NATURE OF GOOD-PARENT BELIEFS OF PARENTS OF CHILDREN SERVED BY A PEDIATRIC COMPLEX CARE PROGRAM

by

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ABSTRACT

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Good-parent beliefs, one's idea of what it means to be a "good parent" to their child, function to help guide parental decision-making and facilitate coping in the context of pediatric illness. Among parents of children with advanced cancer and other complex illnesses, mixed-methods research has identified common themes across individuals' good-parent beliefs. However, the good-parent beliefs of primary caregivers of children served by Complex Care Programs (CCPs) have not yet been explored. CCPs serve children with medical complexity (CMC), a distinct group of pediatric patients with multiple complex chronic medical illnesses and intensive medical involvement. Due to the chronicity and complexity of their conditions, parental medical decision-making for these children, and parent coping, are unique from other pediatric populations. This study aimed to describe the good-parent beliefs of primary caregivers of children served by CCPs and describe how these programs can best provide care in a way that aligns with parents' good-parent beliefs. The current study included 15 primary caregivers of children served by a CCP at a large midwestern academic medical center. Qualitative interviews were conducted and analyzed using thematic analysis. All participants were able to describe their good-parent beliefs, and there were 16 good-parent beliefs identified in the sample. Good-parent beliefs were associated with medication- and surgery-related decision-making. They often provided direction to parents in managing their child's complex needs, but they also served to

incite rumination, identity challenges, and self-judgement for some. Despite not discussing good-parent beliefs directly with CCP staff, most participants felt that providers both understood their good-parent beliefs and acted in ways that helped parents to feel like a "good parent." While many good-parent beliefs in the present study reflect those identified in other pediatric parent populations, current results suggest additional beliefs which have a focus on children's growth and development, and on parent/caregiver well-being, as part of the role of being a "good parent" of CMC. Clinical implications are numerous for both pediatric medical and psychosocial providers, including the possibility of future development of population-specific psychotherapeutic interventions for caregivers. Future research is needed to elucidate the nature of good-parent beliefs more fully in this population, understand their functions, and guide clinicians to work most effectively with these families.

Keywords: good-parent beliefs, pediatric complex care, children with medical complexity

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NATURE OF GOOD-PARENT BELIEFS OF PARENTS OF CHILDREN SERVED BY A PEDIATRIC COMPLEX CARE PROGRAM

Introduction

Parents of children with serious illness must often make challenging medical decisions while managing the complex and emotionally demanding landscape of the pediatric healthcare system. Many initial models of pediatric medical decision-making focus on logistical factors as drivers of decision-making. However, there is an emerging focus on the personal cognitive and affective factors which influence parental decision-making in the context of serious pediatric illness (Feudtner et al., 2018). Parents report deeply held beliefs about their sense of parental duty to their children which inform their decision-making process (Feudtner et al., 2015, 2018; Hinds et al., 2009). As a central component of the parental sense of duty, parents report a need to be a "good parent" to their child. "Good-parent beliefs" are the ideals with which one must align to be a "good parent" on their own terms. These beliefs differ across individuals, yet they have been found to strongly influence parents' medical decisions for their children (Hinds et al., 2009). Furthermore, parents who can align their decisions with these beliefs experience positive psychological outcomes, suggesting that a secondary function of good-parent beliefs is to contribute toward sustaining parents' ability to cope with emotional challenges (Weaver et al., 2020a).

While good-parent beliefs have been identified and assessed in various pediatric serious illness populations, extant research has not yet explored them in the population of parents whose children are served by Complex Care programs. These programs serve a subset of the pediatric population, children with medical complexity, who experience several chronic complex conditions, medical fragility, functional limitations, and high healthcare resource use (Cohen, Kuo, et al., 2011). This population is distinct from those previously studied in the good-parent

beliefs literature due to their medical fragility and the long-term chronic nature of their conditions, typically involving frequent intensive care hospitalizations, surgeries, and/or dependence on life-sustaining technology. The intensive medical care required to care for children with medical complexity often results in a frequent need for parents to make highly consequential decisions. This results in parent decisional fatigue over time (Jonas et al., 2022). In addition, parents of children with medical complexity must also sustain their own coping while managing high caregiving demands. This struggle has been termed "intense parenting" for the emotional, cognitive, and logistical challenges these parents face to care for their children and themselves (Woodgate et al., 2015). For these reasons, an empirical understanding of the nature of good-parent beliefs, and how Complex Care programs can support parents in aligning care with these beliefs, is essential.

The current study has two primary aims: 1) to describe the good-parent beliefs of parents of children who are served by a pediatric complex care program, and 2) to describe ways in which pediatric complex care programs can support parental caregivers in aligning medical care with their good-parent beliefs. To achieve these aims, the study used a qualitative approach involving virtual interviews with a diverse sample of parents of children who are served by the Complex Care Program at a large children's hospital in the midwestern United States.

Defining Good-Parent Beliefs

Parents of medically ill children have an internal sense of what it means to them to be a "good parent" to their child (Feudtner et al., 2015; Weaver et al., 2020a). In fact, 85% of parents with a seriously ill child report that the term "trying to be a good parent" resonates with them (Weaver et al., 2020b). Initial findings from a study of parents of children with cancer (Hinds et al., 2009) defined good-parent beliefs in the following way:

The good parent makes informed, unselfish decisions in the child's best interest; provides the basics of food, shelter, and clothing; remains at the child's side regardless of the circumstances; shows the child that he or she is cherished; tries to prevent suffering and protect health; teaches the child to make good choices, to respect and have sympathy for others, and to know God; advocates for the child with staff; and promotes the child's health.

While these beliefs may be common across parents of children with and without medical conditions, the good-parent concept has been studied solely among parents of children with medical conditions. This is primarily owing to the influence of these beliefs on medical decision-making and family relationships in the context of pediatric illness (Weaver et al., 2020a). In fact, while there is some universality to the idea of being a "good parent" to all of one's children, about half of parents with an ill child report having distinct good-parent beliefs for their ill versus healthy children (Weaver et al., 2020b). The origins of these beliefs often begin prior to a child's birth (Weaver et al., 2020b). While it is unknown whether specific good-parent beliefs influence child medical outcomes, these beliefs have been found to change over time (Weaver et al., 2020b), and, for some, particularly as their child's condition progresses (Hill et al., 2020).

The foundational literature in this domain led to the creation of a list of common "good-parent attributes" (Table 1). Recognizing the importance of these beliefs for helping to guide parents to make highly consequential and emotionally challenging decisions for their children, Feudtner and colleagues (2015) designed a study in which parents of seriously ill children rank-ordered these twelve attributes according to their level of personal significance. The modal prioritized good-parent beliefs were "my child feels loved," "focusing on my child's health," "making informed medical care decisions," and "advocating for my child with medical staff."

However, among this sample of 200 parents, ratings were highly diverse, and parents were classified into four distinct "belief groups" based on their prioritization of the attributes: "child feels loved," "child's health," "advocacy and informed," and "spiritual well-being" (Feudtner et al., 2015).

The heterogeneity of good-parent beliefs and the way parents prioritize types of beliefs invite questions about how and why parents come to endorse them. Causal inferences have not yet been established in the good-parent literature, but associations between individual and group characteristics have been identified. Overall, evidence for variation in good-parent beliefs by parental sociodemographic and psychological characteristics is mixed. One study of parents of children hospitalized in a PICU did not find any associations with specific good-parent beliefs by parental age, race, religion, or socioeconomic status (October et al., 2014). In a sample from a similar population, 200 parents completed a discrete-choice experiment in which they were asked to prioritize various good-parent beliefs, resulting in a rank-ordered list of good-parent beliefs for each participant. Beliefs were grouped into four categories: "child feels loved," "child's health," "advocacy and informed," and "spiritual well-being." This study found non-association between parental race and good-parent beliefs, yet other demographic trends were observed. The "child's health" group (i.e., those who primarily prioritized their child's health as part of being a "good parent") had the highest percentage of parents who were not married and who had greater financial difficulties. The same group also had the lowest percentage of parents who were college-educated and who had private health insurance (Feudtner et al., 2015). This may suggest that parents who are more overwhelmed tend to focus more on the immediate medical needs of their child. In contrast, the "spiritual well-being" group included more parents who were married and who had fewer financial difficulties. Of all four groups, the "spiritual

well-being" group also reported the lowest levels of negative affect and highest levels of hopeful thinking. The authors suggest either that parents who less overwhelmed tend to focus on more on spiritual beliefs, or that engaging with spirituality promotes well-being (Feudtner et al., 2015).

Regarding the relationship between gender and good-parent beliefs, more fathers than mothers prioritized making informed medical decisions as part of their "good parent" definition in a PICU parent population (October et al., 2014) and in a broader pediatric intensive care parent population (Feudtner et al., 2015). Single mothers of seriously ill children were also more likely to be represented in the "advocacy and informed" group (Feudtner et al., 2015). Only one study specifically focused on the good-parent beliefs of fathers. Among fathers of children with complex cardiac conditions, being a supportive presence for their child was the most reported aspect of being a good parent (Robinson et al., 2019). Without larger-scale studies, it remains uncertain the extent to which there are systematic gender differences in good-parent beliefs. Presently, these data may simply serve to underscore the idiosyncratic nature of such beliefs and the possibility that they may be influenced by societal gender expectations.

Since its initial introduction into the literature, the concept has been examined in other pediatric parent populations, and novel good-parent attributes have been proposed. The qualitative study with fathers of children with complex cardiac conditions echoed many thematic findings of the initial good-parent study. It also further highlighted that for men, being a "good father" involves grappling with a "crashing reality" of simultaneously maintaining responsibilities of providing economic and financial stability for a family while also being physically present and emotionally supportive (Robinson et al., 2019). A similar theme relating to conflicting responsibilities was also documented in an online support group for parents of seriously ill children. This theme, "finding a balance," was defined as "striking a balance

between keeping their child safe and letting them live as 'normally' as possible,' of meeting their child's medical needs but also treating them as 'a child first,' of being there for their medically complex child but also for their other children, their partner, and/or their work" (Weaver et al., 2020b). Among parents facing medical decisions in a PICU, most previously reported themes resonated. Another novel theme emerged, however, which researchers termed "having a legacy," defined as "parent wants to honor the ill child's memory by allowing the child to live on in someone else" (October et al., 2014). That the original good-parent attributes resonate with diverse groups of parents, and that additions have been made in subsequent research, point to both the universality and the idiosyncratic nature of good-parent beliefs. While the idea of "being a good parent" is easily understood by those with an ill child, the internally-held definition of the concept is unique across parents.

Despite the heterogeneity in the attributes parents prioritize, the term "trying to be a good parent" resonates with 85% of parents of children with chronic medical conditions (Weaver, et al., 2020b). As such, the high frequency of parents reporting having these beliefs has led to subsequent research attempting to identify the functions of good-parent beliefs. The following sections will address the two primary and interrelated functions of good-parent beliefs for parents of children with medical conditions: guiding decision-making and facilitating coping.

Good-Parent Beliefs as a Guide for Decision-Making

To date, the primary scientific motivation for identifying and understanding good-parent beliefs has been to support clinicians' abilities to help parents facing challenging medical decisions for their children, as good-parent beliefs play a critical role in parental decision-making. To understand this role with more specificity, it is necessary to first examine the practice of parental medical decision making in pediatrics.

In recent decades, the practice of medical decision making has shifted from a paternalistic system in which providers dictate decision-making to a modern system which prioritizes shared decision making (SDM), defined as a collaborative partnership in which parents, children, and health providers are active participants working toward a common goal for the child's health, and in which outcomes are reached through mutual agreement (Park & Cho, 2018). Parents of seriously ill children must often make extremely challenging medical decisions at multiple time points across the illness trajectory. This process is often complex, confusing, and driven by emotion (Bennett & LeBaron, 2019; Feudtner et al., 2018). To describe the components of this process, Feudtner and colleagues suggest a model of parental medical decision-making which prioritizes an understanding of the child's medical situation while also considering parental cognitive and emotional factors (Feudtner et al., 2018) and cognitive heuristics (Renjilian et al., 2013). The model introduces five components of the decision-making process: problem structuring, sense-making, path dependency, personal sense of duty, and self-judgement (Feudtner et al., 2018).

Making a medical decision for one's child first involves not only the identification and prioritization of the problem itself, which is often one of many possible problems for which a solution must be found, but also identifying the many possible solutions. This process is known as problem structuring, and it helps to lay the cognitive foundation for decision making. Sense-making requires the parent to consider the decision in relation to the broader context, such as their treatment goals for their child, the complexity of the child's illness, and the broader healthcare system. The third component, "path dependency," describes the influence of each medical decision on the child's treatment path and subsequent decision points. As such, each medical decision involves a consideration of the next medical decision that may come, which

will be entirely dependent on the decision which is made in the current moment (Feudtner et al., 2018).

The subsequent remaining components of the model consider the cognitive, emotional, and social impact of decision-making for parents. Parents report feeling a "personal sense of duty" toward their children, which is heavily impacted by both one's own sense of parental identity and by cultural expectations. This duty is informed by two components: explicit heuristics and one's good-parent beliefs. Explicit heuristics are cognitive shortcuts and essential tools for parents making medical decisions. The most commonly reported include "I want my child to be comfortable" and "I want my child to have quality of life" (Renjilian et al., 2013). These heuristics serve several core functions: to facilitate sense-making of the medical situation, to organize information in the context of the medical decision, to guide decision-making toward valued goals, to facilitate communication about treatment, and/or to justify decisions before or after they have been made (Renjilian et al., 2013). Good-parent beliefs, the other component of the parental sense of duty, are the values and actions to which parents adhere to be, on their own terms, a "good parent" to their child (Feudtner et al., 2018). The authors posit that failure to act in alignment with these beliefs invites self-judgement, which is the final component of the decision-making model and serves as a moral compass for parents in the decision-making process (Feudtner et al., 2018; Hinds et al., 2005).

Qualitative data supports the model's position that parents' cognitions and emotions, and good-parent beliefs specifically, are primary drivers of decision making during critical medical decision points (Bennett & LeBaron, 2019). Rather than solely relying on medical facts and provider recommendations, parents report that rely on their good-parent beliefs to orient decision-making such that it is as consistent as possible with their values (Feudtner et al., 2015).

This was initially documented among parents of children with advanced cancer who were faced with making end-of-life decisions for their children. When asked about factors that influenced decision-making, "deciding as a good parent would" was reported by 84% of parents. Of nine reported factors, it was the second most-reported factor after "deciding as my child prefers" (95%) and it was tied in frequency with "trusting staff and being supported by them" (Hinds et al., 2005).

That parents experience a nearly universal drive to act as a "good parent" is not sufficiently useful for clinicians attempting to support them in decision-making. It is the content of these beliefs – what, to each parent, it means to them to be a "good parent" – that influences the decision-making course. As one example of this process and the way in which good-parent beliefs can alter treatment trajectory, regoaling is the process that occurs when parents' initial medical goals for their child, such as curing their medical condition, become untenable, and the parent must choose a different medical treatment option (Hill et al., 2014). Good-parent beliefs shape the regoaling process by allowing parents a compass against which to evaluate the acceptability of potential goals for their child (Hill et al., 2020). For example, believing that a good parent "never gives up" on their child may guide a parent to take more life-sustaining measures than a parent who, first and foremost, believes that a good parent "keeps my child comfortable," for whom enrolling their child in hospice care may be the most values-aligned option.

Empirical data supports that differential medical trajectories are associated with different good-parent beliefs. To date, the largest study of good-parent beliefs included 200 English-speaking parents of children hospitalized in an intensive care unit who had been referred to a palliative care service at a single hospital center (Feudtner et al., 2015). As mentioned above,

despite the diverse clinical presentations of the patients whose parents participated in the study, four patterns of parental preferences emerged across participants: "child feels loved," "child's health," "advocacy and informed," and "spiritual well-being" (Feudtner et al., 2015). Between these categories, certain clinical characteristics were associated with differences in good-parent beliefs. Specifically, parents of children with a newly diagnosed complex chronic condition were more likely to prioritize their child's health above other good-parent beliefs than parents whose children had been living with a diagnosed condition for longer, suggesting that the experience of a new diagnosis may influence parents to prioritize more concrete aspects of well-being (Feudtner et al., 2015). Further, the group who most heavily prioritized their child's health was also the group with the fewest do-not-resuscitate orders for their children (Feudtner et al., 2015). In an end-of-life decision-making study among parents of children with cancer, participants who enrolled their children in a Phase I clinical trial more frequently endorsed good-parent beliefs aligned with medical decision-making and prolonging life, while those who instead opted for do-not-resuscitate orders more frequently endorsed good-parent beliefs aligned with prioritizing quality of life and honoring the child's wishes (Maurer et al., 2010).

Taken together, findings suggest associations between clinical characteristics and types of good-parent beliefs most prioritized. It has been posited that good-parent beliefs drive decision-making. It is also possible that parents make decisions using other means and then use good-parent beliefs to help them understand or explain their decision after the fact. Good-parent beliefs are dynamic and can change over time (Hill et al., 2019), which may make it possible for parents to choose one decision early in treatment and a seemingly opposite option later in treatment—and have both align with their most highly prioritized good-parent beliefs at a given time. While it has been the topic of fewer research studies, the use of good-parent beliefs to help

understand or make sense of a given situation appears to be a secondary critical function of these beliefs, as will be explored in the subsequent section.

Good-Parent Beliefs as Tools to Facilitate Coping

Perhaps the clearest context in which good-parent beliefs are known to be implicated in positive coping is in bereavement, during which simply reflecting on one's good-parent beliefs may be a source of comfort. Parents of children with advanced disease report a deep need to feel as though they have been "good parents" to their children to help them feel peace after their child's death (Hinds et al., 2005, 2009; Maurer et al., 2010). Similarly, bereaved parents reflect on communication with providers in which their parental identity and the parent-child relationship were honored as the most supportive form of communication during their child's end-of-life period (Sedig et al., 2020). Bereaved parents often seek confirmation of their roles as "good parents" as part of making meaning following the death of their child, and the belief that one has achieved this role may be a component of positive identity reconstruction (Meert et al., 2015). For many parents, feeling that they are a "good parent" during bereavement involves recalling qualities of self-sacrifice, insight into the child's condition, and focusing on quality of life, and providing as much normalcy as possible for their ill child (Meert et al., 2015).

In addition to internally reflecting on good-parent beliefs, parents may also sustain coping during their child's illness but communicating about these beliefs. Social communication influences one's self-concept, helping individuals understand their own identities (Hecht, 1993). It follows that for parents of children with medical conditions, constructing and maintaining a "good parent" identity may occur most effectively through communication with their child's medical team (Weaver et al., 2021). The medical team is particularly important for parents of children with medical conditions because families of children undergoing medical treatment

spend much of their time in this environment and build close relationships with their providers. As such, parent-clinician communication about good-parent beliefs may be an effective pathway by which parents sustain their own well-being during their child's medical treatment (Weaver et al., 2020a).

There is an emerging understanding of the ways in which the "good parent" identity may be fostered through interactions with medical providers. In care conferences, clinicians often use good-parent praise statements, defined as statements that demonstrate appreciation for the parents' role in caring for their children, in anticipation of discussing an upcoming critical decision or in response to displays of parents' emotions. Such praises serve to provide emotional reassurance and comfort and to reduce feelings of guilt regarding challenging medical decisions (Porter et al., 2021). Further, parents of children with medical complexity report feeling the need to be perceived as "good parents" by others (Woodgate et al., 2015), and clinicians who know their children well may be uniquely situated to provide this type of praise. Put simply, specific reassurance from providers in which a parent's identity as a "good parent" may facilitate parent coping. Accordingly, from diagnosis onward, clinicians are encouraged to acknowledge parents' need to feel that they are "good parents" and communicating reassurance that they are, in fact, "good parents" (Haward et al., 2020; Hinds et al., 2001). Emerging research, detailed in the following section, has begun to elucidate the ways in which clinician behavior may serve this purpose, and in contrast, the ways in which it may disrupt parent coping.

Good-Parent Beliefs and Clinician-Parent Relationships

Parents of seriously ill children can readily identify certain clinician behaviors which they feel can either foster or hinder good-parent beliefs (Weaver et al., 2020a). When asked to describe clinician behaviors that would "foster your ability to work toward your personal

definition of 'being a good parent,'" parents of children with serious illnesses reported three broad themes: "*acknowledge the parent's caregiving role*," "*truly see the child*," and engage in "*kind and caring communication with parents*" (Neumann et al., 2021). Similarly, parents of children with advanced cancer most commonly describe that clinicians help them in their efforts to be "good parents" by "*respect*[ing] *me and my decisions*" (33%). Other common responses include "*like our child*," defined as "openly convey affection and positive regard for ill child" or "show humor with child" (30%), "*continue to comfort me and my child*" (27%), "*know our special needs*" (27%), and being "*pleasant*," defined as being "consistently positive, caring, understanding of patient/parent mood swings, affectionate, and playful" (22%, Hinds et al., 2009). In a study investigating good-parent beliefs among parents of children hospitalized in a PICU, clinician behaviors that would reportedly help individuals parent their ill children included "*keep me informed"* (32%), "*be attentive*" (12%), and "*keep providing good care*" (12%). Parents also valued clinicians who were considerate (8%), collaborative (8%), supportive (7%), honest (7%), and those who allowed for parents to "*let me be a parent to my child*" (e.g., participate in daily care of child, 4%). Few parents reported that there was "*nothing*" the care team could do because the "care of the ill child is the sole responsibility of the parent" (10%, October et al., 2014). Fathers of children with cardiac conditions reported that clinicians could support them in succeeding as "good parents" by communicating with them directly, providing opportunities for social support, providing information directed to fathers specifically, and aiding with economic support (Robinson et al., 2019).

In contrast to these valued behaviors, certain clinician actions are perceived to threaten or challenge parents' ability to be "good parents." These include engaging in "poor communication with parents," such as engaging without empathy and openness and not listening to parents, "not

seeing the big picture or recognizing family impact of treatment decisions," and "not valuing parent expertise or wishes" (Neumann et al., 2021). Across studies, clinician behaviors which are perceived to support parents in feeling as though they are "good parents" include respecting parental autonomy, providing knowledgeable and compassionate care, and maintaining communication with parents. Parents may feel that behaviors which are misaligned with these tenets make it more challenging for parents to act in alignment with their good-parent beliefs.

Population of Focus: Children with Medical Complexity

Advances in pediatric medicine have allowed an expanding cohort of children with chronic medical conditions to experience improved survival outcomes (Burns et al., 2010; Cohen, Kuo, et al., 2011). One such group of pediatric patients, children with medical complexity (CMC), experience the highest intensity of medical involvement (Kuo et al., 2016). Historically, these children were identified primarily by the complexity of their medical conditions (Feudtner et al., 2014), such as neurologic or neuromuscular disorders, gastrointestinal conditions, and/or congenital or genetic conditions (Murphy et al., 2020). However, more recent efforts to define this population have included consideration of additional functional and need-related factors to encompass the clinical context of these children and families more fully (Cohen, Kuo, et al., 2011). According to Cohen et al. (2011), CMC are identified using the following definitional framework:

a) Diagnosed or suspected complex chronic medical conditions, usually associated with medical fragility
b) High levels of family-identified service needs and significant impact on family
c) Severe functional limitations, often associated with technology dependence
d) High utilization of healthcare resources requiring multiple medical providers

In addition to care from multiple medical providers, many CMC also receive home- or school-based cares and therapies. They also frequently receive care in the hospital environment. CMC have represented an increasing proportion of overall pediatric hospital stays over the last several decades (Kuo et al., 2014; Simon et al., 2010). In a sample of CMC cared for by one of four hospital systems, each patient carried, on average, 9.5 distinct diagnoses and had been admitted to the hospital a mean of three times, each for a mean of 12 days, over a two-year period (Berry et al., 2011). These intensive medical needs explain the high healthcare cost incurred by CMC, who represent 34% of pediatric Medicaid expenditures, but comprise only 0.4 to 0.7% of the pediatric population (Berry et al., 2014; Cohen et al., 2012).

Given the complexity and chronicity of their conditions, CMC have many needs from their caregivers. This type of caregiving requires extreme vigilance in the face of constant medical uncertainty (Cousino & Hazen, 2013; McCann et al., 2012; Nygård & Clancy, 2018). Consequently, parents of CMC often struggle to maintain their own wellbeing while simultaneously juggling their children's care needs (Woodgate et al., 2015). Compared with other pediatric parent samples, parents of CMC report the highest mean distress scores (Verma et al., 2020), which increased during the COVID-19 pandemic (Pitch et al., 2023). In fact, the COVID-19 pandemic added additional psychological and logistical burdens which may have ongoing impacts even post-pandemic (Tager et al., 2024). They are at high risk of clinical depression (Chan et al., 2019) and they often experience anticipatory anxiety related to their children's future needs (Murphy et al., 2007). Further, these psychosocial challenges occur within a system that provides very few resources to promote family well-being, such as respite care (Sobotka et al., 2019).

While not available to all families who would be eligible, pediatric Complex Care programs (CCPs) are one resource which aim to support families who care for CMC. To assist with intensive healthcare needs, pediatric CCPs provide care coordination and medical management, meeting unique needs of CMC and their families which are often not met in the general pediatric primary care setting (Kuo et al., 2016). Given the CMC population increase in recent decades, pediatric complex care has been identified its own emerging medical subspecialty (Cohen et al., 2018; Cohen, Kuo, et al., 2011). Approximately half of such programs are based entirely in a hospital system, while others have components based in the community or provide clinical services via home visit, and additional services provided by some CCPs include treatment planning, case management, family support, consultative visits with healthcare providers, and referrals to appropriate services (Cohen, Jovcevska, et al., 2011).

Some studies have begun to explore good-parent beliefs among broad samples of children with chronic conditions (e.g., Weaver et al., 2020). Still, to date, there has been no research systematically investigating good-parent beliefs or communication about this topic among parents of children who are served by CCPs. However, parents of children served by a CCP have been found to be readily able to define their good-parent beliefs in a pilot study investigating stress and coping in this population, and good-parent beliefs were understood to be a component of meaning-focused coping (Tager et al., in press). This is an important area of study given that CCPs are specifically designed to meet these families' unique needs. Because of the chronic and complex nature of medical conditions among children served by pediatric CCPs, providers in such programs help guide families through frequent high-risk medical decisions. Medical decisions for CMC commonly include 1) use of tracheostomy and ventilation (i.e., technology used to help patients breathe), 2) use of technology to enable feeding, such as a gastronomy tube,

3) surgeries and other interventions, and 4) advanced care planning and end-of-life decision making (Jonas et al., 2022). Just as the broad parent experiences in this population are qualitatively different from those of other pediatric parent populations (i.e., "intense parenting," Woodgate et al., 2015), the decision-making experience is also likely distinct (Jonas et al., 2022). This is due to the chronicity of the medical conditions occurring among CMC, requiring frequent, lifelong, highly consequential decisions to be made, as compared to those for parents of children with a serious but time-limited illness trajectory (e.g., during treatment for cancer, during an isolated PICU stay). It is not currently known whether these experiential differences would translate to unique good-parent beliefs among parents of children served by CCPs as compared to those populations previously studied.

The Current Study

Good-parent beliefs are strongly held beliefs which describe parental priorities regarding their medically ill children. The functions of these beliefs include driving medical decision-making and contributing to or facilitating coping. Children with medical complexity are a distinct group of pediatric patients characterized by intensive healthcare involvement and medical fragility. Families of patients served by pediatric CCPs have unique parenting experiences and make frequent, highly consequential medical decisions. However, it remains unknown whether these differences correspond with distinct good-parent beliefs as compared to those identified in other populations. It is also unknown how, if at all, CCPs can help parents more effectively align care with their good-parent beliefs. Accordingly, the aims of the current study are:

1. To describe the good-parent beliefs of parents of children who are served by a pediatric complex care program and contextualize these beliefs in relation to findings in other parent populations
2. To describe ways in which pediatric complex care programs can support parents in aligning care with their good-parent beliefs

Methods

Positionality

I identify as a white, cisgender female clinical psychology graduate student. I am not a parent. I have clinical experience working in a pediatric medical setting. I have worked clinically with patients who are served by a Complex Care program, but I do not have experience working as an embedded provider in pediatric Complex Care. Over the past nearly five years, I have conducted mixed-methods research focusing on stress, coping, and meaning making in the population of families whose children are served by Complex Care. As part of Pediatric Collaborative for Resilience and Emotional Wellness Science (CREWS), the research team collaborating with me to conduct the research, I am a member of a study team including pediatricians in Complex Care and Critical Care, psychologists, nurses, project managers, graduate students, and research coordinators.

The following assumptions underlie this research project:

1. As a result of sociocultural and systemic barriers to accessing needed resources (e.g., quality respite and nursing care), and the intensive needs of their children, the lives of parents who care for children with medical complexity are inherently stressful. Most parents and families are also highly resilient. Their stressors and caregiving responsibilities do not define parents' lives, and yet these are important aspects of their experiences.
2. Most parents are trying their best to care for their children and have a desire to be, in their own ways, "good parents." The way in which one understands and practices their parenting identity is individual. There is no right or wrong way to be a "good parent."

Good-parent beliefs, while not necessarily reflective of an objective truth, are important personal truths for parents of children with serious illness.

3. While further research is needed to understand possible disadvantages of holding "good parent" beliefs, the current study assumes that good-parent beliefs are facilitative of, or co-occurring with, generally positive outcomes for patients and families. This position is in alignment with priorities expressed by community-engaged partners.
4. Research which centers the voices of patients and families can meaningfully impact clinical practice and policy to improve the lives of children and families.

Participants

Parents of children served by the Complex Care Program at Children's Wisconsin were invited to participate in the study, with the goal of recruitment of 10-15 participants. The term "parents" was used in the current study to include individuals who provide daily care for their children, including adoptive and biological parents and family caregivers. The Complex Care Program serves pediatric patients who have medical conditions affecting three or more organ systems and/or have providers in three or more medical specialties; one or more unplanned hospital stays per year, of at least 5 days duration, and/or 10 specialty clinic visits; and unmet care coordination needs. Each patient receives care from a nurse care coordinator, a care coordination assistant, and a physician or nurse practitioner. Patients have frequent contact with their care teams and have regular outpatient clinic visits to help with managing their complex medical conditions.

Eligible participants were primary caregivers of their child, able to speak and read English, and had access to a telephone, webcam, and internet. Aligned with standard expectations for qualitative studies (Braun & Clarke, 2013), 15 participants completed the study.

Procedure

The present study was conducted to build upon a prior study investigating stress and coping among caregivers of children served by the Complex Care Program at Children's Wisconsin. This study was reviewed by the University of Wisconsin-Milwaukee Institutional Review Board. To recruit participants, a study coordinator based at the Complex Care Program identified potentially eligible patient families at the start of each clinic day. They used a representative sampling technique in attempt to maximize diversity in racial, ethnic, and gender identities of potential participants. As such, throughout recruitment, the study coordinator tracked de-identified demographic information for those invited to participate. As recruitment continued, the study coordinator prioritized recruitment of those who held identities which were been less frequently represented among those already invited to participate.

Once the study coordinator identified an eligible patient family, they informed the family's primary provider (e.g., physician or nurse practitioner). Using an IRB-approved recruitment script, the provider informed the family about the study and asked whether the family was interested in receiving additional information. If the family declined, no further action was taken, and no data were collected for the study. If the family indicated interest, the provider requested the family's permission to share the potential participant's name and contact information with a graduate student interviewer.

Once eligible participants expressed interest, a graduate student interviewer contacted them by phone. The interviewer described the study in detail and answered questions, and if the participant remained interested, a verbal consent for participation was obtained. They were also provided with an electronic copy of the study consent form, for which the IRB had allowed a waiver so that no signatures were needed. Demographic information were collected and a virtual

interview was scheduled. Virtual interviews were conducted and recorded via Microsoft Teams, a confidential electronic video calling software. For participants experiencing technical difficulties, or for those who preferred, audio-only calls were conducted. Half the interviews were conducted via video call (7, 46%) and half via audio-only call (8, 53%). Interviews took 41 minutes on average (range 20-66 minutes). Video recordings were auto transcribed via Microsoft Teams and transcriptions were reviewed for accuracy by a study team member. Following completion of the interview, participants received a $25 gift card in appreciation of their time. They were also sent a list of free, accessible mental health resources via email immediately following the interview.

Discussing good-parent beliefs is acceptable to parents of children with serious illness, and most research participants experience benefits and report minimal burden from discussing medical decision-making and good-parent beliefs (Hinds et al., 2012). Nonetheless, there were several safeguards used to protect participant mental health. While not needed in this study, if participants disclosed suicidal ideation or intent to harm themselves or others, the interviewer would have consulted with Dr. W. Hobart Davies, the clinical psychologist on call for the study, to determine appropriate next steps.

Measures

Demographic Questionnaire.

Demographic data, displayed in Table 2, were collected verbally upon completing the informed consent process for the study.

Qualitative Interview Guide

An interview guide was created for the purpose of this study based on the existing good-parent literature. Several questions in the interview guide were adapted for this study directly from wording used in prior studies (Feudtner et al., 2015; Hinds et al., 2009; Neumann et al., 2021; Weaver et al., 2020b). The interview guide was then reviewed and edited by research team members with expertise in pediatric psychology, Complex Care, Critical Care, and qualitative methods. A Complex Care Program parent representative then reviewed and provided feedback. Prior to launching the study with participants, a pilot interview was completed with a parent volunteer who had a child in the Complex Care Program to make final edits and further assess likely interview duration. The interview guide is provided in the Appendix. Because of the semi-structured nature and time constraints of the interviews, not every question was asked of every participant. Thus, denominators are provided in descriptions of all results to ensure appropriate understanding of the number of participants asked each question.

Data Analysis

Thematic analysis (TA) was used to qualitatively analyze the interview data. Often used in healthcare research, TA enables researchers to report a nuanced account of narrative data (Vaismoradi et al., 2013). In contrast to similar qualitative methods, it is not aligned with a single theory or worldview, allowing it to be used in concert with a range of theoretical approaches (Braun & Clarke, 2006). There are two primary subtypes of TA: coding reliability approaches and reflexive TA. Coding reliability approaches assume that there is a single "accurate" way to code data, and that this "accuracy" of coding can be enhanced with the use of multiple coders. Inter-rater reliability, then, is an appropriate way of assessing the accuracy of a completed analysis. Reflexive TA posits that it is theoretically impossible to remove the researcher from the analysis process. Because coding is an inherently subjective process, which involves human

coders, there is no single way to determine the "accuracy" of data. As such, inter-rater reliability is not calculated, because it would only show the similarity between coders rather than an underlying "truth" about the validity of the data. As an additional difference, coding reliability approaches determine themes first and then fit the data to themes, whereas reflexive TA deduces themes from codes, the smaller units of data (Joy et al., 2023).

Reflexive TA was chosen for the current study. This was due to both the research team's dedication to practicing reflexivity (see positionality statement above) and their belief that all research is inherently biased by those who take part in its creation. Furthermore, the reflexive approach allows for more direct influence of individual data points on broader themes. In contrast, researchers using coding reliability approaches risk prematurely determining broad themes, and then seeking individual data points to serve as evidence for the existence of those themes (Joy et al., 2023). The coding plan for the current study is demonstrated in Figure 1. Two to three coders with training in qualitative methods participated in coding for each question.

Two alternative qualitative methods were considered and rejected as alternatives to TA: content analysis and interpretive phenomenological analysis (IPA). While TA focuses on the identification of patterns in the data and understanding their nuances, CA prioritizes the description of narrative text, allowing for the potential to quantify qualitative data (Vaismoradi et al., 2013). Further, CA involves the use of a priori codes which are fit to a dataset, followed by the creation of new codes as appropriate. This methodology would allow for more direct integration of previously identified good-parent attributes as codes applied to the current dataset. However, the deductive nature of this methodology does not appropriately support the study aims. It discounts the possibility that the CMC parent population would have an entirely unique set of good-parent beliefs (Aim 1) and an entirely different set of preferred and non-preferred

clinician behaviors (Aim 2), the nuances of which are not described by the existing good-parent framework. Such differences may be due to unique decision-making needs, as outlined above, or other potentially unknown factors.

IPA was considered as another alternative model. IPA was used in a preceding study, focused on parent stress and coping, due to its focus on the way in which individual research participants make sense of their own lives. IPA focuses on phenomenology, the study of experiences (J. A. Smith & Osborn, 2003). Embedded within the practice of IPA is the assumption that, in understanding the participants' lived experiences, the researchers are also making their own interpretations, known as the "double hermeneutic" approach (Braun & Clarke, 2013; Smith et al., 2009; Smith & Osborn, 2003). As such, it is best suited for projects about individuals' life experiences. Given that this study centers the "good parent" concept, rather than a single life event, it was determined that IPA would be a poor fit.

In reporting qualitative results, numerical data (e.g., percentiles, frequency counts) represent only the responses for binary (e.g., Yes/No) questions or those displayed in table format. When percentiles are used, the number of participants asked these questions are specified to ensure appropriate understanding of the denominator. Otherwise, quantitative methods are not used to report findings in text. This is in line with the focus on patterns, but not exact frequencies, central to TA (Braun & Clarke, 2022). "Most" describes themes identified in >50% of responses, "many" in 25-50% of responses, and "few" in <25% of responses.

Modified Member Checking

Following analysis, the preliminary qualitative results were shared with the CCP's Family Leadership Committee (FLC), a group of 5-10 parent/caregiver representatives whose

children are served by the CCP. Organized by the CCP social worker, the group meets quarterly to provide feedback regarding ongoing CCP programming, clinical initiatives, and research. Member checking is used in many types of qualitative research to assess trustworthiness of the findings (Birt et al., 2016). It was modified for use in this project such that it did not conflict with the theoretical background thematic analysis, which posits that "accuracy" of results cannot be externally determined (Braun & Clarke, 2022). Instead, the meeting was used to invite feedback regarding the findings and promote discussion about next steps. This group has been involved in modified member checking activities in past research and has shaped researcher understanding of clinical, research, and advocacy implications of prior studies (Tager et al., 2024).

Results

Nature of Good-Parent Beliefs

How Do Parents Describe their Good-Parent Beliefs?

All participants were personally involved in medical decision-making for their children, and all participants were able to describe their good-parent beliefs. Themes describing good-parent beliefs are visualized in Figure 2, which readers are encouraged to review before reading through the full results section. Between 2 and 10 of 15 participants endorsed each of the included themes, and the following themes are categorized by frequency of their appearance across transcripts.

Good-Parent Beliefs Described by Most Participants (>50%)

The largest group of participants described the need to meet their child's basic needs, including involvement in providing medical care for their child. This theme, endorsed by most participants, was termed *Meet Day-to-Day Needs.* Participant 112 summarized some of the responsibilities involved for their child: "[We] try to give him the medical care that he deserves or that he needs, you know, so I am the one to take him to all of his appointments, all his therapists." Participant 109 described some specific needs they helped meet, including "making her appointments, [taking care of] her trach and her G-tube needs." When parents could not be present to care for their child, this also included ensuring that personal care workers or others were meeting those needs, as noted by Participant 114:

> "[…] Choosing the right people for him. You know, if personal care workers aren't available and I got something going on, just making sure that someone who I can trust

that I know can come into my home and take care of him the way you know he should be taken care of."

Most participants also described the need to be present with their child, communicate with their child, and spend quality time together, coded as *Honor Parent-Child Relationship*. This included "sharing those happy memories" (Participant 113), "making sure that she has our attention" (Participant 107), and finding ways to engage with their children in a mutually satisfying way. For example, Participant 114 described:

> "We are always engaging [Child]. You know, whether it's just talking to him or kind of, you know, getting in his face and, like joking with him […] or talking about something on TV or something that happened in school or a video that the teacher sent to me that he did at school, you know, showing him. So I think that's also kind of encompassing, you know, being a good parent just, you know, engaging in your child."

Most participant also described the need to meet their child's emotional needs, nurture their child, and show affection, compassion, and understanding to their child (*Love My Child)*. For example, in describing challenging medical situations, Participant 105 stated, "You know, being a good parent in those situations is, you know, loving your kids." Put simply, Participant 107 summarized, "I love her to death."

Good-Parent Beliefs Described by Many Participants (25-50%)

Nearly half of participants described the importance of ensuring that their child was progressing developmentally, reaching goals, and/or gaining independence (*Make Progress)*. Being a good parent was described as "making sure your child's growing and succeeding" (Participant 6), giving their child "as many opportunities as possible to progress" (Participant

103), and refraining from helping their child with tasks "when she doesn't need it" (Participant 111).

Next, many participants described working to advocate for their child's needs across many different environments (e.g. medical system, school system), termed *Advocate and Protect*. For some, this theme described a general mindset about their child's life, such as Participant 106:

> "Advocating for her health has been a big, big factor since she was born. One of the first things [Spouse] and I were told were, 'She's not going to have the best life. It's better to just abort.' And [Spouse] and I are pro-life and we have said that she needs to be here."

Other participants shared examples of advocating for their child in specific ways, such as asking for medical tests or interventions. This was described by Participant 103:

> "So instead of waiting for the provider or specialist to make a comment about something they're seeing, go to the provider with your concerns and really push for the testing or whatever you think your child needs."

To be a good parent, it was also important for many participants to *Provide Opportunities*, defined as providing their child with rich, diverse experiences characterized by joy, pleasure, growth, and/or a general sense of health and happiness. This included making sure "she feels fulfilled in her [life] journey" (Participant 106) and "trying to expose her to different environments" (Participant 107). According to Participant 110, "we have to make sure she lives her life to her fullest. That's my job as a parent." Similarly, Participant 102 described:

> "As a parent, it's my job to give [my children] as many platforms as possible to be successful. […Child] is able to do some things and so I'm a good parent by giving him as many platforms as I can to allow him to do everything he's got the abilities to do."

Many participants also described a general need to *Do My Best*, defined as doing the best they could for their child at every possible moment. Participant 106 summarized this as, "I think being a good parent is doing the best that you can at that point in time." Before describing specific behaviors they needed to do to be a good parent, Participant 114 reflected, "I mean, being a good parent is, in my opinion, doing what is best."

Next, *Adjust Expectations* referred to the need to change parenting expectations and goals to accommodate the unique needs of their child. Participant 105 recalled, "I can tell you, I've had so many expectations on what being a good parent looks like, but it has changed so vastly [during my child's life]." Participant 111 reflected on the need for patience related to adjusting expectations regarding specific goals:

> "And just remembering that she will do things when she's ready. As much as we push her, we try to get her to school. Just remember that when she's ready, she'll do it. I think being her mom is hard in that way sometimes because we live in a very goal-oriented society and she has all these goals herself that she's, you know, trying to meet but yet at the same time recognizing […] she's gonna do things when she's ready."

In contrast, many participants also spoke about the judgement inherent in parenting children with medical complexity, coded as *Have High Standards for Parenting*. Participant 113 had a belief that "depending on how they come out in the future, it relies on how good of a parent you were." Participant 107 reflected that part of being a good parent was anticipating others' judgements of their parenting decisions:

> "I'm constantly feeling like I am thinking about how other people are judging my parenting. [...] Do they think I'm being a good parent for [Child], for example, for her

medical needs or […] there are, you know, looks and surprised expressions that she's as tiny as she is or doesn't have the vocabulary language skills [she is expected to have]."

Good-Parent Beliefs Described by Few Participants (<25%)

A few participants reflected on the importance of maintaining a sense of faith and/or prayer practice as part of being a good parent, coded as *Have Faith*. For Participant 113, "[...] the first thing is, basically, praying to God. And that helps a lot." Participant 105 expanded:

> "I think faith is huge [...] whether it's God or the universe or whatever you give that stuff up to, like, I had to surrender control. [...] I have to recognize, like, not everything's in my hands. So I pray about, you know, the things that I can change and I can and do. I think that's like the serenity prayer. And I try to figure out, like, the difference between the two because I could literally rack my brain daily otherwise about how I can better support [my child] or do things differently. And so I think my faith, really my husband's faith and my family's faith, really inform that process."

While some participants described the importance of faith, others described a felt need to *Do "More Than I Should*" to be a good parent, defined as investing more time or energy into their child's care than was healthy, manageable, or sustainable for them. As part of this need, Participant 4 described,

> "My belief to be a good parent for my medically complex child means, you know, I guess I'm very controlling or I'm always there. I kind of take everything or maybe more than I should. […] I think just kind of that typical parent, "I gotta do it all," but to another level."

Participant 7 described a more specific time period when they nursed their child much longer than felt feasible for them: “I was trying to quote unquote, you know, ‘be a good parent’ and felt like her weight was so low and [...] it was just such a struggle to get anything oral besides formula and breast milk in her.”

A few participants felt the need to *Make Decisions* as part of being a good parent, defined as serving in a decision-making role across many domains of their child’s life, especially medical decisions. Speaking about the process of making a challenging decision to have their child evaluated for autism spectrum disorder, Participant 107 stated, “that's one of those, ‘being a good parent’ kind of feelings. Like, ‘What do we do that's best for Child?’” For Participant 114, “being the good parent [means] making the tough decisions […] do I put him through a surgery? Don't I put him through a surgery? What is going to be best for him?”

Next, a few participants described the need to honor their child’s unique strengths and appreciate them as a whole person (*Celebrate Uniqueness)*. Participant 110 stated, “We celebrate the small things as special needs parents,” such as new milestones met. For Participant 111, “I think being a good parent to [Child] certainly means recognizing her uniqueness. It's really easy to lump a person with Down syndrome as always happy […] she certainly has a full range of personality.”

A small number of participants described the need to *Find Balance* between their priorities. Participant 107 needed to balance their own medical needs with their child’s (“I'm dealing with medical stuff in addition to you know, mom, wife and caretaker […] of somebody with medical needs of their own”), while Participant 110 reflected on the need to “try to make life as normal as we could for everybody” in their family while meeting their child’s complex needs.

Few participants also sought to *Know Medical Information* to ensure they were sufficiently informed about their child's medical condition. Participant 113 described, "you have to think about it, research, ask for second opinion" when managing complex medical conditions. Similarly, Participant 101 felt that "you have to research every diagnosis" to be a good parent.

Lastly, a small number of participants described the need to *Practice Self-Care* as a good parent. For Participant 115, "taking care of yourself […] before you can take care of your child" was important to ensure they would be able to continue caring for their child. Participant 105 described this in the following way:

> "Giving myself a shit ton of grace. [...] That's like a cornerstone trying to be compassionate to myself. You know, really, those are things that make me a better parent because I've realized when I have kind of inflexible thinking about how things should be with my kids, I get myself really in a bad spot [...]"

How are Good-Parent Beliefs Used?

Good-parent beliefs were relevant to a broad variety of medical decisions. Of 13 participants asked to identify specific medical decisions in which their good-parent beliefs were relevant, most described decisions about surgery or medications. Few described decisions about sedation, tracheostomies, therapies, and evaluations.

Participants were asked to describe the purposes of their good-parent beliefs through responding to the question, "It sounds like you have a personal definition of what it means to be a "good parent" to [Child]. You described things like […]. How does that definition help you in caring for [Child]?" The coding team noted that several participant responses to this question did not appear to directly answer the question; rather, many participants rephrased or repeated their

good-parent beliefs. Still, among those asked this question in any way (n=13), most described that having good-parent beliefs provided *Direction*, defined as a roadmap for what parents need to do to provide the best possible values-aligned care for their child. For example, Participant 107 stated that due to having good-parent beliefs,

> "I think I have that ideal in mind of what I want to be […] I think maybe having that idea in mind is helpful. Just, you know, to latch on to, this is what I want to be and this is, you know, the kind of mom that I want to be."

Most participants also felt that good-parent beliefs enabled them to give *Empathy and Care for Child*, defined as meeting their child's needs by providing love and care, focusing on quality of life, and/or monitoring overall progress. For example, Participant 110 remarked, "[…] when you understand your child, you can do what's best for them." Participant 114 felt that having good-parent beliefs motivated them to provide fulfilling life experiences for their child:

> "I've always said, you know, [Child] will never have the experiences that my other children will have. He'll never have, you know, he'll never play sports. He'll never get his driver's license and drive a car. He'll never vote. You know, any of that kind of stuff, right? So, to me, like making sure like there's programs out there […] taking him to the county fair or, you know, state fair, whatever. Taking him to water parks. I think that that's important because that's also part of his quality of life."

Few participants described that having good-parent beliefs allowed them to have *Empathy for Self*, defined as acknowledging that there would be challenges in their lives and/or being self-compassionate. Referring to the challenges of parenting, Participant 111 stated, "I guess as her mom, so I have to remember, it's not always going to be this way." A few

participants also noted that having good-parent beliefs gave them access to a source of personal *Strength*, such as Participant 113. They described that, in the wake of receiving bad news about their child's health and trying to make memories with their child, "it makes you stronger to keep being a very good parent." For Participant 103, who had described helping their child access specialists and therapies as part of being a good parent, noted that having these good-parent beliefs was a source of *Positive Emotion*. When asked specifically how their good-parent beliefs were helpful to them, they stated, "it feels good to see that he is progressing."

Finally, when asked about the purpose of their good-parent beliefs, a few participants instead described that having good-parent beliefs was insufficient because of their own unrealistic ideals or self-judgement. Participant 103 described this self-judgement, saying, "I'm hard on myself as a person in general, so I feel like whatever I do is never enough. Because there can always be more, something different, or I find something new that they could help them more." Put simply, Participant 107 stated, "I'm not meeting that, you know, good parent ideal that I want to be. "

What Are the Perceived Downsides to Having Good-Parent Beliefs?

Related to the challenges outlined by a few participants in response to a question about the purposes of good-parent beliefs, participants were also asked about the downsides of having such beliefs. Of 13 respondents, many reported there being no downsides to having good-parent beliefs. This included Participant 114, who, when asked about potential downsides, stated, "No, because […] as a parent you just do for your kids and you're going to do what's best." Of those who identified downsides (n=9), almost half described *Overthinking*, defined as over-analysis of each parenting decision one makes. Participant 109 described their frustration about this tendency: "I overthink of doing something a certain way and it just takes up more time than it

benefits anybody. If I'd just take my time on making a decision based on what I believe and want for her [that would be best]."

A few participants described that having good-parent beliefs invited *Challenges with Parenting Identity*, defined as difficulties with parents viewed themselves and their roles. Participant 104 shared this challenge as a static experience across their child's life ("I think in some ways I'm fighting that perception of being the superhero parent"), while Participant 106 found that this challenge arose because of their own career change:

> "As I've started working, my definition of being a good parent has been a little bit harder […] I was her sole caretaker because I wasn't working. And now that I am working, there are days where I feel kinda, I don't know what the right word is -- not really left out, but yeah, I guess left out because now [SPOUSE] and [Child] are doing everything, so, you know, roles are reversed. He's taking her to all the appointments and doing a lot of things. […] It doesn't really change my definition of being a good parent, it's just in your head, kind of, skewed a little."

A few participants described that having good-parent beliefs invited *Self-Judgement*, defined as judging their parenting against their own or others' expectations, and/or experiencing perfectionism or a sense of failure. Participant 101 described this in the following way:

> "I'm a perfectionist. I need to be doing it all the time. I always need to be, you know, on top of everything and the things that I'm not on top of everything -- then I feel guilty and that makes it harder. It's like you feel guilty. 'I'm not doing enough. Oh, my God. I'm not a good enough parent.' And it's like, it spirals and you just sit and you can't do anything

kind of get, you know, paralyzed, like, OK, I'm handling the basic needs. I can't do more."

Finally, a few participants described that *Personal Cost* was a downside of having good-parent beliefs. This was defined as the idea that wanting to be a good parent, and taking actions accordingly, came at great personal cost to parents. Participant 115 described:

> "Sacrificing. It's like when you have kids, it's not about you no more. It's about your child. So I have to sacrifice a lot of jobs [...] I had to lose so many jobs, you know, to be in the hospital with him and you know, going through those things by yourself [...] it was stressful, and it hurt."

Interactions Regarding Good-Parent Beliefs with Complex Care Program Staff

Do Parents Feel That Complex Care Staff Understand Their Good-Parent Beliefs?

Of 11 participants asked whether staff from the CCP understood their good-parent beliefs, 10 (91%) answered affirmatively. A single participant (9%) was unsure how to answer this question, but noted that CCP staff used "their expertise, what and how to make [Child]'s life more fulfilling and not just stuck in a hospital bed kind of life" (Participant 106).

Those who answered that they believed the staff from the CCP understood their good-parent beliefs (n=10) were asked why they believed so. Most respondents described that they could tell the CCP staff understood their good-parent beliefs because they acted with *Compassion*, defined as being considerate and caring and/or actively listening to families. For example, Participant 115 stated, "[The Complex Care social worker says], "'I just want to let you know you're a good mom. Keep doing it' […]. She really cares." Participant 104 noted, "I feel

like a lot of times it's the reassurance from them that we're on the right track or that we were getting issues addressed that need to be addressed."

Most participants also described actions by CCP staff that were *Helpful*, defined as supporting parents in aligning care with their good-parent beliefs (e.g., providing needed resources, scheduling appointments, being available to discuss patient/family needs). Participant 112 appreciated that "every time I have a question and a concern, I know I can count on them too and I call them and they help me right away." This included actions the CCP staff took to advocate for patients within the medical system as well, as described by Participant 102:

> "Sometimes it's not just society. It's not just my parents. It's not just the person at the grocery store. Sometimes it's a doctor looking at you like, 'Why are you here? […] You're wasting my time' or something and [Complex Care] comes and sits with me through appointments. They stand with me."

Many participants remarked that they knew the CCP staff understood their good-parent beliefs because of the familiarity they had with members of the team. *Familiarity* was defined as using the long-term nature of the relationship and knowledge of family goals for the child. For example, Participant 107 shared, "I feel like [Complex Care] know[s] us best out of all of her medical providers [...] So I feel like they do know what we value as parents and what we want for [Child]." Participant 114 felt that the CCP staff knew their good-parent beliefs intuitively because of this familiarity: "It's like those unspoken words. They just know, you know, without even having to say it, they just -- they get it."

Few participants described that CCP staff knew their good-parent beliefs because of their deliberate focus on the whole child and the child's quality of life (*Value Quality of Life)*. For

example, Participant 114 appreciated the CCP team's knowledge of this priority: "The biggest thing for me is, you know, comfort and quality of life for [Child]. And they know that." Similarly, Participant 111 felt that the CCP staff "look at everything as a whole" rather than solely focusing on one aspect of medical care.

A single respondent, Participant 108, described knowing the CCP staff knew their good-parent beliefs because of the team's *Communication*, defined as providing thorough, effective communication about medical needs: "Any time I talk to them and they know that I don't understand something, [they] say, "'Let me explain it to you' so I can understand it better."

Have Parents Spoken about their Good-Parent Beliefs with Complex Care Staff?

Six participants responded to a question about whether they had discussed their good-parent beliefs with their child's CCP team. Many stated that they had not, for example, "No, I don't think in so many words, no" (104). Few participants felt that they had *not directly* discussed these beliefs but they had had similar conversations. Participant 114, for instance, remembered a similar conversation: "I think when we initially started with Complex Care, you know, one of their questions was, […] "What are the goals that you have for [Child]?"" So it's more about like his goals that I had for him." A single participant (103) felt that they had directly spoken about good-parent beliefs with their child's CCP team, noting there was a focus on parent well-being during that conversation: "I think they're aware of […] us wanting to be a good parent and how, you know, mentally tolling that is."

How Do Complex Care Staff Make it Easier and/or Harder to Feel Like a Good Parent?

Eleven participants responded to questions about how their child's CCP staff make it easier to feel like a "good parent" to their child. Responses about how Complex Care staff make it easier to feel like a "good parent" are displayed in Table 3.

Twelve participants responded to questions about how their child's CCP staff make it harder to feel like a "good parent" to their child, and whether there was "anything you wish the Complex Care team did differently to help you feel that you are doing everything you can to be a "good parent" to your child." In responding to these questions, some mentioned additional ways in which CCP staff made it easier, and these responses were coded with responses to the previous question (see above paragraph). Most respondents reported that there is nothing the CCP could do differently (*No Changes*). For example, Participant 106 shared, "I can't think of anything negative about any of them […] they do a really good job."

Other responses to this question were coded under the themes *Knowledge, Staff Consistency, Parent Connections, Additional Appointments, Extra Work,* and *Criticism,* none of which represented responses from more than 2 participants. *Knowledge* described occurrences when the CCP did not have sufficient information to answer a family's question about their child's unique needs. For example, Participant 103 described searching online for several hours by herself to find a medical device their child needed, adding that, "there have been, I would say, at least a few instances where they [child's CCP team] weren't knowledgeable enough to answer my question, but I definitely think that their knowledge base in general could be a little, I guess broader to all of the different specialties. Or have, I don't know, maybe have better resources to contact to be able to get the […] harder questions answered." Changes between CCP staff, coded as *Staff Consistency,* was also described as a barrier to feeling like a good parent. Participant 104 remarked that it was important to them to have the same care team members involved at each

hospital admission, and that it is less helpful when unfamiliar members of the CCP join the team only during a particular admission:

> "It's always appreciated, but there's a difference between somebody that's from the team but not his team who is involved in this conversation when he's in the hospital versus somebody that I know has known him since the start, […] that can kind of say, "Yeah, that's [Child],' or, you know, 'Mom's right. That's not [Child].' […] or sometimes even just be in my memory for me, cause it's all mush."

Parent Connections describes the need for more opportunities for support across parents whose children are served by the CCP. For example, Participant 111 noted that while some of their children participated in the CCP's sibling programming, opportunities for parents to meet together were lacking. It was also noted that by nature of having a child served by the CCP, there were additional appointments to attend, which "adds to the long appointment list that we already have" (Participant 103).

The final two codes to this question describe the challenging emotional responses of parents to their interactions with the CCP. *Extra Work* described the guilt and associated difficult emotions with the CCP's frequent additional reminders of undone medical tasks for their child. Participant 104 found that despite the positive intentions for these reminders,

> "[...] they're reminding me of the stuff I haven't been doing. [...] There's a weird, twisted guilt in that, and then it's the, 'Well, do I just do it myself because I don't wanna make more work for them? Or do I let them go ahead and do it for me [...]?'"

Similarly, when a participant was unable to keep up with certain medical tasks for their child, they described experiencing *Criticism* from the CCP:

> "When you miss an appointment [… the CCP staff] call -- you can just hear in the tone sometimes, like, they're irritated about all this disappointment. But it's like, OK. You have to understand, you guys are far. I have other kids. I have to work. So [if] it's urgent, you guys know I'm there […] they can be hard on me sometimes […]."

Modified Member Checking

Preliminary results were shared with the FLC following completion of data analysis. FLC members reported that the results aligned with many of their initial expectations of the project. They did not suggest making any changes to the phrasing of theme names. No members had concerns about moving forward with dissemination about the results. A few FLC members reported feeling emotionally validated by the findings. Specifically, one parent shared that they had previously felt alone in worrying whether they had done the "right" thing with past medical decisions, but that they were relieved to learn that this was a shared parenting experience. Additionally, many FLC members reported that the CCP has been very helpful, and they were not surprised that very few participants described ways in which the CCP could change or work differently. Regarding future directions, the group reported an interest in understanding differences in good-parent beliefs between parents in the same family, exploring this concept with a more racially and ethnically diverse sample, and finding ways to help connect parents of CMC to one another for social support.

Discussion

Overview

The present study qualitatively described the nature of good-parent beliefs among parental caregivers of children served by a pediatric Complex Care Program (CCP). All participants were readily able to state their good-parent beliefs and many readily identified past medical decisions in which their good-parent beliefs were implicated. Many participants had multiple good-parent beliefs, each of which were often coded into different themes. Meeting daily needs, honoring the parent-child relationship, loving their child, and making progress were the most common themes represented among responses. Good-parent beliefs were often referenced by parents in medical decision-making, commonly related to decisions about surgeries and medications. The utility of good-parent beliefs provided a sense of direction in caring for CMC, although this question appeared to be challenging for many parents to respond to directly, perhaps because of the abstract nature of the question. There were few perceived disadvantages to having good-parent beliefs, but for some, these included invited overthinking, identity challenges, and personal cost.

In their interactions with the pediatric CCP, almost no participants had spoken about their good-parent beliefs directly, yet most felt as though their child's CCP team knew their good-parent beliefs without having had such a direct conversation. The personalized care provided by CCP was unanimously appreciated by respondents as a facilitator of feeling like a "good parent," in addition to care coordination and familiarity with the patient and CMC needs in general. Participants rarely identified CCP provider behaviors or practices which made it harder to feel like a "good parent," such that no theme was endorsed by more than two participants. Taken together, these results suggest a high degree of trust and appreciation in CCP staff. Participation

in the CCP appears to facilitate parent satisfaction in aligning care with their own good-parent beliefs.

Relation to Extant Literature

It has been documented that most parents of children with complex medical conditions identify with striving to be a "good parent," (Weaver, Neumann, et al., 2020a) and the present study was no exception. Every participant included in this study was able to identify their good-parent beliefs, serving as further confirmation of the commonality of this way of thinking among parents of children with chronic and complex conditions. Sample participants used their good-parent beliefs to facilitate a variety of medical decisions about chronic medical conditions, including surgical and medication-related decisions, while previous literature found a focus on critical medical decisions such as tracheostomies (October et al., 2014) and end-of-life care (Hinds et al., 2009). This study expands scientific knowledge about the breadth of medical decisions in which good-parent beliefs may be implicated.

Several good-parent beliefs described in extant literature with parents of children with serious illness were echoed in the current study. This included themes relating to loving one's child, making informed medical decisions, relying on faith, being present, advocating, meeting medical needs, providing life experiences, and focusing on quality of life (Feudtner et al., 2015; October et al., 2014, Hinds et al., 2009). This suggests that many of the good-parent concepts may be common across pediatric parent populations, even those whose children face chronic, long-term disabling conditions (Weaver, Neumann, et al., 2020a) rather than only advanced or terminal malignant ones, which was the focus of the initial good-parent research (Hinds et al., 2009).

However, in comparison to good-parent beliefs described in extant literature, there were also notable novel findings resulting from the current study. First, this sample described some novel good-parent beliefs. For example, this sample expressed a focus on children's futures, as described by themes such as *Make Progress* and *Provide Opportunities*. While aspects of the importance of providing life opportunities and focusing on long-term health were reflected in prior studies, themes from those studies also included those focus on end-of-life considerations, such as "Having a Legacy" (October et al., 2014), which was not mentioned among participants in the current study. Of note, much extant literature describing good-parent beliefs has focused on those of families with a child experiencing critical and/or life-threatening illness, such as advanced cancer. The focus of this study, the good-parent beliefs of those with CMC, explored the experiences of a sample whose children have long-term, chronic, intensive, and sometimes life-limiting conditions; however, these children were not necessarily at immediate risk of medical decompensation or death, as were those in many prior studies. This distinction likely played a large role in the reason for future-focused versus legacy-focused good-parent beliefs. As an alternative explanation, much of the extant literature focused on describing good-parent beliefs in the context of a medical crisis (e.g., intensive care hospitalization; October et al., 2014), while the current study asked about these beliefs more broadly in the context of the child's life. The only other study which has broadly explored good-parent beliefs over the course of children's lives also noted included a finding related to helping children achieve to their fullest potential (Weaver, Neumann, et al., 2020a). Like that prior study, the current study's focus on lifetime good-parent beliefs outside the context of an imminent medical crisis may have caused participants to think in a more future-focused way given that they were likely not facing imminent medical difficulties.

Of note, current study results include consideration of caregiver needs and well-being rather than a sole focus on child well-being, as has been a focus of past good-parent research. This is particularly notable among good-parent beliefs such as *Do "More Than I Should," Practice Self-Care, Have High Parenting Standards,* and *Do Your Best*, all of which consider parents' personal experiences of meeting their children's needs. "Putting my child's needs above my own" (October et al., 2014; Feudtner et al., 2015) is the sole theme from the foundational good-parent literature which makes mention of parental needs. However, that theme focused on parental needs in the context of the outcomes of specific medical decisions, rather than in the broader scope of day-to-day parenting. A somewhat related theme, summarized in part as "seeking some balance amongst my many roles," described the need to balance and coordinate their children's needs (Weaver, Neumann, et al., 2020a). However, the representation of themes describing parental well-being in the current study is unprecedented among the current good-parent literature. As one of the first good-parent studies since the Coronavirus-2019 (COVID-19) pandemic, this may speak to a level of increased caregiver stress, and subsequent awareness of their own needs, since that time. The pandemic was a time of notable stress and challenge among families of CMC (Diskin et al., 2022; Hall et al., 2021; Tager et al., 2024). This distinction could also be due to the difference between the current study's focus on broader good-parent beliefs as compared to those described in the context of a medical crisis, and/or it could speak to differences between parenting children with acute or chronic medical conditions (e.g., advanced cancer; Hinds et al., 2009) as compared to parenting CMC. Regardless, the representation of parental needs and self-care (or lack thereof) as part of the "good parent" definition in families of CMC reflects the high degree of psychological, practical, and physical effort involved in parenting CMC.

Exploration of the possible downsides of having good-parent beliefs has been limited in the extant research, perhaps because only a small minority of parents of children with chronic medical conditions have reported negative emotions (e.g., stress, 10%; confusion, 2.5%) in response to being asked about their good-parent beliefs (Weaver, Neumann, et al., 2020a). Further, much extant research has explored the importance of these beliefs without much focus on their potential costs (Weaver, October, et al., 2020). However, there is a possibility that having beliefs about what constitutes being a "good parent" can actually have negative implications for parents. Literature in parents of non-chronically ill children has found that not identifying as a "good parent" can be associated with negative cognitions and emotions (Dobson et al., 2024) and can be a source of parental self-stigma (Eaton et al., 2016). The current study demonstrated that good-parent beliefs do come with a cost for parents of CMC. In addition to using good-parent beliefs as a cognitive tool prior to or during medical decision-making, parents in the current study also seemed to use their good-parent beliefs to self-evaluate their parenting performance. Participants spoke about both the challenges of aligning medical care with their good-parent beliefs as well as instances of questioning how sufficiently they had met their personal standard of being a "good parent." For example, having good-parent beliefs was perceived to be a source of ruminative and self-judgmental thinking for some, while for others it brought up uncertainty about parenting roles. The present study is the first to identify the downsides of good-parent beliefs among a chronic illness population. It also adds nuance to previous findings that CMC desire for others to perceive them as "good parents" (Woodgate et al., 2015), detailing the costs associated with this desire. Results indicate the potential for good-parent beliefs to facilitate increased distress among parents who self-evaluate against their good-parent personal standards, and it suggests a potential area for psychotherapeutic intervention.

To mitigate some of the stress and challenges associated with parenting CMC, CCPs are intended to fulfill many care needs (Kuo et al., 2016). The current study reflected the appreciation families have for their CCP teams and the ways in which involvement with these teams supports feeling like a "good parent," and the ways in which it may invertedly challenge this feeling or make it harder to feel like a "good parent." First, for pediatric clinicians, familiarity with good-parent beliefs and associated goals is central to providing high quality healthcare (Weaver, Neumann, et al., 2020a). However, participants in this sample rarely, if ever, had communicated directly about their good-parent beliefs with CCP staff. This finding may reflect a gap in this communication between CCP staff and families. There is limited extant literature examining communication quality between parents and pediatric Complex Care teams, yet there are many potential barriers to communication for these families, such as missed opportunities for parent-provider collaboration (Adams et al., 2021; Williams et al., 2021). Parents of CMC often report feeling unheard or undervalued as part of their child's medical care team (Bogetz et al., 2021). Discussing good-parent beliefs may be one such missed opportunity which could further improve care quality. Notably, pediatric palliative care providers receive concerted training in advanced care planning, including aligning parent values with goals of care, and evidence suggests a likely benefit to increased palliative care involvement with the CMC population (DiDomizio et al., 2023). It is possible that increased palliative care involvement would facilitate improved parent-provider communication about good-parent beliefs among families of CMC.

Even despite the lack of direct conversations about good-parent beliefs with CCP providers, participants believed that the CCP understood their good-parent beliefs. It was commonly reported by study participants that there was nothing the CCP could do differently or

change to make it easier to feel like a "good parent." CCP provider and staff practices to help facilitate good-parent identities usually involved providing individualized medical attention to patients and families, a basic tenet of the field of pediatric complex care (Cohen, Kuo, et al., 2011). When participants did endorse challenges with the CCP which made it harder to feel like a "good parent," they described a range of more nuanced themes including programmatic challenges and negative interpersonal interactions with CCP staff. That there were six themes, none of which was endorsed by more than two participants, indicates the wide variety of provider and staff behaviors and practices which may threaten one's perceived ability to be a "good parent."

Clinical Implications

Despite the recognized importance of good-parent beliefs in facilitating medical decision-making and supporting parent coping (Weaver, October, et al., 2020), evidence-based interventions which consider these beliefs remain to be developed. Even despite evidence supporting involvement of mental health providers as part of the pediatric patient-centered medical home (Asarnow et al., 2017; Kazak et al., 2017) and proposed pathways to provide caregiver-directed psychological support in the healthcare system (Salley et al., 2023), many systems lack integrated mental health providers and access to evidence-based clinical interventions for families. Pediatric psychologists and other mental health providers with a background in providing family-centered psychological care in the context of the pediatric healthcare system may be uniquely poised to provide this support.

Fortunately, there has been growing interest in providing pediatric caregivers with tailored psychosocial support within the pediatric medical home (Salley et al., 2023). Part of this effort has included the development of population-specific psychotherapeutic interventions for

parents of children with pediatric medical conditions. Most focus on maternal distress, and many include a component related to accepting and/or finding meaning in challenges, in addition to cognitive-behavioral and problem-solving skills (Koumarianou et al., 2021). For example, Promoting Resilience in Stress Management for Parents (PRISM-P), is a brief, manualized intervention for parents of children with cancer which teaches skills for managing stress, setting goals, cognitive reframing, and meaning-making (Rosenberg et al., 2019; Yi-Frazier et al., 2017). Similarly, the Surviving Cancer Competently Intervention Program teaches adolescents with cancer and their families coping skills to manage cancer-related distress using cognitive-behavioral principles (Kazak et al., 2004). It has also been modified for use with families facing a new pediatric cancer diagnosis (Kazak et al., 2005) and for use in a digital format (Canter et al., 2019). Given the focus on manipulating cognitions and behaviors in these interventions, and the centrality of good-parent beliefs in caring for children with chronic illnesses (Weaver, October, et al., 2020), it would follow that good-parent beliefs should be included in such interventions. Parents would likely benefit from considering the positively and negatively valanced emotions related to their good-parent beliefs and aligning their behaviors with these beliefs (i.e., values-focused actions). To date, however, no interventions have been modified to include consideration of good-parent beliefs, despite robust evidence of their importance in facilitating parent coping with pediatric critical illnesses (Weaver, October, et al., 2020).

For parents of CMC specifically, fewer population-specific interventions have developed for caregivers to date. Those recently developed or adapted for this population have included a focus on peer support and cognitive-behavioral approaches (Dews et al., 2023) and mindfulness (Gallegos et al., 2024), yet none have incorporated consideration of good-parent beliefs. Emerging evidence suggests that finding meaning in their parenting challenges is an essential

aspect of coping (Bogetz et al., 2024; Tager et al., in press) and that being a "good parent" may be one aspect of meaning-making for some parents of CMC (Tager et al., in press). This expands other findings that reflecting on one's "good parent" role may facilitate coping among bereaved parents (Meert et al., 2015). While further research is needed to elucidate the range and relative frequencies of good-parent beliefs among families of CMC, families may benefit from the development of psychotherapeutic interventions targeting these beliefs. This may be especially true given the current study's findings that good-parent beliefs are associated with distress, including increased rumination and self-judgement. While further research is needed to understand the relationship more comprehensively between good-parent beliefs, distress, and positive coping, future interventions which address good-parent beliefs should be evaluated for efficacy. For example, the development and testing of a "good-parent" module as part of PRISM-P, which already includes a focus on meaning-making (Rosenberg et al., 2015), and the adaptation of this module for use with parents of CMC, may be a worthy endeavor.

For pediatric medical clinicians working with families of CMC, the present study's findings suggest many opportunities to facilitate and reinforce parents abilities to meet their own goals in their parenting roles. Pediatric CCP providers may find pediatric palliative care providers especially helpful in facilitating positive parent-provider interactions with this population (DiDomizio et al., 2023). Further, integrating pediatric palliative care early in care may help parents feel satisfaction with the extent to which their child's care meets their good-parent beliefs (Mekelenkamp et al., 2020). Results from the current study describing these facilitative practices, for use by pediatric medical clinicians, are summarized in Table 4. Additional research with participants who have children served by other healthcare systems is needed to further inform these clinical implications across CCPs.

Limitations and Future Research Directions

Qualitative data are not intended to be statistically generalizable to a population other than the sample being described, an idea which thematic analysis experts argue is not an inherent limitation of this methodology (Braun & Clarke, 2022). Instead, qualitative data serves to provide information about the nature, but not necessarily the frequency, of a given phenomenon. Still, in contextualizing the results, it is important to recognize the characteristics of the sample to ensure appropriate interpretation and to foster thought about future research directions.

This single-site qualitative study described the good-parent beliefs of a sample of exclusively female caregivers of children with medical complexity served by a CCP. It also described participants' perspectives regarding ways the CCP could help align medical care with their good-parent beliefs. All study participants lived in the same state in the Midwestern United States and had children served by the same program at one hospital system. It also did not include the perspectives of families of CMC whose children were not served by the CCP for any reason, such as having been discharged, having declined to enroll, or having never been prompted to enroll. The study also excluded those whose children had joined the program within one year. It is thus unknown the extent to which current study participants' contact with the CCP influenced the content or expression of their good-parent beliefs. Further, despite efforts to maximize sample diversity, participants were all female. This limitation should be seriously considered in the design of future research studies, especially given the under-representation of fathers in pediatric psychology research (Phares et al., 2005) and the unique good-parent beliefs fathers may have (Robinson et al., 2019) or the ways in which fathers prioritize good-parent beliefs differently than mothers (Feudtner et al., 2015). There was also limited racial and ethnic diversity, including several participants who were the sole member of their racial/ethnic group

among the sample. Many participants racial and ethnic identities which are non-marginalized in the United States (e.g., white, non-Hispanic/Latino/a/x/e). While major systematic differences in good-parent beliefs between racial and ethnic groups have not been documented in other samples (Feudtner et al., 2015), limited ethnic and racial diversity among the current study prevents a more comprehensive understanding of the variety of good-parent beliefs which may be present across diverse families of CMC. Data about family income was also not collected. This limits the potential to understand results in the context of socioeconomic status, which has been associated with differences in good-parent beliefs in previous research (Feudtner et al., 2015).

Unfortunately, study design played a role in reducing potential cultural diversity among the sample. For example, due to the lack of translated materials and interviewers who speak more than one language, all interviews were conducted in English. This prevented the study from exploring experiences of caregivers who speak languages other than English. The experiences of speakers of languages other than English have been missing from extant literature on good-parent beliefs to date and must be a future focus. Relatedly, a more culturally informed approach to understanding good-parent beliefs should be considered in future work. For example, the familial and cultural (i.e., religious, spiritual, political) roots of good-parent beliefs were not explored in the current study, but understanding these roots may enhance scientific understanding of their source and their malleability, or lack thereof, over time. Good-parent research has been exclusively conducted in the United States, thus provoking questions about the potential generalizability of the construct across cultures and regions of the world. Expanding the focus to include international populations, both focused on families of CMC and more broadly on parents of children with chronic and serious illnesses, is thus imperative. It is unclear the

extent to which the concept of good-parent beliefs, or individual good-parent attributes themselves, are culturally specific.

This study also included several questions which asked parents to self-reflect about their own cognitive and behavioral patterns. For example, the question about how parents use their good-parent beliefs ("How does that [good-parent] definition help you in caring for [Child]?") required participants to not only hold in mind their good-parent beliefs, which were often nuanced and numerous, while also reflecting on the ways in which these heuristics had impacted their parenting choices. As noted earlier, many participants were unable to directly answer this question. Perhaps parents were not directly aware of the ways in which these beliefs impacted their decisions, could not remember, or became confused or overwhelmed by the metacognitive demands of this question. It is also possible that good-parent beliefs did not directly impact decisional processes for some parents. Future research studies should aim to use simpler language, and researchers should consider use of vignettes or examples when asking participants to reflect on the uses and impacts of their good-parent beliefs.

Regarding additional future research directions, the other limitations of this study point to several major priorities in good-parent research. Primarily, there is a need for additional qualitative and mixed-methods studies, inclusive of a racially, ethnically, and gender-diverse family members, exploring good-parent beliefs among caregivers of CMC. This should include exploring similarities and differences in good-parent beliefs between members of the same family. Ultimately, gaining an understanding of the good-parent beliefs held by members of diverse research samples will help replicate or adapt the good-parent research which has been done in other pediatric populations to this one. For example, use of a "good parent" ranking tool (Feudtner et al., 2015; Hinds et al., 2009) to determine relative importance of each good-parent

belief across the CMC parent/caregiver population may be clinically useful to facilitate parent-provider communication and shared decision-making in CCPs. Such a tool may be especially necessary for families of CMC, for whom the decision-making experience is distinct as compared to other pediatric populations (Jonas et al., 2022).

The present study indicated that the good-parent concept is relevant to families of children with complex, chronic, and long-term medical conditions (Weaver, October, et al., 2020). While all research exploring good-parent beliefs has been conducted among parents of children with medical conditions, the applicability of the concept across sub-populations begs questions about its applicability with other populations. It remains uncertain whether good-parent beliefs are indeed shared by parents of children without health conditions, and if so, the nature of those beliefs. Alternatively, it is possible that good-parent beliefs emerge, or at least become of primary import, only when parents are faced with some form of adversity in their parenting journey. Even if this were true, there are many other populations for whom the "good parent" concept may resonate. For example, parents of children who identify as transgender or gender non-conforming and who access gender-affirming care are also met with intensive medical decision-making demands, and they may hold beliefs about what it means to be a "good parent" in this context. These parents may commonly ask themselves if they are doing the "right thing" for their child (Gray et al., 2016), which echoes the concerns of parents facing other kinds of medical decisions for which good-parent beliefs feel relevant. Even beyond pediatric medical conditions and treatments, the concept may hold relevance to the experiences parents of children experiencing traumatic experiences and mental health concerns (Eaton et al., 2016). For example, those parenting children in the face of challenges such as interpersonal trauma histories – either their own (Siverns & Morgan, 2019) or their children's (Willcott-Benoit & Cummings,

2024) – may also experience parenting identities which are impacted by these challenges. As such, these individuals may also hold beliefs about what it means to be a "good parent" which may be relevant to clinical interventions with these populations.

Scientific understanding of good-parent beliefs is still progressing, with more research needed to fully understand the roles and implications of these beliefs for parents and caregivers (Weaver, October, et al., 2020). Still, opportunities for clinical intervention may represent important new pathways for improving caregiver well-being. Clinical research with families of CMC should also seek to identify additional ways in which good-parent beliefs can or should be centered in psychotherapeutic interventions with this population, as noted earlier. Successful development of such interventions should begin with qualitative and mixed-methods explorations of feasibility and acceptability within this population. This is particularly important given the practical difficulties these families face (Sobotka et al., 2019; Woodgate et al., 2012, 2015), and there is a real possibility that without appropriate accessibility measures, psychotherapeutic interventions for this population will not reach those who need it most. Such accessibility measures could include providing childcare during the intervention, transportation to the intervention site, and/or digitizing interventions for use at home and at flexible times.

Additional research is also necessary to further inform and train pediatric medical clinicians in working effectively with CMC and their families (Bogetz et al., 2014). While the current study outlines parent-perceived ways in which CCP staff and providers do and/or do not facilitate self-satisfaction with their ability to be a "good parent," the perspectives of CCP staff and providers are lacking. It is necessary to seek an understanding CCP medical professionals' knowledge about good-parent beliefs, comfort discussing these beliefs with colleagues and families, and perceived barriers and benefits regarding these discussions. Gaining this

understanding would allow for medical educators to incorporate this topic in their teaching, thus equipping future generations of pediatric medical providers with the skills to better support parent coping and decision-making. Such research should also seek to demonstrate ways in which staff, providers, and CCPs can feasibly make changes to their systems and workflows to allow for improved communication about good-parent beliefs. For example, if additional research finds continued support for the importance of direct parent-provider communication about good-parent beliefs, it may be beneficial to seek ways to document good-parent beliefs in the electronic health record, to ensure shared knowledge of these beliefs among staff caring for patients and families. As another possibility, incorporation of good-parent beliefs discussions into regular CCP clinic visits may also be beneficial for fostering parent-provider trust and ensuring alignment of medical care with family values.

Conclusion

The present study explored the good-parent beliefs held by primary caregivers of a child served by the CCP at a single midwestern pediatric hospital. Good-parent beliefs are unanimously held but differ greatly across individuals. In contrast with findings among pediatric acute illness populations, participants described novel good-parent beliefs which prioritized developmental progression and their own experiences as caregivers. Parents used their good-parent beliefs to facilitate decisions involving surgeries and medications. Good-parent beliefs were associated both distress and positive emotion. While most had not spoken directly about their good-parent beliefs with providers, participants felt that the CCP understood these beliefs. The CCP's provision of personalized care was commonly referenced as a facilitator of one's own ability to feel like a "good parent." Results suggest the need for additional research to better understand the range of good-parent beliefs and their functions among families of CMC, as well

as exploration into the association between good-parent beliefs and interactions with healthcare providers. Pending further scientific inquiry, this population may benefit from cognitive-behavioral psychotherapeutic interventions addressing good-parent beliefs.

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Figure 1. Thematic Analysis Coding Plan, adapted from Braun & Clarke (2006).

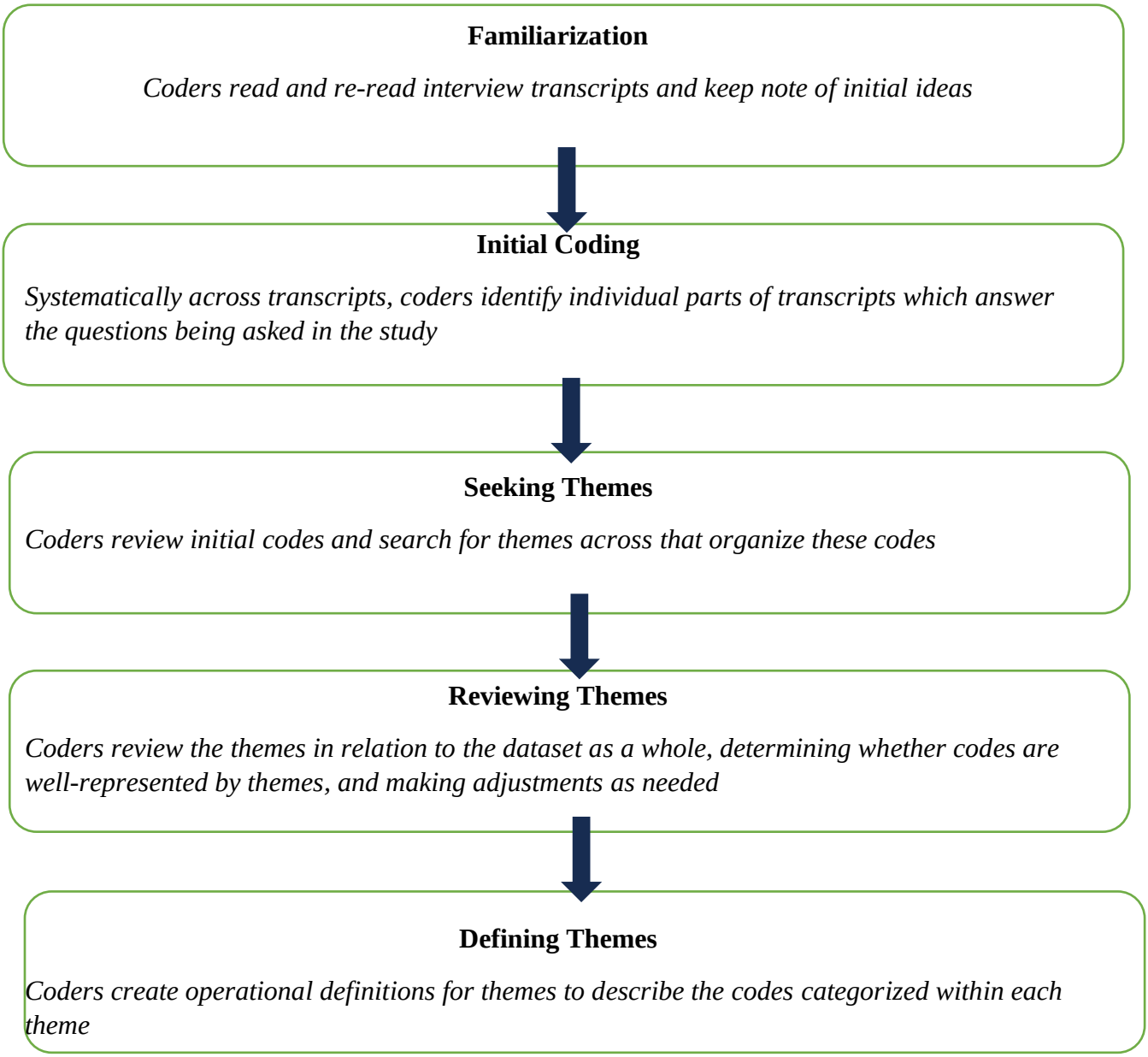

Figure 2. Visual Display of Good-Parent Beliefs

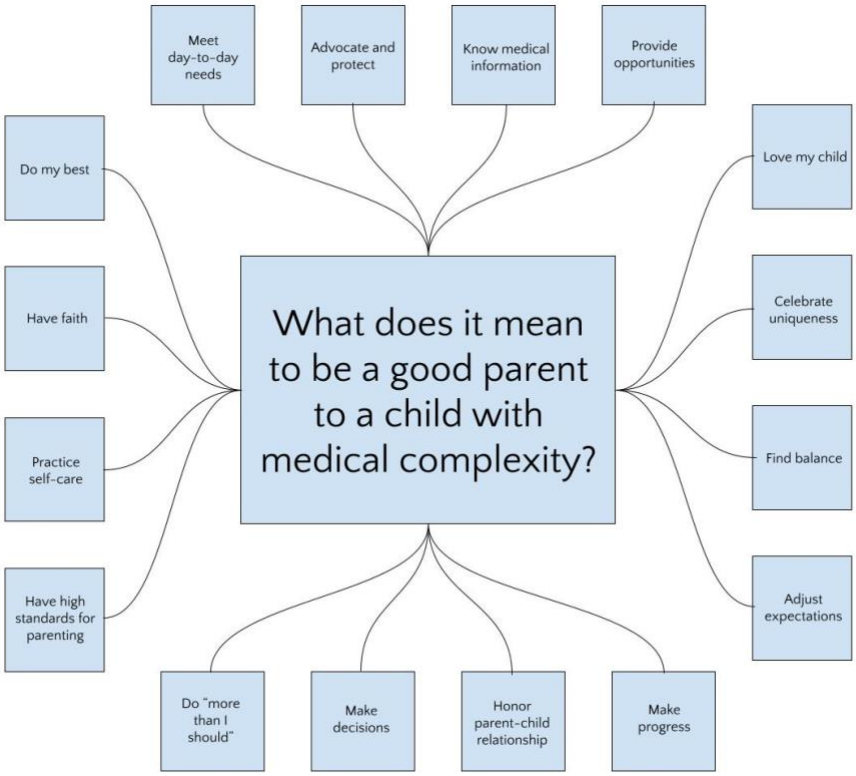

Table 1. Good-Parent Attributes Reported in Foundational Literature.

Study	Sample	Method	Good Parent Attributes
Hinds et al., 2009	62 parents of children with advanced cancer	Qualitative interviews	• Doing right by my child • Being there for my child • Conveying love to my child • Being a good life example • Being an advocate for my child • Letting the lord lead • Not allowing suffering • Making my child healthy
October et al., 2014	43 parents of children hospitalized in a Pediatric Intensive Care Unit	Qualitative interviews; coded using the 8 resulting themes from Hinds (2009), "the Good Parent Tool"	• Focusing on my child's quality of life • Advocating for my child • Putting my child's needs above my own • Making informed medical care decisions • Staying at my child's side • Focusing on my child's health and longevity • Making sure my child feels loved • Maintaining faith • Having a legacy
Feudtner et al., 2015	200 parents of children with serious illnesses	Reviewed extant decision-making literature and pilot tested with pediatric palliative care providers; then asked participants to rank-order attributes	• Making sure my child feels loved • Focusing on my child's health • Making informed medical care decisions • Advocating for my child with medical staff • Focusing on my child's comfort • Focusing on my child's quality of life • Putting my child's needs above my own when making medical care decisions • Staying at my child's side • Keeping a positive outlook • Focusing on my child having as long a life as possible • Focusing on my child's spiritual well-being • Keeping a realistic outlook

Table 2. Demographics of Study Participants (N=15) and Their Children Served by the CCP

Participant Demographics	
Variables	*n* (%) / *M* (*SD*) [Range]
Gender	
Female	15 (100%)
Relationship to child	
Mother (adoptive or biological)	14 (93%)
Grandmother	1 (7%)
Race	
White	9 (60%)
Hispanic	2 (13%)
Black	1 (7%)
Native American	1 (7%)
White and Native American	1 (7%)
White and Hispanic	1 (7%)
Ethnicity	
Not Hispanic/Latino/a/x	12 (80%)
Hispanic/Latino/a/x	3 (20%)
Marital status	
Married	10 (67%)
Single	4 (27%)
Partnered, not married	1 (7%)
Highest education completed	
High school/GED	5 (33%)
Associates	1 (7%)
Bachelors	7 (47%)
Masters	1 (7%)
Doctoral	1 (7%)
Parent Age (years)	43.5 (10.4) [27-65]
Characteristics of CMC whose Parents were Participants	
Gender	
Female	8 (53%)
Male	7 (47%)
Length of time served by CCP	
1-2 years	1 (7%)
3-5 years	6 (40%)
6+ years	8 (53%)
Child Age (years)	8.1 (5.2) [2-17]

Table 3. Qualitative Responses Describing How Complex Care Makes It Easier to Feel Like a "Good Parent" (N=12).

Theme and Operational Definition	**Frequency**	**Example**
Personalized Care: being devoted to patient care, which includes providing medical and/or parenting advice for patients and families, completing regular check-ins with families, and spending as much time as needed with families	12	"I like how the Complex Care appointments aren't rushed and […] they listened to all of your concerns and they're always listening for [Child]'s accomplishments and all the things that she's done and where she's going in life and how she's doing and...out of all the clinics that [Child] sees, I think they're really the only one that I can guarantee that we're going to be there for probably 3 hours just because we're talking and trying to make sure that whatever [Child] does need is fulfilled in one way or another." -106
Care Coordination: saving family time and travel to hospital by scheduling appts more quickly, efficiently, and/or closer together; providing appointment reminders; helping with navigating different specialists; reaching out to medical supply companies	7	"Let's say […] it takes a very long time for me to get an appointment with whatever specialty. I always reach out to the Complex Care team and […] when I tell you I love them, I love them because they help me so much all these years. I will reach out and say, "Hey, I need an appointment for vision" or, "Hey, I need an appointment with GI." They really get hands on and they get the appointment, I would say, ASAP." -113
Familiarity: having a long-term relationship/connection with CCP staff, involving trust between family and staff and staff's familiarity with the difficulties involved in parenting CMC	6	" […] Whatever situation I bring up from the past, like, [the CCP staff says,] "Oh yeah, I remember that and this is how it panned out medically." So there's just an extra level of reassurance with his team." -104
Availability: CCP can always be contacted if needs arise or a family has questions	4	"If I don't know how to navigate a problem they're my first person to call, medically speaking." -102
Compassionate: providing kind, empathic, and compassionate care;	3	"They just come along and reassure me that I'm doing a good job, that

ensuring family they are doing a good job meeting child's needs		[...] things are all, all falling into place as to our goal."109
Communication with other teams: spending time communicating with other medical professionals on behalf of child/family	1	"There's there's so many times where they've played middleman between me and teams [...] it's been important and sanity saved." -104
Resources: providing helpful resources to family (e.g., in-home care)	1	"They're the ones who helped me get the extra help I needed for [Child] in-home so that we didn't have to give him up." -102
Summary Sheet: providing summary sheets including all of child's medical information/specialists for family and/or other medical providers to use	1	"[…] the one thing that comes to mind right away is the summary sheet that Complex Care provides that has, like all of her diagnoses for like medical professionals and their phone numbers." -107

Table 4. Recommendations for Complex Care Staff to Support Parents' Efforts to Be a "Good Parent."

Recommendation	**What Does it Mean?**	**How?**
Build Trust with Families	Know Each Family	Spend time with families, conduct regular check-ins, demonstrate genuine interest in patients and families beyond medical conditions
	Be a Consistent Presence	Maintain staffing consistency as much as possible across inpatient, outpatient, and telehealth/phone contact
Reduce Mental and Physical Load on Families (if/when desired)	Coordinate Care	Save family time and travel to the hospital/clinic by grouping appointments together whenever possible
	Communicate on Family's Behalf	Coordinate with other medical providers (e.g., subspecialists) across the medical system
	Provide Availability	Be responsive via on-call line and/or electronic messaging systems to enable families to contact CCP medical provider when needed
Support Family Well-Being	Provide Peer Support	Enable families of CMC to meet one another for social support (e.g., in person meet-ups, online support groups, exchange contact information between consenting families)
	Provide Reassurance and Praise	Notice and express when parents /caregivers are meeting child's needs adequately

Appendix. Interview Guide

Initial Instructions:

- *Greet participant, confirm video/audio working, confirm they are still available for interview, ask if they have initial questions*
- *Say:* You received a consent form via e-mail and reviewed it with a member of the study team by phone. I'd like to briefly review some important information before we get started. You can also review this information on your consent form.
    - I will be audio-recording the interview today. We will not record videos or photos of you. I will let you know before I start audio recording. I am not recording now.
    - Data will be stored on secure servers and will only be accessible to members of the study team. Also, members of your child's medical care team will not have access to any identifiable data, so the information you provide today will not affect your child's medical care.
    - Please let me know if you need to stop the interview at any time. You are free to not respond to any question. We will also provide you with some mental health resources in case you feel upset by any of the things we discuss today. The list of mental health resources was emailed to you after our initial phone call and I can send it again if you need it.
    - After the interview, we will send you a gift card.
    - Do you have any questions for me?
        - We're ready to begin the interview. I have lots of questions to ask you today about your experience as a parent and caregiver to your child. Some of the questions might be easy to answer, while others may be difficult or remind you of upsetting times in your life. As a reminder, just let me know if you'd like to skip a question, move on, or stop the interview. I'm going to start recording now. *[Start recording]*

Interview:

- Today is [date]. I am interviewing participant # ___. Do I have your verbal consent to audio record this interview? *[Participant should say yes before you continue. If not, turn off recording and remind them that participation involves recording so we can use the information they share. If unwilling to be recorded, participant may not take part in the study.]*

1. First, 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.
    a. *Possible Probes: Interests, hobbies, career, family, other children*
    b. *[If you don't know already, ask the first name of child served by Complex Care Team. Be sure to ask them to repeat if needed so you get the correct pronunciation. For the rest of the interview, use the child's name as much as possible. Remind participants that all names will be removed from the transcript.]*

2. Before we talk about CHILD's medical journey, tell me about CHILD as a person.

3. What have been some highs and lows in CHILD's medical journey?

4. Are you involved in making medical decisions for CHILD?

    a. If not, who is involved in making medical decisions for CHILD?
    b. If yes, who, if anyone, helps you in making medical decisions for CHILD?

5. When you are making hard medical decisions for CHILD, are there any thoughts or beliefs that help you make those decisions? For example, some parents have different ways of thinking about what they want for their child, like "I want my child to experience as little discomfort as possible" or "I want to my child to have access to lots of different experiences in their life."

6. It sounds like you have some ways of thinking that help you make decisions for CHILD. We have learned that parents often have a sense of what they believe they need to do to be a "good parent" to their child. This is not to say that there are "good" or "bad" parents. Rather, parents know their children and their needs better than anyone else. What do you think about that?
    a. For you, what does it mean to be a "good parent" to CHILD?
    b. [*Restate/summarize what they have said*] Is there anything else you believe you need to do to feel like a "good parent" to CHILD?

7. It sounds like you have a personal definition of what it means to be a "good parent" to CHILD. You described things like […] How does that definition help you in caring for CHILD?

8. What are some things that make it <u>easier</u> to feel like you are meeting that definition of being a "good parent" to CHILD?
    a. [*If needed*] For example, this could include things your child's providers do or the resources you have access to.

9. What makes it <u>harder</u> to feel like you are meeting that definition of being a "good parent" to CHILD?
    a. [*If needed*] For example this could include things your child's providers do or don't do, or the resources you wish you had access to but currently do not.

10. Are there any downsides to having a personal definition of what it means to be a "good parent"? For example, are there times when your idea of what it means to be a "good parent" makes things harder for you?

11. Can you think of a recent medical decision you made for your child? *[Pause for time to think and describe the decision.]* How, if at all, did your beliefs about being a "good parent" to your child affect that decision?

12. How, if at all, have your beliefs about what it means to be a "good parent" shifted over your child's life? If so, did those align with particular events or medical decisions?

13. Do you feel that your child's Complex Care providers understand what it means to you to be a "good parent" to CHILD?

    Possible rephrases:
    - *Do you feel that the Complex Care team understands the things you'd want to do as part of being a good parent to your child? [Can refer back to their beliefs if needed]*
    - *We've talked a lot about what it means to you to be a "good parent." Do you think the Complex Care team understands that about you?*

    a. Why or why not?
    b. Have you ever spoken with them about it?

14. What are some things that the Complex Care staff do that make it <u>easier</u> for you to feel like a "good parent" to CHILD?

15. What, if anything, does the Complex Care staff do that may make it harder to feel like a "good parent" to CHILD? Again, please feel comfortable to share honestly; we will delete all personal information before we share our results.

16. Is there anything you wish the Complex Care team did differently to help you feel that you are doing everything you can to be a "good parent" to your child?

17. One of our ideas for a future study is to first collect parents' thoughts about what it means to be a "good parent" to their child. Then, we would share that information directly with that child's Complex Care team. While we are not doing that today, how would you feel about participating in a study like this?

18. *If CHILD has siblings:* How is being a "good parent" to CHILD the same or different from being a "good parent" to your other children?

19. We have talked a lot about your journey caring for your child and the beliefs you have. Thank you for sharing your experiences with me. Is there anything else you'd like to share?