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Longitudinal understanding of prognosis among adolescents with cancer

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Abstract

Objective: Despite calls to increase prognosis communication for adolescents with cancer, limited research has examined their perceptions of prognosis as compared with their parents. We assessed adolescents' understanding of their prognosis relative to parents and oncologists.

Methods: Families of adolescents (aged 10-17) were recruited at two pediatric institutions following a new diagnosis or relapse. Seventy-four adolescents, 68 mothers, and 40 fathers participated at enrollment; 76 adolescents, 69 mothers, and 35 fathers participated one year later. The adolescent's primary oncologist reported on prognosis only at enrollment. Participants rated the likelihood of the adolescent's survival in five years, as well as reporting prognosis communication and sources of information.

Results: Most oncologists (65%) and fathers (63%) discussed prognosis in numerical terms with the adolescent at baseline, which was greater than mother report (49%) of discussions of numerical prognosis with adolescents. Adolescents reported a better prognosis than oncologists, but comparable with mothers at diagnosis and one year. Adolescents' prognosis estimates were stable over time ($P > .05$). At diagnosis, adolescent-father ($P = 0.025$) and adolescent-oncologist ($P < 0.001$) discrepancies were larger for youth with advanced than non-advanced cancer. Adolescents whose parents received numerical prognosis estimates from the oncologist, and whose fathers reported providing numerical prognosis estimates had more accurate understandings of prognosis ($P < 0.05$).

Abbreviation: ICC, intraclass correlation coefficient

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Conclusions: Adolescent prognosis estimates were comparable with those of parents at diagnosis and one year but more favorable than that of oncologists. Although additional research is needed, results suggest discrepancies in prognosis estimates between family members and oncologists, particularly for adolescents with advanced cancer.

KEYWORDS
oncology, palliative care, psycho-oncology, psychosocial

1 | INTRODUCTION

Despite treatment advances, childhood cancer remains a leading cause of death among children.[1] Although prognosis estimates are often uncertain, many families want to know their child's likelihood of survival.[2] Yet, conveying prognosis is difficult; providers may anticipate that predictions of treatment failure will cause distress for their young patients.[3,4] Parents share these worries and often report unrealistic or overly optimistic understandings of prognosis—which may be shared with their children.[3,5–7] Indeed, research reflects that children, adolescents, and young adults overestimate their cancer prognosis.[8,9] Overly optimistic views of prognosis may be associated with interest in high-intensity treatment rather than symptom management or palliation, as found among parents.[6,10]

Prognosis communication may be particularly important for adolescents, who are developing greater autonomy and may want to share in decision-making but are not legal custodians of their care. Youth with cancer are interested in their likelihood of survival, and many desire direct medical discussions and prognosis information. However, there is variability in this interest, and a small subset of youth may have little desire for this information.[9,11–13] In one study, 86% of adolescent survivors indicated they would want to be informed if their illness was terminal.[14]

Research with adolescents and young adults with cancer has found that extensive prognosis disclosure is associated with increased trust in one's oncologist, peace of mind, and hope.[9] Thus, most adolescents value this information, which may promote positive psychosocial functioning.

Research is needed on how adolescents understand their prognosis compared with their healthcare providers *and* caregivers. Furthermore, we do not know how understanding of prognosis changes over time or what personal, medical, and communication factors predict more accurate estimates among youth. Thus, we evaluated adolescents' understanding of their prognosis at diagnosis and one year later, expecting that adolescents would be more optimistic when compared with their oncologists and caregivers. Further, we explored demographic, medical, and communication factors related to (1) adolescents' understanding of prognosis relative to their oncologist and (2) adolescents' agreement with their parents on their prognosis, expecting that numerical communication from oncologists and parents to adolescents would support better understanding of prognosis and agreement.

2 | METHOD

2.1 | Procedures

Data presented are part of a longitudinal study examining coping and family communication following a new or relapsed diagnosis of childhood cancer.[5,15,16] Participants eligible for the larger study were (a) 5-17 years old, (b) diagnosed with new or relapsed cancer, (c) English-speaking, and (d) without preexisting developmental delay. Following Institutional Review Board approval, study staff at two U.S. pediatric institutions identified children from cancer registries and approached families in clinic. Parents and their children provided written informed consent and assent (ages 10-17) to participate. Parents and children over the age of 10 completed paper questionnaires. Families were compensated for participation ($25 for each family member). The child's primary oncologist completed a survey about the adolescent's prognosis and communication near initial enrollment (described below).

2.2 | Participants

Only families with participating adolescents, who were ages ≥ 10 and able to provide self-report, were included in analyses. Of the 195 families with eligible adolescents at diagnosis, 85% (n = 167) agreed to participate and completed surveys. Because the questionnaire assessing prognosis was added after initiation of the study, some families were not offered this questionnaire. Thus, our sample with complete data included 74 adolescents, 68 mothers, and 40 fathers. Oncologists for 48 of the 74 adolescents (65%) also completed the survey.

One year later, families and all adolescents, including those who did not complete surveys at enrollment, were re-approached. Three adolescents had died; 56% ($n = 109$) of adolescents from 195 eligible families agreed to participate and completed surveys at follow-up. Our final sample with complete data included 76 adolescents, 69 mothers, and 35 fathers. Oncologists were not re-approached at this time. Attrition analyses compared demographic characteristics (i.e., child and parent age, race, ethnicity; family income, parent education, diagnosis) of participants to nonparticipants. Families reporting income less than $50 000 were less likely to participate at one year, X^2 (4, $N = 96) = 15.75$, $P = 0.003$.

2.3 | Measures

2.3.1 | Cancer information questionnaire

Similar to previous work,[5,9] this questionnaire assesses understanding of the adolescent's prognosis and outcomes after treatment. Primary oncologist, adolescent, and parent prognosis perceptions were assessed by asking, "What do you think the chances are that your [your/this child's] treatment will be successful and you/they will be cancer free 5 years from now?" Participants responded on a 0%-100%, 4-inch visual analogue scale. Trained research assistants scored this scale by measuring the paper scale with a ruler (with precision to the millimeter) and converted this measurement to a percentile. Parents and adolescents responded to the question "Where did you get this [prognosis] information?" with response options: (a) oncologists, (b) other medical professionals, (c) other families at the hospital, (d) personal research (e.g., the Internet), and (e) family or friends. Parents were asked "Have you discussed this information with your child?" with three response options: (a) "concrete numbers," (b) "general discussions," or (c) "not discussed." Similarly, we asked oncologists "How directly have you stated this information to this child's parents?" with the same response options. Additionally, we asked "If general or specific discussions have occurred, has the child been present?" with three response options: (a) "the child was present when I discussed the prognosis with their parents," (b) "I discussed this prognosis with the parents alone, but I subsequently talked to the child about it as well," and (c) "I have not discussed this prognosis with the child." Parents and adolescents completed this measure at both time points. Oncologists participated only at enrollment.

2.4 | Data analysis plan

2.4.1 | Agreement

Three methods were used to measure agreement between the adolescents' understanding of their cancer prognosis compared with their oncologists, mothers, and fathers in SPSS version 25. Pearson correlations tested if prognosis estimates were significantly correlated within dyads (e.g., adolescents and mothers). To account for skew, prognosis estimates were log transformed. Average intraclass correlation coefficients (ICCs) and their 95% confidence intervals (CIs) served as a measure of correlation *and* agreement between reporters' prognosis estimates.[17] Two-way, mixed-effects models estimated absolute agreement. Values less than 0.5 indicated poor agreement, 0.5 to 0.75 indicated moderate agreement, 0.75 to 0.9 indicated good agreement, and > 0.9 indicated excellent agreement.[17] As an additional comparison, we subtracted the adolescents' prognosis estimates from the prognosis estimates of oncologists, mothers, and fathers to characterize discrepancies between reporters. Discrepancy scores within the range of −3% to 3% indicated relative agreement because scores in this range were not significantly different from each other. Thus, discrepancy scores equal to or lower than −4% indicated that the adolescent reported higher prognosis (*more optimistic*) than their parent/oncologist, and discrepancy scores equal to or higher than 4% indicated adolescents reported lower prognosis than their parent/oncologist (*more pessimistic*).

We then tested predictors of discrepancy scores to determine if variables were associated with better or worse agreement between reporters. Variables included demographic characteristics (i.e., child sex, child age, parent age, parent education, parent income), medical factors (i.e., diagnosis, advanced cancer), and prognosis communication (i.e., oncologist and parent reported communication about prognosis). Associations with discrepancy scores were tested via independent sample *t* tests, analysis of variance (ANOVA), and Pearson correlations using SPSS version 25. Absolute values of the prognosis discrepancy scores were used in these analyses to enhance interpretability (i.e., for these analyses, higher discrepancy scores indicated poorer agreement, lower scores indicated higher agreement, scores of zero indicated relative agreement).

2.4.2 | Change over time

Mixed models with the PROC MIXED procedure in SAS software[18] tested whether prognosis estimates (i.e., adolescent, mother, father) changed over time for all families whose adolescent participated at either time point, while accounting for missing data at each time point and assuming data are missing at random. Change in prognosis estimates was analyzed with a statistical model that included time as a repeated-measures factor with two levels.

3 | RESULTS

At enrollment, adolescent participants were predominantly white (*n* = 63; 90%) and non-Hispanic/Latino (*n* = 69; 93%), and 34% had advanced cancer (*n* = 25). Advanced cancer was defined as relapsed disease or a < 65% five-year survival rate per primary oncologist.[16] Primary caregivers were female, mostly white and non-Hispanic/Latina, and an average age of 41 years. Most were the biological parent (*n* = 62, 89%), and the remaining were a stepparent, adoptive parent, or grandparent. Secondary caregivers were male, mostly white and non-Hispanic/Latino, and an average age of 43 years. Most were the biological parent (*n* = 31, 78%). See Table 1 for demographic characteristics.

3.1 | Prognosis estimates

At diagnosis, oncologists (*n* = 48) reported an average prognosis of 67% (SD = 20.7). Adolescents estimated an average prognosis of 90% (SD = 11.4) at diagnosis and 88% (SD = 17.1) at one year. Mothers estimated an average prognosis of 87% at diagnosis (SD = 14.14) and

TABLE 1 Participant demographic characteristics

Variable	Diagnosis	1 Year post-diagnosis
Adolescent mean Age (*SD*)	13.86 (2.40)	14.30 (2.42)
Survivor age range	10-17	11-18
Adolescent gender		
Male (%)	26 (65%)	35 (46%)
Female (%)	48 (35%)	41 (54%)
Adolescent race		
White (%)	63 (90%)	64 (88%)
Black (%)	6 (9%)	6 (8%)
Other (e.g., multiracial) (%)	1 (1%)	3 (4%)
Cancer diagnosis		
Leukemia (%)	24 (32%)	23 (30%)
Lymphoma (%)	22 (30%)	26 (34%)
Brain tumor (%)	2 (4%)	2 (3%)
Other solid tumor (%)[a]	25 (34%)	25 (33%)
Advanced cancer (%)[b]	25 (34%)	17 (22%)
Mother mean age (SD)	41.54 (8.57)	42.16 (7.80)
Mother race		
White (%)	63 (90%)	62 (89%)
Black (%)	6 (9%)	6 (8%)
Other (e.g., multiracial) (%)	1 (1%)	3 (3%)
Father mean age (SD)	42.78 (8.71)	45.06 (11.34)
Father race		
White (%)	38 (95%)	31 (89%)
Black (%)	2 (3%)	3 (9%)
Other (e.g., multiracial) (%)	0 (0%)	1 (2%)
Family income		
$25 000 or under (%)	25 (36%)	16 (22%)
$25 000 to $50 000 (%)	17 (25%)	22 (31%)
$50 000 to $75 000 (%)	13 (19%)	11 (15%)
$75 000 to $100 000 (%)	7 (10%)	8 (11%)
$100 000 or more (%)	7 (10%)	15 (21%)

[a] Other solid tumors include sarcoma diagnoses, as well as neuroblastoma and Wilms' tumor.

[b] Participant defined as having advanced cancer if he or she had (1) history of relapsed cancer and/or (2) less than 65% prognosis per his or her oncologist.

86% at one year (SD = 15.98). Fathers estimated an average prognosis of 88% (SD = 15.55) at diagnosis and 89% (SD = 14.70) at one year . Mixed-model analyses detected no significant changes over time in mother ($P = 0.50$), father ($P = 0.74$), and adolescent ($P = 0.34$) prognosis estimates.

3.2 | Prognosis communication

At diagnosis, most oncologists reported discussing the prognosis in numerical terms with parents (60%, $n = 29$) and with the adolescent present (60%, $n = 29$). A minority reported only general prognosis discussions with parents (38%, $n = 18$), and relatively few oncologists reported discussing prognosis with the adolescents in a subsequent discussion without their parents (19%, $n = 9$). Oncologists reported no discussion of prognosis for one parent (2%) and 10 adolescents (21%). About one-half of mothers (49%, $n = 33$) and 63% of fathers ($n = 25$) reported discussing the prognosis in numerical terms with adolescents. About one-half of mothers (49%; $n = 33$) and 30% of fathers ($n = 12$) reported discussing prognosis generally with their adolescent. Few parents (two mothers and three fathers) had not discussed prognosis with their adolescent. Sources of prognosis information for adolescents included their doctor (84%, $n = 62$), parents (57%, $n = 42$), personal research (e.g., the Internet; 27%, $n = 20$), other medical staff (27%, $n = 29$), family/friends (18%, $n = 13$), and other children or families at the hospital (8%, $n = 6$).

At one year, most mothers (61%, $n = 42$) and fathers (51%, $n = 18$) discussed prognosis in numerical terms with adolescents. Thirty-five percent of mothers ($n = 24$) and 40% of fathers ($n = 14$) discussed prognosis generally with adolescents. Few parents (three mothers and three fathers) had no discussions about prognosis with their child. Sources of prognosis information at one year for adolescents included their doctor (82%, $n = 62$), parents (53%, $n = 40$), personal research (e.g., the Internet; 33%, $n = 20$), other medical staff (27%, $n = 29$), family/friends (18%, $n = 9$), and other children or families at the hospital (13%, $n = 10$).

3.3 | Pearson correlations

Adolescent prognosis estimates and oncologist estimates were not significantly correlated at diagnosis, $r(46) = 0.25$, $P = 0.096$. Adolescent and mother prognosis estimates were significantly correlated, $r(66) = 0.32$, $P = 0.009$, whereas adolescent and father prognosis estimates were marginally significant, $r(38) = 0.30$, $P = 0.064$. Similarly, at one year, adolescent prognosis estimates were significantly correlated with mother prognosis estimates, $r(67) = 0.48$ $P < 0.001$, and not significantly correlated with father prognosis estimates, $r(33) = 0.23$, $P = 0.193$.

3.4 | Intraclass correlation coefficients

At diagnosis, results reflected no significant agreement between adolescents and oncologists on prognosis estimates (ICC = 0.175, 95% CI = −0.169 to 0.464), as confidence intervals included zero. Adolescents had an average of poor to moderate agreement with mothers (ICC = 0.458 95% CI = 0.135 to 0.662) and no significant agreement with fathers (ICC = 0.431, 95% CI = −0.062 to 0.697).

At one year, adolescents had poor to moderate agreement with mothers (ICC = 0.645, 95% CI = 0.431-0.779) and no significant agreement with fathers (ICC = 0.366, 95% CI = −0.279 to 0.683). Notably, our smaller samples of oncologists and fathers may have resulted in wide CIs.

TABLE 2 Adolescents' understanding of prognosis compared with oncologists, mothers, and fathers based on discrepancy scores

	Adolescent agreement		
Reporter	Lower prognosis estimate (*n*, %)	Relative agreement (*n*, %)	Higher prognosis estimate (*n*, %)
Oncologist (*n* = 48)	1, 2%	2, 4%	45, 94%
Mother			
Diagnosis (*n* = 68)	17, 25%	27, 40%	24, 35%
1 Year (*n* = 69)	19, 28%	23, 33%	27, 39%
Father			
Diagnosis (*n* = 40)	13, 32%	9, 23%	18, 45%
1 Year (*n* = 35)	13, 37%	9, 26%	13, 37%

3.5 | Prognosis discrepancy scores

Adolescents tended to report a more favorable prognosis than their oncologist, by an average of 25 percentage points (Mdn = −19.5, IQR = 16.0), with a range of 86% lower to 15% higher. Only two adolescents and their oncologist reported relative agreement. Prognosis discrepancy scores reflected that adolescent estimates were comparable with mother (Mdn = 2.00, IQR = 13.0, range = −48% to 25%) and father (Mdn = −5.0, IQR = 19.0, range = −65% to 26%) estimates, with adolescents reporting prognosis estimates three to four percentage points higher than their parents on average.

At one year, adolescents again reported prognosis estimates comparable with their mothers (Mdn = −1.0, IQR = 14.0; range = −56% to 34%) and fathers (Mdn = 0.0, IQR = 17.0; range = −62% to 62%), with adolescents reporting prognosis estimates 3% higher than mothers and equal to fathers on average. See Table 2 for categories of prognosis discrepancy scores at both time points.

3.6 | Predictors of prognosis agreement at diagnosis

Of demographic, medical, and prognosis communication variables, several were significantly associated with prognosis discrepancy scores. Male adolescents and their mothers had lower discrepancy scores at diagnosis (M = 6.65, SD = 8.53) than female adolescents and their mothers (M = 11.78, SD = 12.30), *t*(59.85) = 2.01, *P* = 0.049, Cohen's *d.* = 0.46. At diagnosis, discrepancy scores for adolescents and their oncologists were larger for those with advanced cancer (M = 36.43, SD = 22.00) than without advanced cancer (M = 15.64, SD = 8.64), *t*(28.17) = −4.24, *P* < 0.001, Cohen's *d.* = 1.26.

Prognosis communication delineated some differences in adolescent understanding of prognosis. At diagnosis, prognosis discrepancy scores between adolescents and their oncologists were smaller for adolescents whose parents received numerical prognosis estimates from oncologists compared with general discussions (M = 21.28, SD = 16.79 vs M = 33.06, SD = 21.84), *t*(45) = 2.081, *P* = 0.043, Cohen's *d.* = 0.62. Due to sample size, comparisons were not calculated when parents and oncologists had no discussion (*n* = 1). Notably, adolescents who were present during concrete, numerical prognosis discussions with their parent(s) and oncologist had no better understanding than adolescents only receiving private communication with their oncologist. Additionally, at diagnosis, prognosis discrepancy scores between adolescents and oncologists were smaller for adolescents whose fathers shared numerical prognosis estimates with them (M = 19.00, SD = 14.14) compared with only general discussions (M = 33.06, SD = 18.62), *t*(24) = 2.15, *P* = 0.042, Cohen's *d.* = 0.90. Due to sample size, comparisons were not calculated when adolescents and oncologists had no discussion (*n* = 3).

3.7 | Predictors of prognosis agreement at one year

At one-year follow-up, we identified one predictor of agreement. Adolescent-mother prognosis discrepancy scores were larger for adolescents who reported using personal research (i.e., the Internet) for prognosis information (M = 16.90, SD = 16.80) than for adolescents who did not (M = 8.19, SD = 7.82), *t*(25.35) = −2.32, *P* = 0.029, Cohen's *d.* = 0.87.

4 | DISCUSSION

This is the first study, to our knowledge, to evaluate how adolescents understand their cancer prognosis compared with not just their oncologists at diagnosis but also their parents from diagnosis to one year. Most oncologists reported communicating prognosis to parents and adolescents, similar to some research,[9] but a larger proportion than found in other studies.[6,19] However, oncologists reported they did not provide any prognosis information to at least one parent and 10 adolescents, raising important questions about whether this was driven by the oncologist or family. Furthermore, the majority of parents reported discussing prognosis with their child, with most parents reporting numerical discussion of prognosis. Our results suggest that, similar to parents,[20,21] adolescents fill gaps in their knowledge through alternate sources, with many deriving their understanding of prognosis from parents, other medical staff, personal research, or family or friends. Thus, adolescents frequently desire prognosis information,[9,11,12] but their needs are often unmet, which may influence personal goals of care.[6]

Similar to their parents,[5,10] adolescents reported more favorable prognosis estimates compared with their oncologists, which is consistent with research with adolescents and young adults with cancer.[9] Further, adolescents seem to primarily derive their understanding of prognosis from their mothers, with agreement strengthening over time. However, 25% to approximately one-third of adolescents reported *lower* prognosis estimates than their parents. Thus, youth may process their likelihood of cure and survival more realistically than parents, a finding that contrasts with a study of youth (3-16 years old) with acute lymphoblastic leukemia, who were more optimistic about the likelihood of cure than parents.[8] Parents may be overly optimistic to protect their children, to reflect their hopes rather than their expectations, or because of a belief that their child is the exception.[6,22] Taken together, it seems that parents' and oncologists' expectations of treatment success may occasionally diverge from the expectations of their adolescent child, perhaps complicating decision-making, particularly for adolescents with advanced cancer.[6,21,23]

We observed no marked changes in adolescents' prognosis understanding over time. We did not find longitudinal studies of this nature for comparison; thus, this represents a novel contribution to the literature. However, oncologists did not provide data for some adolescents, perhaps in cases where conversations did not occur or for other unknown reasons. We also did not collect oncologist data at one year, but ongoing provider-family communication is likely an important predictor of adolescents' longitudinal prognosis understanding. Given generally high survival rates for pediatric cancers, it would be advantageous to examine changes in understanding of prognosis over a longer time and at key points in care (e.g., relapse, refractory/disease progression, transition off-treatment). Although further research is needed, results suggest that adolescents' prognosis understanding may not change appreciably over the first year of treatment.

Additionally, adolescents with advanced cancer reported a less accurate understanding of their prognosis compared with adolescents without advanced cancer. This is similar to findings that parents of children with a low likelihood of survival nevertheless report optimistic prognoses, confirming that this subgroup has the greatest need for improved prognosis communication.[6,10,19] Recommendations exist for how medical staff and parents can best communicate prognosis information and educate youth with poor prognoses to inform decision-making,[22,24,25] but further research evaluating and testing these recommendations is needed.

We identified several variables that may help identify adolescents with poorer understanding of their cancer prognosis. Adolescent males may be more likely to derive prognosis information from their mothers than females, but this finding was not evident one year later. Furthermore, adolescents who used personal research (such as the Internet) for prognosis information had poorer agreement with their mothers at one year. Considering that mothers often report overly optimistic prognosis estimates,[5,10] this may imply that the Internet or other resources can provide information to form a more independent estimate from parents. However, this trend may indicate that adolescents search for prognosis information online when their parents do not provide it—warranting concern if the resource is not credible. Nevertheless, adolescents that encounter reputable sources (e.g., National Cancer Institute, American Cancer Society) may develop a more realistic understanding. Personal research, especially Internet-based research, may be an important source of prognosis information for adolescents that merits further examination.

Our findings suggest some advantages to certain styles of communicating prognosis to adolescents. Those whose oncologists provided their parents with numerical estimates reported a more realistic and concordant understanding of their prognosis. Adolescents whose fathers, not mothers, shared numerical prognosis estimates with them reported a more realistic understanding of prognosis (i.e., as compared with oncologist report) than adolescents whose fathers discussed prognosis generally. Yet, adolescents who were in the room when their oncologists provided the family with numerical estimates did not report better understanding of prognosis than adolescents who received only general prognosis estimates from their oncologist. Together, these findings suggest that parents of adolescents might serve as gatekeepers of prognosis information[22]—parents who have communicated openly about prognosis with the oncologist may facilitate a more realistic understanding for their child. Yet, parents may feel unprepared to address their child's informational needs, particularly when the child has a poor prognosis,[21] and require support from healthcare providers to facilitate honest, developmentally appropriate communication with their child. Notably, the survey items used may not capture the nuances of complex conversations about prognosis. Although more research is needed, the healthcare team plays an important role in ongoing conversations, often balancing families feeling informed and involved but not overwhelmed.[3,4,20,22,25]

Several study limitations merit discussion. Methodologically, parents and adolescents may have difficulty understanding numerical prognoses and may find these distinctions challenging to understand. Further, parents and adolescents may remain intentionally optimistic in their reported estimates and perhaps not report their true estimates.[6,22]Although we created categories of agreement from continuous discrepancy scores for ease of understanding, these categories may lack clinical meaning, because indicating a precise number may be challenging for participants due to low health literacy or numeracy.[26]

Furthermore, our sample was relatively small and lacked the diversity needed to examine differences in understanding of prognosis across racial and ethnic groups. Such questions may be highly relevant, as one study found that physicians assume Black, Hispanic, or Asian parents have poorer understanding of medical information and less interest in prognosis information than white parents.[19] Further, sociocultural characteristics are known to influence decision-making, communication about death, and end-of-life preferences in the context of pediatric palliative care.[13,27] Future studies should examine differences in prognosis communication and understanding among diverse youth with cancer. Additionally, surveying more than one oncologist as an additional standard of comparison would be helpful. Moreover, prognosis communication was reported subjectively and retrospectively and thus is susceptible to recall bias. Finally, because these data were a subset of a larger, longitudinal project, there were inconsistencies in sample size across participants and time -- particularly with regard to the number of oncologists and lack of oncologist data at one year.

Despite these limitations, the current study's findings fill significant gaps in the literature and clarify how adolescents understand the likelihood that they will survive cancer relative to not just their oncologists, but also their parents. Our use of multiple informants and collection of data at two time points are strengths. Results highlight the importance of prognosis communication in numerical terms, and the critical role that parents, particularly mothers, play as gatekeepers to their adolescent's understanding of prognosis in tandem with the oncologist.[28] Open and respectful medical communication (i.e., truth-telling) is consistently recommended in pediatric oncology and with youth with terminal conditions,[3,29] and discussions about prognosis do not necessarily result in diminished hope or cause long-term distress.[9] For example, advance care planning interventions for adolescents with cancer may increase their understanding of prognosis and participation in decision-making at the end of life.[30] However, not all adolescents and parents wish to know prognosis information,[9,11–13] and clinicians should periodically assess family preferences to guide communication practices throughout care.[22] Further, and beyond the scope of these data, many other communication factors may be important to adolescents and relevant to their understanding of prognosis. For example, adolescents' perception of the quality of the information they receive and the extent that they like their oncologist appear to be relevant to adolescent and young adult's satisfaction with prognosis information.[13] Prognosis communication is often an evolving process, and healthcare providers should work as a team with families to ensure that adolescents have the opportunity to understand their future to facilitate goals of care and shared decision-making.[21,22]

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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