Decision Making by Parents of Children With Incurable Cancer Who Opt for Enrollment on a Phase I Trial Compared With Choosing a Do Not Resuscitate/Terminal Care Option

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A B S T R A C T

Purpose

Parents of children with incurable cancer make complex and difficult decisions about remaining treatment options. We compared the self-reported rationale, good parent definition, and desired clinical staff behaviors of parents who recently decided for phase I (P1) chemotherapy with parents who chose a do not resuscitate (DNR) or terminal care (TC) option.

Patients and Methods

Sixty-two parents of 58 children were asked for the basis of their decision, their definition of a good parent, and what staff behaviors supported their good parent role. After semantic content analysis, results were compared in the P1 versus DNR/TC groups. These categories were mutually exclusive but did not necessarily represent an either/or decision.

Results

Thirty-one decisions were for P1 chemotherapy and 27 for DNR/TC. Median survival time after study enrollment was greater in the P1 group (0.4 v 0.1 years). Most P1 group parents reported having felt compelled to continue cancer-directed therapy (71% v 7%), whereas those who opted for DNR/TC cited quality of life (QOL; 74% v 3%) and patient wishes (67% v 13%). Decision factors common to both groups were medical facts, doing right, and others' opinions. Both groups believed that a good parent did right, provided support and presence, and sacrificed for the child. The groups desired similar support from clinicians and expressed gratitude.

Conclusion

Despite similar definitions of a good parent and desired staff behaviors, parents in the P1 group reported having felt compelled to continue cancer-directed therapy, whereas QOL and patient wishes were emphasized in decisions for DNR/TC.

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INTRODUCTION

Despite substantial advances in treatment, approximately 20% of children with cancer in the United States die of their disease.¹ Parental decision making in the setting of incurable cancer is a complex and poorly understood process. Options vary depending on access to investigational chemotherapy and the opinions of the child's physician. Further, parents' role in decision making and their understanding of the risks and benefits of treatment may change over time,² as may their expectations regarding the duration of their child's survival. Therefore, decisions are made within a changing context, often multiple times. Parents say that decisions about phase I (P1) study enrollment, discontinuation of cancer-directed therapy, do not resuscitate (DNR) status, and withholding of life-sustaining therapies are the most difficult they make.³ Many parents also regret

opting for their child's last chemotherapy regimen.⁴ However, parents report that a sense of having been a good parent to the dying child provides emotional relief^{5,6} and that clinicians' response to their decisions influences their perception of their competence as parents.³

In a previous study, parents who had made treatment decisions on behalf of their child with incurable cancer defined a good parent as one who makes informed, unselfish decisions in the child's best interest, meets the child's basic needs, remains at the child's side, shows the child love, protects the child's health, prevents suffering, teaches the child moral values, and advocates for the child.⁶ However, it is not known whether parents who have chosen P1 enrollment and those who have chosen DNR/terminal care (ie, comfort care only) differ in their definition of a good parent, the rationale for the decision, or desire different types of staff support. Good

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communication with clinicians and psychosocial support at the end of life improve parental satisfaction, emotional relief, and bereavement adaptation,⁷⁻¹⁰ especially when it identifies patient preferences and supports advance care planning.¹¹ Insight into the parental decision-making process can help clinicians offer effective, compassionate care, support decisions consistent with parental integrity, and minimize decisional regret.

We compared the reported definition of the good parent role, the decisional rationale, and the desired supportive clinician behaviors of parents who had made a decision to pursue a P1 trial and of parents who had chosen a DNR order and/or terminal care.

PATIENTS AND METHODS

This institutional review board–approved study is a secondary analysis of data from a descriptive study at St Jude Children’s Research Hospital, a pediatric comprehensive cancer center.⁶ Eligible subjects were the parents of a child with, according to their primary oncologist, incurable cancer. They were identified by research assistants who regularly monitored clinics and inpatient rounds and by alerts from the central protocol office. All parents were at least 19 years of age, English speaking, and had made one of the following decisions during the previous 72 hours: enrollment in a P1 trial, agreement to a DNR order, or initiation of terminal care (ie, cessation of disease-directed therapy while continuing aggressive symptom management). Parents who chose both a DNR order and oral palliative chemotherapy were eligible. Parents whose child independently made the decision were ineligible. Before being approached, parents were identified by their oncologist as likely to understand the consent process and to be at low risk of excessive emotional stress due to participation. The parents of 76 patients were approached, and 62 parents of 58 patients gave informed consent for participation. Participants selected the location of the face-to-face interview; one parent was interviewed by telephone. Parents were interviewed only once. Four couples were interviewed together; their responses were aggregated as one interview, although individual responses were noted. The interviewer wrote down parents’ responses to four questions (Table 1), read them back to the parents to confirm accuracy, and documented them. Parents then reviewed the documented responses and made minor corrections ($n = 2$), validated them as documented ($n = 58$), or elaborated on them ($n = 2$).

Patient charts were reviewed for demographic data, time from study enrollment to death, prior and subsequent enrollment in P1 trials, and subsequent DNR/terminal care decisions in the P1 group.

Qualitative Data Analysis

Participants were divided into two groups: those who chose a P1 trial and those who chose a DNR order or terminal care. Although such deci-

sions are often complex, the latter two were combined because of their emphasis on noncancer directed therapy. While participating in P1 research and having a DNR order are not mutually exclusive, no parents in this study chose both options.

Responses to questions 2 to 4 in all validated interviews underwent qualitative semantic content analysis.¹² The unit of response was the response to each question, and the unit of analysis within each response was the phrase. Each phrase was analyzed for meaning. Two study team members with extensive experience in this method jointly reviewed the first four interviews and applied codes to each key phrase to capture its meaning. Three other team members (one palliative care physician and two nurse researchers) then completed study-specific training in semantic content analysis and independently analyzed the remaining interviews. Mean inter-rater reliability was 92% for question 2, 92.6% for question 3, and 92% for question 4.

Table 2. Demographic Characteristics of Parents and Patients

Characteristic	Phase I Group		DNR/ Terminal Care Group		Total	
	No.	%	No.	%	No.	%
Parents	32	52	30	48	62	
Patients	31	53	27	47	58	
Primary caregiver						
Female	29	91	24	80	53	85
Male	3	9	6	20	9	15
Patient sex						
Female	14	45	11	41	25	43
Male	17	55	16	59	33	57
Parent race						
White	16	50	12	40	28	45
African American	3	9	6	20	9	15
Biracial	0		0		0	
Asian	0		1	3	1	2
Other	0		2	7	2	3
Not given	13	41	9	30	22	35
Patient race						
White	20	65	18	67	38	66
African American	6	19	6	22	12	21
Biracial	3	10	0		3	5
Asian	0		1	4	1	2
Other	2	6	2	7	4	7
Patient religion						
Protestant	22	71	19	70	41	71
Catholic	4	13	5	19	9	16
None	5	16	3	11	8	14
Diagnosis						
Leukemia	0		7	26	7	12
Solid tumor	17	55	12	44	29	50
CNS tumor	14	45	8	30	22	38
Mean years of age at study enrollment						
Parent	38.4		37.2		37.9	
Median	37.8		38.4		38.2	
Child	10.9		11.6		11.3	
Median	8.8		12.9		11.4	
Mean years from diagnosis to death	3.4		2.6		3	
Median	2.2		1.2		1.9	
Mean years from study date to death	0.8		0.2		0.5	
Median	0.4		0.1		0.2	

Abbreviation: DNR, do not resuscitate.

Table 1. Interview Questions for Parents

1. Please tell me the options that you considered when you made this treatment decision [for your child]
2. Please tell me your reasons for choosing the treatment decision you helped to make on behalf of your child
3. Please share with me your definition of being a good parent for your child at this point in your child’s life*
4. Please describe for me the actions from staff that would help you in your efforts to be a good parent to your child now*

*Questions 3 and 4 were preceded by the statement: “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.”

The frequency of each code was tallied in both groups. To compensate for the multiple appearance of a code in a single interview, we also tallied the percentage of parents for whom the code appeared. In questions 2 and 4, multiple codes coincided frequently or overlapped in meaning. Such codes were grouped and identified as a theme that captured the shared meaning. The definitions of each of the combined codes were compared to arrive at a final definition for each theme.¹² As with the codes, the frequency of occurrence of each theme and the percentage of families to which each theme applied were tallied.

RESULTS

The median interview time was 22 minutes. Sixty-two parents (including four couples) of 58 patients participated. Most were white mothers (median age, 38.2 years). The median patient age was approximately 11.4 years. Most patients were identified as Protestant and most ($n = 51$) had solid tumors (Table 2).

Of the 58 decisions made, 31 (53%) were for P1 trial enrollment and 27 (47%) were for a DNR order or terminal care. Of the six

patients who were on the bone marrow transplant service at the time of death, four were in the DNR/terminal care group. All seven of the patients with leukemia were in the DNR/terminal care group.

In interview question 1, eleven (41%) of 27 families who chose DNR/terminal care reported considering cancer-directed treatment options with their physician, but only three (11%) remembered being offered a P1 trial or experimental chemotherapy. Nine of these families had previously participated in a P1 trial, and two had participated in multiple P1 trials. In contrast, 15 (48%) of 31 families in the P1 group had previously participated in one or more P1 trials, and only 10 (32%) of 31 reported having discussed discontinuing cancer-directed therapy. The P1 group had a longer median time between diagnosis and death ($2.2 \nu 1.2$ years) and between enrollment in this study and death ($0.4 \nu 0.1$ years) than did the DNR/terminal care group. Subsequent to this study, 22 (70%) of 31 parents in the P1 group opted for DNR/terminal care. There was no medical record of a DNR/terminal care decision for the remainder of the group. At the time of data analysis, one study patient (in the P1 group) remained alive.

Table 3. Themes Generated From Responses to Question 2: "Please Tell Me Your Reasons for Choosing The Treatment Decision You Helped to Make on Behalf of Your Child"

Theme	Definition	Frequency in Phase I Group (n = 31)	No. of Parents in Phase I Group		Frequency in DNR/Terminal Care Group (n = 27)	No. of Parents in DNR/Terminal Care Group		Example Statement
			No.	%		No.	%	
Quality of life concern	Parents based the decision on the patient's inability to have a life of good quality in the face of failure of the body or other considerations; they wanted to maximize their time with the child and minimize suffering	1	1	3	36	20	74	"I want [my child] to have quality of life. I don't want him to suffer, and I don't want to see him in pain."
Need to continue therapy	If an available option provided a chance of cure or life prolongation, the parent felt compelled to choose it; other options seemed unreasonable; the opportunity to participate in research and/or receive a treatment that was familiar to the parent made the option even more attractive	51	22	71	3	2	7	"They said there is no drug to cure [her cancer], so [Phase I] was my only real choice. That or nothing... I have to try something."
Doing what is right	Parents chose in their child's best interests; parent was motivated to do what was most fitting for his/her child	8	8	26	9	9	33	"I want to do what is best for her."
Medical facts	The parent based the decision on the medical knowledge obtained through research, MD expertise, and familiarity with treatments	16	14	45	9	7	26	"We have done the research, know the prognosis..."
Memory making	The parent made the decision with the child's legacy in mind; they wanted to remember good times, provide love, acknowledge the child's strength, and create moments valuable to the child	8	6	19	7	6	22	"There is no magic cure. We choose research to make a difference."
Others agree with my decision	The parent determined the "right" decision based on outward endorsements or perceived affirmations from authoritative or sympathetic figures (ie, deity, clinical experts, other parents)	26	14	45	17	13	48	"I spoke with other parents who have been where we are at... and [our doctor's] expertise."
Patient wishes	The parent's decision honored the child's preferences with or without mention of the parent's desire to prevent or end suffering	5	4	13	28	18	67	"This is not what I would have chosen, but I am doing this because this is what [my child] wants."

Abbreviation: DNR, do not resuscitate.

Interview Question: Please Tell Me Your Reasons for Choosing the Treatment Decision You Helped to Make on Behalf of Your Child

Parents' responses generated 181 codes (94 for the P1 group and 87 for the DNR/terminal care group), which were analyzed, as described above, to generate seven themes (Table 3). In the DNR/terminal care group, the quality of life (QOL) concerns theme was observed in 74% of responses, as compared to 3% (one response) in the P1 group. The wishes of the child were emphasized in 67% of the DNR/terminal care group but only 13% of the P1 group. The need to continue cancer-directed therapy was cited by 71% of parents in the P1 group but only 7% in the DNR/terminal care group. Both groups expressed the need to make a decision that did right by their child, took account of the medical facts, and preserved their child's legacy. Parents in both groups indicated that they desired or received endorsement of their decisions from clinicians or sympathetic figures (eg, the parents of other children with cancer, friends, family).

Interview Question: Please Share With Me Your Definition of Being a Good Parent for Your Child at This Point in Your Child's Life

Responses to this question yielded 222 codes (115 in the P1 group and 107 in the DNR/terminal care group), which differed very little between the groups. Table 4 lists the most frequent codes. Parents in both groups stated that a good parent should be present, fulfill the child's wants and needs, and provide protection and support. Approximately one third of parents in the DNR/terminal care group mentioned a desire to protect the child from suffering (as compared with 7% in the P1 group); they also spoke of love for the child more often (26% v 7%). Parents in the P1 group placed more emphasis on teaching right from wrong (26% v 4%).

Interview Question: 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 responses generated 229 codes (119 in the P1 group; 110 in the DNR/terminal care group) that yielded six themes (Table 5). Both groups desired that staff continue to provide thoughtful care, including emotional care, verbal agreement with their decisions, and reassurance that staff would not abandon the family or child. This theme emerged in 85% of the DNR/terminal care and 81% of the P1 group.

The groups showed similar gratitude for the way in which staff gave their time, met needs, provided information, listened, were pleasant and open, gave expert care to the child, and made a positive difference before and after the decision. This theme occurred in the responses of 82% of the DNR/terminal care group and 87% of the P1 group.

The groups similarly, but less frequently, mentioned a desire that staff share information, accept them, advocate and be there for their child, give comfort, and not treat the child differently after the decision. Only parents in the P1 group (23%) stated a need for staff support of a continued quest for cure.

DISCUSSION

We found that the parents of children with incurable cancer report different rationales for enrollment on P1 therapy and for initiation of a DNR order/terminal care. In the latter case, parents more often cited QOL concerns and their child's wishes. In contrast, parents in the P1 group reported a need to pursue any remaining cancer-directed treatment options, and they wanted staff to support them in this decision. Further, only one third of parents in the P1 group said they had

Table 4. Codes Generated From Responses to Question 3: "Please Share With Me Your Definition of Being a Good Parent For Your Child at This Point in Your Child's Life"

Code	Definition	Frequency in Phase I Group (n = 31)	Parents in Phase I Group		Frequency in DNR/terminal Care Group (n = 27)	Parents in DNR/terminal Care Group		Example Statement
			No.	%		No.	%	
Be there for the child	Willingness to support and guide their child, both physically and mentally	16	13	48	20	15	56	"A good parent to me is being there when your child needs you the most."
Do the right thing	Choosing in the best interests of the child; parent is motivated to do what is most fitting for his/her child	12	9	33	12	11	41	"...every decision we have had to make, we considered what is best for [her]."
Love	Parent chooses based on love of the child	2	2	7	9	7	26	"It's unconditional love and support."
Relieve suffering	Striving to reduce the child's pain and/or discomfort, avoid additional hardships, and/or preserve the child's dignity	2	2	7	11	10	37	"To first and foremost make sure he is comfortable."
Right and wrong	Teaching the child life values and boundaries of acceptable behavior	8	7	26	1	1	4	"Try not to spoil him. It's hard to say, 'no.'"
Sacrifice	Willingness to do anything to benefit the child; putting the child's needs first	9	9	33	6	6	22	"It's putting your child first, ahead of everything else."
Provide support	Conveying respect for the child's choices and decisions	3	3	11	6	6	22	"...I felt like I was a bad person [for] honoring his wish, but I told myself to go on and be a bad person because [I'm] doing what [my child] wants."
Tend to child	Providing the means for satisfying the child's wants and needs	5	5	18	4	4	15	"I try to fulfill all of his wants and needs."

Abbreviation: DNR, do not resuscitate.

Table 5. Themes Generated From Responses to Question 4: "Please Describe for Me the Actions From Staff That Would Help You in Your Efforts to Be a Good Parent to Your Child Now"

Theme	Definition	Frequency in Phase I Group (n = 31)	Parents in Phase I Group		Frequency in DNR/Terminal Care Group (n = 27)	Parents in DNR/Terminal Care Group		Example Statement
			No.	%		No.	%	
Provide thoughtful care	The parent would like clinicians to provide comfort and be available to the family by listening and giving emotional care; they appreciate verbal approval of their decisions and abilities as a parent and hope staff are mindful of their faith and their need to protect and remember the child; they seek reassurance that staff will not abandon or "give up" on the child	60	25	81	58	23	85	"...let me know that [staff] are here for me and my child."
Help family support patient	Parents would like staff to accept them, to advocate and be there for their child, to provide comfort, and to treat the child the same as before the decision was made	7	7	23	17	8	30	"Continue treating [my child] the same way they always have...this is the best medicine for her and her family."
Appreciating staff	The parent values the current state of care and expresses gratitude for clinicians' giving their time, meeting needs, providing expertise, listening, being pleasant and open, giving expert care to extend the child's life, and making a positive difference before and after the decision	66	27	87	64	22	82	"These nurses and doctors do everything in my son's best interests. A lot of them go way above and beyond."
Information	The parent desires better and smoother transmittal of information between providers and between clinics; they do not like having to repeat things to multiple new people; they like to be included in decisions, have options explained plainly, and be given time to consider options	10	7	23	4	3	11	"I told people I need it laid out on the table. Even if what they tell me hurts, I need to know..."
Having objective needs met	The parent desires concrete care such as parent support groups, quiet spaces, material needs, more staff, or help with planning the funeral	4	4	13	3	2	7	"I would like to learn from others about planning a funeral"
Do not give up	The family continues to believe there is a chance for cure, and they expect the staff to support their desire for continued therapy	7	7	23	0	0	0	"I am grateful...no one is giving up on us."

Abbreviation: DNR, do not resuscitate.

considered stopping cancer-directed therapy, and 48% had previously enrolled their child in a P1 trial. This finding is consistent with previous studies showing that many parents choose chemotherapy, if available, even when there is no realistic chance of cure.^{4,13} Both groups cited the need to do the right thing, carefully consider the medical facts, and make decisions that would honor the child's memory. Nearly half of parents in each group sought the opinions of those around them.

QOL and patient wishes were the decision factors most frequently identified in the DNR/terminal care group. These findings, like those of others,¹⁴ indicate that parental realization that the child will not survive and the desire to limit suffering are key in making this decision. Observed physical changes (eg, fatigue, decreased interaction, altered appearance) may be important indicators to parents that their child will not survive.¹⁵ The fact that parents in the P1 group did not mention QOL concerns may indicate that they had not observed or acknowledged significant suffering at the time of the decision or that other factors had greater importance. Parents who do not perceive suffering or poor day-to-day QOL may prefer to continue treat-

ment even if the long-term outcome is understood to be fatal. In this context, it may be useful to assist this population of parents in thoughtfully weighing the likelihood of benefit against the likelihood of poor QOL for the child's remaining time.

In this study, 67% of parents who chose DNR or terminal care reported being influenced by their child's wishes. Children and adolescents with progressive cancer can understand the concept of death¹⁶ and the consequences of end-of-life decisions.¹⁷ Further, latency-aged and teenaged patients tend to consider their relationships with others when making their own end-of-life decisions.¹⁷ Communication between parent and child about death can also be beneficial, especially if the parent believes the child understands his or her prognosis.¹⁸ Early involvement of the child in decision making may aid this process for the parent, child, and clinician.

Although the factors considered by parents in the two groups differed, the parents' definition of a good parent did not. Both groups described the importance of doing right by the child and similarly expressed how clinical staff could help them fulfill this role. Therefore, the perceived attributes of a good parent appear to remain stable

across the contexts of these decisions and may reflect a key shared perception, such as a serious threat to their child's survival. An important exception is that parents in the DNR/terminal care group more often mentioned that a good parent relieves suffering, further underscoring the importance of this perception in the decision-making process. Clinicians who help parents to identify and be true to their values may alleviate parents' emotional distress⁵ and promote the maintenance of their personal integrity and dignity during extraordinarily difficult circumstances. The similar perceptions about being a good parent in both decision groups may help alleviate clinicians' reluctance to have such conversations.

Parents in both groups felt strongly that their child should continue to receive the same level of clinical care and concern after the decision. In addition, when asked how staff could help them at this time, more than 80% of families in both groups spontaneously expressed gratitude for the care they were receiving. Although this response did not directly address the interview question, it is significant because it suggests that parents generally do not blame clinical staff when curative options have been exhausted. Rather, parents continue to look to them for support and value their continued care and commitment.

Notably, most P1 group parents (70%) subsequently made a DNR/terminal care decision for their child, and one third of DNR/terminal care group parents had previously opted for P1 research. Further, 89% of the DNR/terminal care group made no mention of having considered or having been offered P1 or experimental therapy, and less than half reported having been offered further cancer-directed therapy. The groups also differed in the length of time between study enrollment and death, likely because enrollment on P1 protocols generally requires a predetermined life expectancy. These data underline the complexity of the decisions studied and imply that the choices made by these parents may have been significantly influenced by the degree of progression of their child's illness at the time of the decision. That is, the same parents might have chosen differently at a different time point in their child's treatment course. In contrast, in 30% of the P1 group, we found no evidence of a subsequent decision for DNR/terminal care, and only 7% of patients in the DNR/terminal care group (*v* 48% in the P1 group) had previously participated in phase 1 trials. Therefore, there is likely to be a subset of parents who would not have chosen differently under other circumstances. A longitudinal study of these decisions would clarify how parental decision making changes during the course of a child's illness. The greater relative emphasis on QOL as the disease progresses and the likelihood of cure diminishes demonstrates the value of integrating QOL assessments into P1 research.

It is important to note that our two groups differed somewhat in diagnosis and that most study patients were white males with solid tumors. Patients with hematologic malignancies were well represented in the DNR/terminal care group but not in the P1 group, as the

availability of P1 studies was limited for these patients. This study was also limited in that the majority of participants were mothers; therefore, the viewpoints of patients' fathers were not well represented and may well have been different.¹⁹ Also we did not study the decisions of parents to pursue palliative chemotherapy unless they also chose a DNR order. Such parents may offer a different perspective and should be included in future longitudinal studies. There were also a small number of potential subjects whom we did not approach, on the recommendation of the primary medical team. Our understanding of the treatment choices available to the family was limited by what the parent could recall at the time of the interview and by how the parent perceived those options.

In summary, parents of children with cancer report different reasons for specific decisions they have recently made on behalf of their child with incurable cancer. Those who choose cancer-directed therapy are likely to focus on sustaining life and a need to continue cancer treatment, while parents who choose DNR or terminal care emphasize the child's QOL or wishes. However, parents' concept of being a good parent to their child and the supportive staff behaviors they desire are similar regardless of the decision made. Clinicians can aid families at this difficult time by being aware of the factors families consider when making end of life decisions, by helping families to identify and prioritize their goals, and by helping them to carefully weigh the potential benefits and burdens of the available options. They should also know that regardless of the decision made, families value the care they have received and wish to see it continued at the same high level.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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

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