Health Literacy Variables Related to Parents' Understanding of their Child's Cancer Prognosis

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Background. Obtaining an accurate understanding of a child's cancer prognosis can help parents make informed decisions about treatment. Research has shown that parents tend to overestimate their child's cancer prognosis relative to physicians. Thus, we examined whether the content of physician communication, parent sources of medical information, and parent demographic factors affected the association between oncologist and parent estimates of a child's cancer prognosis. **Procedure.** Families were recruited 3–8 weeks after a child's new diagnosis or relapse of cancer. Parents (77 mothers; 42 fathers) completed questionnaires regarding their sources of medical information, age, and education. The child's oncologist reported on the content of their communication with parents regarding prognosis. Parents and oncologists estimated the child's chance of 5-year survival using a visual-analogue scale. **Results.** Mothers and fathers reported a more favorable prognosis for their child, which was on average about 30% higher than oncologists. Time since diagnosis was correlated with less discrepancy between physician and mother prognosis ratings, with a similar trend noted for fathers. Agreement between oncologists and parents was better for younger fathers, but it was unrelated to physician communication, sources of medical information, or other demographic factors. **Conclusions.** Fathers' age may be important to their understanding of their child's cancer prognosis, but we did not find support for other factors related to prognosis literacy. Given the homogeneity of our sample, future research should assess differences in parents' prognosis knowledge across cancer diagnosis, race, ethnicity, and socioeconomic status (SES), which may aid in developing interventions to improve parent understanding. Pediatr Blood Cancer 2012;59:914–918. © 2012 Wiley Periodicals, Inc.

Key words: health literacy; parent; pediatric oncology; prognosis; psychology

INTRODUCTION

Over 12,000 children under age 20 are diagnosed with cancer annually in the United States, with 5-year survival rates now approaching 80% [1]. A major challenge for their parents is to obtain accurate information to make informed decisions regarding treatment. Parents serve a unique role as gatekeepers who receive the majority of medical information and manage communication between physicians, the ill child, and the family [2]. Accurate knowledge of the child's prognosis may help families balance aggressive treatment with maintenance of the child's quality of life.

Research on individuals' understanding of prognosis is limited, focusing more on adults with cancer as opposed to parents of children with cancer. Adults often have inflated estimates of their prognosis relative to actual disease progression [3] or physician estimates [4], particularly in the case of late-stage cancers [5]. Parents of children with cancer also overestimate their child's prognosis relative to physicians, but mothers and fathers are similar to each other [6–8].

The primary source of prognostic information for parents is often the initial consultation with the child's doctor. The task of delivering bad news may be a source of stress and uncertainty for physicians, and they often report poor or inadequate training in communicating such information [9–13]. Physicians wishing to instill hope in families may give limited or overly broad prognostic information with a greater focus on curative treatment rather than disease severity [14]. Not surprisingly then, significant gaps in communication have been found between families and physicians [15]. In one study, physicians were aware of the terminal state of a child's illness more than 3 months before parents [6].

The content of physician communication among adults with cancer varies based on patient preference, with some patients requesting quantitative information (e.g., percentages, proportions) about their prognosis and others preferring more general terms [16]. Among parents requesting a numeric prognosis, Mack

et al. (2006) [12] found that 73% received such information from the physician. Physicians may have some difficulty providing concrete numbers or percentages due to a lack of data, as many childhood cancers are rare and unpredictable in course, particularly after relapse. One might expect that parents who receive concrete numbers or percentages would have better agreement with physician estimates of prognosis, but more research is needed.

The extent to which parents rely on physicians for medical information may also affect knowledge of their child's prognosis. Although half of adults with cancer preferred the medical team as their primary source of information, only 11% reported their physician served this role [17]. One study found that less than half of parents of children with cancer felt well informed about who to ask regarding medical questions [18]. Subsequently, parents may rely on other sources, including family, friends, and the internet [19,20]. Interestingly, parents of children with cancer may be more optimistic than physicians when relying on non-medical sources of information [8].

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Finally, research on health literacy (i.e., an individual's understanding of basic health information and services needed to make appropriate health decisions) indicates that personal characteristics influence understanding of prognosis [21]. In a review of studies of adults with a variety of conditions and their caregivers, higher education and younger age were most commonly associated with greater illness knowledge [22]. Similarly, parents' understanding of pediatric heart disease has been associated with higher parent education [23], but for parents of children with retinoblastoma knowledge was positively associated with parent age, regardless of education [24].

Mack et al. [8] proposed a heuristic model of prognosis literacy suggesting that parent characteristics (e.g., education, coping style) and physician characteristics (e.g., communication style) influence parents' understanding of their child's likelihood of cure, both directly and indirectly through aspects of parent-physician communication (e.g., communication quality, information sources). To our knowledge, their work is the first to study the effect of multiple factors on parents' understanding of their child's cancer prognosis. Drawing on this, our aim was to examine if the content of physician communication, parent sources of medical information, and parent demographic factors moderated the association between oncologists' and parents' prognosis estimates. We expected that mothers and fathers of children with cancer would report a more favorable prognosis for their child than the child's primary oncologist, but there would be a positive association between reports from oncologists and parents and between mothers and fathers. The association between oncologist and parent prognosis estimates would be stronger when: (a) Oncologists used concrete numbers as opposed to general terms, (b) parents relied on information from oncologists rather than other sources, and (c) for younger and more educated parents.

METHOD

Procedure

This study is part of a larger, multi-site study of family adjustment to childhood cancer. Following approval by the Institutional Review Board, children and their parents were identified from the cancer registry of the Hematology/Oncology Department at a large children's hospital. Eligible families had children who were: (a) 5–17 years old, (b) within 3–8 weeks after diagnosis or relapse, and (c) English speaking. Children were excluded if they had a pre-existing developmental disorder or were receiving hospice services. Families were recruited by a research assistant to complete questionnaires on their own at home or in the hospital, and the child's primary oncologist also completed a brief questionnaire.

Participants

Of 85 eligible families, 77 (91%) participated. Children were on average 10.77 years old (SD = 3.88); most were male (52%; n = 40) and White (90%; n = 69). Time since diagnosis or relapse was 5.9 weeks (SD = 0.9). Diagnoses included leukemias (26%; n = 20), lymphomas (36%; n = 28), brain tumors (12%; n = 9), and other solid tumors (26%; n = 20). Fifteen children had relapsed (19%). Data were available from 77 mothers and 42 fathers, with 81% of fathers in two-parent homes participating. Mothers were on average 36.89 years old (SD = 7.57); 92%

(n = 71) were White, and 68% (n = 52) were married. Mean maternal education was 14.90 years (SD = 3.53). Fathers were on average 40.45 years old (SD = 7.01); 98% (n = 41) were White, and 83% (n = 35) were married. Mean paternal education was 15.26 years (SD = 4.04).

Measures

Demographics. This questionnaire assessed background information about the respondent (e.g., age, ethnicity, education). Modal family socioeconomic status (SES) was computed using the Revised Duncan (Mo = 42.26; SD = 22.82) and reflected occupations in clerical, sales, or managerial positions (e.g., secretaries, sales clerks, office managers) [25].

Medical data. Chart reviews obtained information regarding type of cancer, date of diagnosis/relapse, and types of treatment (e.g., chemotherapy, surgery, radiation).

Prognosis data and medical communication. Similar to previous studies, [8] primary oncologists and parents provided their perceptions of the child's chance of disease free survival at 5 years post diagnosis on a 0–100% visual analogue scale. Oncologists also noted whether the prognosis was communicated to the parents in: (a) Concrete/numeric terms, (b) general ideas, or (c) not at all. Parents noted whether they used the following sources of medical information: (a) Oncologists, (b) other medical professionals, (c) other families at the hospital, (d) the internet, and (e) family or friends. For analyses, participants were coded as either (a) relying on information from medical professionals only, or (b) relying on information from at least one non-medical source in combination with medical professionals.

Data Analyses

Paired *t*-tests (α = 0.05, two-tailed) examined differences in prognosis estimates between mothers, fathers, and oncologists, while Pearson's correlations (α = 0.05, two-tailed) examined associations between prognosis estimates for oncologists and parents, as well as between mothers and fathers. Separate hierarchical regressions for mothers and fathers examined whether the content of oncologist communication (i.e., concrete numbers, general terms, or no communication), parent sources of medical information (i.e., medical professionals only or medical professionals in conjunction with at least one other source), parent age, and parent education moderated the association between oncologist and parent prognosis ratings. Post hoc tests were conducted when appropriate to determine whether simple slopes of the predictors on the dependent variables were significantly different from zero [26]. The sample of mothers (N = 77) produced power (0.79–0.85) to detect medium effects for analyses, while the sample of fathers (N = 42) produced power (0.88–0.98) to detect large effects.

RESULTS

Descriptive statistics are in Table I. No differences in variables of interest (i.e., mode of physician communication, parent sources of medical information, and parent age and education) were found when our sample was examined with and without relapse cases. As expected, both mothers and fathers of children with cancer reported, on average, a more favorable prognosis for their child than oncologists, t(74) = −6.16, P < 0.01, and t(40) = −5.18,

TABLE I. Descriptives for Prognosis Data, Demographic Variables, and Content and Source of Medical Information for Oncologists, Mothers (N = 77), and Fathers (N = 42) of Children With Cancer

	M ± SD	Range
Child's prognosis estimated by oncologist	61.78 ± 29.14	0–96.00
Child's prognosis estimated by mother	81.65 ± 19.41	0–100.00
Child's prognosis estimated by father	84.85 ± 14.97	35.00–100.00
Mother age (Years)	37.05 ± 7.38	24.00–57.00
Father age (Years)	40.45 ± 7.01	27.00–58.00
Mother education (Years)	14.90 ± 3.53	9.00–18.00
Father education (Years)	15.26 ± 4.04	10.00–20.00

	% (n)	
Oncologist content of communication		
Concrete/numeric terms	74 (57)	
General ideas	22 (17)	
None	4 (3)	
Mother source of medical information		
Medical professionals only	33 (25)	
Medical professionals+	62 (48)	
None	5 (4)	
Father source of medical information		
Medical professionals only	32 (13)	
Medical professionals+	63 (26)	
None	5 (2)	

Medical professionals+, medical professionals in combination with at least one other source of medical information (i.e., other families at the hospital, the internet, family or friends).

$P < 0.001$, respectively. However, prognosis estimates between oncologists and mothers, r(75) = 0.44, $P < 0.001$, and between oncologists and fathers, r(41) = 0.56, $P < 0.001$, were correlated. The range of discrepancies between oncologist and parent prognosis estimates was 0–67% for mothers and 2–41% for fathers. Time since diagnosis was correlated with less discrepancy between physician and mother prognosis ratings, r(75) = −0.31, $P < 0.01$, with a similar trend occurring between physicians and fathers, r(41) = −0.13, $P = 0.41$. Mother and father prognosis estimates did not differ, t(40) = 0.42, $P = 0.68$. Although mother and father prognosis estimates were not significantly correlated, r(41) = 0.26, $P = 0.10$, a trend in the expected direction suggests we simply did not have sufficient power to detect the effect as significant.

Prior to tests of moderation, cases were excluded if the oncologist indicated that they did not communicate prognosis information directly to the family (n = 3) or if a parent did not report obtaining information from any of the sources queried (three mothers, two fathers). Overall regression models were significant when examining whether the content of oncologist communication affected the association between oncologist prognosis estimates and mother or father prognosis estimates, $R^2 = 0.22$, F(3, 68) = 6.30, $P < 0.01$ and $R^2 = 0.39$, F(3, 35) = 7.59, $P < 0.01$, respectively. However, the interaction terms were not significant, $P = 0.13$ and $P = 0.64$, respectively, suggesting that physician communication did not moderate these associations.

Mothers reported relying on their child's physician (71%, n = 55), internet research (55%, n = 42), other medical professionals (34%, n = 26), family or friends (26%, n = 20), and other families at the hospital (16%, n = 12). Similarly, fathers reported relying on their child's physician (73%, n = 30), internet research (54%, n = 22), family or friends (34%, n = 14), other medical professionals (22%, n = 9), and other families at the hospital (12%, n = 5). Regression models for mothers and fathers were significant, $R^2 = 0.21$, F(3, 69) = 6.25, $P < 0.001$ and $R^2 = 0.22$, F(3, 35) = 3.25, $P < 0.05$, respectively. However, the interaction terms were not significant, $P = 0.77$ and $P = 0.88$, respectively, suggesting no moderation.

With respect to demographic factors, father age moderated the association between oncologist and father prognosis estimates, $R^2 = 0.52$, F(3, 37) = 13.51, $P < 0.001$. Post hoc tests showed the association between oncologist and father prognosis estimates was stronger for younger fathers (i.e., under age 43 based on regions of significance), b = 0.60, t(39) = 6.08, $P < 0.001$, and weaker for older fathers, b = 0.03, t(39) = 0.30, $P = 0.77$ (Fig. 1). Although the overall regression was significant for mother age, $R^2 = 0.22$, F(3, 71) = 6.68, $P < 0.001$, the interaction term was not ($P = 0.14$). Lastly, the overall regressions were significant for mother and father education level, $R^2 = 0.19$, F(3, 71) = 5.73, $P < 0.01$ and $R^2 = 0.33$, F(3, 37) = 6.19, $P < 0.01$, respectively. However, the interaction terms were not significant, $P = 0.51$ and $P = 0.37$.

DISCUSSION

With advances in medicine leading to an increasing number of life-sustaining therapies and complex treatment alternatives, it has become especially important for parents to accumulate accurate
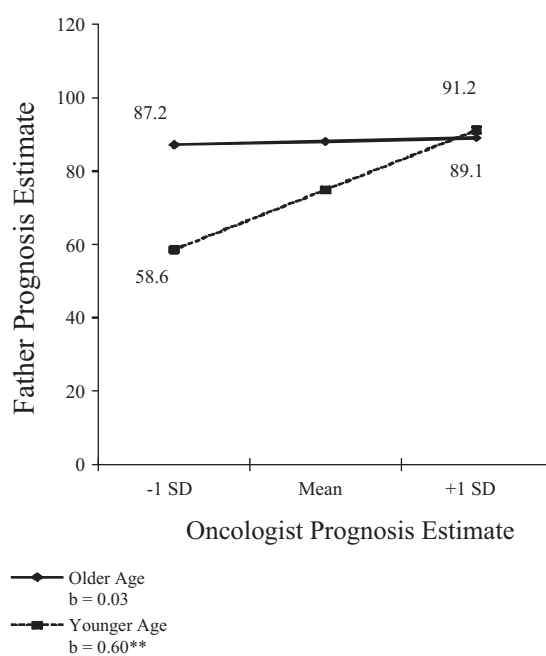

Fig. 1. Moderating effect of father age on the association between oncologist and father estimates of the child's cancer prognosis. Note: b, unstandardized regression coefficient; **$P < 0.01$, two-tailed.

information to make informed decisions regarding their children [1]. Research has found that parents of children with cancer tend to overestimate their child's prognosis relative to physicians [6,8]. We examined if the content of oncologist communication, parent sources of medical information, and parent demographic factors moderated the association between oncologist and parent estimates of their child's cancer prognosis. Overall, we found limited support for our hypotheses, with only fathers' age moderating the association between father and oncologist prognosis estimates.

Consistent with previous studies [6,8], we found that parents of children with cancer reported, on average, a more favorable prognosis for their child than oncologists, and there was a positive association between oncologist and parent prognosis estimates. The average discrepancy between oncologist and parent prognosis estimates was 23 percentage points for mothers and 19 percentage points for father, with 84% of mothers and 83% of fathers estimating a more optimistic prognosis. Our sample is slightly more optimistic than Mack et al. [8] who found that 61% of parents overestimated their child's prognosis relative to physicians, with a discrepancy range of approximately 0–65%. Because those children were farther from diagnosis (i.e., median of 3.5 months), parents may have had more time to acquire information in order to understand their child's prognosis. We found no significant difference between prognosis estimates for mothers and fathers. Studies examining mothers and fathers separately also have found no gender differences in prognosis understanding at diagnosis [7], but research comparing caregivers is limited.

Contrary to expectations, the way in which oncologists communicated the prognosis to parents did not influence agreement between parent and oncologist prognosis estimates. Most oncologists (i.e., 72%) reported they had communicated prognosis information in concrete or numeric terms. Although the delivery of frank and accurate prognostic information may be more likely for adults with "intermediate" as opposed to "short" anticipated survivals, the content of prognostic information delivered by our oncologists was unrelated to oncologist prognosis estimates [14]. While promising, these numbers suggest that some families may still not receive complete information, potentially due to the challenges physicians face during these discussions [14]. Physicians may benefit from training in the delivery of prognostic information, regardless of how poor the prognosis.

The source of parents' medical information did not affect agreement with the oncologist. Mothers and fathers were similar in their reliance on at least one non-professional source of medical information; however, we did not collect data on the frequency with which different information sources were used. Research has found that most adults with cancer preferred to discuss illness-related questions with their doctor [27], and reliance on information from other sources may be associated with more optimistic views [8]. Few parents in our sample reported that their child's medical team was not a source of medical information, but about half of parents used the internet to gain knowledge. The development of websites by legitimate health organizations (e.g., American Cancer Society: www.cancer.org, National Cancer Institute: www.cancer.gov) may make it relatively easy for parents to obtain accurate information regarding pediatric cancer. Also, the acquisition of medical knowledge from outside sources, regardless of validity, may assist parents in formulating specific questions for the child's oncologist.

We did find that agreement between oncologist and father prognosis estimates was stronger for younger fathers and weaker for older fathers. This is in line with research on adult health literacy linking younger age with greater illness knowledge [22]. Older fathers may have had more experience with cancer in other family or friends prior to their child's diagnosis. Comparison of their child's disease with anecdotal information or previous experiences with adult malignancies may cause older parents to adopt an inaccurate understanding of prognosis. Older parents also may be more reluctant to ask for clarification of prognosis from the child's oncologist, as a study of adults undergoing medical consultations found that older patients were less likely to ask medical questions and to receive diagnostic information from physicians [28]. In addition, previous research on computer literacy in the United States has found that regular computer usage is negatively associated with adult age [29]. Thus, younger parents who are better versed in using technology to acquire information may be more likely to use online health resources to gain knowledge of their child's disease [30].

In contrast to age, parent education level was unrelated to prognosis accuracy. Studies finding significant effects for parent education have tended to include participants with a wide range of educational levels (i.e., 0–23 years of schooling) [23]. On average, our sample of mothers and fathers had 2–3 years of post-secondary education, with only 4% of mothers (n = 3) and 10% of fathers (n = 4) with a graduate or professional level education (i.e., >16 years). Thus, it may be that our parents did not differ enough in their educational attainment for significant associations to be detected. Some studies have also suggested that education level may not be an appropriate indicator of health literacy, as 60% of adult family practice patients were found to have reading skills (i.e., another common indicator of health literacy) that were at least three levels below the highest grade they attended [31]. Future research may consider examining specific cognitive and academic variables (i.e., reading level, language skills) related to health literacy.

Our study has several additional limitations. First, our sample was relatively homogeneous with regard to several factors, including oncologist estimated prognoses (i.e., half of children were rated as having above a 70% chance of 5-year survival), participant race, and parent education level. Although our sample is reflective of the demographic makeup of the patient population in the institution where it was collected, a more heterogeneous sample would have improved our ability to generalize results to the broader population. Second, we had limited power to detect significant effects for interactions, particularly among fathers. Third, we used only basic information regarding content of oncologist communication and parent sources of medical information. More detailed information regarding the specific content, timing, and frequency of conversations about prognosis, who initiated discussions, and the communication style of oncologists may shed more light on the ways in which parents acquire this knowledge. Finally, as we only collected data near the time of initial diagnosis or relapse, the examination of physician prognosis ratings over the course of a child's illness may provide important information regarding physicians own accuracy in understanding and predicting childhood cancer outcomes and may further clarify the methods in which physicians choose to provide prognosis information to parents. Similarly, measuring parent prognosis estimates at multiple points during a child's

treatment may provide support for an alternative explanation of differences in prognosis literacy. Given that time since diagnosis in our sample was significantly correlated with less discrepancy between physician and mother prognosis ratings, it follows that parent prognosis understanding may likely be associated with the amount of time they have had to acquire and process medical information.

Overall, our study confirms that parents of children with cancer tend to overestimate their child's prognosis, and factors influencing this understanding may vary between parents. Because age appears to play a role in fathers' understanding of their child's cancer prognosis, the use of different communication strategies and more time may be needed for older fathers to improve their knowledge. A thorough and continuous assessment of parent preferences for communication, as well as the design and evaluation of interventions that improve communication among health-care providers, may improve parents' prognosis understanding. The examination of whether differences in parental knowledge ultimately go on to influence the decisions that parents make over the course of a child's cancer treatment is an important area of future research, as this may further underscore the necessity of accurate parent prognosis understanding beginning at the time of diagnosis.

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