the United States population, CMC account for over 10% of pediatric hospital admissions, a proportion which has increased in recent decades (Kuo et al., 2014; Simon et al., 2010). These patients are at high risk of visits to the emergency room, intensive care unit stays, and death (Gouveia et al., 2019). One study of children enrolled in four United States hospital-based clinical programs for CMC carried a mean of 9.5 distinct diagnoses and were hospitalized a mean of three times over a two-year period, with each hospitalization lasting, on average, 12 days (Berry et al., 2011). To address the complex and intensive nature of the medical systems needed to care for CMC, many of these patients are cared for in a "medical home," a healthcare system in which family-centered, continuous, and comprehensive care is provided to maximize efficiency and communication between families and medical providers (Keller, 2016). This care is now commonly provided through comprehensive medical programs based in tertiary hospital systems that promote care coordination across medical specialists, rather than community primary care clinics which may be less capable of meeting the multifaceted needs of CMC and their families (Murphy & Clark, 2016).

The field of Pediatric Complex Care has recently emerged to address the needs of CMC (Cohen et al., 2018). Outpatient hospital-based Complex Care programs provide care coordination services via a multidisciplinary team including pediatric medical professionals, social work, and administrative support (Hogan et al., 2020). In addition to care coordination, these programs provide management of complex symptoms and promote goal-setting, such as

the use of advance directives (Cohen, Lacombe-Duncan, et al., 2012). It has been repeatedly documented that comprehensive outpatient care programs for CMC reduce hospitalizations, intensive care unit stays, and health care costs (Hogan et al., 2020; Mosquera et al., 2020; Peter et al., 2011). Program participation has also been associated with improved child social and emotional quality of life (Cohen, Lacombe-Duncan, et al., 2012).

The Importance of the Family Context

Within pediatric psychology, a family systems model is used to understand the relationship between the chronically ill child and their family, community, and sociocultural environment. Kazak's (1989) Social Ecological Model posits that chronically ill children exist within an interrelated family system in which the child's illness affects the system and vice versa. The Social Ecological Model is greatly influenced by Bronfenbrenner's original Social Ecology Model, which posits that the individual is at the center of multiple concentric circles representing systems which are increasingly distal to the child at each outer level. In Kazak's model, the most proximal level, the microsystem, comprises the situations in which the child is a primary operational member, as occurs in the child's home, school, and healthcare environment. The mesosystem includes interactions between the family and school or family and healthcare team; this level includes educational and healthcare decision-making. Parent employment and social networks occur at the level of the exosystem. Finally, the macrosystem is the outermost level includes cultural influences, such as beliefs and values (Bronfenbrenner, 1977; Kazak, 1989; Mullins et al., 2015).

Inherent in this model is the idea that the well-being of the family and its individual members directly relate to the well-being of the ill child and vice versa. Early research informing this model supported the necessity of a family systems focus to understand adjustment to

pediatric illness, particularly related to family cohesion and adaptability, both of which impact family functioning and, thus, child well-being (Kazak, 1989). As such, inquiry within pediatric psychology is best framed in terms of family systems to appropriately contextualize the experience of the ill child (Kazak, 1997). Most families care for CMC in the home environment, with care primarily provided by parents or guardians. Thus, in service of better understanding CMC well-being, an investigation of parent well-being is warranted. To distinguish parental caregivers from medical caregivers, the term “parents” will be used henceforth to refer to any adult serving in a familial caregiving role (e.g., biological and adoptive parents, legal guardians).

Parenting Children with Medical Complexity

Parents play an integral role in the daily care of CMC, often providing medical care to their children in addition to typical parental responsibilities. Parenting CMC can be extremely stressful due to the uncertainty and vigilance involved in caring for a critically ill child (Cousino & Hazen, 2013; McCann et al., 2012; Nygård & Clancy, 2018). As such, the experience of parenting CMC has been termed “intense parenting” given its physically and emotionally intensive nature (Woodgate et al., 2015). As compared to parents of CMC receiving services in a long-term care or medical day care facility, parents who care for CMC at home experience significantly more problems with personal physical health, poorer social functioning, and having less time and energy (Caicedo, 2015), suggesting that home care of CMC is particularly taxing.

Practical challenges for parents of CMC include managing significant burdens on time and finances. The vigilance necessary to maintain children’s wellbeing, in addition to other health care provision tasks completed by parents, place significant time demands unique to parents of CMC (Kuo, Bird, et al., 2011; McCann et al., 2012; Romley et al., 2017). Related to the extensive periods of time spent at home providing care, these families commonly face

financial hardships such as high out-of-pocket medical costs and negative career outcomes (Ghandour et al., 2017; Goudie et al., 2005; Kuo, Cohen, et al., 2011; Romley et al., 2017; Thyen et al., 1999). Of note, the Tax Equity and Financial Responsibility Act (TEFRA) Medicaid Eligibility Option enables expanded Medicaid insurance access for CMC, allowing for increased access to medical care regardless of parental income. While this provides some relief of financial burden, there are significant differences in TEFRA option enrollment by state, with some states enrolling very few children (Semansky & Koyanagi, 2004). This suggests a lack of broad application of the TEFRA waiver, and there is likely still significant unmet insurance need among families of CMC. TEFRA option eligibility is also restricted to those with United States citizenship or eligible immigration status (Wisconsin Department of Health Services, 2019), so children and families with other immigration statuses may experience increased unmet insurance needs as a result. Finally, employment loss is common among families who care for CMC, with over 54% of families requiring one caregiver to stop working to care for their child (Kuo, Cohen, et al., 2011), with even greater employment loss and greater likelihood of poor healthcare insurance coverage among families who do not speak English as a first language (Yu & Singh, 2009). Taken together, these findings suggest significant practical challenges for families of CMC which are likely increased for families holding identities associated with less societal privilege.

Considering these practical challenges, it follows that parenting CMC is also associated with poor physical and mental well-being. Regarding physical health concerns, caring for children with health problems is associated with higher odds of parent chronic conditions and poorer general health (Brehaut et al., 2009). Further, compared to parents of healthy children, parents of CMC experience shorter sleep duration and poorer sleep quality, which could have

serious health implications (Keilty et al., 2018). Further evidence suggests that ventilator dependency, which is common among CMC, is also associated with increased caregiver nighttime awakenings, which were due to both caregiving responsibilities and caregiver stress (Meltzer & Mindell, 2006). Sleep deprivation and associated fatigue have been identified as main factors contributing to parental stress in this population (McCann et al., 2015). Moreover, due to the deleterious effects of caregiving stress on caregiver immune function, parents of CMC may be at particular risk for illness and infection (Gallagher et al., 2009; Kuster & Merkle, 2004).

Regarding mental health challenges, parents of chronically ill children often experience high stress and poor psychological adjustment compared to parents of healthy children (Cousino & Hazen, 2013; Goudie et al., 2005). One study found that parents of CMC have one of the highest mean scores on the Psychosocial Assessment Tool, a measure of psychosocial risk, compared to other previously assessed pediatric parent populations (Verma et al., 2020). Nearly half of parents of technology-dependent or -assisted children are at high risk of clinical depression (Chan et al., 2019; Thyen et al., 1998). Some research has begun to investigate the types of psychological distress unique to parents of CMC. Anticipatory anxiety about the long-term wellbeing of their children should they outlive their parents seems to be a common factor contributing to stress among parents of children with disabilities (Murphy et al., 2007). Parents of children who use ventilators at home have expressed a tension between accepting their family's situation and rejecting the "unfairness" of their child's condition. Despite not having chosen a life of medical complexity for their children, parents must learn to move forward with their circumstances, which brings about a sense of questioning the "moral order" of the world (Carnevale et al., 2006). Finally, social hardship is common among families of CMC, with

nearly half of families unable to expect help from family or friends if it was needed (Thomson et al., 2016). A qualitative inquiry revealed that many families experience “profound loneliness” related to lack of social support (Carnevale et al., 2006). Social restriction due to caregiving needs may lead to social isolation, which serves to promote symptoms of depression (Chan et al., 2019).

Furthermore, while child health outcomes related to parent distress have not been studied in the CMC population, a relationship between parent distress and child well-being has been documented among other pediatric populations, suggesting that parent psychosocial well-being may influence child outcomes (Bakula et al., 2019, 2020; Brown et al., 2019; Chow et al., 2016). For example, among families of children with chronic arthritis, parent stress was a significant predictor of both child anxiety and child pain (Anthony et al., 2011). Parent depression and anxiety is significantly related to child disability in the pediatric chronic pain population (Donnelly et al., 2020). Pediatric solid organ transplant patients experience differences in discharge readiness, number of hospitalizations, and medication adherence related to parent and family functioning (Cousino et al., 2017). Among children with chronic illnesses more broadly, parent stress relates to both child psychological functioning and health outcomes, although more longitudinal studies are needed to further understand these relationships in various pediatric illness populations (Cousino & Hazen, 2013). These findings are broadly consistent with the Social Ecological Model, which posits that child health and well-being is strongly interconnected to the well-being of others in their system, especially parental caregivers.

In sum, it is well-documented that parenting CMC is intensely stressful given inherent practical, health-related, and psychosocial challenges. Further, considering the influence of parent wellbeing on child wellbeing as suggested by the Social Ecological Model, reducing stress

among parents who care for CMC would likely positively impact child wellbeing. In service of ultimately promoting stress reduction in this population, an investigation of how parents manage their stress is warranted.

Transactional Model of Coping

To manage the challenges in their lives, parents must engage in processes of coping. The Transactional Model of Coping (TMC), which conceptualizes coping as a process occurring at the intersection of the individual and their environment, defines coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984). Cognitive appraisal is the process by which an individual evaluates a stressful situation to determine its significance (primary appraisal) and one’s own ability to manage the situation (secondary appraisal, Lazarus & Folkman, 1984, pp. 31–38). The model emphasizes the effortful and process-oriented nature of coping, which indicates that coping is neither a trait nor an outcome, but rather a range of dynamic responses to circumstances understood by an individual to be stressful. This model has been widely cited in psychological literature and has been the theoretical basis of much of the literature in child and adolescent coping (Compas et al., 2001).

The TMC classifies coping strategies in two ways: emotion-focused and problem-focused. Emotion-focused coping describes any attempt to manage one’s distress related to an event, including the use of cognitive techniques (e.g., avoidance, minimization, reappraisal), whereas problem-focused coping describes attempts to manage the source of distress (e.g., defining the problem, brainstorming alternative solutions; Lazarus & Folkman, 1984, pp. 149–152). Given that coping is highly context-specific, many coping strategies cannot be definitively categorized as either problem-focused or emotion-focused without specificity regarding their

use. For example, seeking social support could either be a way of acquiring instrumental assistance to manage a challenge (i.e., problem-focused) or a means of receiving emotional comfort (i.e., emotion-focused). Thus, the delineation between emotion- and problem- focused coping describes the function of a given coping strategy rather than the strategy itself.

Related to necessary distinctions regarding the function of coping strategies, the “goodness-of-fit” hypothesis posits that the effectiveness of a given coping strategy is context-dependent such that stressful events which are more “controllable” are best handled using problem-focused strategies, while stressful events that are out of one’s control are best handled using emotion-focused strategies. This hypothesis has been partially supported, such that problem-focused coping predicts positive affect in high-control stressful events (Park et al., 2004). Given that both problem-focused and emotion-focused coping can lead to either reduction or exacerbation of distress, neither is inherently more or less effective outside of coping context (Skinner et al., 2003).

In its original version, the TMC failed to explicitly account for positive reappraisal of the meaning of stressful events after an unsuccessful attempt to use emotion- or problem-focused coping. Park & Folkman (1997) hypothesized that profound stress occurs as a reaction to a proximal stressor in one’s life (e.g., sudden life-threatening illness) which violates their deeply held values, beliefs, and expectations about the world (e.g., “I am healthy and I will live a long life”). Such values, beliefs, and expectations represent an individual’s sense of *global meaning*. To fulfill the foundational need for congruence between one’s worldviews (i.e., global meaning) and one’s experiences (i.e., situational meaning), cognitive adaptation must occur by which an individual reappraises stressors to either incorporate the stressor as part of their sense of global meaning (e.g., making sense of why a stressor occurred) or to adjust their sense of global

meaning entirely (e.g., adopt a new religious belief). In so doing, the individual accesses positive emotions which serve to sustain the coping process (Folkman, 1997, 2008).

In recognition of this process as a distinct component of coping, the TMC was revised to explicitly include meaning making (Park & Folkman, 1997). Specific types of meaning making were later introduced (Folkman & Moskowitz, 2007) and supported by existing literature (Folkman, 2008). Types of meaning making include benefit-finding and benefit-reminding (i.e. reflecting on or remembering benefits that exist due to the stressor), adaptive goal processes (i.e. substituting untenable goals with realistic valued goals), reordering priorities (i.e. reappraising what is important and acceptance of change), and infusing ordinary events with positive meaning (Folkman & Moskowitz, 2007).

Coping Strategies among Parents of Pediatric Patients

To date, no research has specifically sought to phenomenologically explore the coping strategies employed by parents of CMC. However, extant research has documented coping strategies among parents of other pediatric patients, such as those hospitalized in the Pediatric Intensive Care Unit (PICU), which has some overlap with the CMC population. Demographically diverse parents of children hospitalized in the PICU use both emotion- and problem-focused coping in response to their child's medical challenges (LaMontagne & Pawlak, 1990). Parents who are more involved in caring for their child during the hospital stay tend to use more problem-focused coping, while those less involved use more emotion-focused coping (LaMontagne et al., 1992). While directionality of these variables is unclear, this finding could support the goodness-of-fit hypotheses (Park et al., 2004); perhaps parents who are at the bedside feel better able to control stressors and thus find active ways to resolve them. Similarly, in a narrative review of blogs written by parents of PICU patients, Jones & Lynn (2018) concluded that emotion-focused

strategies were most frequently used in response to stressors when parents could not influence outcomes. However, as the child's stay progressed, parents used more problem-focused strategies, such as engaging in direct care of their child and working to normalize the hospital environment. This shift over time may reflect increased ability to engage in active problem-solving due to increased familiarity with the hospital environment and child's medical condition (Jones & Lynn, 2018).

Further studies of parents of pediatric patients outside the PICU have similarly found evidence for both emotion- and problem- focused coping, with some variation in the frequency with which parents use each type of coping. For example, one study of parents of children in a neurorehabilitation unit found that while parents of children with neurodevelopmental conditions (e.g., intellectual disability, autism spectrum disorder) tended to use emotion-focused coping, those of children with neurological conditions (e.g., epilepsy, cerebral palsy) used more problem-focused coping (Craig et al., 2019), which may be driven by the amount of active problem-solving that can be used in each type of condition. Among parents of children with rare inherited metabolic conditions, use of both emotion- focused and problem- focused were reported and highly correlated, with problem-focused coping used significantly more frequently than emotion-focused or dysfunctional coping (Schadewald et al., 2018).

While extant literature lacks sufficient phenomenological coverage of coping strategies specifically among the CMC parent population, a meta-synthesis of qualitative research among parents of CYSHCN suggests the presence of both emotion- and problem-focused coping. In many studies included in one meta-synthesis, parents reported emotion-focused strategies such as avoiding people in their life who reminded them of the stressors, reminding themselves of stories of other families who had been through similar struggles as a source of optimism and hope, and

trying to pretend that everything was okay (Nygård & Clancy, 2018). Examples of problem-focused coping included carefully managing one's own schedule to balance caregiving demands and practicing personal flexibility and patience in attempts to manage the stress related to the constant nature of their child's needs (Nygård & Clancy, 2018). Additionally, parents have described the necessity of social support, both to manage practical needs and for emotional support (Bally et al., 2018; Nygård & Clancy, 2018), which could represent either problem-focused or emotion-focused coping, depending on the purpose.

Since the revision of the TMC, pediatric psychology research has also begun to characterize meaning making as a coping process among parents of ill children. One study of parents of children with advanced cancer conceptualized meaning making in this population as including: 1) making sense of the child's illness (e.g., by spiritual or scientific explanations), 2) finding benefits in the child's illness (e.g., personal growth), and 3) determining a purpose or legacy related to their child's life (Schaefer et al., 2020). Benefit finding, one of several types of meaning making identified in the revised model and supported empirically (Folkman & Moskowitz, 2007), has further been documented among parents of youth with several congenital, acquired, and developmental conditions. Benefits described by these parents include increased gratitude for life, enhanced spirituality, and positive personality changes in themselves (Kritikos et al., 2021).

Similarly, while there is a dearth of research investigating meaning making in the CMC parent population, emerging qualitative findings in overlapping populations indicate processes that align with meaning making. For example, maintaining hope and staying positive is a central component of parenting in extant qualitative literature among parents of CYSHCN. A meta-synthesis of qualitative research on CYSHCN parenting experiences found that "making the

most” of their child’s life, which involved maintaining hope and an optimistic outlook, was one of eight key concepts explored in interviews with parents. In fact, hope was found to be a “life-promoting phenomenon” juxtaposed with the shame, guilt, and worry that parents simultaneously experienced (Nygård & Clancy, 2018). An additional meta-synthesis further supports this finding; for parents of children with serious illnesses, the “emergence of hope” was a primary factor enabling parents to cope with the uncertainty of death and move forward (Bally et al., 2018). Additionally, personal transformation, growth, and adaptation to children’s needs emerged as key components of meaning and purpose reported by parents of children with severe neurological impairment, a population which overlaps greatly with CMC. In this study, parents described the necessity of flexibility to “transform with our changing reality” while continuing to provide support for their child and finding opportunities for strength and growth (Bogetz et al., 2021). These findings speak to the need to change one’s own worldview to accommodate the stressors related to parenting CMC.

Overall, extant literature suggests the presence of emotion- and problem-focused coping and meaning making in pediatric parent populations, and some findings specific to the CYSHCN parent population have suggested the use of all three coping strategies. However, findings among parents of CYSHCN resulted from research aimed at investigating broader parenting perspectives, but not specifically stress and coping. There has been a dearth of studies specifically targeted at identifying such coping strategies among the CMC parent population. A study specifically focused on the identification of coping strategies in the unique context of stressors specific to CMC parenting is thus needed.

Relevance of the Social Ecological Model to Parent Coping

While the TMC describes coping at the individual cognitive and emotional level, children with medical illnesses and their parents are part of a larger interplay of systems. As such, coping must be understood both at the individual level and at the level of a child's family, community, and culture. Widely employed in pediatric psychology, the Social Ecological Model allows for the identification of both risk and protective factors affecting the family system, enabling it to capture the complexity of coping as part of the pediatric parenting experience (Kazak, 1997; Kazak & Nachman, 1991). To date, the Social Ecological Model has not been specifically applied to understand coping among families of CMC. However, its use for the identification of risk and resilience factors among other pediatric populations, including cancer, spina bifida, and Type 1 diabetes (Mullins et al., 2015), suggests its aptitude for application in the CMC population as well.

Given the high healthcare service use and need of CMC (Cohen et al., 2011), parents of these children have frequent contact with the healthcare system and may also rely heavily on others in their social networks for practical or emotional support. Thus, coping is likely to occur at multiple social ecological levels, suggesting the relevance of the Social Ecological Model in contextualizing parent coping strategies.

The Current Study

It has been established that parenting CMC is associated with substantial challenges, including poor practical, physical health-related, and psychological outcomes. However, less is known about parental attempts to manage their stressors. Developing a more comprehensive understanding of coping among parents of CMC may allow for the promotion of caregiver well-being, ultimately enabling the enhancement of the well-being of CMC as well.

First, this study aimed to describe primary (i.e., emotion- and problem- focused) coping strategies among a sample of parents of CMC. It was hypothesized that parents would endorse both types of coping but that specific strategies will be highly variable across participants. Variability in coping strategies was expected primarily given differences in “controllability” of stressors, considering both the heterogeneity of the CMC population (and thus associated differences in “controllability” of medical stressors) and individual differences in context, culture, and resources to manage stressors. It was expected that parents would describe coping strategies that extended across the social ecological system.

Second, the study aimed to describe meaning making among a sample of parents of CMC. Because of the intensity and chronicity of the medical trajectory of CMC, it was expected that parents of these children experience failed resolution of their stressors when only using problem- and emotion- focused coping. Given research findings emphasizing the centrality of meaning making for parents of other pediatric patient populations, it was expected that parents of CMC will also describe meaning making to help them cope with stressors.

Method

Participants

Caregivers ($N = 20$) of children served by the Complex Care Program at Children’s Wisconsin (CW) completed the present study. The Complex Care Program is an optional care coordination service available to CMC affected by 1) involvement of three or more organ systems in their condition OR care provided by three or more medical specialists; 2) one or more unplanned hospital stays per year lasting at least five days or ten specialty clinic visits; and 3) unmet care coordination needs. As of Fall 2020, the Program served roughly 700 families, with approximately half of outpatient clinic visits conducted via telehealth. At the time of the study,

eligible participants must have been a primary caregiver to the child, able to speak and read English, and had access to a telephone, webcam, and internet. To ensure that participants had sufficient experience providing care to CMC, participants' children had to have been enrolled in the Complex Care Program for at least one year.

Participants were primarily female, white, and non-Hispanic. Table 1 includes full demographic data for participants and Table 2 includes characteristics of CMC cared for by participants. While there was an overrepresentation of female parents in the present study, demographic characteristics aligned with that of the Complex Care patient population in that most participants were white and non-Hispanic or Latinx. As of August 2020, the Complex Care Program patient population was primary male (56.3%), white (66.7%), non-Hispanic or Latinx (83.3%), and had English-speaking caregivers (88.2%; S. Johaningsmier, personal communication, December 8, 2020).

The sample size was chosen in accordance with common practices in Interpretive Phenomenological Analysis (IPA), the qualitative methodological approach of the proposed project. IPA advocates smaller sample sizes in favor of greater contextual detail in interviews (Smith et al., 2009). The proposed sample size was determined due to practical considerations (e.g., recruitment timeline, interviewer and coder availability) and following a review of other IPA studies of parent experiences in pediatric psychology (Cheung & Lee, 2012; Lee & Lau, 2013; Tutelman et al., 2019).

Procedure

The present study was part of a larger pilot project investigating traumatic stress and coping among parents of CMC. The study was approved by the UWM Institutional Review Board and data was collected in April and May 2021.

A purposive sampling technique was used to maximize diversity in the present sample, with particular attention to participant and child gender and participant race and ethnicity, given that emerging evidence suggests racial, ethnic, and gender differences in coping practices of parents of children in the PICU (Hawthorne et al., 2017). As such, efforts were made to recruit both male and female parents and parents holding varied racial and ethnic identities. Even with efforts to maximize representation of racially diverse families, children of participants were expected to be primarily male, white, and non-Hispanic or Latino given the demographic characteristics of the Complex Care Program patient population.

At the beginning of each clinic day, the Clinical Research Coordinator reviewed the patient list and determined eligibility. A total of 35 eligible participants were informed about the study during routine visits via telehealth or in-person at the Complex Care Clinic at CW by a member of their primary medical team between March and May 2021. If the potential participant was interested in the study, the medical team member alerted the study team, who contacted the eligible participant by phone to provide a more detailed description of the study and obtain informed consent. If eligible participants did not answer the phone call, a voicemail was left with instructions to contact the study team member via a direct phone line. Of the 35 eligible participants, 13 did not answer or return phone calls and 2 were no longer interested in participating after speaking with a study team member. The 20 participants who were successfully contacted by phone and expressed interest in the study received a secure email form sent via Medical College of Wisconsin's Research Electronic Data Capture (REDCap) which included a PDF consent form for their records. Once informed consent was obtained verbally, a member of the study team scheduled an appointment with the participant for a video call at a time when the participant had access to a private location.

Following initial invitation to participate in the study by medical providers, all study activities were conducted virtually to enable access to the study for all eligible participants, including those who resided a far distance from the hospital or who lacked reliable transportation. This virtual procedure was selected given the substantial practical challenges already experienced by parents of CMC, in addition to an ongoing pandemic that restricted social contact. Emerging research suggests few differences in quality of qualitative interviews conducted via video calling as compared to in-person (Krouwel et al., 2019). Video calling is thus a viable alternative for interviewing geographically diverse populations, despite some potential for limited rapport (Iacono et al., 2016). Participants were contacted for the interview via Doxy.me, a secure telehealth platform which allows the participant to answer a phone or video call without the need to set up an account or install software. Alternatively, upon participant request, interviews were conducted via phone call. While conducting interviews by phone may decrease potential for rapport building, phone interviews been used successfully in studies consistent with this study's methodological framework, Interpretive Phenomenological Analysis (Sweet, 2002).

Ultimately, 11 parents completed the interview via video call and 9 participants completed the interview via phone. At the start of the call, the interviewer verbally reviewed consent information and confirmed the participant's availability for the full session before beginning the formal interview. Interview length was 54 minutes on average and ranged from 30 to 93 minutes. The interview guide is available in Table 3.

Three clinical psychology graduate students, all of whom have prior experience in qualitative interviewing, completed the interviews. The students were provided with opportunities to review and practice the interview guide prior to their first interview with a

participant. All interviewers were supervised by W. Hobart Davies, PhD, a clinical psychologist with expertise in qualitative research methodologies. Students had weekly individual meetings with Dr. Davies in which they had an opportunity to discuss interviews and elicit feedback, in addition to regular study team meetings which included discussion of data collection and opportunities for debriefing.

Following the completion of interviews, participants received \$50 compensation via e-gift card. Interview transcriptions were completed virtually by TranscribeMe, a secure, HIPAA-compliant platform which has been used extensively by other CW research teams. Following the return of completed transcripts, graduate student research team members reviewed transcripts for accuracy and removed identifying information before they were made available to clinical members of the study team.

Measures

Demographics Questionnaire. Prior to beginning the qualitative interview, participants were asked to respond verbally to a series of demographic questions, including their age, race, ethnicity, marital status, education level, zip code, duration of experience caring for their child, and relationship to child. Demographic questions about the child included age, gender, length of time in the Complex Care Program, and whether there were other caregivers involved in meeting the child's needs (e.g. family members, home nursing staff).

Qualitative Interview Guide. A semi-structured qualitative interview guide was used during the interviews. The guide was created in collaboration with researchers who have expertise in qualitative methodology, pediatric psychology, pediatric complex care, and pediatric critical care. The questions were developed based on past research with related pediatric parent populations and aligned with components of the Social Ecological Model, such that they asked

about influences at multiple levels of the system, including receiving support from community members. In addition, the original draft of the interview guide was also reviewed by a panel of parents whose children are served by the Complex Care Program and an independent qualitative research expert who was not a member of the research team. Feedback was then incorporated in the revised version of the interview guide (see Table 3).

Data Analysis

Demographic Data. Demographic data, including participant gender, participant race/ethnicity, child gender, and child race/ethnicity was analyzed descriptively to characterize the sample.

Qualitative Data. Transcripts of completed interviews were analyzed using an Interpretive Phenomenological Analysis (IPA) approach. This approach emphasizes the exploration of individuals' sense-making of their own life experiences and it was selected given its extensive use in healthcare research to characterize individuals' experiences of distress and illness and its consideration of idiographic differences between members of a group (Smith et al., 2009). These idiographic differences are particularly central in this population given the clinical heterogeneity of CMC (Berry et al., 2016). As such, the IPA approach allowed for sensitivity to the challenges and markers of resilience present in individual family systems. Furthermore, IPA has been used extensively in pediatric psychology, often employed to understand parent experiences of childhood illness. It has been used to study parent experiences of pediatric cancer (Schweitzer et al., 2012; Tutelman et al., 2019), heart defects (Lumsden et al., 2020), atopic eczema (Cheung & Lee, 2012), depression (Armitage et al., 2020), complex chronic pain (Jordan et al., 2007), and acute illnesses and injuries (Lee & Lau, 2013).

The qualitative data analysis process was supervised by a pediatric psychologist with experience using IPA methodology. Coding qualitative data occurred both at the level of individual interview transcripts and among the entire data corpus. Following transcript creation, de-identification, and accuracy review, coders read and re-read each transcript in its entirety. They then created initial codes to conceptualize descriptive (i.e. content), linguistic (i.e. word usage and communication style), and conceptual (i.e., interpretive) factors within transcripts. These codes were closely tied to specific transcript segments, and they were inserted into coding tables where coders copied the transcript segment in one column and the initial code in the next column.

Next, coders developed concise descriptions capturing the main ideas of these initial codes, called emergent themes, at the level of each transcript. These emergent themes were meant to succinctly represent the phenomenon described in the initial codes. At this stage of coding, a third column was added to the coding table for each transcript, and emergent themes were listed in this column. This allowed for clarity in the relationship between emergent themes and specific transcript segments. Further, as proposed by Goldspink & Engward (2019), an additional step at this level involved attending to the “reflexive echoes” (i.e., personal connections to the data). This allowed for sensitivity to the influence of coders’ assumptions and experiences on the coding process. It also enabled coders to track the influence of their personal experiences throughout the coding process for later review. For example, when considering proposed superordinate themes at the end of the coding process, coders could refer to these notes to remind them of their earlier reflections when creating related emergent themes. To complete this step, coders kept notes outlining their personal reflections (e.g., personal experiences, opinions, or memories that related to the content being coded) during their work with each

transcript. To protect confidentiality of coders' personal experiences, "reflexive echoes" were only accessible to individual coders, but coders had the option to share during group meetings.

Following the coding of all transcripts, coders individually and collectively reviewed the list of emergent themes to ensure accuracy and appropriate phrasing of themes. Edits were made to this list to ensure clarity of phrasing accordingly. To ensure that final emergent themes were applicable to a substantial number of transcripts, those present in greater than five (one-fourth) transcripts were retained in the final list, in accordance with prior IPA research approaches (e.g., Everhart et al., 2021). Given the prioritization of nuanced descriptions of phenomena in IPA, the frequency of emergent themes was not quantified beyond ensuring that emergent themes were represented at least once in at least one-fourth of transcripts. After this finalized list of emergent themes had been created, the original coder of each transcript reviewed each of their own transcripts to revise coding in accordance with the revised list.

The following step involved developing superordinate themes by seeking connections across emergent themes in all transcripts. Specific ways of conceptualizing these themes included subsumption (i.e. elevating an emergent theme to a superordinate theme because it encompasses multiple related ideas), abstraction (i.e. combining emergent themes into a single superordinate theme), polarization (i.e. seeking oppositional relationships between themes), and contextualization (i.e. considering the narrative and temporal order of data). Finally, connections were sought across superordinate themes to characterize the data corpus as a whole (Smith et al., 2009).

Several methods were used throughout the process to ensure data quality. First, all graduate student interviewers completed coding of their own interview transcripts, with each transcript reviewed and coded by at least two students, or one student and one faculty member, to

consistency of phrasing of emergent themes. The use of multiple coders during each step of data analysis ensured a thorough review of each transcript and all coding decisions. Additionally, to ensure shared understanding prior to beginning the coding process, the lead coder conducted a pilot interview, the transcript for which was used in a sample coding exercise. Coders reviewed the pilot transcript and practiced creating initial codes. These were reviewed and discussed in a team meeting. Next, coders practiced creating emergent themes on the basis of the initial codes created by the group, and these emergent themes were then discussed in the next team meeting. Finally, a team meeting was held during which coders shared ideas for possible superordinate themes that could come out of the pilot transcript, should the same emergent themes appear throughout the data corpus.

Other approaches considered for qualitative analysis included thematic analysis (TA) and grounded theory. While all three approaches involve a rigorous coding and theme development process, they can be distinguished due to substantial differences in their relationship to theory. TA is not associated with a particular theoretical framework; as such, it can be used flexibly in the context of an existing theory or in the absence of a theory (Braun & Clarke, 2006). In contrast, grounded theory aims to generate a theoretical framework for which to understand a phenomenon (Glaser & Strauss, 1967). IPA uses a phenomenological theoretical framework to understand both individual and collective sense-making of daily life as it relates to a particular phenomenon of interest, such as illness or culture (Smith et al., 2009). Because the current study aimed to characterize coping among a sample of parents of CMC, rather than to establish a theory about coping in this population more broadly, it was determined that grounded theory was not appropriate. Next, given that IPA also considers both idiographic factors (i.e., experiences of individual research participants) as well as patterns present across the data corpus, it was

determined that using IPA would enable a more comprehensive evaluation of the personal factors which might influence or characterize coping. Using a TA approach, conversely, could have prevented coders from appreciating idiographic differences in the data corpus which could ultimately prove meaningful for conceptualizing coping at the level of the individual transcripts. For this reason, it has been suggested that IPA is best used in projects aimed at understanding individuals' own experiences and perspectives, while TA is most appropriate for analyzing data which does not prioritize a thorough understanding of personal experiences (e.g., focus groups; Braun & Clarke, 2019). As such, in considering the aims of the current study, IPA was determined to be the most appropriate methodological approach.

Researcher Positionality and IPA

All graduate students involved in coding were enrolled in a clinical psychology doctoral program with a focus in pediatric psychology. As such, their knowledge, beliefs, and past clinical and research experiences in related projects influenced their approach to interviewing and coding. Specifically, students shared the assumption that parenting CMC is intensely stressful. They also shared the understanding that sociocultural factors including, but not limited to socioeconomic status, race, ethnicity, and caregiving support resources would influence stress and coping strategies among families given inherent systems of oppression in the healthcare environment and in broader United States culture. Furthermore, while the students had familiarity with family members who care for CMC through past research and clinical experiences, none had direct experience parenting a CMC.

Additionally, it is possible that personal experiences (e.g., history with illness or disability) may have evoked emotional reactions which influenced coders' engagement with, and interpretation of, the data. The interpretive nature of IPA accounts for subjectivity throughout the

analytic process, recognizing a “double hermeneutic” structure of the analytic process, meaning that the researcher is making sense of the participant’s own sense-making process. Smith and colleagues (2009) refer to this phenomenon as the IPA researcher’s “dual role,” acting as both a human being with common lived experiences to the participant, and as an outsider attempting to understand the participant’s lived experiences. It was encouraged that coding team members engage in a personal reflective practice, such as maintaining written documentation of the researcher’s own perspectives and emotional experiences throughout the analytic process, to maintain the rigor of the analysis by enabling other coders to trace the development of subsequent themes back to this earlier stage in the coding process (Goldspink & Engward, 2019).

Modified Member Checking Exercise

Given that none of the members of the coding team was a parent to a CMC, the coding team opted to conduct a modified member-checking exercise (Birt et al., 2016) after all coding was complete. The identified purpose of the exercise was to ensure that phrasing of themes was acceptable by members of the CMC parent and medical community, to aid in interpretation of the findings, and to gather feedback regarding future clinical, research, and advocacy priorities. While methodological restrictions prevented re-contacting the original study participants after data analysis, two groups took part in the exercise: 1) a group of clinical staff (physicians, nurses, social workers, support staff) at the CW Complex Care Program, and 2) the Complex Care Program’s Family Leadership Committee (FLC), which is comprised of parents whose children are served by the Program. Both meetings were run by the lead graduate student interviewer and coder (JBT) with co-facilitation from faculty researchers. During both meetings, after a brief overview of the study purpose and methods, a slideshow was presented which summarized the superordinate themes and emergent themes. Example quotations were presented

for each superordinate theme. This presentation was followed by open discussion with guiding questions to spark conversation (Table 4). Participants in both meetings had opportunities to share their opinions either verbally in the group setting, via virtual chat, or anonymously via a Qualtrics link.

Results

A thematic map (Figure 1) provides a visual overview of the results, demonstrated in line with the aims of the current project by primary and meaning making coping strategies. All parents described using more than one coping strategy, including a combination of strategies categorized as both primary and meaning making.

Primary Coping Strategies Among Parents of CMC

The first aim of the current study was to describe the primary coping strategies used by parents of CMC. Relevant superordinate themes, which included *social connections provide support* and *individual parent coping strategies*, described several strategies, many of which were emotion-focused in nature or which could be either emotion-focused or problem-focused depending on function.

Social connections provide support

Parents described the importance of maintaining social connections as sources of emotional and practical support given their challenges related to caring for their child. First, in describing the intensity of their child's daily needs, parents described how *other adult caregivers are helpful*. This additional caregiving was most often provided by family members and friends, but some participants mentioned the support of individuals in paid caregiving roles (e.g., personal care workers). Support included completing any task that relieved parents of daily caregiving demands, which enabled them to focus on other responsibilities or engage in self-

care. For example, participant 4 described how their child's personal care worker "helps with some of the load," including completing the child's morning and evening routines such as getting ready for bedtime. Participant 12 described that, "I recharge sometimes [...] maybe my husband takes over everything for a day or something and I can just sleep." Others described that it was helpful to share an equitable distribution of responsibilities with their spouse or partner. For example, Participant 7 described their spouse's involvement in the child's daily care, saying, "He's a complete partner here. He's not, like, hands-off. He's completely in it, knows all of his meds, knows all of his breathing treatments." In addition to partners and paid support staff, additional caregivers included older children and extended family members. For example, Participant 13 described their daughter's role as a caregiver, stating that she "will be caring for him during the summer for a little while."

The theme *parents benefit from emotional support* describes participants' needs for friends or family members upon whom they could rely for validation and help with processing their challenging experiences. This often involved discussing stressful events related to their child's medical journey. Participant 14 described that when stressful medical events occurred, it is important to "process that stuff together" with family members. Participant 16 echoed this sentiment: "I know [...] you cannot just sit there by yourself. You have to be able to talk to somebody." Emotional support was also sometimes accompanied by the provision of practical support, such as providing food or transportation during medical crises. Participant 23 described their neighbors' support during hospitalizations: "We've had a rough week, they bring us food. Um, I need to sit down and cry, they've sat down and listened." Receiving support from loved ones provided necessary social connections to allow parents to cope with the challenges of caregiving CMC.

Connections with families who have had similar experiences were also described. Being in contact with other families who had children with disabilities or medical illnesses, or those served by the Complex Care Program, challenged the sense of isolation parents felt. These connections with others were described both as sources of emotional support and as resources for gathering information relevant to their caregiving responsibilities. For example, Participant 4 noted that it is helpful to know other parents who care for CMC to have “a good source for, like, just venting and you know, and bouncing questions off of, or, you know, they might know of a resource I don’t or vice versa kind of thing.” Combatting the sense of isolation inherent to parenting a child with a rare illness was a common focus of descriptions of these social connections. Participant 12 valued that, when talking with other families of CMC, “they will understand automatically, because they have gone through everything that you have.”

Many parents noted that *social media is helpful* as a tool for receiving psychosocial support and information about their child’s needs, including from other families of CMC. Social media was often a source for learning about other children with similar conditions, which provided a sense of control by enabling parents to gather information relevant to their own child. For example, Participant 7 stated that after seeing other children with their son’s condition on social media:

I don’t feel totally in the blind, and all of a sudden, the ortho doctor is saying, ‘Oh, did you know that he’s gonna have to have this or that?’ I kind of – I see these kids that are a little older than him going through it.

When there were medical decisions to be made, such as COVID-19 vaccination, it was helpful to hear other parents’ viewpoints on social media: “Some families [are] nervous about giving their

heart kid the vaccine; they haven't heard anything from their team yet about it. Um, they are nervous about getting the vaccine, and some of them are all for the vaccine" (Participant 12).

Due to the unique medical profiles of CMC, social media was a valuable source for connecting with non-local families whose children had the same or similar conditions. For example, Participant 27 stated, "even though his disorder is very, very rare, I found a support group on Facebook [...] it feels very nice for a parent who is navigating this kind of scary situation."

Individual parent coping strategies

In describing their experiences, parents reported on a range of cognitive or behavioral coping strategies they employed in response to their daily and long-term stressors. These included *solitary activities as self-care*, engaging with *religion/spirituality*, *avoidance of negative thinking*, *comparison/perspective-taking*, *staying positive*, and remembering that *copng is day-by-day*.

Solitary activities as self-care included any solo activity parents chose to do in service of maintaining their physical and mental health. Participants named a diversity of activities, including getting their hair or nails done, going for a walk, drinking wine, scrolling on their phone, and taking a bath or shower. To some parents, the activity itself mattered less than its purpose, which was to allow the parent a cognitive, emotional, and/or physical rest from the demands of caregiving. Participant 19 described that the purpose of any solitary activity is "trying to decompress and quiet my brain." Many parents described such activities as necessities to manage the stress of daily lives, rather than luxuries. For example, Participant 10, who takes nightly baths to maintain their well-being, stated, "As long as I have that, then I'm good." As forms of self-care, these activities were often mentioned in addition to engaging with social connections as described previously.

A minority of participants described that religion or spirituality played a role in their coping, described as *engaging with religion/spirituality*. Responses typically described either engagement with prayer or thinking about religious beliefs as a source of strength. While some participants engaged in prayer themselves, others asked their community members to pray for their child during specific times of need. For example, Participant 30 described, “For the surgeries, I usually do reach out to my parents and a couple other people and ask them to pray.” Others referred to the presence of a higher power when discussing challenges in their child’s life, indicating a reliance on their faith as a source of strength. Participant 35, for example, understood their child’s unique birth date on a particular holiday as “a message from God to never underestimate her.” Similarly, Participant 12 explained that it was God who “gives us the strength we have to get through all the tough times.”

As an effort to gain control over difficult thoughts and emotions, participants frequently described the *avoidance of negative thinking*. Negative thoughts to be avoided were almost always either memories of past medical difficulties or worries about possible undesired medical outcomes. For Participant 12, remembering a difficult surgery in the past triggered fears that a poor outcome would occur in the future, so “I try not to think about that unless I have to.” In interviews, discussion of avoidance often came up when parents spoke about fears that their child would die. Participant 17, who spoke about their fear of their child dying during a hospitalization, explained, “I didn’t ever want to think bad. Like, I thought that if I didn't tell anybody anything bad, nothing bad would happen, I guess.” Another parent, Participant 30, described chronic use of this avoidance strategy:

I sometimes don't even want to think about [my stress] because, like, um, it's just the way it is and there's not an-- there's really not an end in sight. [...] So like, the things I just-- I just blackout and just keep, keep going.

As an additional cognitive strategy for coping, parents often described their attempts at *staying positive* to maintain optimism in the face of challenges. *Staying positive* often involved the use of self-reassurance, such as telling oneself that "it will work out" (Participant 4) or "it's gonna be okay" (Participant 29). Others sought evidence to support hope even in challenging medical situations by "always try[ing] to see that silver lining" (Participant 19). Participant 35 noted that maintaining positivity is part of the overall CMC parenting experience:

I think sometimes as a special needs parent, you can get caught in the-- like, I always explained it as when we first got [Child], I thought like, "Well, that's it. I don't know if I'm gonna be happy anymore. Like, my life is so different." But there's, there's such a flip side to that that I think it's important to understand. Like, that chronic stress is always there, but there's also, like, a beautiful side to it that's really-- I don't know. It just, uh, just trying to see the positive side.

Comparison/perspective-taking was a cognitive strategy that allowed parents to expand their lens and see the bigger picture. This sometimes involved comparing the child's needs to those of other children with medical conditions and realizing their child's progress or the optimistic possibilities. Participant 17 remarked that they sometimes think about the uncertainty regarding their child's prognosis, but they choose to shift their focus:

There's people out there that have perfectly healthy kids, and they get-- they get hit by a car. Or they can get cancer, or there's just-- not everybody's guaranteed a full life. So I try

not to think about it like that. With [Child], I think I will try to think that may-- he might live longer than somebody with-- that is healthy.

Further, *comparison/perspective taking* often seemed to serve as a mechanism for allowing parents to experience a sense of gratitude, which helped them cope. For example, Participant 18 remarked:

I've definitely Googled other babies like [Child], and [...] on the bad day it makes me feel better [...] A lot of people have it worse than [Child] [...] So, like, a lot of times when I do Google and see other families, I just feel blessed for the baby that I got.

Reminding themselves of how others had it worse, and how their child and family could have had it worse, served to redirect parents' attention toward positive emotions such as gratitude and contentment.

Finally, the theme *coping is day by day* reflects parents' perceptions that coping is an ongoing process rather than a single occurrence. This reflected the continuous and chronic nature of medical challenges and the resulting stress on families' daily lives. This theme identified the necessity of reconceptualizing the caregiving experiences as a series of small, daily steps rather than one enormous, lifelong challenge. This idea was frequently summarized in statements such as "we just take it one day at a time" (Participant 31) and "you gotta take it day by day" (Participant 35). Participant 13 expanded that in relation to coping with medical challenges, "You just have to break it down into little parts. And then conquer the little parts, and then you'll get to the bigger parts."

Meaning Making

The second aim of the study was to examine how parents of CMC use meaning making to cope. Participants' relevant responses were categorized into four superordinate themes:

celebration of child, maintaining a commitment to caregiving, striving to be a good parent, and recognizing gains from caregiving experiences. These themes reflected the ways in which parents reappraised the situational meaning of their child's needs or the global meaning of their lives to accommodate the demands of caregiving and the challenges associated with parenting CMC. As a result of engaging in such reappraisal processes, parents were able to access positive emotion and sustain their coping efforts.

Celebration of Child

First, the theme *celebration of child* describes the ways in which parents described their children positively and expressed their own positive emotions as part of parenting their child. Relevant themes include *emphasis on child's positive qualities and abilities; in many ways, child is typical; recognition of overall progress despite challenges; pride in child's medical progress; child's life has purpose; and gratitude for child's life.* Responses coded within these themes were indicative of an overall tendency toward celebrating their child's identity, and they describe meaning making strategies used to influence either the situational or global meaning of their child's medical condition.

In describing their child as a person, parents tended toward an *emphasis on child's positive qualities and abilities.* Descriptions of positive qualities were often related to the child's personality characteristics, such as referring to the child as "a fighter," (participant 4), "a very happy and smiling person" (participant 8), or "just a sweet little boy" (participant 23). Such descriptions were not provided in the absence of a discussion of their child's medical needs; rather, both disabilities and abilities were described in an integrated fashion, generally with more time spent focusing on abilities or describing what their child enjoys. Participant 35's description of their child illustrates this phenomenon:

Um, she, uh, loves music. Uh, she loves to be outside, going for walks, being outside swinging. Breeze on her face is her-- probably one of her favorite things. Um, she's not mobile. So any movement she does, we have to help her with. Um, what else? She's got beautiful hair. Um, it used to be really thick and, and wavy. Um, but her hospital stay last year, put a lot of strain on her. And so her hair is a little less thick and wavy, but still beautiful.

Even when parents focused on their child's medical challenges in response to being asked to describe their child's identity, they still tended to balance their responses in favor of talking about their child's positive qualities. For example, Participant 7 remarked:

“He's a very happy child for profound special needs, [...] we're pretty lucky that he's not cranky a lot. And doctors kinda use those words, like, "Wow, he sure is-- he sure is a calm dude for, you know, having [medical condition]."

Relatedly, parents described how *in many ways, child is typical*. Parents commonly remarked that other than their medical complexity, their child was just like any other child given their abilities, personality, or interests. As part of integrating normalcy into their lives, parents also talked about incorporating events into their daily lives which did not revolve around their child's needs. Such strategies ranged from the way parents spoke to their children daily (e.g., Participant 4 refused to use “baby talk” with their child) to scheduling activities that involved the entire family (e.g., Participant 14 ensured that their child could attend their family sporting events). Parents described this strategy of recognizing typicality in their children and striving for normalcy in daily life as part of experiences which were punctuated by unpredictable disruptions from medical challenges.

Parents maintained a *recognition of overall progress despite challenges*, often simultaneously describing the difficulty of their child's medical journey while also realizing the triumphs along the way. Participant 18 summarized, "some of it has been just a flat-out pain in the ass, some of it has been, um, beautiful even though it was hard because she's overcome mostly everything put in front of her." Many parents did not think about medical challenges in isolation from the moments of success and celebration in their child's life. Some participants even viewed the consistent challenges as being causally related to positive outcomes. For example, Participant 27, who described their child's medical journey as being extremely intense, requiring hospitalizations from the age of six months old, went on to describe their child's "amazing progress," both medically and developmentally. They stated, "I think in terms of his medical journey, I mean, without that journey, we would never have gotten to see all of those things." Similarly, when asked to describe a typical medical difficulty with their child, Participant 19 expressed:

"I don't ever wanna say that we have medically a bad day, because there's never a bad day with [Child]; it's just something that he has to get through to get to where he needs to be. So I try not to think of it as, like, something bad."

This recognition of progress was often related to experiencing *pride in child's medical progress*. Some parents could pinpoint specific medical achievements, such as weaning off a ventilator or no longer needing a certain medication. Others felt an overarching sense of pride in the child's general medical and developmental trajectory: "I am most proud of all of his medical journeys. He has surpassed anything and everything that he has had to face, so I would say [...] all of it" (Participant 19). Moreover, many parents elaborated on the juxtaposition between

medical expectations of their child in utero or at birth and the accomplishments their child had made in the present. Participant 25 shared:

When they-- you know, they, they told us we should terminate my pregnancy, um, multiple times. And, you know, didn't think he would survive the first, you know, couple of months. And then he did that. And then, you know, just, you know, constantly kind of like pushing the bar [...]

In summarizing the emotional experience of watching their child surpass expectations, Participant 27 explained that “there's no other feeling like that sense of pride in your child.”

As part of describing their child’s medical journey, many parents expressed a belief that their *child’s life has a purpose*. Parents frequently related this to belief in a higher power or a sense that the child’s medical journey was part of a predetermined plan. Participant 19 related that regarding her child’s medical challenges, “I feel like the things that [Child] has to go through and the things that he has been dealt in his life is something that he was meant to go through [...].” Similarly, Participant 12 summarized this idea: “[Child] probably has a purpose. Everything happens for a reason.”

Finally, parents commonly expressed *gratitude for child’s life*. Parents often described this way of thinking as a tool for helping them through the medical challenges and considering the bigger picture. This included feeling grateful for the “privilege” of caring for their child (Parent 29) despite the intensity of caregiving demands. It also involved purposefully noticing positive outcomes. Participant 7 practiced gratitude by recognizing the privilege of knowing their child:

Like, never in a million years is it good luck to have a child with profound special needs. But what would be the alternative? [...] We got to know him. We got to know him. The alternative would be not knowing him, right?

In refocusing on their appreciation for the opportunity to know and parent their children, participants were able to revise their cognitive appraisal of their stressors and access positive emotion to sustain their coping efforts.

Commitment to Caregiving

When discussing their identities and experiences as parents, participants spoke at length about their commitment to their child, which was further evidence of cognitive reappraisal of stressors. Many themes described changes in global meaning of parents' views of themselves as caregivers. Others described the reappraisal of situational meaning via revising one's perspective of more proximal stressors. Relevant emergent themes included *parent role central to identity*, *acceptance of child's medical challenges*, *moving forward is the only option*, *never giving up on child*, *family as experts on child's condition*, and *maintaining hope for child's well-being*.

Parent role central to identity described the salience of the parental role, and often specifically the CMC parental role, in participant's lives. Stating that they were parents, and then describing their child, were typically the first remarks made in the interviews. A few parents expanded on the centrality of their parental identity. Participant 19 expressed, "Everything I do is to make sure he's okay," while Participant 30 summarized that "it's pretty much my whole life is caring for her."

When considering the many stressors in their daily lives, parents frequently expressed *acceptance of their child's medical challenges*. Some parents described acceptance as a process that had to be "learned" over time (Participant 8, Participant 18, Participant 25). In contrast,

others found it easy to be accepting of their child, such as Participant 27, who stated, “[...] Emotionally, I don’t think I ever struggled with, with him being who he is. I don’t think that I ever struggled with having a child with a disability.” In interviews, parents often discussed their mindset of acceptance when describing specific caregiving challenges, such as learning to accept that “there’s nothing we can do” to ameliorate a particular medical concern (Participant 13) or accepting the responsibility of changing diapers after the age when a typically developing child would have been toilet trained (Participant 14). Others described a mindset of acceptance when thinking about their life and their children’s lives more generally. Summarizing this use of acceptance, Participant 7 remarked, “This is just our life and this is what it is.”

Related to accepting difficulty, parents described the feeling that they did not have control over many challenges in their life, such as their child’s prognosis. As such, they could only choose to show up for their child and do their best each day. This experience was described by the theme *moving forward is the only option*. For example, Participant 18 reflected that caring for their child “doesn't feel like a choice. [...] It is what it is. You wake up every day and you do the best you can, and then the next day you try to make the best that you can do, better.” Similarly, Participant 31 summarized, “You just gotta keep going. You’re gonna have days where you fall down. You just gotta keep going.” It seemed that maintaining this mindset helped parents avoid focusing on daily challenges and, presumably, their accompanying difficult emotions. Through acceptance and moving forward, parents cultivated a cognitive mindset that allowed them to maintain their commitment to caregiving in the face of medical challenges.

Parents were highly invested in ensuring the best lives for their children. This mindset is reflected in the theme *never giving up on child*. For some parents, their own belief was reinforced by their child’s medical progress: “He doesn’t quit, so we’re not gonna quit”

(Participant 23). In addition to serving as a source of strength to sustain them, *never giving up* was a mindset that influenced medical decision-making. For Participant 14, who perceived a medical provider's suggestion of a palliative care referral as indicative of giving up, "told [the provider] no in a very unpolite way because we were pissed." Such mindsets illustrated the conviction with which parents upheld their expectations of themselves as caregivers in pursuit of their child's well-being. To the extent that this mindset was adopted as part of parents' identity and worldview in response to the stress of parenting a CMC, it illustrated the use of reappraisal of global meaning.

Given the intensive nature of their children's medical needs, parents were frequently involved in medical decision-making in their daily lives, and interactions with healthcare providers were commonly discussed during interviews. Parents described having extensive knowledge about their child's condition, and sometimes even knowing more than healthcare providers, which was described as *family as experts in child's condition*. Describing their interactions with their child's healthcare team, Participant 7 described:

There's that trauma that you're like, "Oh, here it comes again. I, I felt this before." And then there's some weird comfort in being there and be-- like a team member there. Not, not like, "Oh you're some fragile mom who's, you know, doesn't know anything." You're like, "I know everything about this kid and I know you guys will ask me about him," you know.

Similarly, Participant 12 described their experience of hospitalizations: "So [...] if I'm there [in the hospital with my child], I'm there to see and hear everything. And keep up with her care. And know what's going and what's gonna happen next." For many parents, serving as experts in their child's medical care was an integral component of the commitment to caregiving. While for

many, it appeared to illustrate a reappraisal of meaning, it could also be a problem-focused way of attempting to influence the impact of their child's medical situation through action.

The final component of maintaining a commitment to caregiving was *maintaining hope for child's well-being*. While the theme *staying positive* described a cognitive coping mechanism that allowed parents to cultivate optimism, responses coded within *maintaining hope for child's well-being* more directly referred to the hopes and dreams parents held for their child. For example, many parents expressed a desire for their child to experience satisfaction and fulfillment, such as hoping "that she can do what she loves" (Participant 12), hoping for their child to "have a successful life" (Participant 13), and wanting their child to live a life that "has value to her" (Participant 18). Many parents specifically hoped their child would continue to progress developmentally and medically, such as undergoing the removal of a tracheostomy (Participant 13) and gaining sensory self-regulation abilities (Participant 23). The expression of these myriad hopes indicates parents' optimism about the possibilities for their children's lives. In the context of the daily challenges of caregiving, appraising challenges by maintaining hope may have changed the situational meaning of the stressor (e.g., believing that current medical challenges are temporary or will be limited in their negative impact on the child's life), which likely served to sustain parents' motivation and commitment to continue caregiving.

Striving to Be a Good Parent

Parents described many caregiving responsibilities that were central to their parenting identity. As with *commitment to caregiving*, most themes included in *striving to be a good parent* indicated a reappraisal of global meaning. Parents perceived the necessity to be a "good parent" as central to their identity and thus to the meaning of their lives. Responses coded under the superordinate theme *striving to be a good parent* reflected the influence of providing quality

care for one's child on one's identity as a caregiver. Emergent themes include *managing and attending to complex needs, nurturing child's emotional well-being, advocating for child, adapting to child's needs, trying not to compare to other families, and providing varied experiences for child.*

Inherent in the experience of parenting CMC is the necessity of providing for a child's myriad physical, behavioral, medical, and emotional needs, summarized as *managing and attending to complex needs*. Specific examples of daily tasks that evoked stress included keeping track of medication and dosing (Participant 4), managing frequent diaper and clothing changes (Participant 7), monitoring oxygen levels (Participant 8), and washing a child with an ileostomy bag (Participant 12). Some parents also described managing behavioral difficulties in the context of caring for a medically fragile child. Summarizing the magnitude of responsibilities, Participant 23 stated, "It is an all-consuming job taking care of a child that has medical needs like this." Despite the extent of these ongoing challenges, participants described meeting these demands as integral parts of parenting their children. As such, when asked what it meant to be a "good parent" to their children, participant responses typically included a detailed description of daily caregiving responsibilities.

In addition to managing daily needs, parents prioritized *nurturing child's emotional well-being*. This included being responsive to a child's emotional needs, promoting their happiness, and expressing, through words or actions, that the child was loved unconditionally. Participant 27 stated, "He is always gonna know how loved he is because that's what we do," while Participant 7 described showing physical affection: "I literally snuggle with him every day that I can." Others spoke about ensuring their child's quality of life. For example, Participant 25

expressed, “We try to provide him with as much fun and happiness and good quality of life that we possibly can.”

Advocating for child was commonly described when parents spoke about what it meant to be a good parent. It was important for participants to serve as their child’s “voice” (Participants 25, 27) in a variety of settings. For some parents, advocacy occurred primarily in the healthcare or school setting, while for others, advocacy was a more constant duty in daily life with their child. Speaking about advocating in the hospital, Participant 19 relayed:

Um, as soon as we get to the ER [I make sure] that we are not standing in line with a bunch of people trying to get into the ER, because I'm gonna go right to the front.

Because [Child] is, like, my first priority, and I don't care that everybody else is there--

I'm [saying], "Okay. We called ahead. Cardiology knows we're coming. We're here.”

Other examples of advocacy in healthcare included requesting a different provider (Participant 27) and enduring provider dismissal of parental concerns (Participant 31). Outside of the healthcare setting, Participant 27 acted as their child’s advocate in the community, describing how they ask others in public whether they have questions about their child’s disability, because “you can’t advocate if you don’t educate people.” Unlike *family as experts in child’s condition*, which indicated parents’ commitment to their child by way of seeking to understand and provide medical information, *advocating for child* describes actions taken to promote their child’s wellbeing as part of their duty to be “good parents.” Both themes could be conceptualized as either attempts to actively address stressors affecting their children or as reappraisals of the meaning of challenging situations.

As children progressed through their medical journeys, parents also developed their capacities as caregivers, which was reflected in the theme *adapting to child’s needs*. The type of

skills parents needed to develop as part of this adaptation was dependent on each child's needs, but examples included practicing patience with a child's unique developmental trajectory (Participant 13) and increasing one's ability over time to communicate with a child and understand his needs (Participant 29). Some parents reflected that this adaptation was an ongoing repeated cycle throughout the medical journey. For example, Participant 7 remarked, "You kind of just always keep going and adapt and keep going and then adapt."

Part of good parenting was *trying not to compare to other families*, as doing so seemed to serve as a barrier to adaptation and coping. Participants spoke about trying not to compare in the domains of schooling, medical progress, and services they were providing to their children. Speaking about protecting their child from COVID-19 in school, Participant 12 reflected that they sometimes compared to what other families of CMC were choosing for their children. They stated, "I do compare a little bit, but then I'm like, 'Nope.' [...] My family is my family, their family is their family. And I'm sure they're in a different district than mine, every school district is different." Speaking about comparison to families who do not care for CMC, Participant 35 spoke about a poem their family uses to help them avoid comparison. The poem metaphorically describes raising a special-needs child as having landed unexpectedly in Holland while aboard an airplane to a planned vacation to Italy. Participant 35 expanded:

I think you have to get past the, um, the comparison. Like, our family is different. We went to Holland. If everybody else went to Italy, Italy's great. Maybe we would have rather gone to Italy, but we're in Holland. So we might as well like Holland—and not be jealous of the families that are living in Italy now. So I think that's a huge thing to sort of make your peace with that kind of comparison game.

Finally, participants expressed that being a good parent involved *providing varied experiences* to their children. For some, this was related to infusing normalcy in their child's life, as evidenced by Participant 14's remark that "I really, um, wanna make sure that she can, uh, experience life the way you or I would experience life." Others sought opportunities to make varied activities more accessible to their children, including Participant 18, who stated:

If there's a floatation device that I can get her in the water that will be safe, I want her to experience that. If there's some type of bike that I can get her on to where she could feel the wind blowing her hair, I want her to experience all that, regardless of her challenges.

The choice to infuse a variety of activities into their children's lives was made in service of increasing their child's quality of life, which participants viewed as one of their parental duties.

Gains from Caregiving Experiences

As a final way of reappraising global meaning in response to caregiving demands, participants described the ways in which they had personally benefitted from the experience of caregiving for their child. Emergent themes included *changed view of self and world; new knowledge, experience, and skills; life lessons learned from child; and strength for and from child*.

Participants described the caregiving journey as a catalyst for change in their own self-concept and worldview, which was summarized as *changed view of self and world*. Participants described that altering their view of themselves and the world provided a renewed sense of perspective that helped them cope with life stresses. For example, Participant 7 noted a change in their perception of their own abilities after hearing of their son's diagnosis:

I had somebody sit in my face and tell me that my child has a profound brain injury. You know, [...] that was the hardest thing I've ever done. I think I could give a speech to

somebody or, you know, some of the things that I fear the most in the world. I'm like, I've already had some of the hardest things, hopefully.

Participants also described changes in the way they observed and interacted with the world. For example, Participant 27 explained, “before I had [Child], I really never thought to look twice if a restaurant had a, a Braille menu or a large print menu because I didn't have to. That wasn't an experience that I had lived. I didn't need to consider it.” As a result of parenting their child, the participant gained motivation to “really want to fix” injustices in the world and to “see the world in a much brighter way.”

As part of parenting CMC, participants gained *new knowledge, experiences, and skills*. These included learning new information about medical conditions, meeting new people, and acquiring caregiving skills. For example, Participant 22 described the new skill of learning to tube-feed their child and gaining the ability to “know how to fix the problem” when the feeding tube malfunctions. Summarizing the skills and knowledge they had gained while parenting their child, Participant 33 reflected, “By no means is it a textbook. You learn as you go.” Participant 35 remarked on the broader ways in which their child influenced family experiences: “I think that [Child] just brings a breadth and depth of experiences and people into our lives that we wouldn't have had otherwise.”

In addition to the novel learning opportunities brought about by caregiving, participants also described general *life lessons learned from child*. These lessons, acquired through caregiving experiences, reflected a range of themes, including perseverance, mindfulness, and patience. When prompted to describe what they had learned, Participant 10 responded, “What have I learned from her? Man, that you can do hard things, and it's worth it.” Participant 12 learned “to cherish all the moments, even the bad ones.” Other life lessons included learning “to

slow down” (Participant 13), “to be strong” (Participant 18), and that “the grass is not greener anywhere else, and it’s amazing right here” (Participant 29). These life lessons illustrate some of the most definitive examples of changes in global meaning as a result of parenting CMC.

Finally, through their caregiving experiences, parents gained *strength for and from child*. This theme reflected both the necessity of psychological strength in the face of challenges to serve their child, as well as acquiring strength as a function of observing their child experiencing medical challenges. Participant 18 described needing to gain strength to care for their child, explaining, “Even if you don't know where it's coming from every day, you find it because she needs it. And as the parent, you gotta give her what she needs.” In contrast, Participant 29 spoke about gaining strength as a family from the caregiving experience: “I know a lot of families [of CMC...] can't work through it, maybe. But I think it just made us stronger [...] it forced us to kind of get on the same page and how we looked at things [...]” Participant 19 further described how strength was gained bidirectionally:

Because I've, I've been a mom of just a typical kid who - - you know, just normal school and activities and, you know, just the day -to -day life. And then to turn around and, and become a mom of a special needs kid the way that [Child] is and have to go through the things that we have to go through with him, it's just-- it -it's opened up a totally different kind of strength that I didn't know was there until he was here. And I feel like I've pulled that strength from him. Because without him I wouldn't have been in this world. [...] I wouldn't have known this type of strength for him.

Realizing that their caregiving demands offered an opportunity to gain strength and committing to being strong for and with their children allowed parents to find positive meaning in their caregiving experiences.

Discussion

Summary of Findings and Relation to the Literature

The present study explored experiences of coping among a sample of parents of CMC. As hypothesized, results suggest that parents employed a multitude of ways of problem-focused coping, emotion-focused coping, and meaning making, with each individual reporting use of a range of different coping strategies. Several identified themes described coping strategies which could be conceptualized as more than one type of coping, indicating an overlap between emotion-focused coping, problem-focused coping, and meaning making. Themes that primarily described emotion- and problem-focused coping included *social connections provide support* and *individual parent coping strategies*, which included attempts to cope such as practicing self-care, engaging with religion and spirituality, and comparison/perspective-taking. Themes that primarily described meaning making strategies included *celebration of child*, *commitment to caregiving*, *striving to be a good parent*, and recognizing *gains from caregiving experiences*. Participants who took part in both modified member checking exercise groups stated that the results reflected their expectations and experiences as clinical team members and family members of CMC.

Given that most of the challenges in participants' lives existed outside of their control, it follows that most of the primary coping strategies described were emotion-focused (i.e., attempts to manage distress) rather than problem-focused (i.e. attempts to manage the stressor), as would be predicted by the goodness-of-fit hypothesis (Park et al., 2004). The themes *parents benefit from emotional support*, *solitary activities as self-care*, *avoidance of negative thinking*, *comparison/perspective-taking*, *staying positive*, and remembering that *coping is day-by-day* describe ways of decreasing stress, thus increasing parents' own emotional capacities to manage

their stressful circumstances. While relying on others for caregiving support (*other adult caregivers are helpful*) was the sole coping strategy that was definitively problem-focused because it described others giving instrumental support rather than emotional support, several coping strategies could be either problem- or emotion- focused, depending on their function. For example, *engaging with religion/spirituality* could be both emotion-focused and problem-focused, or it could be only one or the other. It could be problem-focused if parents believed their prayers would directly influence their child's medical outcomes, while it could be emotion-focused if prayers functioned more as a means of relaxation or comfort, thereby serving to reduce distress. Similarly, *connections with families who have similar experiences* and *social media is helpful* could be categorized as either or both types of coping.

Regarding meaning making, parents described multiple strategies that align with those outlined in extant literature (Folkman & Moskowitz, 2007). Parents described the use of meaning making strategies that influenced both their own situational meaning (i.e., appraisal of a given proximal stressor) and their global meaning (i.e., reappraisal of values and beliefs about the world) to fit the situational circumstances. Of note, many strategies fit into both emotion- or problem- focused coping and meaning making. For example, while *comparison/perspective-taking* was an emotion-focused strategy that served as a direct response to parents' distress during stressful events, it could also be conceptualized a form of a reordering of priorities, such that parents needed to change their perspective of the stressor to effectively manage their circumstances.

Considering the Social Ecological Model, coping strategies were described at the levels of various systems. Most notably, *social connections provide support* describes the coping strategies that directly involved interactions with those in the microsystem and mesosystem.

Moreover, while most of the strategies related to meaning making were cognitive efforts which took place at the level of the individual, the Social Ecological Model suggests that broader social factors influence the individual's coping practices (Kazak, 1989). For example, discriminatory societal values about children with disabilities likely influenced parents' stress and coping reactions, such that parents had to critique or even reject societal messaging in the process of shifting their global or situational meaning. Additionally, some of the meaning making strategies were social in nature, such as *advocating for child*, which could occur at the level of microsystem, mesosystem, or exosystem. As such, while coping is an individualized process unique to each participant, employment of strategies involved or were influenced by their families, communities, and cultural context. Moreover, the Social Ecological Model posits a direct relationship between parent well-being and child well-being, including between parent psychological functioning and child medical outcomes. Using the present findings, it can be inferred that use of certain strategies would be directly beneficial to child well-being outcomes, such as having additional caregivers who can provide for the child when the parent must complete other tasks. However, while the relationship between parent and child well-being has been empirically supported in other pediatric populations, there is further need for specificity of these impacts among families of CMC.

Regarding the relationship between extant literature and the present findings, despite sparseness of literature describing coping among parents who care for CMC, results are consistent with established results in similar populations. First, in terms of social support as a form of coping, despite that social hardship is common among families of CMC (Carnevale et al., 2006; Chan et al., 2019; Thomson et al., 2016; Verma et al., 2020), emotional and instrumental support from family, friends, nurses, and others who care for CMC was identified

as “crucial” in one meta-synthesis describing the experiences of parents of CYSHCN (Nygård & Clancy, 2018). The discrepancy between reported social hardship in past literature and the centrality of social support as a coping strategy identified by both Nygård & Clancy (2018) and the present study could indicate that despite the need for broader social networks of support, parents rely heavily on the connections they do have. As an additional possible explanation for the discrepancy, in the present study, this theme included social support found within the family system (e.g., assistance from spouses or co-parents were included in *other adult caregivers are helpful*). Most participants in the present sample shared caregiving responsibilities with a spouse, partner, or coparent, so it is possible that these families still experienced a lack of external support despite the availability of such assistance. Additionally, the data do not account for frequency of use of each coping strategy; it is possible that families highly value social support but still experience great unmet social needs. Further, use of social media as a source of informal support has not been evaluated in past studies of social hardship among families of CMC but was included in the present study’s conceptualization of social support. As a final consideration regarding social support, it is notable that the study was conducted during the COVID-19 pandemic, a time during which many families were restricting social contact for health purposes. While the impact of the pandemic on social support was not directly explored in the present study, participants’ use of in-person social support may have been more limited than it would have been prior to the pandemic, and they may have relied more heavily on social media to maintain social connections.

Considering other identified coping strategies in the present study, past research investigating experiences of parenting children with chronic illness has documented the use of many of the same cognitive and behavioral coping strategies. Emotion-focused attempts to

handle stressors, such as staying positive and reinterpreting events optimistically, were commonly identified strategies among parents of CYSHCN (Nygård & Clancy, 2018; Özdemir et al., 2021). The use of solitary activities as self-care has not been explicitly mentioned in literature on coping among CYSHCN more broadly, but findings in other pediatric populations have identified the use of “me time” (Kuhaneck et al., 2010), and specifically alone time to catch up on sleep (Angelhoff et al., 2015), as primary parental coping strategies to manage caregiving demands. This is the first known study to specify that the recognition that *coping is day-by-day* seemed to serve as a coping strategy itself among parents of CMC, as it served as a reminder to stay present and focused on current challenges rather than possible future ones.

One finding in the present study, the use of avoidance as an emotion-focused coping strategy has been sparsely explored outside of the pediatric oncology literature (Hildenbrand et al., 2014). That study, which investigated parent-facilitated coping of children with cancer, identified cognitive avoidance and distraction as common avoidant coping strategies. While data regarding avoidance in the present study are limited, responses indicated the use of cognitive avoidance, which was used to either prevent rumination about past difficulties or worries about possible future outcomes. Outside of the parenting context, literature suggests that compared to attending to stressors, avoidant coping is initially effective but less effective in the long term (Suls & Fletcher, 1985). Considering the goodness-of-fit hypothesis (Park et al., 2004), this is likely because avoidance is not effective for long-term management of an uncontrollable stressor. Thus, it would follow that in the context of CMC parenting, the stress inherent to parenting a child with chronic children’s medical complexity would be poorly managed solely by use of avoidance. More research is needed to determine the frequency of use and efficacy of avoidance in the CMC population.

Notably, while the use of taking direct action (e.g., planning for future, seeking information) has been identified as a primary coping strategy among parents of children in the PICU (Jones & Lynn, 2018; Seideman et al., 1997), such problem-focused strategies were less commonly identified in the present study. As an exception, some of the emergent themes categorized within *striving to be a good parent*, which could be conceptualized as problem-focused attempts to manage medical stressors (e.g. *advocating for child, managing and attending to complex needs*). That most other identified coping strategies were emotion-focused or meaning making in nature emphasizes the chronicity and unpredictability of the medical trajectories of CMC, such that attempting to maximize parental control over the medical stressors themselves is largely impossible or ineffective.

The meaning making phenomena described in the present study also align with extant literature. A meta-synthesis describing experiences of parenting children with life-limiting and life-threatening illnesses found that adjustment to their circumstances was reached through a process of acknowledging their “disrupted world” and its accompanying uncertainty, establishing hope by altering priorities and repairing and restoring family relationships, and ultimately “moving forward” by establishing a new sense of normality and new meanings in their life (Bally et al., 2018). Such new meanings included increased appreciation for life, making the most of their time with their child, having hope for the future, and recognizing personal transformations (Bally et al., 2018), all of which were identified in the present study. Further, in a systematic review of benefit-finding among parents of children with pediatric conditions, authors found that benefits included gratitude, enhanced strength and spirituality, learning to be an advocate, closeness and reliance on others, ability to face future adversity (Kritikos et al., 2021), many of which were also identified in the present study. A study of parents of children

with severe neurological impairment, many of whom meet criteria as CMC, identified that parents' experiences of meaning making were characterized by personal growth, transformation, and adapting to meet their child's needs (Bogetz et al., 2021), aligning with emergent themes from *gains from caregiving experiences* and *striving to be a good parent* in the present study.

Of note, several of the emergent themes captured within the superordinate theme *striving to be a good parent*, such as *nurturing child's emotional well-being* and *managing and attending to complex needs*, are novel in the meaning making literature but echo the priorities found to be influential in parents' medical decision-making processes for seriously ill children, such as "making sure my child feels loved" and "focusing on my child's health" (Feudtner et al., 2015; October et al., 2014). The present study adds specificity to the good parent attributes identified by parents of CMC and suggests that such attributes comprise some of the meaning making strategies which help sustain parental coping.

Further Interpretation of the Data via Member Checking

During the modified member checking exercises with the FLC, a discussion about interpretation and implications of the data followed a review of the results. During this discussion, a study team member suggested that parents seemed to have a multitude of effective coping skills. Several FLC members responded that while this is true, these skills were attained through experiences of hitting "rock bottom" and then struggling to find ways to cope. When asked what made coping so challenging, parents noted a substantial lack of available respite and nursing care services and a need for more accessible mental health support for parents.

This observation that, while parents of CMC have highly developed coping skills, they are developed through experiences of intense struggle, lends greater insight into the present findings. It is well-documented that the experience of parenting CMC is associated with high

distress (Verma et al., 2020), which is echoed by the observation made by the FLC members. That coping skills are highly developed does not undermine the intensity of hardship these families experience.

Clinical and Advocacy Implications

The results of the present study are applicable to both clinical practice and advocacy efforts. Given that the present study emphasizes the resilience of parents of CMC, it may be particularly informative for clinicians. When working with any family, it is of paramount importance to recognize their inherent strengths, and the present study elucidated such strengths in a sample of parents who care for CMC. Medical providers and mental health professionals working with families who care for CMC are uniquely positioned to notice and respond to family stress and to promote even further development of effective coping skills. This may be especially true for providers in Complex Care Programs, who aim to support family well-being through care coordination and management of complex conditions. For providers, understanding the myriad ways in which families cope with stressors, as detailed in the present study, may enable them to deliver more targeted support. For example, recognition of coping strategies that are used more commonly in healthcare settings, such as *advocating for child and family as experts in child's condition*, could enable providers to encourage these efforts when used by parents, or to purposely create opportunities for such coping strategies to take place (e.g., allowing parents to maintain some of their regular caregiving roles during a child's hospitalization). Further, these implications align with results of a prior study with parents of CMC hospitalized in the PICU, which indicated that recognition of family expertise about their child should be of primary importance for providers caring for this population (Rennick et al., 2019).

Considering options for formal supports that would increase coping capacity among parents of CMC, there is no known literature documenting the presence of psychologists embedded in a Complex Care Program, despite the empirical support for such an integrated behavioral health model in other pediatric settings (Asarnow et al., 2017). Furthermore, in line with the “triple aim” in healthcare of improving patient experiences, promoting health, and reducing costs, psychologists can play a vital role in the patient-centered medical home model. Specifically, the role of psychologists in an integrated approach could include supporting medical providers in their efforts to improve patient and family mental health (e.g., “hallway conversations”) and directly meeting with families to support them in understanding medical information, improving adherence to medications, assessing and addressing psychosocial risk, and engaging in problem-solving of barriers related to social determinants of health (Kazak et al., 2017). Including psychologists in Complex Care Programs would likely improve healthcare equity because psychologists would be an extant part of the Complex Care medical team, rather than existing solely in the community, where additional resources (e.g., time off work, transportation, financial coverage) are needed to gain access to their services.

Regarding specific psychotherapeutic interventions for families who care for CMC, acceptance of the present situation and commitment to their parental roles seemed to be a commonality across several themes in the present study. Such acceptance of challenges and commitment to acting according to one’s values (e.g., being a “good parent”) are core tenets of Acceptance and Commitment Therapy (ACT). This approach fosters skill-building in mindful acceptance of the present moment and commitment to taking values-congruent actions (Hayes et al., 2006). ACT has been widely used in pediatric psychology, most frequently in the treatment of pediatric chronic pain (Pielech et al., 2017). However, recent literature has also begun to

demonstrate some efficacy of ACT with subpopulations of parents of pediatric patients. For example, parents of children with cancer or cardiac conditions who were treated in a pilot study of a novel ACT and problem-solving intervention demonstrated significant improvements in distress, post-traumatic stress symptoms, psychological flexibility, and mindfulness at follow-up as compared to pre-intervention (Burke et al., 2014). Similarly, parents of children with asthma who received an ACT intervention experienced increased psychological flexibility, decreased stress, and fewer visits to the emergency department for their child after the intervention (Chong et al., 2019). Among a sample of parents of children with cerebral palsy, a study examining the use of a parenting intervention combined with ACT demonstrated reductions in parental depressive symptoms and stress, but no changes in parental anxiety or confidence. While further research is needed to comprehensively investigate the efficacy and acceptability of ACT among parents of pediatric patients, and specifically among parents of CMC, it is a promising intervention which teaches many of the coping strategies described by parents in the present sample. Considering the remarks made by parent participants in the modified member checking exercise, if ACT or a similar intervention could be used to scaffold the development of parent coping skills earlier in their child's medical trajectory, perhaps parents could be prevented from experiencing intense distress resulting from limited coping skills.

Given that participants in the present study described the importance of social support as a primary coping strategy, consideration of structured social support interventions may be worthwhile. Limited research has been conducted regarding the efficacy of social support as an intervention among parents who care for CMC as a single population, but findings in specific related populations suggest positive potential (Edelstein et al., 2017). For example, while a study investigating the efficacy of a peer-support program for parents of children with chronic lung

disease found that inconclusive quantitative support for improvements in well-being, qualitative reports suggest considerable emotional benefits to parents (Nicholas & Keilty, 2007).

Furthermore, parents of CYSHCN report high satisfaction relating to use of internet-based parent support groups (Baum, 2004). Considering the present findings indicating that social media may serve as a source of support, and the current ongoing and unpredictable COVID-19 pandemic which restricts social gatherings, development and evaluation of internet support programs may be a worthwhile future direction for intervention.

Other stress-reduction interventions for parents of pediatric patients have included components of meaning making, many of which echo the present study's findings. Promoting Resilience in Stress Management for Parents (PRISM-P) is a novel intervention for parents of children diagnosed with cancer in the United States (Rosenberg et al., 2021). The intervention teaches stress management, goal setting, cognitive restructuring, and benefit finding (Rosenberg et al., 2021). While an initial randomized control trial did not demonstrate long-term improvement in distress symptoms or benefit-finding, qualitative responses suggested that parents highly valued the intervention. It remains to be determined whether this model can be altered to establish long-term positive impacts, and if so, whether it can be applied in pediatric parent populations outside of oncology. Furthermore, the Thank You-Sorry-Love® (TSL®) Program has been introduced with families of children with cancer in South Korea. Given Korean cultural expectations that one should avoid sharing deep emotions with family members, TSL® aimed to increase expressions of gratitude, sympathy, and self-expansion, all of which are believed to promote meaning making and post-traumatic growth (Kim et al., 2012). In a sample of mothers of children with cancer, post-traumatic growth scores had significantly increased after the TSL® intervention (Choi & Kim, 2018), suggesting the potential efficacy of such a treatment

to promote meaning making. While both PRISM-P and TSL® are in the early stages of investigation and will need to be altered and examined further for use with the Complex Care population, their early use in pediatric oncology suggests that structured interventions to promote meaning making may be future options to promote coping among families who care for CMC.

Even in the absence of access to an embedded psychologist or targeted interventions, medical providers caring for families of CMC may be uniquely positioned to encourage coping. Access to patient-centered medical homes, and especially care coordinators, is associated with stress reduction among parents who care for CMC (Edelstein et al., 2017). Beyond providing family-centered care, medical providers should be trained to assess and respond to family distress, while also recognizing and encouraging the myriad coping strategies families develop organically by nature of caring for CMC.

In addition to clinical opportunities for family support, there are also opportunities for stakeholders to advocate in service of increased access to services that would improve parent mental health. First, for parents to maintain their mental health and engage in many of the coping strategies detailed in the present study, they must have the time to do so. In the present study, parents described the importance of having other adult caregivers, including partners, extended family, and personal care workers, who could provide for their child's needs and give the parent an emotional, cognitive, and physical rest. These caregivers allowed parents to take time to practice self-care, which included completing essential tasks as sleeping and bathing. A 2020 call for safe work-hour standards for caregivers of CMC emphasized the necessity of limiting the number of consecutive hours parents could spend caring for their child alone. In addition to improving parent well-being by ensuring ample time to care for themselves and cope with stress,

such limits would also likely improve child health by reducing opportunities for fatigue-related human error in the care of CMC (Schall et al., 2020).

To make such standards feasible, parents would need access to respite caregivers and/or increased nursing support. At present, 47% of families of children with technology dependence experience unmet respite care needs, and of those with unmet needs, 59% receive no respite care (Sobotka et al., 2019). The American Academy of Pediatrics recommends that families who care for CMC should receive respite care benefits (McInerney et al., 2006), and the National Standards for Systems of Care for Children and Youth with Special Health Care Needs note that families who care for CMC must have access to both planned and emergency respite care (Antonelli et al., 2017). Considering the impact of respite care on caregiver distress and coping, literature suggests that parents experience a reduction in distress with provision of respite care, but only if providers are knowledgeable and familiar with their family (Edelstein et al., 2017). As such, systems must be in place to support long-term employment and retention of respite caregivers, such as ensuring desirable compensation packages. Unfortunately, at present, low Medicaid reimbursement of such services result in a lack of available respite providers (Hefner & Tsai, 2013). Legislative advocacy efforts should prioritize advocating for higher Medicaid reimbursement of respite care services, which would likely increase accessibility and retention of such workers in the community. At the local level, advocacy efforts may focus on increasing respite care options available through healthcare systems, such as the development of skilled nursing facilities designed for short-term and emergency stays or the expansion of home nursing services.

Limitations and Future Directions

As with most qualitative methodologies, IPA is meant to describe the existence, but not necessarily the frequency or universality, of given phenomena. Considering the subjective “double hermeneutic” nature of IPA, in which the researcher “make sense” of individual participants’ own sense-making of their experiences, IPA does not aim to represent the existence of entire groups, but rather to inform researchers about personal lived experiences (Smith & Osborn, 2003, Chapter 2). Such information can inform later systematic and representative studies of such phenomena.

Because the study aimed to represent a diversity of coping experiences, a purposive sampling technique was used to increase participant diversity. However, study findings are not representative of CMC coping experiences broadly and should not necessarily be interpreted as representative of families other than those interviewed. More specifically, there are several ways in which the sociodemographic characteristics of the current sample are misaligned with those served by the Complex Care Program or those of families who care for CMC in general. While a nationally representative study of CMC has not been conducted, nationally representative data for CYSHCN is available (Maternal and Child Health Bureau, 2019). Compared to this national sample, white and non-Hispanic/Latino children are over-represented in the population served by the Children’s Wisconsin Complex Care Program and in the study sample. Further, Wisconsin State laws allow for the TEFRA option, which allows for the use of a Medicaid waiver to support CMC living at home (Wisconsin Department of Health Services, 2019). Wisconsin has historically high TEFRA enrollment rates compared to other states offering the option (Semansky & Koyanagi, 2004). Since 97% of children served by the CW Complex Care Program reside in Wisconsin (S. Johaningsmier, personal communication, December 8, 2020), it is likely that most eligible children of enrolled participants receive these insurance benefits. As

such, children of participants in the study may experience fewer unmet insurance needs than would be typical in states with lower TEFRA enrollment. Additionally, due to methodological restrictions, such as lack of interviewer proficiency in other languages, participants in the study were English-speaking. As such, the current study fails to consider the range of coping practices used by families who are not proficient in English. Finally, while study activities were completed virtually to allow for expanded access to the study, the eligibility requirement for phone and internet access likely still resulted in socioeconomic differences between enrolled participants and other caregivers of CMC, in which case the study may underrepresent challenges faced by those with limited financial resources. To minimize this exclusion as much as possible, efforts were made to use phone calls to conduct interviews if internet access was unstable or if preferred by participants.

Considering the interconnected systems outlined in the Social Ecological Model, broader social issues are relevant to the evaluation of parent stress and coping in the pediatric illness context, as societal structures and values influence family well-being (Kazak, 1989). As such, parents' sociocultural identities may be associated with unique assets and challenges for managing the stress of caregiving demands. For example, families who care for CMC and do not speak English proficiently are more likely than English-speaking families to report that their child is uninsured and lacks a medical home (Eneriz-Wiemer et al., 2014), and CMC in families with lower socioeconomic statuses are less likely to receive well-coordinated care in the context of a medical home (Fulda et al., 2009). Having access to resources such as health insurance and quality healthcare for their child likely influence parent stress and coping resources. The many interlocking systems of structural oppression that impact families holding minoritized identities were not explored in the present study, and a comprehensive understanding of the impact of such

systems on families of CMC requires in-depth investigation. In general, further research aimed to represent experiences of nationally representative samples would enable a more comprehensive understanding of the stressors and resilience factors of families holding minoritized identities in the context of parenting CMC and would ensure that future efforts to support these families are culturally informed.

As an additional consideration, all families of CMC in the present study were enrolled in the Complex Care Program and had been served by the program for at least one year. Because the Complex Care Program is voluntary and referral-based, not all Children's Wisconsin patients who meet criteria as CMC are enrolled. At present, there is no available data about the demographic, medical, or psychosocial differences between children who are and are not enrolled in the Program or their families. Given that these programs are designed to support families through coordination of care, the findings may reflect coping strategies that were developed through receiving support from the Program. As an alternative possibility, families with more highly developed coping strategies may have more resources (e.g. financial means, social connections, time to research healthcare options) and thus are more likely to request access to the Program. It may also be the case that more distressed families, or those who care for children with more severe medical complexity, are more likely to be referred to the Program because providers are more likely to acknowledge their need for structured support. Any of these possibilities indicate that present findings align with the coping strategies of a limited proportion of families. More research is needed to determine these differences to maximize Complex Care Program enrollment or other forms of support from the healthcare system when desired by families.

Considering the coping strategies identified in the present study, several empirical questions could be explored. In line with community-based participatory research approaches (Shalowitz et al., 2009), further input from parents who care for CMC will be needed to determine research priorities and maximize positive impact. Pending feedback from community members, the following research agendas may be pursued.

First, further investigation would be warranted to categorize coping strategies in a comprehensive and culturally informed manner, such that the experiences of families holding marginalized cultural identities are explored. Particular attention is warranted to understand the relationship between parent coping practices and sociocultural identities (e.g., race, ethnicity, religion), access to resources (e.g., socioeconomic status, availability of social support), interlocking systems of oppression (e.g., racism and classism), and child illness variables (e.g., acquired vs congenital medical complexity). Furthermore, to inform intervention approaches, it may be helpful to investigate the frequency, trajectory of use, and effectiveness of each coping strategy. For example, it remains an empirical question whether families who care for CMC tend to use more problem-focused coping strategies over time, as has been documented among families of children in the PICU (Jones & Lynn, 2018).

Next, in service of designing evidence-based and culturally informed interventions for this population, it will be important to further understand how coping strategies are developed and whether it is possible to intervene earlier in a child's medical journey to reduce parent distress by teaching such strategies to new parents of CMC. Interventions aimed to increase parental capacity for coping, such as social support programs, ACT, PRISM-P, or TSL®, could be implemented and empirically evaluated. Alternatively, a less direct intervention – but one that could be equally effective given the stress caused by the magnitude of practical challenges and

demands on parent time –would be to expand access to services that reduce caregiving burden, such as respite care facilities or in-home personal care workers. Ideally, parents of CMC would have also access to high-quality mental health support to learn effective coping strategies within the context of comprehensive systems of care that support family well-being (e.g., universal access to planned and emergency respite care).

In summary, considering the chronicity and unpredictability of the medical trajectories of CMC, parents in the present sample demonstrated a remarkable diversity of coping strategies, most of which were ways of making and enhancing meaning in their lives. It must be taken seriously that despite the wide variety of coping strategies parents describe and use, clinicians and researchers have an obligation to further reduce parental distress wherever possible, such as through the implementation of interventions to increase coping capacity at earlier points in the child's medical trajectory.

Conclusion

In a sample of parents who care for CMC, a myriad of coping strategies were described. Emotion-focused and meaning making strategies were the most represented. The results have implications for the clinical care of children and families, such that they elucidate opportunities for providers to facilitate parent coping and they suggest the applicability of psychotherapeutic interventions that center acceptance and meaning making strategies. Advocacy is needed to ensure widespread accessibility of supports, such as respite care and mental health care, which would likely increase parents' abilities to learn and practice effective coping skills. Future research priorities should be informed by community feedback and may include further expansion of the characterization of parent coping in more demographically representative

samples and the development and implementation of family-centered and culturally informed family support interventions.

Figure 1. Thematic Map of Qualitative Results.

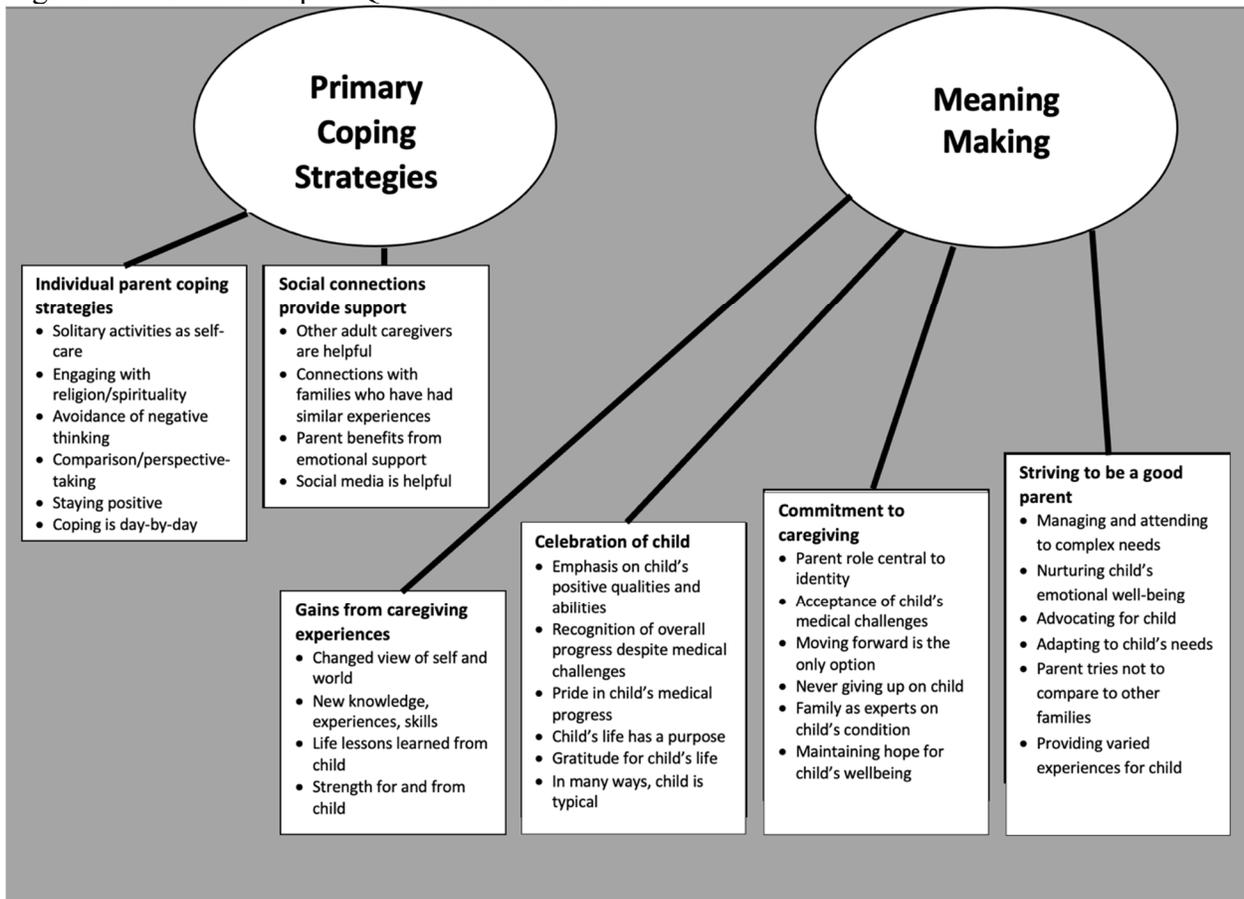


Table 1. Participant Demographic Information

		n (%)	M (SD), range
Age (years)			39.05 (7.0), 27-52
Gender			
	Female	19 (95)	
	Male	1 (5)	
Relationship to child	Mother	19 (95)	
	Father	1 (5)	
Race	White	17 (85)	
	Black or African American	1 (5)	
	Another race or prefer not to answer	2 (10)	
Ethnicity	Not Hispanic/Latinx origin	18 (80)	
	Hispanic/Latinx origin	1 (5)	
	No response	1 (5)	
Marital status	Married	13 (65)	
	Single, never married	5 (25)	
	Divorced	2 (10)	
Highest education completed	High school	9 (45)	
	College	7 (35)	
	Associates Degree	4 (20)	

Table 2. Characteristics of CMC whose Parents were Participants

		n (%)	M (SD), range
Age (years)			8.2 (4.), 2-19
Gender			
	Female	11 (55)	
	Male	9 (45)	
Length of time served by Complex Care Program	0-2 years	2 (10)	
	3-5 years	9 (45)	
	6+ years	9 (45)	
Caregivers besides participant			
	Participant's spouse/partner/coparent	16 (80)	
	Siblings or half-siblings	1 (5)	
	Other family members	4 (20)	
	Babysitter, nanny	1 (5)	
	Home nursing staff	1 (5)	
	Other caregivers	2 (10)	

Table 3. Interview Guide*

Example Interview Questions
<p>I'd like to get to know you a bit before we talk more about your experiences caring for your child. Tell me a little bit about yourself.</p>
<p>Before we talk about CHILD's medical journey, tell me about CHILD as a person.</p>
<p>What does it mean to you to be a "good parent" to CHILD?</p>
<p>What parts of CHILD's medical journey been less difficult or gone well? Why?</p>
<p>What have you learned from parenting CHILD?</p>
<p>Some parents say that having a child with medical complexity changes the meaning of their life or how they make sense of the world. Is that true for you and your family? If so, tell me about that.</p>
<p>"Resilience" is the ability to cope with difficult events. As CHILD's parent, how do you think about resilience?</p>
<p>Some people find strength in connecting with their community, such as extended family, neighbors, religious or cultural groups, or parents of other children with health conditions. Have you had any experiences finding strength in community? If so, tell me about that.</p>
<p>How do you take care of yourself or "recharge" with everything you have going on in your life?</p>
<p>What are your hopes and dreams for CHILD?</p>

*Because the present study was part of a larger study, this table includes only questions relevant to coping. Additionally, due to the semi-structured nature of the interviews, not all participants were asked all questions.

Table 4. Guiding Questions for Modified Member-Checking Exercise

Given your experience:

- What resonates with you?
- What did we forget, misinterpret, or misunderstand?
- What questions remain unanswered?
- How would you interpret these findings?
- What research questions are most important moving forward?

References

- Angelhoff, C., Edéll-Gustafsson, U., & Mörelius, E. (2015). Sleep of Parents Living with a Child Receiving Hospital-Based Home Care: A Phenomenographical Study. *Nursing Research*, *64*(5), 372–380. <https://doi.org/10.1097/NNR.000000000000108>
- Anthony, K. K., Bromberg, M. H., Gil, K. M., & Schanberg, L. E. (2011). Parental perceptions of child vulnerability and parent stress as predictors of pain and adjustment in children with chronic arthritis. *Children's Health Care*, *40*, 53–69. <https://doi.org/10.1080/02739615.2011.537938>
- Antonelli, R., Bethell, C., Health, A., Brosco, J., Brown, T., Maternal, M. A., Health, C., Caldwell, C., Comeau, M., Fleischfresser, S., Fox, R., Garneau, D., Jew, R., Johnson, J., Klitzner, T., Kyle, J., Langer, C., Massachusetts, M. (, Mann, M., ... Zerzan, J. (2017). *Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0*. <https://www.nashp.org/wp-content/uploads/2019/10/Standards-for-Systems-of-Care-for-Children-and-Youth-with-Special-Health-Care-Needs-Version-2.0.pdf>
- Armitage, S., Parkinson, M., Halligan, S., & Reynolds, S. (2020). Mothers' Experiences of Having an Adolescent Child with Depression: An Interpretative Phenomenological Analysis. *Journal of Child and Family Studies*, *29*(6), 1617–1629. <https://doi.org/10.1007/s10826-020-01705-5>
- Asarnow, J. R., Kolko, D. J., Miranda, J., & Kazak, A. E. (2017). The pediatric patient-centered medical home: Innovative models for improving behavioral health. *American Psychologist*, *72*(1), 13–27. <https://doi.org/10.1037/a0040411>
- Bakula, D. M., Sharkey, C. M., Perez, M. N., Espeleta, H. C., Gamwell, K. L., Baudino, M., Delozier, A. M., Chaney, J. M., Alderson, R. M., & Mullins, L. L. (2020). The relationship between parent distress and child quality of life in pediatric cancer: A meta-analysis. *Journal of Pediatric Nursing*, *50*, 14–19. <https://doi.org/10.1016/j.pedn.2019.09.024>
- Bakula, D. M., Sharkey, C. M., Perez, M. N., Espeleta, H. C., Gamwell, K. L., Baudino, M., Delozier, A. M., Chaney, J. M., Matt Alderson, R., & Mullins, L. L. (2019). The Relationship Between Parent and Child Distress in Pediatric Cancer: A Meta-Analysis. *Journal of Pediatric Psychology*, *44*(10), 1121–1136. <https://doi.org/10.1093/jpepsy/jsz051>
- Bally, J. M. G., Smith, N. R., Holtslander, L., Duncan, V., Hodgson-Viden, H., Mpofo, C., & Zimmer, M. (2018). A Metasynthesis: Uncovering What Is Known About the Experiences of Families With Children Who Have Life-limiting and Life-threatening Illnesses. *Journal of Pediatric Nursing*, *38*, 88–98. <https://doi.org/10.1016/j.pedn.2017.11.004>
- Baum, L. S. (2004). Internet parent support groups for primary caregivers of a child with special health care needs. *Pediatric Nursing*, *30*(5), 381–388, 401.
- Berry, J. G., Hall, D. E., Kuo, D. Z., Cohen, E., Agrawal, R., Feudtner, C., Hall, M., Kueser, J., Kaplan, W., & Neff, J. (2011). Hospital Utilization and Characteristics of Patients Experiencing Recurrent Readmissions Within Children's Hospitals. *JAMA - Journal of the American Medical Association*, *305*(7), 682–690. <https://doi.org/10.1001/jama.2011.122>
- Berry, J. G., Hall, M., Cohen, E., O'Neill, M., & Feudtner, C. (2016). Ways to Identify Children with Medical Complexity and the Importance of Why. *Journal of Pediatrics*, *167*(2), 229–237. <https://doi.org/10.1016/j.jpeds.2015.04.068>
- Birt, L., Scott, S., Cavers, D., Campbell, C., Walter, F., & Uk, L. B. A. (2016). Member checking: a tool to enhance trustworthiness or merely a nod to validation? *Qualitative*

- Health Research*, 26(13), 1802–1811.
<https://doi.org/https://doi.org/10.1177/1049732316654870>
- Blum, R. W.M., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. *Journal of Adolescent Health*, 14(7), 570–576.
[https://doi.org/10.1016/1054-139x\(93\)90143-d](https://doi.org/10.1016/1054-139x(93)90143-d)
- Bogetz, J. F., Trowbridge, A., Lewis, H., Shipman, K. J., Jonas, D., Hauer, J., & Rosenberg, A. R. (2021). Parents Are the Experts: A Qualitative Study of the Experiences of Parents of Children with Severe Neurological Impairment During Decision-Making. *Journal of Pain and Symptom Management*. <https://doi.org/10.1016/j.jpainsymman.2021.06.011>
- Bramlett, M. D., Read, D., Bethell, C., & Blumberg, S. J. (2009). Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. *Maternal and Child Health Journal*, 13, 151–163. <https://doi.org/10.1007/s10995-008-0339-z>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2019). *Answers to frequently asked questions about thematic analysis*. [https://cdn.auckland.ac.nz/assets/psych/about/our-research/documents/Answers to frequently asked questions about thematic analysis April 2019.pdf](https://cdn.auckland.ac.nz/assets/psych/about/our-research/documents/Answers%20to%20frequently%20asked%20questions%20about%20thematic%20analysis%20April%202019.pdf)
- Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., & Rosenbaum, P. L. (2009). Health among caregivers of children with health problems: Findings from a Canadian population-based study. *American Journal of Public Health*, 99(7), 1254–1262. <https://doi.org/10.2105/AJPH.2007.129817>
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32, 513–531. <https://doi.org/10.1037/0003-066x.32.7.513>
- Brown, E. A., De Young, A., Kimble, R., & Kenardy, J. (2019). The role of parental acute psychological distress in paediatric burn re-epithelialization. *British Journal of Health Psychology*, 24(4), 876–895. <https://doi.org/10.1111/bjhp.12384>
- Burke, K., Muscar, F., McCarthy, M., Dimovski, A., Hearps, S., Anderson, V., & Walser, R. (2014). Adapting acceptance and commitment therapy for parents of children with life-threatening illness: Pilot study. *Families, Systems and Health*, 32(1), 122–127. <https://doi.org/10.1037/fsh0000012>
- Burns, K. H., Casey, P. H., Lyle, R. E., Bird, T. Mac, Fussell, J. J., & Robbins, J. M. (2010). Increasing prevalence of medically complex children in US hospitals. *Pediatrics*, 126(4), 638–646. <https://doi.org/10.1542/peds.2009-1658>
- Caicedo, C. (2015). Health and Functioning of Families of Children With Special Health Care Needs Cared for in Home Care, Long-term Care, and Medical Day Care Settings. *Journal of Developmental & Behavioural Pediatrics*, 36(5), 352–361.
- Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, 117(1). <https://doi.org/10.1542/peds.2005-0789>
- Chan, Y. H., Lim, C. Z.-R., Bautista, D., Malhotra, R., & Østbye, T. (2019). The Health and Well-Being of Caregivers of Technologically Dependent Children. *Global Pediatric Health*, 6, 2333794X1882300. <https://doi.org/10.1177/2333794x18823000>

- Cheung, W. K. H., & Lee, R. L. T. (2012). Children and adolescents living with atopic eczema: An interpretive phenomenological study with Chinese mothers. *Journal of Advanced Nursing*, *68*(10), 2247–2255. <https://doi.org/10.1111/j.1365-2648.2011.05915.x>
- Child Trends. (2019). *Infant, Child, and Teen Mortality*.
- Choi, K., & Kim, J. Y. (2018). Evaluation of the TSL® program for parents of children with cancer. *Research on Social Work Practice*, *28*(2), 146–153. <https://doi.org/10.1177/1049731516637121>
- Chong, Y. Y., Mak, Y. W., Leung, S. P., Lam, S. Y., & Loke, A. Y. (2019). Acceptance and commitment therapy for parental management of childhood asthma: An RCT. *Pediatrics*, *143*(2). <https://doi.org/10.1542/PEDS.2018-1723/37335>
- Chow, E. T., Otis, J. D., & Simons, L. E. (2016). The Longitudinal Impact of Parent Distress and Behavior on Functional Outcomes among Youth with Chronic Pain. *Journal of Pain*, *17*(6), 729–738. <https://doi.org/10.1016/j.jpain.2016.02.014>
- Cohen, E., Berry, J. G., Camacho, X., Anderson, G., Wodchis, W., & Guttmann, A. (2012). Patterns and costs of health care use of children with medical complexity. *Pediatrics*, *130*(6). <https://doi.org/10.1542/peds.2012-0175>
- Cohen, E., Berry, J. G., Sanders, L., Schor, E. L., & Wise, P. H. (2018). Status complexicus? The emergence of pediatric complex care. *Pediatrics*, *141*(March), S202–S211. <https://doi.org/10.1542/peds.2017-1284E>
- Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, S. K. M., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*, *127*(3), 529–538. <https://doi.org/10.1542/peds.2010-0910>
- Cohen, E., Lacombe-Duncan, A., Spalding, K., MacInnis, J., Nicholas, D., Narayanan, U. G., Gordon, M., Margolis, I., & Friedman, J. N. (2012). Integrated complex care coordination for children with medical complexity: A mixed-methods evaluation of tertiary care-community collaboration. *BMC Health Services Research*, *12*(1). <https://doi.org/10.1186/1472-6963-12-366>
- Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thomsen, A. H., & Wadsworth, M. E. (2001). Coping with stress during childhood and adolescence: Problems, progress, and potential in theory and research. *Psychological Bulletin*, *127*(1), 87–127. <https://doi.org/10.1037/0033-2909.127.1.87>
- Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, *38*(8), 809–828. <https://doi.org/10.1093/jpepsy/jst049>
- Cousino, M. K., Rea, K. E., Schumacher, K. R., Magee, J. C., & Fredericks, E. M. (2017). A systematic review of parent and family functioning in pediatric solid organ transplant populations. *Pediatric Transplantation*, *21*(3). <https://doi.org/10.1111/ptr.12900>
- Craig, F., Savino, R., Scoditti, S., Lucarelli, E., Fanizza, I., de Rinaldis, M., Gennaro, L., Simone, M., Russo, L., & Trabacca, A. (2019). Coping, stress and negative psychological outcomes in parents of children admitted to a pediatric neurorehabilitation care unit. *European Journal of Physical and Rehabilitation Medicine*, *55*(6), 772–782. <https://doi.org/10.23736/S1973-9087.19.05695-8>
- Donnelly, T. J., Palermo, T. M., & Newton-John, T. R. O. (2020). Parent cognitive, behavioural, and affective factors and their relation to child pain and functioning in pediatric chronic pain: a systematic review and meta-analysis. *Pain*, *161*(7), 1401–1419. <https://doi.org/10.1097/j.pain.0000000000001833>

- Edelstein, H., Schippke, J., Sheffe, S., & Kingsnorth, S. (2017). Children with medical complexity: a scoping review of interventions to support caregiver stress. In *Child: Care, Health and Development* (Vol. 43, Issue 3, pp. 323–333). Blackwell Publishing Ltd. <https://doi.org/10.1111/cch.12430>
- Eneriz-Wiemer, M., Sanders, L. M., Barr, D. A., & Mendoza, F. S. (2014). Parental limited english proficiency and health outcomes for children with special health care needs: A systematic review. *Academic Pediatrics, 14*(2), 128–136. <https://doi.org/10.1016/j.acap.2013.10.003>
- Everhart, S. A., Cochran, K. M., Lambrou, N. H., Davies, W. H., & Marik, P. K. (2021). Psychosocial Experiences That Support Positive Self-Concept in Children with Cleft Lip and Palate Adopted From China: <https://doi.org/10.1177/10556656211051222>. <https://doi.org/10.1177/10556656211051222>
- Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J., Miller, V. A., Morrison, W. E., Munson, D., Kang, T. I., & Hinds, P. S. (2015). Good-parent beliefs of parents of seriously ill children. *JAMA Pediatrics, 169*(1), 39–47. <https://doi.org/10.1001/jamapediatrics.2014.2341>
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine, 45*(8). [https://doi.org/10.1016/S0277-9536\(97\)00040-3](https://doi.org/10.1016/S0277-9536(97)00040-3)
- Folkman, S. (2008). The case for positive emotions in the stress process. *Anxiety, Stress and Coping, 21*(1), 3–14. <https://doi.org/10.1080/10615800701740457>
- Folkman, S., & Moskowitz, J. T. (2007). Positive affect and meaning-focused coping during significant psychological stress. In *The Scope of Social Psychology*. <https://doi.org/10.4324/9780203965245-21>
- Fulda, K. G., Lykens, K., Bae, S., & Singh, K. (2009). Factors for accessing a medical home vary among CSHCN from different levels of socioeconomic status. *Maternal and Child Health Journal, 13*(4), 445–456. <https://doi.org/10.1007/s10995-008-0371-z>
- Gallagher, S., Phillips, A. C., Drayson, M. T., & Carroll, D. (2009). Parental caregivers of children with developmental disabilities mount a poor antibody response to pneumococcal vaccination. *Brain, Behavior, and Immunity, 23*(3), 338–346. <https://doi.org/10.1016/j.bbi.2008.05.006>
- Ghandour, R. M., Hirai, A. H., Blumberg, S. J., B, S. B., & Kogan, M. D. (2017). Financial and Nonfinancial Burden Among Families of CSHCN: Changes Between 2001 and 2009–2010 Reem. *Physiology & Behavior, 176*(1), 139–148. <https://doi.org/10.1016/j.physbeh.2017.03.040>
- Glaser, B. G., & Strauss, A. L. (1967). Grounded theory The discovery of grounded theory. In *International Journal of Qualitative Methods*.
- Goldspink, S., & Engward, H. (2019). Booming clangs and whispering ghosts: Attending to the reflexive echoes in IPA research. *Qualitative Research in Psychology, 16*(2), 291–304. <https://doi.org/10.1080/14780887.2018.1543111>
- Goudie, A., Narcisse, M.-R., Hall, D. E., & Kuo, D. Z. (2005). Financial and Psychological Stressors Associated with Caring for Children with Disability. *Family, Systems, & Health, 23*(1), 1–7. <https://doi.org/10.1038/jid.2014.371>
- Gouveia, C., Josefina, S., Costa, S., Della, T., Carlos, A., Antunes, R., Vasconcelos, C., Miranda, S., & Rosaria, A. (2019). COMPLEXITY OF PEDIATRIC CHRONIC DISEASE CROSS SECTIONAL STUDY WITH 16237 PATIENTS FOLLOWED BY MULTIPLE MEDICAL SPECIALTIES. *Revista Paulista de Pediatria, 38*.

- Hawthorne, D. M., Youngblut, J. A. M., & Brooten, D. (2017). Use of spiritual coping strategies by gender, race/ethnicity, and religion at 1 and 3 months after infant's/child's intensive care unit death. *Journal of the American Association of Nurse Practitioners*, 29(10), 591–599. <https://doi.org/10.1002/2327-6924.12498>
- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, 44(1), 1–25. <https://doi.org/10.1016/j.brat.2005.06.006>
- Hefner, J. L., & Tsai, W. C. (2013). Ventilator-dependent children and the health services system. Unmet needs and coordination of care. *Annals of the American Thoracic Society*, 10(5), 482–489. <https://doi.org/10.1513/ANNALSATS.201302-036OC>
- Hildenbrand, A. K., Alderfer, M. A., Deatrck, J. A., & Marsac, M. L. (2014). A mixed methods assessment of coping with pediatric cancer. *Journal of Psychosocial Oncology*, 32(1), 37–58. <https://doi.org/10.1080/07347332.2013.855960>
- Hogan, A. K., Galligan, M. M., Stack, N. J., Leach, K. F., Aredas, B. L., English, R., Dye, M., & Rubin, D. (2020). A tertiary care-based complex care program: Improving care for children with medical complexity. *Medical Care*, 58(11), 958–962. <https://doi.org/10.1097/MLR.0000000000001388>
- Iacono, V. Lo, Symonds, P., & Brown, D. H. K. (2016). Skype as a tool for qualitative research interviews. *Sociological Research Online*, 21(2). <https://doi.org/10.5153/sro.3952>
- Jones, C. W., & Lynn, M. R. (2018). Blogs Written by Families During Their Child's Hospitalization: A Thematic Narrative Analysis. *Journal of Pediatric Nursing*, 41, 110–116. <https://doi.org/10.1016/j.pedn.2018.03.011>
- Jordan, A. L., Eccleston, C., & Osborn, M. (2007). Being a parent of the adolescent with complex chronic pain: An interpretative phenomenological analysis. *European Journal of Pain*, 11(1), 49–49. <https://doi.org/10.1016/j.ejpain.2005.12.012>
- Kazak, A. E. (1989). Families of Chronically Ill Children: A Systems and Social-Ecological Model of Adaptation and Challenge. *Journal of Consulting and Clinical Psychology*, 57(1), 25–30. <https://doi.org/10.1037/0022-006X.57.1.25>
- Kazak, A. E. (1997). A contextual family/systems approach to pediatric psychology: Introduction to the special issue. *Journal of Pediatric Psychology*, 22(2), 141–148. <https://doi.org/10.1093/jpepsy/22.2.141>
- Kazak, A. E., & Nachman, G. S. (1991). Family research on childhood chronic illness: Pediatric oncology as an example. *Journal of Family Psychology*, 4(4), 462–483. <https://doi.org/10.1037//0893-3200.4.4.462>
- Kazak, A. E., Nash, J. M., Hiroto, K., & Kaslow, N. J. (2017). Psychologists in patient-centered medical homes (PCMHs): Roles, evidence, opportunities, and challenges. *American Psychologist*, 72(1), 1–12. <https://doi.org/10.1037/a0040382>
- Keilty, K., Cohen, E., Spalding, K., Pullenayegum, E., & Stremler, R. (2018). Sleep disturbance in family caregivers of children who depend on medical technology. *Archives of Disease in Childhood*, 103(2), 137–142. <https://doi.org/10.1136/archdischild-2016-312205>
- Keller, D. M. (2016). For Children with Medical Complexity, There Is No Place Like (The Medical) Home. *The Journal of Pediatrics*, 169, 11–12. <https://doi.org/10.1016/j.jpeds.2015.11.036>
- Kim, J. Y., Kim, D. G., & Nam, S. I. (2012). TSL Family Therapy Followed by Improved Marital Quality and Reduced Oxidative Stress. *Research on Social Work Practice*, 22(4), 389–399. <https://doi.org/10.1177/1049731512442104>

- Kritikos, T. K., Stiles-Shields, C., Winning, A. M., Starnes, M., Ohanian, D. M., Clark, O. E., del Castillo, A., Chavez, P., & Holmbeck, G. N. (2021). A Systematic Review of Benefit-Finding and Growth in Pediatric Medical Populations. *Journal of Pediatric Psychology*, *46*(9), 1076–1090. <https://doi.org/10.1093/jpepsy/jsab041>
- Krouwel, M., Jolly, K., & Greenfield, S. (2019). Comparing Skype (video calling) and in-person qualitative interview modes in a study of people with irritable bowel syndrome-an exploratory comparative analysis. *BMC Medical Research Methodology*, *19*(1), 1–9. <https://doi.org/10.1186/s12874-019-0867-9>
- Kuhaneck, H. M., Burroughs, T., Wright, J., Lemanczyk, T., & Darragh, A. R. (2010). A Qualitative Study of Coping in Mothers of Children with an Autism Spectrum Disorder. <Http://Dx.Doi.Org/10.3109/01942638.2010.481662>, *30*(4), 340–350. <https://doi.org/10.3109/01942638.2010.481662>
- Kuo, D. Z., Bird, T. mac, & Tilford, J. M. (2011). Associations of family-centered care with health care outcomes for children with special health care needs. *Maternal and Child Health Journal*, *15*(6), 794–805. <https://doi.org/10.1007/s10995-010-0648-x>
- Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*, *165*(11), 1020–1026. <https://doi.org/10.1001/archpediatrics.2011.172>
- Kuo, D. Z., Houtrow, A. J., Norwood, K. W., Adams, R. C., Brei, T. J., Davidson, L. F., Davis, B. E., Friedman, S. L., Hyman, S. L., Noritz, G. H., Yin, L., Murphy, N. A., Pitre, J. B., Mann, M., Peacock, G., Simpser, E., Smith, P. J., & Mucha, S. (2016). Recognition and management of medical complexity. *Pediatrics*, *138*(6). <https://doi.org/10.1542/peds.2016-3021>
- Kuo, D. Z., Melguizo-Castro, M., Goudie, A., Nick, T. G., Robbins, J. M., & Casey, P. H. (2014). Variation in Child Health Care Utilization by Medical Complexity. *Maternal and Child Health Journal*, *19*(1), 40–48. <https://doi.org/10.1007/s10995-014-1493-0>
- Kuster, P. A., & Merkle, C. J. (2004). Caregiving stress, immune function, and health: Implications for research with parents of medically fragile children. *Comprehensive Child and Adolescent Nursing*, *27*(4), 257–276. <https://doi.org/10.1080/01460860490884165>
- LaMontagne, L. L., Hepworth, J. T., Pawlak, R., & Chiafery, M. (1992). Parental coping and activities during pediatric critical care. *American Journal of Critical Care*, *1*(2), 76–80. <https://doi.org/10.4037/AJCC1992.1.2.76>
- LaMontagne, L. L., & Pawlak, R. (1990). Stress and coping of parents of children in a pediatric intensive care unit. *Heart & Lung : The Journal of Critical Care*, *19*(4), 416–421.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. Springer Publishing Company, Inc.
- Lee, R. L. T., & Lau, V. W. K. (2013). An interpretive phenomenological study of Chinese mothers' experiences of constant vigilance in caring for a hospitalized sick child. *Journal of Advanced Nursing*, *69*(8), 1808–1818. <https://doi.org/10.1111/jan.12042>
- Lumsden, M. R., Smith, D. M., Twigg, E., Guerrero, R., & Wittkowski, A. (2020). Children with single ventricle congenital heart defects: An interpretative phenomenological analysis of the lived parent experience. *Progress in Pediatric Cardiology*, *59*(September), 101297. <https://doi.org/10.1016/j.ppedcard.2020.101297>
- Maternal and Child Health Bureau. (2019). *National Survey of Children's Health*. <https://www.childhealthdata.org>

- McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs: A systematic review. *Journal of Child Health Care, 16*(1), 26–52. <https://doi.org/10.1177/1367493511420186>
- McCann, D., Bull, R., & Winzenberg, T. (2015). Sleep Deprivation in Parents Caring for Children With Complex Needs at Home: A Mixed Methods Systematic Review. *Journal of Family Nursing, 21*(1), 86–118. <https://doi.org/10.1177/1074840714562026>
- McInerney, T. K., Barone, C. J., Johnson, A. D., Lander, R., Mitsunaga, R. Y., Reuben, M. S., Walentik, C. A., Wegner, S. E., & Werner, M. J. (2006). Financing of pediatric home health care. Committee on Child Health Financing, Section on Home Care, American Academy of Pediatrics. *Pediatrics, 118*(2), 834–838. <https://doi.org/10.1542/PEDS.2006-1489>
- McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., Perrin, J. M., Shonkoff, J. P., & Strickland, B. (1998). A new definition of children with special health care needs. In *Pediatrics*. <https://doi.org/10.1542/peds.102.1.137>
- Meltzer, L. J., & Mindell, J. A. (2006). Impact of a child’s chronic illness on maternal sleep and daytime functioning. *Archives of Internal Medicine, 166*(16), 1749–1755. <https://doi.org/10.1001/archinte.166.16.1749>
- Mosquera, R. A., Avritscher, E. B. C., Pedroza, C., Bell, C. S., Samuels, C. L., Harris, T. S., Eapen, J. C., Yadav, A., Poe, M., Parlar-Chun, R. L., Berry, J., & Tyson, J. E. (2020). Hospital Consultation From Outpatient Clinicians for Medically Complex Children. *JAMA Pediatrics, 77030*, e205026. <https://doi.org/10.1001/jamapediatrics.2020.5026>
- Mullins, L. L., Molzon, E. S., Suorsa, K. I., Tackett, A. P., Pai, A. L. H., & Chaney, J. M. (2015). Models of Resilience: Developing Psychosocial Interventions for Parents of Children with Chronic Health Conditions. *Family Relations, 64*(1), 176–189. <https://doi.org/10.1111/fare.12104>
- Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development, 33*(2), 180–187. <https://doi.org/10.1111/j.1365-2214.2006.00644.x>
- Murphy, N. A., & Clark, E. B. (2016). Children with Complex Medical Conditions: an Under-Recognized Driver of the Pediatric Cost Crisis. *Current Treatment Options in Pediatrics, 2*(4), 289–295. <https://doi.org/10.1007/s40746-016-0071-7>
- Neff, J. M., Sharp, V. L., Muldoon, J., Graham, J., & Myers, K. (2004). Profile of Medical Charges for Children by Health Status Group and Severity Level in a Washington State Health Plan. *Health Services Research, 39*(1), 73–89. <https://doi.org/10.1111/j.1475-6773.2004.00216.x>
- Nicholas, D. B., & Keilty, K. (2007). An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance. *Social Work in Health Care, 44*(3), 245–259. https://doi.org/10.1300/J010v44n03_08
- Nygård, C., & Clancy, A. (2018). Unsung heroes, flying blind—A metasynthesis of parents’ experiences of caring for children with special health-care needs at home. *Journal of Clinical Nursing, 27*(15–16), 3179–3196. <https://doi.org/10.1111/jocn.14512>
- October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The Parent Perspective: “Being a Good Parent” When Making Critical Decisions in the PICU. *Pediatric Critical Care Medicine: A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies, 15*(4), 291. <https://doi.org/10.1097/PCC.0000000000000076>

- Özdemir, T., Karadağ, G., & Kul, S. (2021). Relationship of Gratitude and Coping Styles with Depression in Caregivers of Children with Special Needs. *Journal of Religion and Health* 2021, 1–14. <https://doi.org/10.1007/S10943-021-01389-1>
- Park, C. L., Armeli, S., & Tennen, H. (2004). *Appraisal-Coping Goodness of Fit: A Daily Internet Study*. <https://doi.org/10.1177/0146167203262855>
- Park, C. L., & Folkman, S. (1997). Meaning in the Context of Stress and Coping: *Https://Doi.Org/10.1037/1089-2680.1.2.115*, 1(2), 115–144. <https://doi.org/10.1037/1089-2680.1.2.115>
- Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *Journal of the American Medical Association*, 297(24), 2755–2759. <https://doi.org/10.1001/jama.297.24.2755>
- Peter, S., Chaney, G., Zappia, T., Van Veldhuisen, C., Pereira, S., & Santamaria, N. (2011). Care coordination for children with complex care needs significantly reduces hospital utilization. *Journal for Specialists in Pediatric Nursing*, 16(4), 305–312. <https://doi.org/10.1111/j.1744-6155.2011.00303.x>
- Pielech, M., Vowles, K. E., & Wicksell, R. (2017). Acceptance and commitment therapy for pediatric chronic pain: Theory and application. In *Children* (Vol. 4, Issue 2). MDPI. <https://doi.org/10.3390/children4020010>
- Rennick, J. E., St-Sauveur, I., Knox, A. M., & Ruddy, M. (2019). Exploring the experiences of parent caregivers of children with chronic medical complexity during pediatric intensive care unit hospitalization: An interpretive descriptive study. *BMC Pediatrics*, 19(1), 1–10. <https://doi.org/10.1186/S12887-019-1634-0/TABLES/4>
- Romley, J. A., Shah, A. K., Chung, P. J., Elliott, M. N., Vestal, K. D., & Schuster, M. A. (2017). Family-provided health care for children with special health care needs. *Pediatrics*, 139(1). <https://doi.org/10.1542/peds.2016-1287>
- Rosenberg, A. R., Zhou, C., Bradford, M. C., Barton, K., Junkins, C. C., Taylor, M., Kross, E. K., Curtis, J. R., Dionne-Odom, J. N., & Yi-Frazier, J. P. (2021). Parent Perspectives after the PRISM-P Randomized Trial: A Mixed-Methods Analysis. *Https://Home.Liebertpub.Com/Jpm*, 24(10), 1505–1515. <https://doi.org/10.1089/JPM.2020.0720>
- Schadewald, A., Kimball, E., & Ou, L. (2018). Coping Strategies, Stress, and Support Needs in Caregivers of Children with Mucopolysaccharidosis. *JIMD Reports*, 42, 89–97. https://doi.org/10.1007/8904_2017_87
- Schaefer, M. R., Kenney, A. E., Himelhoch, A. C., Howard Sharp, K. M., Humphrey, L., Olshefski, R., Young Saleme, T., & Gerhardt, C. A. (2020). A quest for meaning: A qualitative exploration among children with advanced cancer and their parents. *Psycho-Oncology*. <https://doi.org/10.1002/pon.5601>
- Schall, T. E., Foster, C. C., & Feudtner, C. (2020). Safe Work-Hour Standards for Parents of Children with Medical Complexity. In *JAMA Pediatrics* (Vol. 174, Issue 1, pp. 7–8). American Medical Association. <https://doi.org/10.1001/jamapediatrics.2019.4003>
- Schweitzer, R., Griffiths, M., & Yates, P. (2012). Parental experience of childhood cancer using Interpretative Phenomenological Analysis. *Psychology and Health*, 27(6), 704–720. <https://doi.org/10.1080/08870446.2011.622379>
- Seideman, R. Y., Watson, M. A., Corff, K. E., Odle, P., Haase, J., & Bowerman, J. L. (1997). *Parent Stress and Coping in NICU and PICU*.

- Semansky, R. M., & Koyanagi, C. (2004). The TEFRA medicaid eligibility option for children with severe disabilities: A national study. *Journal of Behavioral Health Services and Research*, 31(3), 334–342. <https://doi.org/10.1007/bf02287295>
- Shalowitz, M. U., Isacco, A., Barquin, N., Clark-Kauffman, E., Delger, P., Nelson, D., Quinn, A., & Wagenaar, K. A. (2009). Community-based participatory research: A review of the literature with strategies for community engagement. *Journal of Developmental and Behavioral Pediatrics*, 30(4), 350–361. <https://doi.org/10.1097/DBP.0B013E3181B0EF14>
- Simon, T. D., Berry, J., Feudtner, C., Stone, B. L., Sheng, X., Bratton, S. L., Dean, J. M., & Srivastava, R. (2010). Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics*, 126(4), 647–655. <https://doi.org/10.1542/peds.2009-3266>
- Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the Structure of Coping: A Review and Critique of Category Systems for Classifying Ways of Coping. In *Psychological Bulletin* (Vol. 129, Issue 2, pp. 216–269). <https://doi.org/10.1037/0033-2909.129.2.216>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive Phenomenological Analysis* (1st ed.). Sage.
- Smith, J. A., & Osborn, M. (2003). Interpretive phenomenological analysis. In J. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). SAGE Publications Inc.
- Sobotka, S. A., Lynch, E., Quinn, M. T., Awadalla, S. S., Agrawal, R. K., & Peek, M. E. (2019). Unmet Respite Needs of Children With Medical Technology Dependence. *Clinical Pediatrics*, 58(11–12), 1175–1186. <https://doi.org/10.1177/0009922819870251>
- Suls, J., & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, 4(3), 249–288. <https://doi.org/10.1037/0278-6133.4.3.249>
- Sweet, L. (2002). Telephone interviewing: is it compatible with interpretive phenomenological research? *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 12(1), 58–63. <https://doi.org/10.5172/conu.12.1.58>
- Thomson, J., Shah, S. S., Simmons, J. M., Sauers-Ford, H. S., Brunswick, S., Hall, D., Kahn, R. S., & Beck, A. F. (2016). Financial and social hardships in families of children with medical complexity. *Journal of Pediatrics*, 172, 187–193. <https://doi.org/10.1016/j.jpeds.2016.01.049>
- Thyen, U., Kuhlthau, K., & Perrin, J. M. (1999). Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics*, 103(6 I), 1235–1242. <https://doi.org/10.1542/peds.103.6.1235>
- Thyen, U., Terres, N. M., Yazdgerdi, S. R., & Perrin, J. M. (1998). Impact of Long-Term Care of Children Assisted by Technology on Maternal Health. *Journal of Developmental and Behavioral Pediatrics*, 19(4), 273–282. <https://doi.org/10.1097/00004703-199808000-00006>
- Tutelman, P. R., Chambers, C. T., Urquhart, R., Fernandez, C. V., Heathcote, L. C., Noel, M., Flanders, A., Guilcher, G. M. T., Schulte, F., Stinson, J. N., MacLeod, J., & Stern, M. (2019). When “a headache is not just a headache”: A qualitative examination of parent and child experiences of pain after childhood cancer. *Psycho-Oncology*, 28(9), 1901–1909. <https://doi.org/10.1002/pon.5170>

- Verma, R., Mehdian, Y., Sheth, N., Netten, K., Vinette, J., Edwards, A., Polyviou, J., Orkin, J., & Amin, R. (2020). Screening for caregiver psychosocial risk in children with medical complexity: a cross-sectional study. *BMJ Paediatrics Open*, 4(1), e000671. <https://doi.org/10.1136/bmjpo-2020-000671>
- Wisconsin Department of Health Services. (2019). *Katie Beckett Program: Eligibility*. <https://www.dhs.wisconsin.gov/kbp/eligibility.htm>
- Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, 15(1), 1–15. <https://doi.org/10.1186/s12887-015-0514-5>
- Yu, S. M., & Singh, G. K. (2009). Household language use and health care access, unmet need, and family impact among CSHCN. *Pediatrics*, 124(SUPPL. 4). <https://doi.org/10.1542/peds.2009-1255M>