

Communication About Prognosis Between Parents and Physicians of Children With Cancer: Parent Preferences and the Impact of Prognostic Information

Jennifer W. Mack, Joanne Wolfe, Holcombe E. Grier, Paul D. Cleary, and Jane C. Weeks

ABSTRACT

Purpose

Concerns about the harms of prognostic information, including distress and loss of hope, cause some physicians to avoid frank disclosure. We aimed to determine parent preferences for prognostic information about their children with cancer and the results of receiving such information.

Patients and Methods

We surveyed 194 parents of children with cancer (overall response rate, 70%), treated at the Dana-Farber Cancer Institute and Children's Hospital (Boston, MA) and the children's physicians. Our main outcome measure was parent rating of prognostic information as extremely or very upsetting.

Results

The majority of parents desired as much information about prognosis as possible (87%) and wanted it expressed numerically (85%). Although 36% of parents found information about prognosis to be extremely or very upsetting, those parents were more likely to want additional information about prognosis than those who were less upset ($P = .01$). Parents who found information upsetting were no less likely to say that knowing prognosis was important ($P = .39$), that knowing prognosis helped in decision making ($P = .40$), or that hope for a cure kept them going ($P = .72$).

Conclusion

Although many parents find prognostic information about their children with cancer upsetting, parents who are upset by prognostic information are no less likely to want it. The upsetting nature of prognostic information does not diminish parents' desire for such information, its importance to decision making, or parents' sense of hope.

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From the Departments of Pediatric Oncology and Adult Oncology, the Center for Outcomes and Policy Research, Dana-Farber Cancer Institute; the Department of Medicine, Children's Hospital; the Department of Health Care Policy, Harvard Medical School; and the Department of Medicine, Brigham and Women's Hospital, Boston, MA.

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Address reprint requests to Jennifer W. Mack, MD, MPH, Center for Outcomes and Policy Research, Dana-Farber Cancer Institute, 44 Binney St, Boston, MA 02115; e-mail: Jennifer_mack@dfci.harvard.edu.

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INTRODUCTION

Discussing prognosis with patients is more than just a difficult undertaking; to many physicians, it seems like the wrong thing to do.¹⁻³ The concern that prognostic information can cause distress³⁻⁷ and loss of hope^{4,5,8-13} leads some physicians to avoid the topic,¹⁴⁻¹⁶ to disclose vague⁴ or overly optimistic information^{14,15} when pressed, and to focus on treatment rather than expected outcomes.⁴ Even though physician decisions to limit communication about prognosis often emanate from compassion,³⁻⁵ unrealistic expectations for outcomes can inappropriately alter choices that patients make about treatment and how to live their lives.¹⁷⁻²¹

If physician beliefs about the harms of upsetting information influence communication patterns, then the merits of these beliefs should be examined. Although there is evidence that physicians limit prognostic information to prevent

distress,^{3-5,14,15} whether this practice reflects patient preferences is not known. In addition, although most existing literature focuses on adult patients, we know little about how such work applies to parents of children with cancer. In this study we evaluated parental preferences for prognostic information about their children with cancer. Specifically, we evaluated whether parents who found prognostic information upsetting were less likely to want such information.

PATIENTS AND METHODS

Study Population

The study was conducted at the Dana-Farber Cancer Institute and Children's Hospital (Boston, MA). We surveyed parents and physicians of children undergoing treatment for cancer between April 2004 and September 2005. One parent per family was eligible to participate if he or she could read English, if the child was 18 years old or younger,

if the child was between 30 days and 1 year from the date of cancer diagnosis, and if the child's physician gave us permission for contact (permission was denied for three parents). Eligible parents were mailed or given a letter inviting them to participate, the survey, and a postage-paid postcard to return if they did not wish to participate. Two subsequent identical contacts were made with nonresponding parents. Of 276 eligible parents, 194 (70%) completed the survey. Twenty-four parents declined participation and 53 had not responded after three attempts. Five children died after the parent was approached for the study, rendering the parent ineligible to participate.

After the parent survey had been completed, the primary oncology attending physician for each patient was given the physician survey and a letter. Ninety-nine percent of physician surveys (193 of 194) were completed, representing 20 of 21 possible physicians.

Data Collection

Instrument development. The questionnaires were developed to evaluate parents' desire for prognostic information, its impact, and factors that might influence information preferences, based on literature review and seven exploratory interviews with parents of children with cancer, physicians, psychosocial providers, and a chaplain. A theoretical model included factors that might influence parents' information preferences, such as patient attributes (prognosis, time since diagnosis), physician attributes (communication style, experience), parent attributes (coping, social support, education, sense of hope and meaning) and attributes of the parent-physician interaction (communication process attributes, affective results of communication). Whenever possible, questions were drawn from previously validated surveys. New questions were devised on the basis of general principles of survey development.^{22,23} Pilot testing with seven parents and three physicians allowed for iterative revision and assessment of face and content validity and respondent burden.

The 106-item parent questionnaire included 63 previously validated questions, including questions about the communication process.²⁴ Parents were asked whether an oncologist had ever discussed their child's prognosis, whether prognosis was expressed quantitatively, and who was present for the initial discussion about diagnosis and treatment. Prognosis was defined as "whether or not your child will be cured of cancer, how long your child is expected to live, and the kind of life your child can expect to have." Items assessing goals of care and likelihood of cure were based on previously validated scales.^{17,18,25} Parents were asked "how likely you now think it is that your child will be cured of cancer." Possible responses were: "extremely likely (more than 90% chance of cure)"; "very likely (75% to 90%)"; "moderately likely (50% to 74%)"; "somewhat likely (25% to 49%)"; "unlikely (10% to 24%)"; "very unlikely (< 10%)". Parents were asked "how upsetting" it currently is "to know information about your child's prognosis," and how important it is "to know about your child's prognosis" and "to have a precise understanding of your child's chances of being cured, expressed as a percent likelihood" ("extremely," "very," "somewhat," "a little," "not at all.") Parents were asked about their "preferences for details of information about your child's prognosis" and "diagnosis and treatment." Parents were asked "how helpful knowing about your child's prognosis has been" ("extremely," "very," "a little," "not at all") for "making decisions about treatment," "preparing for the future," "maintaining hope," "coping with the disease," and "overall."

Information preferences were assessed using questions from the Information Styles Questionnaire²⁶ and the Information Needs Questionnaire.²⁷ The questionnaire evaluated the communication process using six items from the Picker Survey,²⁸ trust using an item from the Trust in Physicians scale,²⁹ social support using four items from the Medical Outcomes Study Social Support Survey,³⁰ coping style using the Brief COPE,³¹ and sense of faith and meaning using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-SP).³² The questionnaire also asked about the parent's sex, relationship to the child, age, educational level, marital status, race/ethnicity, and religion.

The 20-item physician questionnaire asked about goals of care and likelihood of cure, with questions and response categories identical to those on the parent questionnaire, and about the patient's diagnosis and treatment.

The institutional review board of the Dana-Farber Cancer Institute approved this study.

Statistical Methods. Analyses were conducted using the SAS statistical package (SAS Institute Inc, Cary, NC). Parent report that information about prognosis was "extremely" or "very" upsetting was used to indicate greater upset, with categories of "somewhat," "a little," or "not at all" indicating lesser upset. Other variables using Likert scales were dichotomized as specified in tables and text. The FACIT-SP sense-of-meaning subscale was dichotomized into an upper quartile and lower three quartiles of scores in the study population, to allow us to consider specifically those parents who were at the upper end of the range. All analyses were replicated with ordinal scoring of variables to ensure that reported associations adequately represented actual relationships.

The weighted kappa [κ] statistic, with default weights specified in SAS, was used to determine agreement between parent preferences for detail about diagnosis and treatment and about prognosis. The χ^2 statistic was used to determine the association between parents' report that information was upsetting and nonordinal multicategory variables. Other bivariable and multivariable analyses were performed using generalized estimating equations (the SAS GENMOD procedure; SAS Institute, Cary, NC) to control for clustering by physician.

Parent perception of information about prognosis being "extremely" or "very" upsetting was the outcome variable in a multivariable logistic regression model. To select independent variables, we included variables for which bivariable associations were significant at the .10 level. Based on our theoretical model, variables considered included parents' information preferences, communication process attributes, physician-rated likelihood of cure, the parent's sense of hope and meaning, time since diagnosis, and parental overestimation of prognosis, defined as any parent rating with a higher likelihood of cure than the physician had reported. Models included parent sex, race, educational level, and child age regardless of the significance of their coefficients. Starting with the least significant variable in the multivariate model, variables were removed sequentially until all remaining independent variables were significant at the .05 level.

RESULTS

Characteristics of parents and children are described in Table 1. Participating physicians were the attending pediatric oncologists (N = 20) for the patients studied.

Nonrespondents did not differ significantly from respondents with respect to child sex, age at diagnosis, or diagnosis. Nonrespondents were more likely than respondents to have children with solid tumors and less likely to have children with hematologic malignancies, but this difference was not statistically significant ($P = .07$).

Most often, both parents were present for the initial discussion about the child's diagnosis and plans for treatment (85%), but 5% of parents were alone for this conversation. Many parents (42%) reported that the child had been present. Children were more likely to be present if they were older ($P = .03$) and if the prognosis was better ($P = .01$).

Nearly all parents (93%) reported that an oncologist had discussed prognosis with them at some time. The majority of parents (67%) said that the oncologist had initiated discussion about prognosis, and that information about prognosis was described numerically (69%), as a percent likelihood of cure. The majority of parents (87%) and physicians (91%) reported that their primary goal of care was to cure the child's cancer.

Nearly all parents wanted as much information as possible about diagnosis and treatment (91%; Table 2) and prognosis (87%). Parents' desire for detail about diagnosis and treatment tended to mirror desire for detail about prognosis (weighted $\kappa = 0.78$), with 7%

Table 1. Parent and Patient Characteristics

| Characteristic | No. | % |
|---|----------|----|
| Parent | | |
| Female sex | 153 | 79 |
| Age 30 years or older | 172 | 89 |
| College graduate | 115 | 60 |
| Married or living as married | 158 | 82 |
| Race/ethnicity (N = 190) | | |
| White, non-Hispanic | | 85 |
| Black, non-Hispanic | | 4 |
| Hispanic | | 7 |
| Asian | | 2 |
| Other | | 2 |
| Child | | |
| Female sex | 92 | 49 |
| Age at diagnosis, years | | |
| Median | 6.6 | |
| Range | 0.2-17.9 | |
| Days since diagnosis | | |
| Median | 105 | |
| Range | 30-552 | |
| Cancer diagnosis (N = 194) | | |
| Hematologic malignancy | | 56 |
| Brain tumor | | 23 |
| Other solid tumor | | 22 |
| Received stem-cell transplant | 28 | 15 |
| Physician-rated likelihood of cure (N = 193)* | | |
| Extremely likely, > 90% | | 9 |
| Very likely, 75%-90% | | 50 |
| Moderately likely, 50%-74% | | 17 |
| Somewhat likely, 25%-49% | | 12 |
| Unlikely, 10%-24% | | 3 |
| Very unlikely, < 10% | | 8 |

*Because of rounding, not all percentages total 100.

Table 3. Relationship Between Parent Distress and Desire for Information (n = 187)

| Distress | % | | |
|---|---------------------------------|--|---------------------------------|
| | "I wish I had more information" | "I now have about the right amount of information" | "I wish I had less information" |
| Information about prognosis was "extremely" or "very" upsetting (n = 68) | 49 | 50 | 1 |
| Information about prognosis was "somewhat," "a little," or "not at all" upsetting (n = 119) | 29 | 71 | 0 |

NOTE. Association between degree of upset and preference for information significant at the $P = .01$ level. Data were missing for seven parents (six for whom the question about upsetting information was not answered, and one for whom the question about desire for information was not answered).

of parents wanting less detail about prognosis than about diagnosis and treatment.

The majority (85%) of parents felt that having a numeric understanding of prognosis was extremely or very important. Among these, most (73%) said that they received such information from the oncologist. Parents who were more upset by prognostic information were less likely to report receipt of a quantitative estimate of prognosis ($P = .01$).

More than one third of parents wanted more information about prognosis than they had received (Table 3). Only one parent wanted less information. Thirty-six percent of parents found information

Table 2. Parent Preferences for Detail in Information (N = 194)

| Preference | % | |
|--|-------------------------------|-----------------|
| | About Diagnosis and Treatment | About Prognosis |
| Prefer not to hear a lot of detail | 5 | 4 |
| Prefer to hear details only in certain situations | 5 | 10 |
| Prefer to hear as many details as possible in all situations | 91 | 87 |

NOTE. Because of rounding, not all percentages total 100.

about prognosis to be extremely or very upsetting ("extremely," 17%; "very," 19%; "somewhat," 22%; "a little," 20%; "not at all," 21%). Parents were more likely to desire additional information if they found information about prognosis to be upsetting ($P = .01$).

Parents who found information about prognosis very or extremely upsetting were no less likely to say that prognostic information was important (odds ratio [OR], 0.57; $P = .39$; Table 4), to want a numeric estimate of prognosis (OR, 0.68; $P = .21$), or to believe that prognostic information had helped them with decision making (OR, 0.73; $P = .40$) than other parents. Although a lower proportion of parents who were upset felt that knowing about prognosis had contributed to maintaining hope (OR, 0.33; $P = .01$), most parents felt that hope for cure (OR, 1.28; $P = .72$) and for a good quality of life (OR, 0.68; $P = .57$) kept them going a great deal, regardless of their degree of upset. In addition, the majority of parents felt that prognostic information had been extremely or very helpful in maintaining hope, even if they were upset (77%), and regardless of the child's prognosis.

Parents who were upset by prognostic information were more likely to report that the oncologist had never discussed the child's prognosis (OR, 5.90; $P = .04$; Table 4). Parents who were more upset were less likely to report positive attributes of parent-oncologist communication, including physician sensitivity (OR, 0.38; $P < .0001$).

In a multivariable logistic regression model (Table 5), parents were more likely to report being upset by prognostic information if the physician-reported prognosis was poor (OR, 1.98; $P < .001$). Parents were less likely to be upset if they reported that the child had been present at the initial conversation about diagnosis and treatment (OR, 0.37; $P < .001$), that the oncologist always conveyed information in a sensitive manner (OR, 0.40; $P = .001$), and that they found a great sense of meaning in the experience of the child's illness (OR, 0.12; $P < .0001$).

DISCUSSION

The vast majority of parents we studied wanted prognostic information about their children in as much detail as possible and expressed numerically. One third of parents reported that the oncologist did not initiate discussion about prognosis, and more than one quarter

Table 4. Factors Associated With Parents' Finding Information About Prognosis "Extremely" or "Very" Upsetting: Bivariate Relationships With Parent-Reported Communication Attributes (n = 188 unless specified)

| Factor | Odds of Parents Finding Prognostic Information "Extremely" or "Very Upsetting" | | |
|--|--|---------------|---------|
| | Odds Ratio | 95% CI | P |
| Parent communication preferences | | | |
| "Extremely" or "very" important to know about child's prognosis | 0.57 | 0.15 to 2.09 | .39 |
| "Extremely" or "very" important to have a precise understanding of prognosis, in numbers | 0.68 | 0.37 to 1.25 | .21 |
| Communication process | | | |
| Oncologist never discussed prognosis | 5.90 | 1.11 to 31.36 | .04 |
| Child was present at initial conversation about diagnosis and treatment | 0.54 | 0.30 to 0.96 | .04 |
| Parent-oncologist communication | | | |
| Oncologist "always" gives understandable answers to parent's questions | 0.53 | 0.31 to 0.91 | .02 |
| Oncologist "always" takes the time to answer parent's questions | 0.44 | 0.22 to 0.90 | .02 |
| Oncologist "always" conveys information in a sensitive manner | 0.38 | 0.24 to 0.61 | < .0001 |
| Parent trusts oncologist's judgment "completely" | 0.40 | 0.22 to 0.73 | .003 |
| Value of information | | | |
| Knowing prognosis has been "extremely" or "very" helpful in making decisions about treatment | 0.73 | 0.34 to 1.53 | .40 |
| Knowing prognosis has been "extremely" or "very" helpful in preparing for the future | 0.39 | 0.14 to 1.12 | .08 |
| Knowing prognosis has been "extremely" or "very" helpful in coping with the disease | 0.33 | 0.15 to 0.73 | .01 |
| Knowing prognosis has been "extremely" or "very" helpful in maintaining hope | 0.25 | 0.09 to 0.67 | .01 |
| Hope and meaning | | | |
| Hope that child will be cured keeps parent going "a great deal" | 1.28 | 0.34 to 4.76 | .72 |
| Hope that child will have a good quality of life keeps parent going "a great deal" | 0.68 | 0.18 to 2.58 | .57 |
| Parent has greater sense of meaning in experience of child's illness | 0.20 | 0.11 to 0.35 | < .0001 |

NOTE. Data were missing for six parents who did not answer the question about finding information upsetting. Additional missing data include one parent each for the questions about the importance of a precise understanding of prognosis, whether the oncologist discussed prognosis, whether the child was present for the conversation, and whether the oncologist gives understandable answers to questions; two parents for the question about hope in the child's quality of life; three parents for the question about helpfulness in making decisions; five parents for the question about helpfulness in coping with the disease; seven parents for the question about helpfulness in preparing for the future; and eight parents for the question about helpfulness in maintaining hope.

reported that they did not receive numeric prognostic information, despite considering it important. Many parents found information about prognosis to be upsetting, but nonetheless they wanted such information, feeling that it was important to have and helpful to decision making, and wanting additional information more often than parents who were not upset.

Table 5. Factors Associated With Finding Information About Prognosis "Extremely" or "Very" Upsetting: Multivariable Logistic Regression Model⁷ (N = 178)⁸

| Factor | Odds of Parents Finding Prognostic Information "Extremely" or "Very" Upsetting | | |
|---|--|--------------|---------|
| | Odds Ratio | 95% CI | P |
| Child was present at first conversation with oncologist about diagnosis and treatment | 0.37 | 0.21 to 0.64 | < .001 |
| Prognosis, per category of decreasing likelihood of cure* | 1.98 | 1.36 to 2.89 | < .001 |
| Parent feels the oncologist "always" conveys information in a sensitive manner | 0.40 | 0.23 to 0.70 | .001 |
| Parent has greater sense of meaning in experience of child's illness [†] | 0.12 | 0.04 to 0.33 | < .0001 |

NOTE. Controlled for parent sex, parent race, child age, parent educational level, and controlling for clustering by physician. Data were missing for 16 parents (6 for whom the question about upsetting information was not answered, and 10 with additional missing values: 4 in race/ethnicity, 1 in physician prognosis, 3 in parent education, 1 in whether the child was present, and 1 in parent gender).

*Reference group, 1 = extremely likely to be cured; 6 = extremely unlikely to be cured.

†Reference group was the lower three quartiles of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-SP) meaning score.

Physicians sometimes worry that information about prognosis may take away hope, but we found no evidence of such an effect. The majority of parents found prognostic information important to maintaining hope, even when it was upsetting, and even when the child's prognosis was poor. In addition, the degree to which parents placed hope in a cure was not related to how upset they were.

The tendency to tailor information on the basis of the reaction of the parent, consciously or unconsciously, may leave parents who display greater emotional distress less informed. Nearly half of the parents in our study who were upset by prognostic information wanted more information about prognosis, reporting this feeling more often than those who were less upset, and suggesting that indeed these parents often feel underinformed. Parents who were upset were also more likely to report that the oncologist had never discussed prognosis. In previous studies, parents have reported that stress impairs understanding and retention of medical information.³³ Parents who are upset may be affected both by the physician's reluctance to increase distress by discussing information in further detail, and by their own inability to process information effectively during a time of emotional distress. Physicians therefore may need to review prognostic information when the acute distress has faded.

Not surprisingly, parents of children with poor prognoses are more likely to find prognostic information upsetting, but sensitive communication was associated with decreased upset, a finding that supports the idea that, whatever the medical content of the conversation, the parent-physician interaction has value. Can physicians both be sensitive and deliver detailed prognostic information? While these seemingly conflicting attributes drive many physicians to avoid such conversations, our findings suggest that delivery of detailed information may be a fundamental part of sensitive care.

Parents tended to be less upset when the child was present for the first major conversation about the diagnosis and treatment. This effect remained after adjustment for the child's age and prognosis, raising the question of whether more families may benefit from having children present in such encounters. Having the child present could alter the tone of conversation, so that prognostic information is portrayed with greater optimism. Our analysis of parent-perceived and physician-perceived prognosis does not support this; agreement between parent and physician reports of prognosis was no less likely when the child had been present for the discussion. A second possibility is that having the child present helps the parent in other ways. Some studies emphasize the importance to parents of direct communication between physicians and children.^{34,35} In addition to involving the child in plans for care and addressing their questions openly, direct communication may relieve parents of the anxiety associated with transmitting this information to their children.

Parents who had a greater sense of meaning in the child's illness tended to find prognostic information less upsetting. The process of forming meaning is complex and highly individual. Even so, this finding challenges us to consider how health care providers can support this process.

There are several potential limitations of this study. Parents who found prognostic information upsetting may have been less likely than other parents to participate in the study. Parents of children with hematologic malignancies were slightly more likely to participate than parents of children with solid tumors. The generally better prognoses among children with hematologic malignancies raise the concern that our sample under-represents parents of children with poor prognoses. Future research should include strategies to ensure that parents of children with poor prognoses are represented and that participation is not overly burdensome for such parents.

We used a questionnaire to assess communication of prognostic information, and evaluated parental distress with a single question. These issues are complex, and parent reports of being upset by prognostic information could mean many different things. We also did not explore in depth the meaning parents ascribe to hope. Future research should include attention to the separate issues involved in these concepts. We did not evaluate in detail what prognostic discussions en-

tailed, and we assumed a model of prognosis in which the likelihood of cure is the relevant outcome. We believe that information about cure is most meaningful to parents of children with cancer, as reflected in our finding that cure was the primary goal of care for most participating parents, and we chose to focus our work on this issue.

We conducted our study at a single institution. However, children with cancer often receive their care in pediatric cancer centers where subspecialty services are available.³⁶ We believe that our findings may therefore be generalized to the care of most children with cancer. We studied only preferences for, and the effects of, prognostic information in parents of children with cancer. Although the role of parents in a child's care differs from that of an adult cancer patient in his or her own care, many of the emotional and communication challenges of the two situations are the same. We believe, therefore, that findings may be similar for adults. Cultural differences in information and end-of-life care preferences³⁷⁻⁴¹ make examination of these issues in a more diverse population an important future step.

Conversations about prognosis should take into account the family's preferences and the medical importance of disclosure. Because preferences can change as the clinical situation changes,⁴² such discussions should not be limited to a single conversation.⁴³ The study was cross-sectional. We do not know if parents would have wanted the same information at the time of diagnosis. However, time since diagnosis was not related to parent reports of feeling upset, and controlling for time in our multivariable model did not change our results.

Previous studies have explored the accuracy of prognostic understanding,⁴⁴⁻⁴⁶ patient preferences for information,^{24,47-52} and physician styles of giving prognostic information.^{2,3,6,11,14,53,54} Although patients often want prognostic information, many physicians believe that communication of prognosis can cause harm by creating emotional distress and loss of hope.

The desire among many physicians to avoid detailed discussions of prognostic information is a compassionate instinct, emanating from the desire to avoid causing pain. But parents want this information, even though it may be upsetting. For many parents, compassion by the physician includes a willingness to inform. Parents have the capacity to hope for a cure while simultaneously preparing for the possibility of death,^{8,18} but they need information to do so.

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Author Contributions

Conception and design: Jennifer W. Mack, Joanne Wolfe, Holcombe E. Grier, Paul D. Cleary, Jane C. Weeks

Provision of study materials or patients: Jennifer W. Mack

Collection and assembly of data: Jennifer W. Mack, Jane C. Weeks

Data analysis and interpretation: Jennifer W. Mack, Joanne Wolfe, Paul D. Cleary, Jane C. Weeks

Manuscript writing: Jennifer W. Mack, Paul D. Cleary, Jane C. Weeks

Final approval of manuscript: Jennifer W. Mack, Joanne Wolfe, Holcombe E. Grier, Paul D. Cleary, Jane C. Weeks