

Parent and Physician Perspectives on Quality of Care at the End of Life in Children With Cancer

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ABSTRACT

Purpose

To ascertain parents' and physicians' assessments of quality of end-of-life care for children with cancer and to determine factors associated with high-quality care as perceived by parents and physicians.

Methods

A survey was conducted between 1997 and 2001 of 144 parents of children who received treatment at the Dana-Farber Cancer Institute and Children's Hospital (Boston, MA) or Children's Hospitals and Clinics of St Paul and Minneapolis, MN, between 1990 and 1999 (65% of those located and eligible) and 52 pediatric oncologists.

Results

In multivariable models, higher parent ratings of physician care were associated with physicians giving clear information about what to expect in the end-of-life period (odds ratio [OR] = 19.90, $P = .02$), communicating with care and sensitivity (OR = 7.67, $P < .01$), communicating directly with the child when appropriate (OR = 11.18, $P < .01$), and preparing the parent for circumstances surrounding the child's death (OR = 4.84, $P = .03$). Parent reports of the child's pain and suffering were not significant correlates of parental ratings of care ($P = .93$ and $.35$, respectively). Oncologists' ratings of care were inversely associated with the parent's report of the child's experience of pain (OR = 0.15, $P = .01$) and more than 10 hospital days in the last month of life (OR = 0.24, $P < .01$). Parent-rated communication factors were not correlates of oncologist-rated care. No association was found between parent and physician care ratings ($P = .88$).

Conclusion

For parents of children who die of cancer, doctor-patient communication is the principal determinant of high-quality physician care. In contrast, physicians' care ratings depend on biomedical rather than relational aspects of care.

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INTRODUCTION

Recent research has revealed significant problems in the care of dying children and their families. Symptoms and symptom-related suffering are highly prevalent at the end of life.¹ In addition, parents' recognition of their dying child's poor prognosis lags far behind that of physicians, which is a delay that has been linked to aggressive care at the end of life.² Qualitative research has under-

scored the relevance of these problems to individual children and families.³ This work has led to the creation of guidelines for the end-of-life care of children, with a focus on effective symptom management and clear communication.⁴⁻⁶ Yet parents' values for physician care of their dying children have not been fully defined. Without a direct assessment of parents' values, we may create standards of care that meet physician values better than those of parents.

Existing literature has demonstrated that patient and physician values for care in the primary care setting differ. Whereas physicians consider clinical skill and symptom management as the most important physician attributes,⁷ patients and parents highly value both clinical skill and supportive communication.⁷⁻¹² Similarly, adult patients at the end of life consider both attributes important¹³⁻¹⁵ but may value effective communication over clinical skill.¹⁶

The values of parents of dying children are still largely unknown. Given the magnitude of suffering previously demonstrated in children at the end of life,¹ symptom management may have a prominent role in parent perceptions of care quality. In addition, although we know that communication is important to many patients, whether this attribute is similarly valued by parents of dying children and which aspects of communication are most important to parents remain unclear. Some physicians have argued that communication about difficult aspects of illness and the dying process may not meet the needs of all patients.^{17,18} Whether parents desire detailed medical information about what to expect at the end of life or simply supportive and caring communication is an unanswered question with broad implications for end-of-life decision making.

Such a complex situation cannot be adequately addressed without asking parents for their perspectives on quality end-of-life care for children, including the importance of symptom management and specific communication experiences. Similarly, although physicians' perceptions of children's deaths have been explored¹⁹ and despite their integral role in directing care of these children, we know little about physician values for care of dying children. We sought to understand, from the viewpoint of parents and physicians, the determinants of high-quality care at the end of life for children with cancer.

METHODS

The study was conducted at the Dana-Farber Cancer Institute/Children's Hospital, Boston (DFCI/CHB) and at Children's Hospitals and Clinics, St Paul and Minneapolis (CHC). This study and its methods, as conducted at DFCI/CHB, have been described previously.^{1,2} This report includes further analysis of data previously collected as well as additional data collected from participants at CHC. We interviewed parents of children who had died of cancer between 1990 and 1999. Interviews were conducted between 1997 and 2001. Parents were considered eligible if they were English speaking, they resided in North America, their child died of cancer more than 1 year before enrollment, and their child's former physician permitted contact with the family (such permission was denied for 19 families.) Eligible parents were sent a letter containing a postage-paid opt-out postcard (DFCI/CHB) or opt-in postcard (CHC), chosen according to the institutional review board standards of the site of care. Of 244 eligible parents, 222 were located, and 146 agreed to participate. We conducted a single interview of one parent per family; the family designated the parent who participated. One hundred forty-four parents were interviewed, for a response rate of 65% (144 of 222 parents located). The mean duration of the interview was 132

minutes (standard deviation [SD], 46 years). The parent interview was conducted a mean of 3.2 years after the death of the child (range, 1.1 to 8.0 years). We also administered a standardized questionnaire to the child's primary oncologist, who was defined as the oncologist who had been most closely involved with the child's care and who remained involved in care at the time of the child's death. Physician response rate was 100% (52 of 52 physicians surveyed). In addition, we reviewed the medical records of the children studied.

Instrument Development

Relevant domains and draft items were developed from literature review and focus groups of parents and medical caregivers. Whenever possible, items were taken from previously validated surveys. However, the majority of items were newly created following guidelines suggested by Streiner and Norman.²⁰ All items were closed ended with categorical responses or Likert scales. A pretest of the instrument assessed content, wording, response burden, cognitive validity, and parental willingness to participate.

Parent Survey

Three trained interviewers and three of the investigators conducted the parent interviews. The majority of interviews were administered by telephone; 35 were conducted in person at the request of the parent. Parents were asked to rate the primary oncologist's overall care during the end-of-life care period; response categories were excellent, very good, good, fair, and poor. Parents were also asked to rate whether their child had experienced pain in the last month of life, the degree to which the child suffered from pain in the last month of life (with response categories of a great deal, a lot, some, a little, and not at all), and the number of days the child spent in the hospital in the last month of life (no days, 1 to 5 days, 6 to 10 days, 11 to 20 days, and more than 20 days). Parents were asked to rate aspects of communication with the primary oncologist, including whether bad news was delivered in a sensitive and caring manner (always, usually, sometimes, rarely, or never), whether the oncologist gave clear information about what to expect in the end-of-life period (agree strongly, agree somewhat, disagree somewhat, or disagree strongly), whether the primary oncologist communicated directly with the child (yes, no, or child was too young), whether the parent felt he or she had received conflicting information (always, most of the time, some of the time, rarely, or never), and whether the parent felt prepared for the circumstances surrounding the child's death (very prepared, somewhat prepared, a little prepared, or not at all prepared). In addition, parents were asked to rate the degree of trust they held in the child's primary oncologist (a great deal, a lot, somewhat, a little, or not at all). Additional data were collected from parents on demographic features (age, sex, race, education, income, and religion) and other aspects of the child's end-of-life care, as previously reported.^{1,2} Parents were informed in the introductory letter and interview that psychosocial support was available to them if desired.

Physician Survey

Physicians were asked to rate how care went in the end-of-life care period, with response categories of as well as can be expected, with some difficulty, and with a lot of difficulty. The physician's sex and number of years of experience (calculated by subtracting the physician's date of starting internship training from the date of the child's death) were also recorded.

Chart Review

Charts of the children of all eligible parents were abstracted by trained research assistants, with every tenth chart also abstracted by one of the study investigators. When discrepancies

were found, both abstractors reviewed the chart and determined the appropriate response by consensus. Data collected included sex of the child; diagnosis; dates of birth, diagnosis, and death; number, types, and timing of cancer-directed regimens and enrollment onto clinical studies; cause of death (classified as progressive disease and/or a treatment-related complication); use of cardiopulmonary resuscitation or intubation; and location of death. Number of hospital days in the last month of life, as documented in the medical record, was used to validate parent assessment of hospital days in the last month of life.

Statistical Methods

Analyses were conducted using the SAS statistical package (SAS Institute, Inc, Cary, NC). No efforts were made to impute missing data.

For the purposes of analysis, parent ratings of care were dichotomized into categories felt to be clinically meaningful, with ratings of excellent or very good considered higher parent quality of care ratings and good, fair, or poor ratings considered lower quality of care ratings. Physician ratings of care were similarly dichotomized, with care having gone as well as can be expected considered a higher physician quality of care rating and care having gone with some difficulty or with a lot of difficulty considered lower quality of care ratings. Other variables using Likert scales were dichotomized as specified in the tables and text.

Because of the possibility that children who were cared for by the same physician might share characteristics, all analyses were performed using generalized estimating equations (the SAS GENMOD procedure) to control for clustering by physician. Bivariate analyses were used to test for associations between dichotomized parent and physician quality of care ratings and between quality of care ratings and communication factors, symptoms, hospital days in the last month of life, parent race, and parent education. The parent quality of care rating of excellent or very good was used as the outcome variable in a multivariable logistic regression model. Model building used the results of bivariate analyses between quality ratings and aspects of care, with a threshold for entry into the model of $P < .10$ and a threshold for retention in the model of $P \leq .05$. The physician perception of care having gone as well as can be expected was used as the outcome variable in a second multivariable logistic regression model, with the same criteria for variable entry and retention.

RESULTS

Characteristics of Parents

The median age of participating parents was 43.4 years (SD, 7.7 years). Most parents were female (83%) and married (79%). The majority of parents were white (93%), had received postsecondary education (78%), had annual household income of \$35,000 or more (77%), and identified themselves as Catholic (72%).

Characteristics of Children

The characteristics of the children are listed in Table 1. More than two thirds of children received care at DFCI/CHB. Nearly half of children had hematologic malignancies; the remainder had diagnoses of brain tumors or other solid tumors. Most children died with progressive cancer,

Table 1. Characteristics of Children

Characteristic	No. of Children (N = 144)	%
Patient		
Care at DFCI/CHB	103	72
Sex, female	67	47
Age at diagnosis, years		
Median	7.0	
Range	0.0-20.1	
Age at death, years		
Median	8.9	
Range	0.3-25.3	
Death at home	67	47
Type of cancer		
Hematologic malignancy	70	50
Brain tumor	28	20
Other solid tumor	43	31
Treatment		
No. of cancer-directed regimens		
Median	3	
Standard deviation	2.0	
Enrollment onto clinical study	101	72
Enrollment onto phase I study	24	17
Bone marrow transplantation	54	38
Cause of death		
Treatment-related complication	29	21
Progressive cancer	111	79
Abbreviation: DFCI/CHB, Dana-Farber Cancer Institute/Children's Hospital, Boston.		

although 29 children died as a result of a treatment-related complication without evidence of progressive disease.

In response to a question about whether the physician communicated directly with the child, 38 parents (27%) felt the child was too young for direct communication with the physician. Median age of children considered by parents old enough for communication with the physician was 12.0 years (range, 1.8 to 25.3 years); median age of children not considered old enough for communication was 3.6 years (range, 0.3 to 13.3 years). Among children who were not perceived to be too young, 87 (87%) received direct communication from the physician.

Characteristics of Physicians

The 144 children were cared for by 52 physicians; the median number of years of experience was 7.2 (SD, 5.5 years). Fellows represented 52% of the DFCI/CHB physicians and 37% of overall physicians. Because CHC does not have a fellowship training program in pediatric hematology/oncology, all participating physicians from CHC were attending physicians. Thirty-five percent of participating physicians were female.

Differences in Characteristics by Site of Care

The duration of the interviews differed by site of care, with a mean of 108 minutes (SD, 25 minutes) at DFCI/CHB and a mean of 168 minutes (SD, 48 minutes) at

CHC ($P < .001$). Other measured characteristics of parents and children did not differ according to site of care, with the exception of the percentage of children who had been enrolled onto phase I clinical trials; all of the children who participated in phase I clinical trials were cared for at DFCI/CHB, representing 23% of DFCI/CHB participants and 17% of participants overall. Overall rates of patient participation in clinical trials did not differ by site of care.

Parent and Physician Ratings of Quality of Care

Parent and physician ratings of quality of care are listed in Table 2. Physician care was rated as excellent or very good by 112 parents (82%), and physicians felt care had gone as well as could be expected for 86 patients (64%). Parent and physician quality of care ratings did not differ by site of care ($P = .37$ and $.33$, respectively.) No association was found between parent and physician ratings of care ($P = .88$, Table 3).

Factors Associated With Parent Assessments of Quality of Care

Factors associated with higher parental ratings of the quality of physician care in bivariate analyses are listed in Table 4. The odds of high ratings were associated with a parental perception that the primary oncologist gave bad news in a sensitive and caring manner ($P < .001$) and clear information about what to expect in the end-of-life period ($P < .001$), a sense of trust in the primary oncologist ($P < .001$), a feeling of preparedness for the circumstances surrounding the child's death ($P = .001$), and parental report that the primary oncologist communicated directly with the child (any children whom parents considered old enough for such communication; $P < .001$). High parental ratings were inversely associated with the parents' perception that they received conflicting information ($P = .009$). Parental ratings of the child's pain ($P = .93$) and suffering from pain ($P = .35$), the number of hospital days in the child's last month of life ($P = .15$), parent race ($P = .84$), parent education ($P = .35$), type of death ($P = .16$), use of cancer-directed therapy in the last month of life ($P = .57$),

Care Rating	No.	%
Parent ratings of quality of care by primary oncologist		
Excellent	95	70
Very good	17	12
Good	14	10
Fair	3	2
Poor	7	5
Physician ratings of quality of care, how well medical care went		
As well as can be expected	86	64
With some difficulty	39	29
With a lot of difficulty	10	7

Table 3. Agreement Between Parent and Physician Quality of Care Ratings*

Physician Rating	Parent Rating			
	Parent Rated Quality Low		Parent Rated Quality High	
	No.	%	No.	%
Physician rated quality low	8	6	37	29
Physician rated quality high	14	11	70	54

* $P = .88$ by generalized estimating equation.

and physician experience ($P = .63$) were not significantly associated with parent ratings of physician care.

Factors associated with parent ratings of physician care in a multivariable regression analysis were similar (Table 5). Parental reports that the primary oncologist gave bad news in a sensitive and caring manner ($P = .01$) and clear information about what to expect in the end-of-life period ($P = .02$), that the parent felt well prepared for circumstances surrounding the child's death ($P = .03$), and that the primary oncologist communicated directly with the child when appropriate ($P = .001$) were all associated with parent ratings of physician quality. Adjustment of the model to site of care did not significantly change these findings.

Factors Associated With Physician Assessments of Quality of Care

Bivariate analyses were used to determine factors associated with higher physician ratings of care quality; results are listed in Table 4. Higher physician ratings of quality of care were inversely associated with parental reports of pain in the child's last month of life ($P = .03$) and suffering from pain in the child's last month of life ($P = .04$), more than 10 hospital days in the last month of life ($P = .002$), and parent report of receipt of conflicting information ($P = .02$). Type of death ($P = .24$), physician experience ($P = .38$), use of cancer-directed therapy in the end-of-life period ($P = .43$), and parent ratings of other communication factors were not associated with physician ratings of quality of care.

In a multivariable logistic regression model, the only factors associated with physician ratings of care were parent report of pain in the last month of life ($P = .01$) and a hospital stay of 10 days or more in the last month of life ($P < .001$; Table 6). As in the model of parent ratings of care, adjustment of the model to site of care did not significantly alter these findings.

DISCUSSION

We sought to understand parents' and physicians' values for care of children with cancer at the end of life. We found that parents of children who died of cancer feel that quality

Table 4. Bivariate Analyses of Factors Associated With Parent and Physician Ratings of Care

Covariate	Parent Ratings of Care							Physician Ratings of Care						
	High				Low			High				Low		
	No./Total No.	%	No./Total No.	%	OR	95% CI	P	No./Total No.	%	No./Total No.	%	OR	95% CI	P
Pain in last month of life	96/112	86	19/22	86	0.95	0.27 to 3.32	.93	68/84	81	47/49	96	0.18	0.04 to 0.84	.03
A great deal or a lot of suffering from pain	56/70	80	54/62	87	0.59	0.20 to 1.76	.35	40/84	48	32/47	68	0.43	0.19 to 0.97	.04
Primary oncologist always communicated bad news in a sensitive and caring manner	102/111	92	10/23	43	14.73	4.63 to 46.93	< .001	69/82	84	38/47	81	1.26	0.49 to 3.25	.64
Primary oncologist gave clear information about what to expect, parent agreed strongly	75/109	69	1/23	4	48.53	6.14 to 383.37	< .001	47/83	57	27/45	60	0.87	0.45 to 1.68	.68
Primary oncologist communicated with child when appropriate	78/83	94	9/16	56	12.13	3.03 to 48.56	< .001	59/66	89	28/33	85	1.51	0.40 to 5.73	.55
A great deal of trust in primary oncologist	102/111	92	6/24	25	34.00	9.90 to 116.77	< .001	70/86	81	35/48	73	1.62	0.67 to 3.94	.28
Parent felt very or somewhat prepared for circumstances surrounding death	70/107	65	6/24	25	5.68	1.97 to 16.34	.001	47/84	56	27/46	59	0.89	0.44 to 1.82	.76
Parent received conflicting information	25/110	23	12/24	50	0.29	0.12 to 0.73	.009	19/85	22	20/48	42	0.40	0.18 to 0.88	.02
More than 10 hospital days in last month of life	46/111	41	14/24	58	0.51	0.20 to 1.27	.15	28/85	33	32/49	65	0.26	0.11 to 0.61	.002

Abbreviation: OR, odds ratio.

of physician care at the end of life is excellent or very good in most cases (82%) and that they are especially likely to rate it positively when they also believe that communication with physicians has gone well. Specifically, parents rated the quality of care provided by oncologists more highly when they felt they had received clear information about what to expect during the end-of-life period, when news was delivered with sensitivity and caring, and when doctors communicated directly with the child when appropriate. In contrast, medical outcomes, including time spent in the hospital and pain control in the last month of the child's life, were not important determinants of parental ratings of the quality of physician care.

These findings contrast with the correlates of physician-rated care, with high-quality care characterized by little pain

and minimal time in the hospital at the end of life and not associated with communication factors. Finally, we found no association between parent ratings of physician care quality and physician ratings of care quality.

Because different questions were used to understand physician and parent views of care quality, any direct comparison between their ratings should be interpreted with caution. However, the differences in ratings raise the concern that physicians and parents may not be working toward shared goals for the care of individual children. Physicians seem to be working toward a traditional model of a good death, which involves being at home and without pain. Notably, the importance of effective pain management is also among the values emphasized by dying adult patients and their bereaved family members.¹³⁻¹⁵ However, parents do not seem to emphasize

Table 5. Factors Associated With High Parent Ratings: Multivariate Model

Covariate	OR*	95% CI	P
Primary oncologist gave clear information about what to expect	19.90	1.71 to 231.76	.02
Primary oncologist conveyed bad news in a sensitive and caring manner	7.67	1.65 to 35.72	.01
Primary oncologist communicated directly with the child, adjusted for children who were too young for communication	11.18	2.63 to 47.52	.001
Parent felt well prepared for circumstances surrounding death	4.84	1.13 to 20.78	.03

Abbreviation: OR, odds ratio.
*Odds of high parent rating of primary oncologist's overall care.

Table 6. Factors Associated With High Physician Ratings: Multivariate Model

Covariate	OR*	95% CI	P
Pain in the last month of life	0.15	0.03 to 0.69	.01
More than 10 hospital days in last month of life	0.24	0.10 to 0.54	< .001

Abbreviation: OR, odds ratio.

*Odds that oncologist felt care went as well as possible.

one particular model of end-of-life care; rather, they value effective and caring communication, which may help them to reach the goals important to the child and family.

A lack of association between the pain experience and parent ratings of quality of physicians' care may suggest that parents do not hold physicians responsible for the child's suffering or, similarly, that parents believe pain is an expected, irremediable aspect of the dying process. Sadly, pain and pain-related suffering were prevalent in this group of children, and we do not believe that these findings should be interpreted as an indication that pain management is unimportant to parents. Rather, the association between a caring manner and high parent ratings of care quality should remind us that the relationship between the physician and family can be a therapeutic agent. When a cure is not possible, the physician's care of the child and family remains highly valued.

Indeed, the association between parent quality ratings and the parent's perception that the physician communicated with sensitivity and caring highlights the relational aspect of end-of-life care for children. Of note, physicians whose communication skills were highly rated by parents were no more likely to feel that care had gone well. This apparent focus by physicians on biomedical aspects of care may lead physicians to undervalue their care as a whole, perhaps contributing to the sense of failure that many pediatricians report feeling in a child's death.²¹

The factors associated with parents' quality ratings suggest additional areas of communication-related competence needed in physicians who provide end-of-life care. Importantly, parents who gave high ratings of care quality were those who felt most prepared for the end-of-life care period. This finding suggests that, beyond the need for sensitive communication, parents need to understand how the end of the child's life may unfold. Previous work has shown that physicians may be reluctant to discuss prognosis with patients out of a sense of the pain these conversations may bring to patients and families and because predicting a patient's future course may be fraught with inaccuracy.^{17,22,23} Perhaps physicians avoid conversations detailing the expected course of the end-of-life period for similar reasons. However, being prepared may be the only means parents have to gain some control over otherwise unpredictable and unbearable circumstances.

Parents were especially likely to rate physician care highly when the physician communicated directly with the child, as long as the parent believed that the child was old enough for this communication. This type of communication, which is little emphasized in medical school or residency training programs,²⁴ requires sensitivity to the child's understanding of illness and developmental level, along with an understanding of what communication the parent feels is appropriate for the child. Many families in this study felt that their children were too young for direct communication, but the ages of children believed by parents to be too young were diverse and overlapped with ages other parents considered appropriate. The child's age may be less important than the communication style of the family, the child's individual ability to understand and process information about the illness and its prognosis, and the child's relationship with the physician. Communication with children, particularly children near the end of life, has not been a focus of extensive research, although recent findings underscore the importance of end-of-life communication with children.²⁵ Our findings that parents value clinical competence in this area suggest that understanding the communication needs of families and children and educating those who care for children are necessary aspects of improving care for children at the end of life.

The child's direct perspective is notably absent from our study. We relied on parent ratings of communication factors, with the child's perspective present only as the parent was able to voice it. Our reliance on parent care ratings, a natural consequence of our retrospective study design, is an accepted standard in the pediatric literature, and communication with parents is particularly relevant to their roles as decision makers for their children. However, in future research and in our care of individual children, we need to continue to work to elicit children's perspectives and values for care.

Generalizability is another important consideration in interpretation of these findings. Although our overall response rate was 65%, it is possible that parents who declined participation had different experiences of care in the end-of-life period. However, as previously reported, patients at DFCI/CHB whose parents declined participation had no significant medical differences from patients whose parents participated other than a higher likelihood of receipt of cardiopulmonary resuscitation in the end-of-life period.¹ In addition, although differences between the two study sites do exist, site of care was not associated with the outcomes of interest. Finally, although the study population is consistent with that seen at both sites of care, the lack of significant representation of participants with racial, ethnic, and socioeconomic diversity may also influence generalizability. However, the message of tailoring care to individual children and families, without assumptions about what

constitutes a good death, should be considered as important among populations who have not been well studied.

The retrospective nature of this study and the presence of variability in timing of the interview after the child's death may have influenced our findings. It is possible that parents' perceptions of care quality have changed over the course of time since the child's death. However, our results were similar when the analysis was performed with adjustment for time between the child's death and the interview.

Finally, the associations found between aspects of care and ratings of quality should not be interpreted as evidence of causality. In some cases, good communication may result from care that is going well overall, rather than the reverse. In addition, other unmeasured factors may mediate the relationship between communication factors and care quality.

Are parent and physician values for care of children at the end of life truly different? Further research must continue to address values for end-of-life care and the outcomes of these values, including the implications of discrepant parent and physician values. Along with this work, we need to continue to examine specific communication needs of families of children with life-threatening illnesses, with a focus on changing needs over time, along with efforts toward physician education and interventions designed to improve the communication pro-

cess. However, in keeping with our findings, we as physicians need to attend to the communication needs of patients and families in a way that reflects their values for care. In addition, we should consider the implications of these findings for health care policy; if physicians are to value communication, then physicians must also be appropriately reimbursed for this time-consuming work. Inadequate reimbursement for time spent in communication^{4,26} sends a message to physicians that this work is unimportant and creates disincentives to optimal communication. Only through effective communication can physicians and families work toward shared goals in caring for children with advanced illness.

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Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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