Honoring the Good Parent Intentions of Courageous Parents: A thematic Summary from a US-Based National Survey

Summary of survey results published in *Children, December 2020* Meaghann S. Weaver, MD, MPH; Marie L. Neumann, MA; Blyth Lord, MEd; Lori Wiener, PhD, DCSW, LCSW-C; Junghyae Lee, PhD; Pamela S. Hinds, RN, PhD, FAAN

Introduction

Courageous Parents Network is proud to work with provider-researchers who are investigating issues and questions common to the lived experience of families caring for very sick children. This study, published in the December 2020, explores the concept of "being a good parent" from the perspective of parents of children with chronic or complex illness. For the study, the investigators recruited CPN families to expand on the medical field's understanding of how parents' ideas about "good" parenting are formed and how, or if, they evolve over time. This is a non-technical description of the study and results. For more in-depth information, read the <u>published article</u>.

The study

The medical field has been studying the "good-parent beliefs concept" for more than a decade. Since the first qualitative study was released in 2009, care teams have partnered with parents of pediatric patients across settings to further explore the meaning and impact of the idea of trying to be a good parent. The initial research, follow-on projects, and many conversations between providers and parents have taught the field that individual, and deeply personal, concepts of good parenting guide medical decisions. The research also suggests that these individual concepts are influenced by experiences ("medical encounters") as parents care for their children.

The original study identified these good-parent definitions: "making informed, unselfish decisions in the child's best interest; remaining at the child's side; showing the child that he is cherished; teaching the child to make good decisions; advocating for the child with the staff; and promoting the child's health." Later studies found differences between groups of parents based on certain decisions they had made on their child's behalf; also, that fathers, mothers and single parents ranked the values differently. Nevertheless, "doing what they believed was 'right' for their child in the current situation" has been a constant theme.

"Honoring the Good Parent Intentions of Courageous Parents" explores gaps in the collective understanding of "good" parenting; for example, if, when and how a parent becomes aware of their own definition; whether they perceive that this definition changes over time; what, or who, may influence their personal definition; the ways "being a good parent" to an ill child may be the same or different than for well siblings; benefits or obstacles perceived by parents in striving to reach their definition; and whether parents perceive themselves as attaining that definition.

The families

Sixty-seven parents participated in the study, including 60 biological mothers, five fathers, and two foster parents or legal guardians of sons (52%) and daughters (48%). The age of living children ranged

from four months to 16 years (average 7.6 years), and the duration of illness ranged from three months to 15 years (average 6.7 years). Eleven bereaved parents' children lived an average lifespan of six years. Participants were primarily Caucasian (white), college-educated mothers (90%) in a married partnership and co-parent role from suburban (58%) or urban (25%) geographies across the United States.

The children's' diagnoses included metabolic and genetic (41%), neurologic (22%), oncologic (15%), pulmonary (15%) and gastrointestinal (7%) conditions. Two respondents shared that their children reside in an inpatient care setting. Two-thirds of parents reported that six or more medical subspecialists were actively involved in their child's care. Thirty-nine percent (39%) of families had current palliative care involvement.

Study design

The study was conducted through an online survey of parents of children (age birth to 18 years) with chronic or complex illness, from June to August 2020. Bereaved parents were included in the survey, in parallel with parents of living children. The survey was distributed by Courageous Parents Network through its communication channels, which include a monthly newsletter and social media. In addition, a live virtual discussion hour featuring study team members was hosted by CPN in July 2020 to highlight the good parent concept. This program included a link to the survey.

Findings

This is a summary of the more nuanced findings of the study. For greater detail please see the published report.

- Definitions of "being a good parent" aligned around ten major themes: Being an advocate; Conveying love; Providing the best possible care; Comforting my child; Creating meaningful memories with my child; Helping my child reach fullest potential; Seeking some balance amongst my many roles; Developing my own medical insights; Respecting my child as a person; Weighing my child's possible quality of life
- More than half of respondents (55%) reported feeling supported by asking to discuss what it means to be a good parent; however, more than a quarter (27.5%) were unsure of their feeling
- Sixty percent (60%) had communicated and reflected with others on their definition as a way to gain perspective and find ways to improve
- The majority (70.2%) reported that the concept had started to exist in their awareness before their child's birth or at the time of their child's medical diagnosis (21.3%)
- For the 68% of responding parents with more than one child, 46% reported that their definition
 of "good" parenting was the same for their ill child and their well child(ren), while 54%
 perceived that their ways of being a good parent was the same or unique for their ill child. The
 key differences for this group related to the need to give the ill child more attention and care;
 spending more time researching and advocating on behalf of the ill child; feeling even greater
 responsibility; and recognizing that parenting an ill child did not involve the same degree of
 preparing the child for autonomy as one does for a well child

- Influencing the personal definition are: Awareness of the child's prognosis (43.5%); Changes in the child's health (37.7%); Family interactions (31.8%); Spiritual considerations (24.7%); Clinician behaviors (18.8%); Physician interactions (14.1%); Nurse interactions (11.8%); and other influencers, including the child's preferences and lessons from other families (15.3%)
- Families described the benefits of striving to be a good parent as receiving rewarding and centering focus on what really matters; personal growth and transformation; and their child receiving unconditional love and living the fullest life possible
- The challenges included providing complex care, both time-wise and meaning hands-on care needs; navigating multiple needs and opinions of family members; diverse perspectives and opinions of medical providers; inability for others to fully understand the family's situation, resulting in a sense of loneliness, judgement or exclusion; internal expectations and self-judgement; concern for increases in the child's suffering; and structural obstacles (e.g., accessing services, resources, medications, case management, support)
- Two-thirds (67.5%) of parents reported that their definition changed over time. The
 predominant experience was a transition to focusing more on quality experiences and memorymaking as time passes; shifting from having perfectionist ideals to recognizing what is most
 important: "play, laughter, love and comfort." The study indicated that parents of older children
 or a child with longer duration of illness were more likely to perceive that they had attained or
 reached their definition. The researchers suggest that these parents may experience increasing
 familiarity with the child's unique needs, preferences and likes over time; or, the shift from
 focus on medical knowledge to prioritizing loving the child may be part of the sense that the
 parent has attained their own goals
- Half (51.3%) of the parents felt that they were able to be the parent they want to be for their child "some days yes and some days no." These parents recognized that they sometimes experienced sadness, exhaustion and a sense of feeling overwhelmed, but that they just tried again the next day. For some, their definition was linked to how the child was doing on that particular day. Parents who "often" or "always" met their own definition (43.6%) generally recognized that they were not perfect but strove to show the child every day what they thought was important, and they focused on enjoying the child

Conclusion

The study suggests that the concept of "being a good parent" does exist early and evolves over time. The themes identified are consistent with those of prior research, but also include a new, or novel, theme: "finding a balance." The respondents noted the importance, and difficulty, of striking a balance between keeping their child safe and allowing them to 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. For some, striking this balance is an important part of the definition of "being a good parent." The researchers suggest that how often parents are attaining their personal definition merits careful consideration for medical teams in providing support, co-advocacy, and high regard for parents' "courageous, caring, and good intentions toward their loved children." They further note that:

- The sense of being an effective advocate plays a role in the perception of having reached a "good parent" definition. Future research could further explore how parents define advocacy. The idea of medical team members partnering with parents in this role is recognized as a core value in well-regarded relationships
- 2. Pediatric palliative care is under-represented in the children's care circles, which is considered a missed opportunity for supporting the children and their families
- 3. The "good parent" concept is notably influenced by socioeconomic status, gender, familial, cultural and social determinants of health. The survey respondents were a somewhat homogenous group, although the findings were congruent with prior "good parent" thematic explorations

Thank you

Many thanks to the CPN parents who participated in this study! If you are interested in contributing your knowledge and experience to future efforts, please watch your CPN newsletter and be certain to follow CPN on Facebook and LinkedIn.