

“Trying to Be a Good Parent” As Defined By Interviews With Parents Who Made Phase I, Terminal Care, and Resuscitation Decisions for Their Children

Pamela S. Hinds, Linda L. Oakes, Judy Hicks, Brent Powell, Deo Kumar Srivastava, Sheri L. Spunt, JoAnn Harper, Justin N. Baker, Nancy K. West, and Wayne L. Furman

A B S T R A C T

Purpose

When a child's cancer progresses beyond current treatment capability, the parents are likely to participate in noncurative treatment decision making. One factor that helps parents to make these decisions and remain satisfied with them afterward is deciding as they believe a good parent would decide. Because being a good parent to a child with incurable cancer has not been formally defined, we conducted a descriptive study to develop such a definition.

Methods

In face-to-face interviews, 62 parents who had made one of three decisions (enrollment on a phase I study, do not resuscitate status, or terminal care) for 58 patients responded to two open-ended questions about the definition of a good parent and about how clinicians could help them fulfill this role. For semantic content analysis of the interviews, a rater panel trained in this method independently coded all responses. Inter-rater reliability was excellent.

Results

Among the aspects of the definition qualitatively identified were 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. We also identified 15 clinician strategies that help parents be a part of making these decisions on behalf of a child with advanced cancer.

Conclusion

The definition and the strategies may be used to guide clinicians in helping parents fulfill the good parent role and take comfort afterward in having acted as a good parent.

J Clin Oncol 27:5979-5985. © 2009 by American Society of Clinical Oncology

INTRODUCTION

Parents of children who are expected to die of cancer often describe themselves as trying to be a good parent in making care decisions in the child's best interest.¹ Parents' perceived success in this effort is influenced by their interactions with the child's clinicians. The support of trusted clinicians in decision making conveys that the parents are viewed as good parents.¹⁻³ Clinicians' reactions to parental decisions (respect for the decision *v* doubt) can enhance or diminish parents' sense of competence at a time when there are few remaining opportunities to be a good parent. Clinicians' reactions also influence parents' level of trust at a time when trust is essential to meet the child's and family's needs.⁴⁻⁶ In addition, parents of children who have died of cancer report that their sense of having been a good parent at the end of

their child's life helps them to emotionally survive the experience and the child's loss.² In our previous research, 84% of participating parents of children with incurable cancer identified a factor influencing their decision making to be “deciding as a good parent would.”¹ We recognized that we did not know the meaning of this commonly considered factor for parents.

An understanding of the meaning of being a good parent to a child dying of cancer may help guide clinical care, optimize support for difficult treatment or care decisions, and allow parents the comfort of having made a good parent's decision. We conducted interviews with parents who participated in making one of three decisions for a child with cancer to elicit their definitions of being a good parent. We also asked what clinician behaviors would be helpful to parents in fulfilling the good parent role at this time in their child's care.

From the School of Medicine, Department of Pediatrics, George Washington University; Department of Nursing Research at Children's National Medical Center, Washington, DC; Patient Care Services, Department of Biostatistics, Department of Oncology, and Division of Nursing Research, St Jude Children's Research Hospital; and Department of Pediatrics, University of Tennessee Health Sciences Center, Memphis, TN.

Submitted September 7, 2008; accepted June 18, 2009; published online ahead of print at www.jco.org on October 5, 2009.

Supported in part by Grant No. R21 NR008634 from the National Institute of Nursing Research, Cancer Center Support Grant No. P30 CA21765 from the National Cancer Institute, and the American Lebanese Syrian Associated Charities.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Corresponding author: Pamela S. Hinds, PhD, RN, FAAN, Children's National Medical Center, 111 Michigan Ave, NW, Washington, DC 20010, e-mail: pshinds@cnmc.org.

The Acknowledgment is included in the full-text version of this article, available online at www.jco.org. It is not included in the PDF version (via Adobe® Reader®).

© 2009 by American Society of Clinical Oncology

0732-183X/09/2735-5979/\$20.00

DOI: 10.1200/JCO.2008.20.0204

METHODS

Setting and Sample

This descriptive study took place at St Jude Children's Research Hospital and was approved by the institutional review board. Eligible parents were English speaking, and had made a noncurative treatment decision during the previous 72 hours for their ill child. We approached only parents identified by clinicians as having made one of three decisions, able to provide informed consent, and unlikely to be emotionally burdened by an invitation to participate. The three decisions were whether to enroll in a phase I study, to initiate a do not resuscitate (DNR) order, and whether to initiate terminal care (ie, to end all disease-directed therapy while continuing aggressive symptom management). Each parent could participate in the study only once.

Procedures

Eligible parents were identified through our attendance at clinical rounds, daily review of physician documentation in the intensive care and bone marrow transplant units, electronic notification of each enrollment on a phase I trial, and by clinician referral. When a potentially eligible parent was identified, a study team member confirmed the parent's eligibility with both the child's physician and psychosocial specialist. After signed informed consent was obtained, the parent selected the interview location.

Using our standard decision making study interview format,¹⁻³ we first asked parents to describe the decision they had made. As described in our explanation of the study to parents and in the consent documents, we then read the following statements to the parents: In our previous studies with parents and guardians who have made a difficult decision, such as the one you recently made on behalf of your child, we learned that the parents/guardians made their decision to benefit their child in some way. These parents/guardians described their decision making as "doing what a good parent would do" or "deciding as a good parent would." It is important to staff to do all that they can to support your definition of what a good parent is or what a good parent would do. (1) Please share with me your definition of being a good parent for your child at this point in your child's life. (2) Please describe for me the actions from staff that would help you in your efforts to be a good parent to your child now.

The interviewer wrote down the parent's responses, read them back to the parent for verification, immediately typed them, and returned the typed interview to the parent(s) for review. The three interviewers were retrained in obtaining consent and interview technique every 3 months throughout the 22-month study period.

Analysis

After accuracy was confirmed by parents, the transcribed responses were analyzed for semantic content to identify the parents' intended meaning.⁷⁻¹¹ Two study team members jointly reviewed the first four interviews and applied codes to each phrase to capture its meaning. Three team members (one palliative care physician and two nurse researchers) then completed study-specific training in semantic content analysis using the four interviews and independently analyzed the remaining interviews. The specific steps in this analysis were as follows. (1) Each phrase was labeled with a code derived from the exact and recurring verbiage used by the parents and that represented the parents' intended meaning and thus the codes' meaning. (2) Each individual coded phrase was repeatedly compared with the actual parent interview quotes and with all other coded phrases to make sure the parents' intended meaning was accurately captured in the label and to assess for overlapping or expanded meaning among the recurring codes. (3) A conceptual definition was developed for each code based on the parents' verbiage and the assessed parents' meaning. (4) Inter-rater reliability estimates (percent agreement) were computed for each code. (5) Codes with overlapping meaning and that recurred together frequently were combined to reduce the number of unique codes; as a result of the combining, a reworking of the code definitions was completed to include all aspects of the combined codes (now labeled themes) and the definitions of the themes. (6) All elements of each theme were compared and extracted to form the overall conceptual definition of being a good parent.

RESULTS

Sixty-two parents (including four couples) of 58 patients participated. Most parents were mothers (91.4%) and white (44.8%); their ages were 19.7 to 55.2 years. Only the interview responses from the parents who identified themselves as the primary caregiver are included in this analysis to avoid the possibility of duplicative responses from couples that could inflate frequency rates of findings. The most frequent decisions were about phase I study enrollment (51.7%) and DNR status (29.3%). Each parent responded to both interview questions; there were no missing data. Most of the 58 patients were white (65.5%) and male (56.9%); their ages were 6 months to 21.6 years. Solid tumors

Table 1. Characteristics of the Study Group

Characteristic	Patients (N = 58)	
	No.	%
Primary caregiver		
Mother	53	91.4
Father	5	8.6
Sex		
Male	33	56.9
Female	25	43.1
Ethnicity		
Parent		
White	26	44.8
Black	7	12.0
Other	3	5.1
Unknown	22	37.9
Patient		
White	38	65.5
Black	12	20.7
Biracial	3	5.2
Asian	1	1.7
Other	4	6.9
Age, years		
Parent		
Mean		37.6
SD		7.8
Median		38.2
Range		19.7-55.2
Patient		
Mean		11.3
SD		6.2
Median		11.4
Range		0.6-21.6
Diagnosis		
Solid tumor	30	51.7
Brain tumor	21	36.2
Leukemia	7	12.1
Decision made		
Phase I study		
Yes	30	51.7
No	0	0.0
DNR		
Yes	17	29.3
No	1	1.7
Terminal care		
Yes	9	15.5
No	1	1.7

Abbreviations: SD, standard deviation; DNR, do not resuscitate.

Being a Good Parent

were the most common diagnoses ($n = 30$; 51.78%; Table 1). All but two patients are now deceased. Death occurred 3 to 103 days (median, 10 days) after a DNR decision; 3 to 685 days (median, 46 days) after a terminal care decision; and 39 to 1,508 days (median, 138 days) after a phase I decision.

Each parent was interviewed once; the mean interview time was 31 minutes (median, 23 minutes). Most interviews ($n = 63$) occurred in clinical or domiciliary settings; one parent requested a telephone interview. Two couples requested that they be interviewed simultaneously; all other parents were interviewed singly. Three parents made minor corrections to the interview transcripts, 57 approved them without change, and two elaborated on them. Mean inter-rater reliability (% agreement) for each code was 92.6% (median, 75%; range,

50% to 100%) for the first question and 92.0% (median, 75%; range, 50% to 100%) for the second.

Interview question 1: Please share with me your definition of being a good parent for your child at this point in your child's life. Eight themes identified among the 220 meaning codes assigned to parent responses (Table 2) formed the basis of our definition of being a good parent. The most frequent theme (in 89.1% of interviews) was "doing right by my child," conveying parents' desire to make decisions in the child's best interest and meet the child's basic needs to the extent possible, in an unselfish manner. The next two most frequent themes, identified in 48.4% and 42.2% of interviews, respectively, were "being there for my child" and "conveying love to my child." Parents felt that it was important to be continually supportive,

Table 2. Parental Definition of "Being a Good Parent to My Dying Child"

Theme (n = 8)	Definition	Codes		Parents Reporting		Sample Quote
		No.	%	No.	%	
Doing right by my child	Making prudent decisions in best interest of child (even when parent would prefer different course) after weighing all options; meeting basic needs (eg, clothing, food, education) in unselfish way that may require sacrifices	67	30.45	57	89.1	"We tried as much as we could to get her the best treatment." "This is simple—doing what is best for your child."
Being there for my child	Always at child's side and supportive regardless of challenges; knowing at all times which activities child is engaged in and with whom	50	22.7	31	48.4	"Always being at her side." "Being with her every step of the way."
Conveying love to my child	Demonstrating to child by actions and words how cherished child is, even under difficult circumstances; focusing on child's quality of life and happiness	30	13.0	27	42.2	"Most of all, giving him the love that I have." "Tell them you love them every day, and never take anything for granted."
Being a good life example	Trying to live life that teaches child to behave in positive ways, know right and wrong, make good choices, be respectful of others, and show sympathy to others	17	7.7	13	20.3	"Training your child to make good choices." "Doing things that will make the child be a better person rather than slipping through life." "Sympathy—make sure your kids learn sympathy for others."
Being an advocate for my child	Knowing what child wants and alerting staff to those wants; involving staff in care that parent is unable to perform; trying to stay focused on meeting child's needs at all times	14	6.4	14	21.9	"We try to tell the staff if it is something we can't do." "For a while, I felt like I was a bad person because I'm honoring his wish, but I told myself to go on and be the bad person because you are doing what your child wants."
Letting the lord lead	Bringing child up to know God and find comfort in his constant presence; letting child know that parent prays for child every day	14	6.4	11	17.2	"To provide a Christian home, to bring them up in a Christian home learning about God and knowing how important that is." "Pray every day for yourself, your children, and others. And let your kids know that you do this."
Not allowing suffering	Trying to prevent care that causes child to suffer but may not benefit child; wanting child to be able to die with dignity	21	9.54	12	18.8	"Making her as comfortable as we can—little things like what type of saline—the purple top—doesn't make her nauseous." "A good parent is also to let her leave this world with dignity that she entered it with and not with someone beating on her chest."
Making my child healthy	Helping child to be as healthy as possible and to function as normally as possible for as long as possible	7	3.2	6	9.4	"Do everything you can to help your child live longer and healthier." "To help him be as functional as he can be for as long as he can be."

to remain at the side of their child, and to convey their love to the child. Additional themes in descending frequency included “being a good life example,” “being an advocate for my child,” “letting the Lord lead,” “not allowing suffering,” and “making my child healthy.” The qualitatively derived definition of being a good parent to a child with incurable cancer is: 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.

Although not all eight themes were represented in every parent’s responses, all themes were represented across each of the three types of decisions.

Interview Question 2: Please describe for me the actions from staff that would help you in your efforts to be a good parent to your child now. From a total of 210 codes assigned to the parent responses, 15 themes were identified (Table 3). The most frequent theme (“all that can be done is being done”) represented the foremost importance of knowing that the child and family were receiving the best possible clinical care. Of the remaining themes, five (“staff respect me and my decisions,” “staff know our special needs,” “staff like our child,” “staff tell us we are good parents,” and “staff give us time to decide”) represented supportive, positive clinician behaviors consistently experienced by parents. Nine themes (“continue to comfort my child and me,” “be pleasant,” “coordinate care,” “ask about our faith,” “give us the facts,” “don’t quit on us,” “don’t forget us,” “keep including my child,” and “provide more material items and support options”) represented clinician behaviors that parents desired to see increased or initiated.

DISCUSSION

To the best of our knowledge, this is the first study to explicate the meaning of being a good parent to a child with incurable cancer. The definition reflects parents’ perceived obligation to make beneficial medical decisions for their child and remain at the child’s side despite difficult circumstances. Certain components of this semantically derived definition confirm the findings of others. Making well-informed, unselfish decisions, having the courage to pursue favorable outcomes for the child, and facing difficult treatment decisions were the leading values of parents of neonates with life-limiting congenital abnormalities.¹² Parents’ desire to uphold their responsibilities toward their critically ill or dying child¹³⁻¹⁶ was reflected in our themes of “being there for my child” and “being an advocate for my child.” In addition, using a phenomenological method to describe the transition experience of 28 bereaved parents through the death of their child, Woodgate¹⁷ labeled aspects of that experience as being a good parent. These aspects included preventing suffering and ensuring happiness for their child, being physically present, and providing emotional support to their child. These aspects are reflected in our themes of “being there for my child,” “conveying love to my child,” “being an advocate for my child” and “not allowing suffering.” The emergence of similar parental meaning across different infant, child, and adolescent age patients and through different research methods further

supports the existence of the concept of being a good parent to a seriously ill child.

Our themes of “making my child healthy,” “being a good life example,” and “letting the Lord lead” were not identified in previous studies. The differences between our findings and those of Rushton¹² and Woodgate¹⁷ may reflect medical circumstances or the status of the ill child (deceased *v* living). Parents of a child with cancer typically pursue potentially curative treatment until cure is no longer a medical possibility, whereas curative options were unavailable for the neonates¹² or the children who died of sudden infant death.¹⁷

Although every theme identified in our parent interviews was reflected in all three decision types, not every parent interview contained all of the identified themes. This may be related to differing parental perceptions of what it means to be a good parent and to different clinical contexts, including parents’ perceptions of care goals and of the seriousness of their child’s clinical situation. In one recent study, spouses reported perceiving the primary treatment goal for their child differently (palliative care *v* curative therapy).¹⁸ In another study, most of the parents of 24 children who had died of cancer perceived the goal of palliative care as comfort, but several desired broader goals (eg, activities to engage their child in daily life).¹⁶ Clinicians mindful of possible differences in parental perceptions may help parents increase their understanding of their child’s clinical status and achieve their definition of being a good parent by providing opportunities to discuss care goals. Parents’ intellectual and emotional awareness of their child’s incurable disease appears to be influenced by the type and amount of information provided to them by their child’s clinicians.^{19,20}

Clinician strategies that help parents fulfill their definition of a good parent appear to fall into three categories: strategies that parents currently benefit from and want to see continued (“staff like our child”), those that the parents want increased (“ask about our faith,” “give us the facts”), and those the parents want initiated (“don’t forget us”). Clinicians may directly query parents about the clinician behaviors they would like to see continued, increased, or initiated. The theme “staff like our child” reflects the importance of positive relationships in end-of-life care^{1,21} and the comfort parents derive from clinicians’ positive regard for their child; this regard is effectively conveyed when clinicians show emotion about the child’s clinical situation.²² The theme “give us the facts” represents parents’ desire for accurate, clear, understandable information about their child’s condition. Others have reported that parents of children dying of cancer want clear, understandable, concise, complete, accurate, and compassionately delivered information^{2,16,22,23}; this strategy is included in the end-of-life care recommendations of professional associations²⁴⁻²⁶ and in evidence-based guidelines from a multisite study.³ Our findings also indicate that parents benefit from their child’s clinicians telling them that they are good parents.

A faith-related theme in the good-parent definition (“let the Lord lead”) and among the helpful clinician strategies (“ask about our faith”) highlights parents’ perceived responsibility to guide their child spiritually and their reliance on personal faith. The theme “ask about our faith” conveys parents’ desire that clinicians know about and respect their religious beliefs and practices. Among parents whose child died in a pediatric intensive care unit, 73% identified faith-based sources of comfort at the end of their child’s life.⁵ Four religious themes were identified: prayer, faith, access to clergy, and belief that the parent-child relationship endures beyond death. Other studies of

Being a Good Parent

Table 3. Clinical Care Strategies Parents Reported Would Support Their Efforts to Be Good Parents to Their Dying Child

Theme (n = 15)	Definition	Codes		Parents Reporting		Sample Quote
		No.	%	No.	%	
All that can be done is being done	Parent suggests no change to current care or atmosphere; parent satisfied with warmth of staff and openness of staff to family seeking additional opinions	50	23.8	41	64.1	“They do it all well here.” “Everything has been done well for us here. The support they give you for one.”
Staff respect me and my decisions	Clinicians respect and support parent’s wishes, decisions, and efforts to advocate for ill child, thus allowing parent to retain full parental role at end of child’s life	25	11.9	21	32.8	“I like how everyone listens to us.” “For staff to continue to respect his feelings and preferences, even if they come at 4 [SCAP]AM [R].”
Staff continue to comfort my child and me	Staff show emotion about child’s clinical situation, allow parent to vent, and show sincere care for child and parent	22	10.5	17	26.6	“They showed us how they care about all of us.” “It is hard for me when she [daughter] has these mood swings...[I want staff] to pull me to the side and let me vent sometimes without her around. That helps me deal with her.”
Staff know our special needs	Skilled and experienced staff provide care tailored to unique aspects of child and family and do so in caring and professional manner	21	10.0	17	26.6	“She [clinic nurse] was really good at putting my mind at ease. We went right through my list of questions and she said to me, ‘It’s going to be okay. We’ll get through this.’” “We have been given the information we needed to make the choices.”
Staff like our child	Staff openly convey affection and positive regard for ill child; staff show humor with child	20	9.5	19	29.7	“Here staff want to make a difference in her life.” “The care she is getting here—the way the staff treat her—talking to her sweetly—I like that, and I hope she can hear them.”
Staff are pleasant	Clinicians are consistently positive, caring, understanding of patient/parent mood swings, affectionate, and playful	14	6.7	14	21.9	“Everyone here is so excellent and so supportive, but if you have a day without a smile, just explain why there is no smile...It is important to know that not having a smile is just because of a bad day or something.” “This is the warmest place we have ever been.”
Staff coordinate care	Staff initiate smooth transition between different clinical teams/units; share all relevant clinical information with different clinical teams/units so families do not need to repeat it	10	4.8	8	12.5	“The staff in the other clinic didn’t seem to know we were on the same team. That was kind of a let down.” “To keep explaining our situation to new people is very hard...It just helps not to have to keep explaining to new people what is going on.”
Staff ask about our faith	Parents prefer that clinicians convey respect for parental religious beliefs, make spiritual materials (eg, Bibles, movies) readily available, and ask parents about beliefs	8	3.8	8	21.5	“Ask people about their faith, and put us in touch with a counselor or someone who can support you in your faith.” “I miss Bibles being in the patient rooms. To come in a room here, there ought to be spiritual literature.”
Give us the facts	Clinicians provide accurate information about child’s clinical situation and viable care options in way that is not confusing	8	3.8	7	10.9	“Having too many options got confusing.” “I wish there was a way that someone like me could hear what needs to be said more detailed and straightforward.”
Staff tell us we are good parents	Clinicians tell parents that they have made reasonable care decisions and recognize and respect their role as parents	8	3.8	6	9.4	“Because she said I was the best mom.” “They talk to us like we are the parents.”
Do not quit on us	Clinicians continue to convey hope and have positive demeanor; provide excellent care until child dies	8	3.8	8	12.5	“When you are searching for something positive, you watch the staff demeanor, voice, how they hold themselves. They are our information life line, and if they are negative—then there is no hope.” “I want them to know why I do not want him on machines. Maybe they don’t understand the decision I made, but I do...yet I do not want them to think just because I don’t want all those machines, they need to push me out of the door.”

(continued on following page)

Table 3. Clinical Care Strategies Parents Reported Would Support Their Efforts to Be Good Parents to Their Dying Child (continued)

Theme (n = 15)	Definition	Codes		Parents Reporting		Sample Quote
		No.	%	No.	%	
Do not forget us	Clinicians in care setting stay in touch with bereaved parents after they have returned home	4	2.0	4	6.2	“It’s important to me that staff not forget us.” “Don’t forget us—see how we are without us have to call. I pray that Dr X, Dr Y, and some of the nurses will call.”
Keep including our child	Clinicians continue to speak directly to child and involve child in discussions and procedures	4	2.0	4	6.2	“Allowing him to be a part of the procedures.” “Include us both in conversations about her treatment.”
Provide more material items and support options	Provide additional financial resources for family needs and trusted staff to remain with ill child while parent participates in self-help activities	4	2.0	4	6.2	“Give us anything. I would help.” “Financial resources for families without social security.”
Staff give us time to decide	Parents are given protocols to take away to review before making decision or are given time to consult with others, including family members and other clinicians, before making decision	3	1.4	2	3.1	“They gave me the protocols in advance; let me take them home with me to study; I came back with my questions.” “That was when I called my family—called my mom and told her I was packing to come home because I needed my family’s help. I couldn’t detach emotionally enough to read each protocol. I needed to get help with that.”

parents and clinicians of children dying in intensive care^{15,27-30} and hospice settings^{31,32} also demonstrated the importance of spiritual beliefs. Because faith is important to some parents at this point in their child’s care, clinicians can support parents’ faith-related practices by asking about parents’ beliefs, religious symbols, or practices and asking how clinicians can best show their respect. The American Academy of Pediatrics position article on palliative care acknowledges the essential inclusion of spirituality, including access to spiritual advisors.³³

Clinician behaviors reported by parents to help them make the studied decisions have striking similarities to those identified in other studies. The theme we identified as “not allowing suffering” is comparable to that of avoiding negative outcomes for the ill child.^{1,15} Additional similarities include staff emotional supportiveness and comforting of parents,^{22,34} keeping parents well-informed about their child’s status,²² including the child in discussions and decisions to the extent possible,²⁴⁻²⁶ continuing to convey hope and have a positive demeanor,¹³ allowing parents time to make end-of-life decisions,¹⁵ and being direct and forthcoming with information even if it is distressing.^{22,34} These similarities indicate that certain clinician behaviors help parents make end-of-life decisions and fulfill the good parent role in general.

Four supportive clinician behaviors identified in this study were not associated with end-of-life decision making but were identified as helping parents feel that they were “good parents”: “staff tell us we are good parents,” “don’t forget us,” “provide more material items and support options,” and “coordinate care.” These four behaviors appear related to parents’ desire to maintain a personal association with the child’s clinicians. The remarkable nature of this relationship is a comfort to parents. In sum, although behaviors that help parents make end-of-life decisions and fulfill their definition of a good parent have similarities, some helpful clinician behaviors are unique to the latter effort. Clinicians will benefit from knowing which behaviors are most helpful to parents in both of these clinical situations.

Components of the definition of a good parent (contributing to the child’s moral, physical, and emotional well being) meet social expectations of all parents. Our findings and others^{1,16} indicate that the parents of seriously ill children remain concerned about the child’s development; clinicians need to anticipate these concerns. The absence of missing data for either interview question indicates that all participating parents, including several first-time parents, were able to articulate their personal definition of a good parent. It is possible that some parents may not be aware of this personal definition until asked about it by a clinician. Helping the parent to explore his or her definition of a good parent may offer parents and clinicians insight into parent choices and preferences for the child with progressed cancer.

Our study was limited by the predominance of mothers and of white male patients, and by being conducted at a single site. It is also possible that the wording used in our interview query (“...we learned that the parents made their decision to benefit their child in some way...”) may have influenced the parents’ responses by framing the question. Our findings do not represent all parents involved in these three decisions for a child with incurable cancer, given that some parents were not approached for this study because of clinician concern that it would be too burdensome. Some aspects of the definition of being a good parent do not apply equally to all parents (eg, “to know God”) or to children of all ages (eg, “teaching the child to have sympathy for others”), as conveyed by the number of parents represented by each code or theme. Therefore, clinicians may find it more helpful to select from among themes rather than attempt to apply the entire definition in every clinical situation related to the three studied decisions. Finally, some aspects of care that may influence parents’ definition of a good parent may differ with cancer versus other clinical conditions. The information provided here may help to guide clinicians’ care of children with advanced cancer, optimize support for the studied decisions, and allow grieving parents the comfort of having been a good parent.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Pamela S. Hinds, Linda L. Oakes, Brent Powell, Deo Kumar Srivastava, Wayne L. Furman

Financial support: Pamela S. Hinds

Administrative support: Pamela S. Hinds

Provision of study materials or patients: Pamela S. Hinds, Linda L. Oakes, Judy Hicks, Brent Powell, JoAnn Harper, Wayne L. Furman

Collection and assembly of data: Pamela S. Hinds, Linda L. Oakes, Judy Hicks, Brent Powell, Sheri L. Spunt, JoAnn Harper, Justin N. Baker, Nancy K. West, Wayne L. Furman

Data analysis and interpretation: Pamela S. Hinds, Linda L. Oakes, Judy Hicks, Brent Powell, Deo Kumar Srivastava, Sheri L. Spunt, JoAnn Harper, Justin N. Baker, Nancy K. West, Wayne L. Furman

Manuscript writing: Pamela S. Hinds, Linda L. Oakes, Judy Hicks, Brent Powell, Deo Kumar Srivastava, Sheri L. Spunt, JoAnn Harper, Justin N. Baker, Nancy K. West, Wayne L. Furman

Final approval of manuscript: Pamela S. Hinds, Linda L. Oakes, Judy Hicks, Brent Powell, Deo Kumar Srivastava, Sheri L. Spunt, JoAnn Harper, Justin N. Baker, Nancy K. West, Wayne L. Furman

REFERENCES

- Hinds PS, Drew D, Oakes LL, et al: End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol* 23:9146-9154, 2005
- Hinds PS, Oakes L, Furman W, et al: Decision making by parents and health care professionals when considering continued care for pediatric patients with cancer. *Oncol Nurs Forum* 24:1523-1528, 1977
- Hinds PS, Oakes L, Furman W, et al: End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology. *Cancer Nurs* 4:122-136, 2001
- Hinds P, Oakes L, Furman W: End-of-life decisions in pediatric oncology, in Ferrell BR, Coyle N (eds): *Textbook of Palliative Nursing*. New York, NY, Oxford University Press, 2001
- Robinson MR, Thiel MM, Backus MM, et al: Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics* 118:e719-e729, 2006
- Meert KL, Thurston CS, Briller SH: The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: A qualitative study. *Pediatr Crit Care Med* 6:420-427, 2005
- Krippendorff K: *Content Analysis: An Introduction to its Methodology* (ed 2). Thousand Oaks, CA, SAGE Publications, 2004
- Krippendorff K, Bock MA: *The Content Analysis Reader*. Thousand Oaks, CA, SAGE Publications, 2009
- Rogers B, Knafelz K (eds): *Concept Development in Nursing: Foundations, Techniques, and Applications*. Philadelphia, PA, Saunders Publishers, 1993
- Hamblin RL: On Definitions as Guides to Measurement, Technical Report 6. St Louis, MO, Small Groups Research Center, Social Science Institute, 1960
- Bazeley P: Computerized data analysis for mixed methods research, in Tashakkori A, Teddlie C (eds): *Handbook of Mixed Methods in Social and Behavioral Research*. Thousand Oaks, CA, SAGE Publications, 2003, pp 385-422
- Rushton C: *Moral Decision Making by Parents of Infants Who Have Life-Threatening Congenital Disorders*. Washington, DC, Catholic University of America, 1994
- Kirschbaum MS: Life support decisions for children: What do parents value? *ANS* 19:51-71, 1996
- Stewart MJ, Ritchie JA, McGrath P, et al: Mothers of children with chronic conditions: Supportive and stressful interactions with partners and professionals regarding caregiving burdens. *Can J Nurs Res* 26:61-81, 1994
- Sharman M, Meert KL, Sarnaik AP: What influences parents' decisions to limit or withdraw life support? *Pediatr Crit Care Med* 6:513-518, 2005
- Monterosso L, Kristjanson LJ: Supportive and palliative care needs of families of children who die from cancer: An Australian Study. *Palliat Med* 22:59-69, 2008
- Woodgate RL: Living in a world without closure: Reality for parents who have experienced the death of a child. *J Palliat Care* 22:75-82, 2006
- Edwards KE, Neville BA, Cook EF, et al: Understanding of prognosis and goals of care among couples whose child died of cancer. *J Clin Oncol* 26:1310-1315, 2008
- Valdimarsdottir U, Kreichbergs U, Hauksdottir A, et al: Parents' intellectual and emotional awareness of their child's impending death to cancer: A population-based long-term follow-up study. *Lancet Oncol* 8:706-714, 2007
- Mack J, Wolfe J, Cook EF, et al: Hope and prognostic disclosure. *J Clin Oncol* 25:5636-5642, 2007
- Clayton JM, Hancock K, Parker S, et al: Sustaining hope when communicating with terminally ill patients and their families: A systematic review. *Psychooncology* 17:641-659, 2008
- Tomlinson D, Capra M, Gammon J, et al: Parental decision making in pediatric cancer end-of-life care: Using focus group methodology as a prophase to seek participant design input. *Eur J Oncol Nurs* 10:198-206, 2006
- Meert KL, Eggly S, Pollack M, et al: Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med* 9:2-7, 2008
- American Academy of Pediatrics: Committee on Bioethics: Guidelines on forgoing life-sustaining medical treatment. *Pediatrics* 93:532-536, 1994
- Society of Crit Care Med: Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill: Task Force on Ethics of the Society of Crit Care Med. *Crit Care Med* 18:1435-1439, 1990
- American Nurses Association: Task force on the nurse's role in end-of-life decisions: Compendium of position statements on the nurse's role in end-of-life decisions. Washington, DC, American Nurses Association, 1991
- Meyer EC, Burns JP, Griffith JL, et al: Parental perspectives on end-of-life care in the pediatric intensive care unit. *Crit Care Med* 30:226-231, 2002
- Meyer E, Ritholz M, Burns J, et al: Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics* 117:649-657, 2006
- Caitlin EA, Guillemin JH, Thiel MM, et al: Spiritual and religious components of patient care in the neonatal intensive care unit: Sacred themes in a secular setting. *J Perinatol* 21:426-430, 2001
- McSherry M, Kehoe K, Carroll JM, et al: Psychosocial and spiritual needs of children living with a life-limiting illness. *Pediatr Clin North Am* 54:609-629, 2007
- Donnelly JP, Huff SM, Lindsey ML, et al: The needs of children with life-limiting conditions: A healthcare-provider-based model. *Am J Hospice Palliat Med* 22:259-267, 2005
- Swinney R, Yin L, Lee A, et al: The role of support staff in pediatric palliative care: Their perceptions, training and available resources. *J Palliat Care* 23:44-50, 2007
- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care: Palliative care for children. *Pediatrics* 106:351-357, 2000
- Wharton RH, Levine KR, Buka S, et al: Advance care planning for children with special health care needs: A survey of parental attitudes. *Pediatrics* 97:686-688, 1996