"Good-Parent Beliefs": Research, Concept, and Clinical Practice

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Parents of ill children have willingly identified their personal beliefs about what they should do or focus on to fulfill their own internal definition of being a good parent for their child. This observation has led to the development of the good-parent beliefs concept over the past decade. A growing qualitative, quantitative, and mixed-methods research base has explored the ways that good-parent beliefs guide family decision-making and influence family relationships. Parents have expressed comfort in speaking about their good-parent beliefs. Whether parents achieve their unique good-parent beliefs definition affects their sense of whether they did a good job in their role of parenting their ill child. In this state-of-the-art article, we offer an overview of the good-parent beliefs concept over the past decade, addressing what is currently known and gaps in what we know, and explore how clinicians may incorporate discussions about the good-parent beliefs into clinical practice.

A decade and a half ago, a qualitative inquiry regarding the decision-making of parents of children with terminal cancer revealed that these parents readily defined themselves as "trying to be a good parent in making care decisions in the child's best interest."[1] When the parents specifically offered the term "good parent" to describe what they aimed to do, and to be, with their decision-making, they maintained that this term was affirming both the duty and devotion relevant to their role.

Parents of ill patients can describe a working definition of their personal set of beliefs that inform their sense of duty with regard to parenting their child. Parents have stated that speaking about their good-parent beliefs does not cause them stress; instead, speaking about these beliefs is often cited as a source of support and guidance.[2–4] Even first-time parents with neonates in the neonatal intensive care setting have shared an internal working definition of "being a good parent" that existed for them before clinicians were involved, a primal and personal definition that was relevant before the child's birth and lived through the longevity of parenting.[5]

Since the initial recognition of a good-parent beliefs concept, authors of a variety of research studies have explored the situations impacting the initial and longitudinal definition of the good-parent beliefs as self-defined by parents of ill children. The extent that parents of ill children achieve their personal definition of being a good parent has been described by parents as helping them cope with their child's clinical situation.[3,6] The extent that bereaved parents perceive they reached their personal definition of being a good parent during their child's lifetime affects the parents' sense of guilt or peace.[7–12] The good-parent beliefs are recognized as a guiding compass in parental decision-making and parental sense of personal duty.[13]

This article offers an overview of the concept of the good-parent beliefs, addressing what is currently known

abstract

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about these beliefs, gaps in what we know, why discussions about the good-parent beliefs should be incorporated into clinical practice, and how clinicians can do so.

WHAT IS KNOWN?

The original good-parent beliefs definition included the following: "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 a Greater Being; advocates for the child with the staff; and promotes the child's health."[3] Qualitative, quantitative, and mixed-methods research has clarified that parents' good-parent beliefs are definable, distinct, dynamic, either fostered or hindered by staff behaviors, and duty-directing for the parents who hold them.

Definable

Across a variety of patient illnesses or conditions and clinical settings, parents have been able to define what being a "good parent" to a sick child means to them (Table 1). The good-parent beliefs have been defined by parents facing end-of-life decisions for children with cancer,[3] parents of children hospitalized with serious illness,[2] parents of seriously ill children,[14] parents making critical treatment decisions for their children in the PICU,[4] and fathers of children with brain tumors[15] and complex cardiac conditions perioperatively.[16]

Distinct

The distinctness of these beliefs has been documented in a sequence of studies, evidenced by the variation among parents regarding the specific beliefs that they endorse as being most important to them. First, qualitative studies of how parents approach the task of making medical decisions for children with serious illness led to the identification of distinct thematic categories that describe parents' definition of being a good parent.[3,17,18] These thematic groups were then used to construct discrete-choice experiments in which parents chose the categories of the good-parent beliefs that were the most important to them, enabling the relative rating and rankings of these groupings of beliefs, and demonstrating marked differences in how parents rate the importance of different beliefs.[2,4] Finally, research has identified groups of parents with similar ratings of specific sets of good-parent beliefs, emphasizing overall affirmation of beliefs, such as emphasizing that the child feels loved, seeking to improve the child's health, advocacy on behalf of the child and making informed decisions, and emphasizing the child's spiritual well-being, revealing that common patterns of how parents prioritize core duties and parental attributes may exist.[2]

Dynamic

A parent's definition of "being a good parent" is not static but instead may shift over time and across situations. A longitudinal study of 124 parents of 100 hospitalized children revealed that at 12 months, 21 parents (20%) had shifted from the "making informed decisions" priority group to the "making sure my child feels loved" priority group, whereas no parent transitioned from the "loved" priority group to the "informed" priority group.[14] At the 2-year time point, 8 parents had transitioned to the "loved" priority group and 4 had transitioned to the "informed" priority group (13%).[14] Whereas baseline factors such as hopefulness and perception of the child's health impact the good-parent beliefs over time,[14] other factors not measured in this study, such as disease progression or changes in the child's symptom burden, changes in the parent's degree of prognostic awareness, trust in the clinical team, or family factors such as financial stress, may all affect whether and how the good-parent beliefs might change over time.[3]

Influenced by Staff Behaviors

Parents are able to name behaviors and actions of staff that either foster or impede their ability to live up to their personal good-parent beliefs. Nine themes (continue to comfort my child and me [26.6%], be pleasant [21.9%], coordinate care [12.5%], ask about our faith [21.5%], give us the facts [10.9%], do not quit on us [12.5%], do not forget us [6.2%], keep including my child [6.2%], and provide more material items and support options [6.2%]) represented staff behaviors that parents desired to see increased or initiated to foster their good-parent beliefs definition.[3] Similarly, 9 themes were identified by parents of children in the ICU of staff actions that would help the parent. Keeping us informed (32%) was the most common theme. Other themes were be attentive (12%), keep providing good care (12%), be considerate (8%), have a team approach (8%), provide support (7%), be honest (7%), and let me be a parent to my child (4%).[4] These themes overlap and interact with one another because good care for a child requires a team approach and keeping parents informed necessarily includes honest communication. Parents are able to identify staff behaviors that collectively respect their child and support their family unit.

Fathers of children in the cardiac perioperative setting readily provided clear and actionable suggestions when asked how staff could support them in reaching their personal good-parent beliefs. These included, when communicating, making eye contact not just with the mother but also the

TABLE 1 Good-Parent Beliefs Studies

Study	Study Design	Population Refusal Rate	Contribution to Concept Development Key Study Findings
Hinds et al[3]	Prospective, qualitative study	62 parents interviewed within 72 h of an end-of-life decision for a child with cancer (mother, *n* = 55; father, *n* = 7). Refusal rate, 2 of 64[a]	Established the GP definition. "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."
Feudtner et al[2]	Prospective, cross-sectional, discrete-choice experiment study	200 parents of ill children (mother, *n* = 136; father, *n* = 60; other, *n* = 4). Refusal rate, 95 of 295	Used a novel ranking tool to help parents prioritize the GP attributes. "Parents ranked making sure my child feels loved, focusing on my child's health, and making informed medical care decisions as most important good parent attributes."
October et al[4]	Prospective, cross-sectional, discrete-choice experiment study	43 parents of children in the ICU for whom a family conference was being convened to discuss a clinical treatment decision for their child (mother, *n* = 25; father, *n* = 18). Refusal rate, 3 of 53	Constructed GP definition in the ICU setting. Parents in the ICU made similar themed statements as parents of the oncology cohorts: "Focusing on my child's quality of life (21%), advocating for my child (20%), and putting my child's needs above my own (19%) were the most commonly identified themes. The other themes identified were making informed medical care decisions (14%), staying at my child's side (11%), focusing on my child's health and longevity (8%), making sure my child feels loved (5%), maintaining faith (1%), and having a legacy (1%)." Mothers who were coupled had different GP attributes compared with mothers who were uncoupled.
Hill et al[14]	Prospective, longitudinal 2-year cohort, discrete-choice experiment study	124 parents of hospitalized children (mother, *n* = 90; father, *n* = 32). Refusal rate, 95 of 295; 124 had sufficient follow-up data	Expanded GP concept into a longitudinal concept; revealed some parents change GP beliefs over time. "Top priorities among entire sampling of parents were making sure my child feels loved and child's health." The loved group "placed highest priority on making sure the child feels loved (85%), child's quality of life (49%), child's health (48%), and child's comfort (38%)." The informed group "prioritized making informed medical care decisions (87%), advocating for the child (62%), child's health (51%), and making sure child felt loved (42%)."
Robinson et al[15]	Mixed-methods case series	10 fathers of children with complex cardiac conditions perioperatively (mother, *n* = 0; father, *n* = 10). Refusal rate, 0 of 10	Applied GP concept to paternal-specific cohort; identified staff support actions to help fathers reach their GP definition. "Fathers definitions of being a good father identified 5 main themes: supportive presence, being there, bonded insight, strong provider, informed advocate."

GP, good parent.

[a] Obtained through correspondence with study team.

father; providing social support through hobby-based groups, such as woodworking; providing information via booklets specific for dads, written by dads; and facilitating economic support via a job program with local employment agencies near the hospital.[16]

Duty-Directing

Parents report that their personal good-parent beliefs serve as an ethically important internal compass when making medical decisions for their child.[17] Parents often view themselves as duty-bound to act in accordance with their good-parent beliefs. Clinicians frequently cite best-interest standards, and yet parents carry the weighty internal compass of their good-parent beliefs.[13] Exploring with parents their motivations and sense of parental duty in decisions may facilitate improved understanding about how parents perceive that they are acting in the best interest of the child.

WHAT ARE IMPORTANT GAPS IN THE GOOD-PARENT BELIEFS CONCEPT RESEARCH?

To date, published good-parent beliefs research has been limited to English-speaking participants, most of whom have been white, female,

and educated (Table 2). Future studies would benefit from additional diversity in language, ethnicity, sex, educational level, and marital status as well as inclusion of same-sex parenting couples. The good-parent beliefs concept would be further enriched by inclusion of experiences from different cultural, socioeconomic, family structure, and language backgrounds to further expand the set of identified good-parent beliefs and better understand how these diverse characteristics are associated with different good-parent beliefs.

Social, socioeconomic, and cultural factors should also be examined, specifically regarding social determinants of health. Thus far, no clear pattern of association between socioeconomic factors and the good-parent beliefs has emerged: in a study of parents making critical decisions for their child in an urban PICU, no association was found,[4] whereas in another study, the group of parents who most prioritized focusing on their child's physical health was noted to have the highest level of financial difficulties, the smallest percentage of college graduates, and the lowest level of private health insurance.[2]

The gendering, or "mothering and fathering," of the good-parent beliefs also warrants attentiveness. The category "making informed medical decisions" was ranked the most important theme by fathers 75% of the time and by mothers 25% of the time (P = .045). Interestingly, all mothers who identified "making informed medical decisions" as the most important theme were not part of a coupled parent unit.[4] How parental dyads differ or concur in their good-parent role definitions warrants specific future attentiveness.

Participants have identified their good-parent beliefs priorities as often existing "in tension" as key beliefs conflict with each other, and these tensions should be explored. For example, parents have reported feeling conflict between their beliefs in their duty to provide financially for the child by working (and thus not being always with an ill child) was at odds with their beliefs that they should provide emotional support for the child, requiring them to be at the ill child's bedside.[16] In the expanded context of parenting a family of children, parents also report tension between their beliefs about "being a good parent to the sick child" and "being a good parent to the well sibling(s)." Better understanding of how parents manage these tensions over time would provide insight regarding their ability to achieve an overall sense of role congruence or persistent role conflict. How the

TABLE 2 Parent Demographics

Study	Race (%)	Marital Status (%)	Highest Level of Education (%)	Religion (%)	Economics (%)	Child's Diagnoses (%)
Hinds et al[3]	White (44.8); African American (12); other (5.1); unknown (37.9)	Not reported	Not reported	Not reported	Not reported	Solid tumor (51.7); brain tumor (36.2); leukemia (12.1)
Feudtner et al[2]	White (80.5); African American (11); other (7.5); unknown (1)	Married (85.5); single (11.5); divorced (3)	SC (46.5); CC (53.5)	Not reported	Financial difficulties: none (54), some (36.5), many (9), unknown (1). Health insurance: Medicaid (46.5), other government (7), private (71.5), none or missing (1)	Genetic (70.7); respiratory (55.8); cardiac (48.2); neurologic (39.7); metabolic (11.5); oncologic (10); renal (9.5); other (30)
October et al[4]	White (25); African American (65); Asian American (5); Other (5)	Married (51); single (49)	HS (37); SC (26); CC (21); postgraduate (16)	Christian (63); Jewish (5); other (18); not designated (14)	Household income: $0–30 000 (21); $30 000–50 000 (11); $50 000–90 000 (26); $90 000+ (16); do not want to say (26)	Hematologic or oncologic (34); respiratory (21); neurologic (14); trauma (14); gastrointestinal (7); metabolic or genetic (7); sepsis or shock (3)
Hill et al[14]	White (86.3); African American (5.7); Hispanic (8.9); Other (8.1)	Married (89.52)	SC or CC (60.5)	Not reported	Financial hardship (41.46)	Not reported
Robinson et al[15]	White (80); African American (10); Hispanic (10)	Married (70); engaged (20); single (10)	HS (40); SC (30); CC (30)	Not reported	Not reported	Complex cardiac (100)

CC, college completion; HS, high school; SC, some college.

good-parent beliefs may shift or solidify over time in the context of these existing tensions is underexplored.

Finally, we should explore the ways in which a parent comes to hold their good-parent beliefs, which may be influenced by their personal exposure to parenting beliefs and behaviors during their own childhood, based on formative parental figures and how these figures shape their own parental values.[19–21] Viewed from the context of families, the good-parents beliefs concept has also been expanded to examine other relational roles. Ill children with advanced cancer have defined their sense of "being a good patient," and this includes care for their parents.[22] A recent case series in which researchers ask grandparents of ill children, "How do you define being a good grandparent to your ill grandchild?" revealed that grandparents readily identify the parent–grandparent relationship as influential to the child–grandparent relationship and role definition.[23]

WHY IS THE GOOD-PARENT BELIEFS CONCEPT AN IMPORTANT CLINICAL CONCEPT?

For parents who are caring for a child with a serious illness, the good-parent beliefs frame parental perspective on the child's best interest, shape parental role priorities, and influence perceived parental duties.[2] The good-parent beliefs guide parental decision-making.[2–4]

For parents who have passed through one or more episodes of serious illness for their child (which may last for days or years), they want, very much, to know that they were a good parent to their ill child; bereaved parents particularly crave and need this peace.[1,3,6]

Considering how a parent defines "being a good parent to my ill child" allows clinicians to "see" the parent in that role at the bedside or in rounds. Clinicians may consider affirming or even complementing the parent in this parenting role ("Your love for your child is evident in the way you advocate for his needs," "Your caring, consistent presence at the bedside speaks to your incredible parenting," or "Your child is really special to have such an attentive mom"). Verbal recognition of the way a parent is loving their child or living into their good-parent beliefs may serve as a source of encouragement. For clinicians, understanding what parents believe to be their most important duties to their child provides key insight regarding parental motivations and behaviors and how best to support families.

Clinicians may ask parents what special role the parent brings to the care of the child and may even then inquire how the medical team can further foster or recognize this role. For example, the mom of a newborn in the critical care unit who identifies "offering physical touch and soothing" as one of her good-parent beliefs may recognize the nurse moving a rocking chair next to her infant's isolette and adding a maternal voice recording to the child's room not only as a convenience for comfortably remaining at the bedside but also as a form of fostering her good parenting during necessary absences. A father whose day job maintains his son's health insurance and who defines being a good parent as "being informed of my hospitalized child's rapidly changing medical needs" may perceive consistent telephone calls after morning rounds not only as helpful information-sharing but as an actual empowerment for his definition of being a good father.

WHERE COULD GOOD-PARENT BELIEFS RESEARCH GO AWRY?

Although thematic grouping exists in the research base, this comes with a stark caution about presumed clinical application. The study team cautions against suggesting an etiologic connection between parent demographics or characteristics and the good-parent beliefs groupings (eg, level of formal education in the family is substantially causing certain good-parent beliefs). The study team would further warn against allowing a clinical decision to be made because of presumed association between patient or parent characteristic and good-parent beliefs group profile (eg, because these parents have this socioeconomic characteristic, the communication approach should be tailored because the clinician assumes the parents are more likely to fit certain good-parent beliefs without first establishing a relationship with the family and asking the parents about the good-parent beliefs).

The good-parent beliefs concept should not be presumed to harbor a contrasting bad parent concept. The purpose, nature, intention, and purity of the good-parent beliefs concept is the freedom from judgment of a parent and the fortitude of lifting a parent toward his or her definition of virtue. Learning about a parent's good-parent beliefs is a way to learn more about tangible staff actions to support the parental role.

HOW CAN THE GOOD-PARENT BELIEFS CONCEPT BE APPLIED IN CLINICAL PRACTICE?

Within the context of a supportive therapeutic relationship with a parent, clinicians should consider inquiring about the parent's good-parent beliefs. Although no evidence base supports a particular way to pose this topic of discussion, we have found words that work are similar to the following: "I have talked with many parents over the years, and I have learned they often have within themselves a sense of what they believe they need to do to be a good parent on their own terms. Do you have any feelings like that?" A time of silent presence then allows the parent to share his or her response. If the

parent looks uncertain or quizzical, a conversation prompt may include offering examples: "For some parents, they believe they need most of all to make sure their ill child feels loved; for other parents, they believe they need to advocate for their child, focus on their child's health, or make the most informed decisions that they can. All of these are important beliefs. Do you have any beliefs like this for yourself?"

The goal here is to gently explore. Helping parents to explore what they believe about parenting a critically or chronically ill child and why they hold those beliefs is a personalized dialogue of discovery. These discussions often play out over time and may include talking about deeply held parenting beliefs, held with love and devotion, but often also with some degree of pain or tension based on difficult realities or intergenerational influences. Being curious about a parent's good-parent beliefs should also extend to asking how staff may best support parents in achieving their beliefs, specifically querying parents about clinician behaviors they would like to see continued, increased, or initiated.[3] Parental beliefs and feelings should be considered in clinical decisions because the unit of care in pediatrics is the child within the context of a family. Even if there is disagreement between medical team members and parents on the certain medical treatments or decisions, the opportunity remains for the parent to identify tangible ways that the medical team can continue to care well for the child and support the parent through compassionate action or communication. An example would be that the parent who identifies being a good parent as "trying to prevent suffering" may find ongoing solace in the medical team's thoughtful pain management interventions even if there is disagreement about continuation of life-sustaining treatment.

Those parents who are able to make their personal good-parent beliefs explicit may experience enhanced self-insight of their parenting behaviors. Given the opportunity to reflect on their good-parent beliefs, parents may experience the benefit of recognizing that they have, indeed, parented well according to their beliefs. They may have opportunity through this good-parent beliefs definition exercise to explore how they determine to parent their ill child and to reflect on the benefits that abiding by their good-parent beliefs has offered to their ill child.

Importantly, trust is established through this dialogue,[24] and clinical teams should treat what is shared by a parent in a vulnerable moment with respect. Clinicians should only inquire about good-parent beliefs if they are committed to then working to help the parent achieve her beliefs. To inquire about beliefs without follow-up may generate in the parent a sense of either judgment or abandonment. To pass judgments on these beliefs, or to attempt to use them for persuasion leverage regarding a particular medical decision, would be far worse, tantamount to a breach of trust.

CONCLUSIONS

The good-parent beliefs concept has over the past decade opened a dimension of medical decision-making for parents that complements and extends our understanding of how they view both the decisions they face and the considerations they should focus on. The qualitative, quantitative, and mixed-methods good-parent beliefs concept research has revealed that parents are able to define and describe these beliefs. The good-parent beliefs reveal parental priorities, influence decision-making, and ultimately affirm for the parents the importance of their role in their child's life, expressing both their personal sense of duty and their devotion. In the context of relationships with families, caring providers should consider entering into supportive dialogue with parents to explore their personal good-parent beliefs, which may evolve over time, and finding ways for health care teams to best support parents.

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