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Original Research Article

Parent–Child Communication and Adjustment Among Children With Advanced and Non-Advanced Cancer in the First Year Following Diagnosis or Relapse

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Abstract

Objectives To examine parent–child communication (i.e., openness, problems) and child adjustment among youth with advanced or non-advanced cancer and comparison children. **Methods** Families ($n = 125$) were recruited after a child's diagnosis/relapse and stratified by advanced ($n = 55$) or non-advanced ($n = 70$) disease. Comparison children ($n = 60$) were recruited from local schools. Children (ages 10–17) reported on communication (Parent–Adolescent Communication Scale) with both parents, while mothers reported on child adjustment (Child Behavior Checklist) at enrollment (T1) and one year (T2). **Results** Openness/problems in communication did not differ across groups at T1, but problems with fathers were higher among children with non-advanced cancer versus comparisons at T2. Openness declined for all fathers, while changes in problems varied by group for both parents. T1 communication predicted later adjustment only for children with advanced cancer. **Conclusions** Communication plays an important role, particularly for children with advanced cancer. Additional research with families affected by life-limiting conditions is needed.

Key words: adjustment; cancer and oncology; parent–adolescent communication.

Almost 16,000 children are diagnosed with cancer annually in the United States (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Although 5-year survival rates now exceed 80%, many children still succumb to the illness after surpassing this milestone, making cancer the leading cause of disease-related death in childhood (Ward et al., 2014). A subset of children with recurrent, refractory, or high-risk disease can be described as having advanced cancer, which connotes a much higher likelihood of death and puts greater demands on family communication (Peppercorn et al., 2011; Wolfe, Friebert, & Hilden, 2002). Thus, depending on the cancer type and treatment response, a diagnosis may have different consequences for children and families in terms of mortality (Ward et al., 2014), illness burden (Wolfe et al., 2002), and distress (Rosenberg et al., 2013). Considering the disparate treatment goals and trajectories for these families, research should be sensitive to potential differences in the quality of communication among families of children with advanced and non-advanced cancer relative to healthy peers, as well as the implications for child adjustment (i.e., emotional functioning). However, no research has examined the impact of advanced cancer on parent–child communication and child adjustment over time (Hinds, Pritchard, & Harper, 2004).

Severe psychopathology appears to be no more common among children with cancer than among the general population, but subgroups may be at a higher risk for psychological distress relative to control groups or normative samples (Patenaude & Kupst, 2005). A recent meta-analysis found mild-to-moderate elevations in anxious/depressed symptoms on the Child Behavior Checklist (CBCL, $g = .47$), with somewhat weaker effects on the Youth Self-Report ($g = .25$; Pinquart & Shen, 2011). However, most psychosocial research in pediatric oncology focuses on children and families who are off-treatment or well into survivorship. In recent years, a growing body of work has followed families prospectively from diagnosis or during treatment (Long & Marsland, 2011), yet few studies have included families of children with advanced disease or near the end of life (Hinds et al., 2004). Although there is some qualitative evidence that a recurrence may be more challenging for families (Hinds et al., 1996), other quantitative studies suggest no differences in the adjustment of children with a new diagnosis compared with relapsed disease (Compas et al., 2014; Grootenhuis & Last, 2001). One possible explanation for equivocal findings is that groups of children with new diagnoses are heterogeneous and often include those with an initial poor prognosis or refractory disease. Thus, we propose that advanced or non-advanced disease status may better delineate those families at highest risk for difficulties.

Communication is an important aspect of parent–child relationships that reflects the quality of dyadic interactions, including the level of intimacy, trust, or conflict (Laursen & Collins, 2004). It is the avenue by which parents share information, offer support, and socialize their children. Furthermore, the quality and nature of parent–child communication may be subject to many natural fluctuations and changes, even in typically developing youth (Laursen, Coy, & Collins, 1998; Laursen & Collins, 2004). In the context of childhood cancer, parent–child communication is integral to obtaining knowledge of the disease, making decisions, and promoting adherence and positive adaptation (Last & van Veldhuizen, 1996; Murphy, Murray, & Compas, 2016; Patenaude & Kupst, 2005; Wolfe et al., 2002). As such, the National Cancer Institute recommends open and developmentally appropriate communication with children about cancer (National Cancer Institute, 2015). However, parents indicate that talking about cancer with their child is one of the most significant sources of stress during treatment (Rodriguez et al., 2012). Discussions about cancer can include strong affective components, abstract concepts, and complex information, which make it challenging for parents to understand and then convey important information to their children.

Although the quality of parent–child communication predicts child health and adaption to adversity more broadly (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005; Laursen & Collins, 2004), most research on communication in childhood cancer has focused on the content of communication. For example, qualitative research indicates that parents often act as gatekeepers, managing what and how information about cancer is shared with their children (Young, Dixon-Woods, Windridge, & Heney, 2003). No work has focused on openness or problems in communication between parents and their children with cancer. These aspects of parent–child communication may be particularly relevant in cases of advanced disease, wherein uncertain prognosis and anxiety about illness trajectories may pose barriers to high-quality communication (Wiener, Zadeh, Wexler, & Pao, 2013).

Despite the difficult nature of these conversations, children want to be included and provide input (Coyne & Gallagher, 2011). Children fear being alone at the end of life, and may feel isolated if they are aware of their impending death and are unable to talk about it (Hilden, Watterson, & Chrastek, 2000; Theunissen et al., 2007). Although most school-aged children with cancer want to know if they are dying (Ellis & Leventhal, 1993), they may have difficulty discussing death with their parents (Theunissen et al., 2007). For example, in one study, after a child's death from cancer, only one-third of bereaved parents reported they had talked openly with their child about death (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). At the same time, other research highlights pediatric cancer as an opportunity for growth and resilient parent–child relations. Importantly, child distress and the threat of limited time with each other may serve as motivation to increase closeness and open communication (Kars, Grypdonck, & van Delden, 2011; Williams, McCarthy, Eyles, & Drew, 2013). These inconsistencies in the literature suggest that patterns of parent–child communication may be better elucidated through longitudinal examination within the context of disease prognosis (Long & Marsland, 2011).

To summarize, the few studies of parent–child communication in the context of pediatric cancer have relied heavily on cross-sectional data, qualitative approaches, and a primary focus on content and disclosure. No studies have longitudinally examined the quality of parent–child communication following a cancer diagnosis relative to a comparison group to delineate how typical developmental patterns may differ in the context of a life-threatening illness (Long &

Marsland, 2011). Furthermore, differences in communication have not been examined with respect to disease prognosis. Therefore, we examined the quality of parent–child communication (i.e., openness and problems) and associations with mother reports of child adjustment for children with advanced and non-advanced cancer over the first year following a new diagnosis or relapse. While we have outlined potential reasons for either higher- or lower-quality communication in families of children with advanced cancer, we expected that these children would report less open and more problems in communication with parents than both children with non-advanced cancer and comparison children. In addition, given the gravity of the situation and support needs of children with advanced cancer, we expected the association between parent–child communication and later adjustment would be stronger for these children relative to non-advanced cancer or comparison children.

Method

Procedure

Data about children with cancer were collected as part of a larger multi-site, longitudinal study examining family coping and adjustment to pediatric cancer (Compas et al., 2014). Families were identified from the cancer registries of two large children's hospitals in the United States after a new initial diagnosis or relapsed diagnosis following a period of remission. Following approval by the institutional review board, families were recruited in the clinic or hospital. Each participating mother provided written informed consent, and children (ages 10–17 years) provided assent before completing questionnaires at approximately one month ($M = 1.30$ months, $SD = 0.89$) after diagnosis or relapse (T1) and again at one year (T2; $M = 13.02$ months, $SD = 2.07$). Families participated in their homes or at the clinic/hospital, and each participant was compensated $25 for their time.

Participants

For the larger study of children with cancer, eligible participants were: (a) aged 5–17, (b) diagnosed with new or recurrent cancer, (c) English-speaking, (d) without a preexisting developmental disorder, and (e) living within 100 miles of the hospital. Approximately 87% ($N = 334$) of the 385 families eligible at T1 agreed to participate (Compas et al., 2014). For this article, we included a subset of 125 children who were older than 10, able to provide self-report, and for whom physician prognosis ratings were obtained. There were no significant differences in demographic factors or primary variables of interest between the larger sample and this subsample. On average, mothers were 40.50 years old ($SD = 7.92$); 89% were White ($n = 111$), and 63% ($n = 79$) had at least one year of post-secondary education. On average, children were 13.53 years old ($SD = 2.35$). The sample was 52% ($n = 65$) female and 89% ($n = 111$) White. Diagnoses included lymphoma (35%; $n = 44$), leukemia (30%; $n = 38$), brain/CNS tumors (6%; $n = 7$), and other solid tumors (29%; $n = 36$). Similar to previous work (Wolfe et al., 2002; Peppercorn et al., 2011), advanced cancer diagnoses were coded based on: (a) relapsed or refractory disease, (b) oncologist estimate of treatment success lower than 65%, and/or (c) death on study (i.e., ≤ 2 years of enrollment). This post hoc approach to classification is consistent with SEER data indicating that the majority of deaths from childhood cancer occur within 2 years after diagnosis (National Cancer Institute, 2011). Based on these criteria, 55 children (44%) had advanced cancer, while 70 (56%) had non-advanced cancer. Average 5-year, physician-predicted disease-free survival was 43% ($SD = 22\%$) for children with advanced cancer and 80% ($SD = 9\%$) for those with non-advanced cancer.

A comparison group of 60 children (ages 10-17) were concurrently recruited from local schools for a similar study of families bereaved by cancer (Gerhardt et al., 2012). Comparison children were English-speaking, had no developmental disorders, were healthy/not bereaved, and lived within 100 miles of the hospital. Following a survey of children's friendships in the classroom, families of comparison children participated in a home visit to collect additional information about the parents and children. On average, comparison mothers were 42.93 years old ($SD = 7.85$); 90% ($n = 51$) were White, and 74% ($n = 42$) had at least one year of post-secondary education. On average, comparison children were 13.15 years old ($SD = 2.20$). The sample was 53% ($n = 32$) female and 90% ($n = 51$) White. Families were similar across groups and sites on all background characteristics (e.g., child age, gender, race, income).

At one year (T2), the majority of families of children with non-advanced cancer ($n = 50$; 79%) and comparison children ($n = 46$; 77%) participated, while fewer families of children with advanced cancer ($n = 30$; 55%) were retained. This discrepancy can be attributed to disease-related attrition. Of the initial 55 children with advanced cancer at T1, 6 died before T2, but others declined because the child was too ill at T2. Accordingly, those retained at T2 had a more favorable physician-predicted prognosis, $t(119) = 2.53$, $p = .014$. Retained families also had a higher annual family income, $\chi^2(4, N = 184) = 11.26$, $p = .024$.

Measures

Demographic Characteristics

Mothers reported on family background information (e.g., age, ethnicity, education) on a demographic questionnaire.

Oncologist Prognosis and Medical Information

Similar to previous work (Mack et al., 2007; Miller et al., 2012), the child's primary oncologist provided their perceptions of the child's chance of disease-free survival at 5 years post-diagnosis on a 0–100% visual analog scale. Chart reviews obtained information such as type of cancer, date of diagnosis/relapse, and types of treatment (e.g., chemotherapy, surgery, radiation).

Child Adjustment

Mother report of child adjustment was assessed with the CBCL, a widely used measure that assesses emotional and behavioral problems, as well as social competence, for children aged 6–18 years (Achenbach & Rescorla, 2001). The CBCL includes 112 items scored on a 3-point scale to describe the child during the preceding 6 months. Eight cross-informant syndromes reflecting emotional and behavioral problems are derived, along with three subscales for social competence. Higher-order factors include Total Competence, Total Problems, Internalizing, and Externalizing scores. Due to the potential for inflated scores for somatic complaints on the Internalizing Problems scale in populations with pediatric illness (Friedman, Bryant, & Holmbeck, 2007), we focused on the Anxious/Depressed and Withdrawn/Depressed subscales. Reliability and validity are established, and *T*-scores are derived from a nationally representative sample (Achenbach & Rescorla, 2001). Analyses used raw scores to preserve variability, but *T*-scores are reported.

Parent–Child Communication

Communication between participants and their parents was assessed using the 20-item Parent–Adolescent Communication Scale (PACS), which was based on the Circumplex Model of Marital and Family Systems (Barnes & Olson, 1985). Children completed the PACSs separately for their mother and father, as appropriate (i.e., if they reported regular contact with the parent). Thus, across our three subsamples, data were obtained for about 184 mothers (99%) and 172 fathers (93%). Twenty items are rated 1–5 and produce factor-derived scores (range: 10–50), which measure the degree of Openness in Communication (e.g., "It is very easy to express all of my true feelings to my mother/father," "My mother/father is always a good listener") and the extent of Problems in Communication (e.g., "Sometimes I have trouble believing everything my mother/father tells me," "When we are having a problem, I often give my mother/father the silent treatment"). Items were summed for each scale, such that higher scores indicated more openness and more problems. Both subscales have demonstrated strong internal consistency ($\alpha = .87$–.78) and test–retest reliability ($r = .78$–.77; Barnes & Olson, 1985). The PACS has been used successfully with children aged 10 and older, with similar evidence of internal consistency and validity (Caldwell, Horne, Davidson, & Quinn, 2007; Gazendam-Donofrio et al., 2009; Jang & Kim, 2012; Lambert & Cashwell, 2004; Ponnet et al., 2013). In our sample, Cronbach's alpha ranged from .78 to .92 for reports about mothers and fathers, and they were similar for 10–11-year-olds (.78–.83) and older children (.75–.93).

Analyses

Descriptive statistics were calculated for variables of interest, and attrition analyses were conducted. Group differences, the effect of time (T1 versus T2), and group by time interactions were analyzed using the MIXED procedure in SAS (version 9.3; SAS Institute, Cary, NC) with time as a repeated measures factor. We ran two distinct longitudinal models. First, we analyzed change in each of our communication and child adjustment outcomes with a statistical model that included time as a repeated measures factor, group as a between-subjects factor, and a time by group interaction. This allowed us to examine whether change in each of these outcomes was dependent on group status. We report results for pairwise comparisons that reached statistical significance, along with effect sizes. We do not report omnibus *F*-tests for these multiple-group comparisons because past statistical research has shown that these omnibus tests should not be used as "gatekeepers" for examining pairwise multiple comparisons (Hsu, 1996). Second, we ran statistical models that examined each of the T1 communication variables (openness, problems) as a predictor of each of the T2 child adjustment outcomes (anxious/depressed, withdrawn/depressed), including a simple effect for group and an interaction between group and the particular T1 communication variable. This allowed us to test whether each communication variable was predictive of future child adjustment and whether the strength and/or direction of this relationship depended on group status.

All children provided reports of parent–child communication at T1. However, the child's decision to report on one or two parents, as well as participation discrepancies (i.e., mother participated at T2, but child did not), led to slight inconsistencies in the sample across measures and time. Participants with incomplete data were retained to present the largest possible samples, particularly for the advanced cancer group, an understudied and often inaccessible population. Also, maximum likelihood estimation was used to ameliorate issues concerning missing data (Rubin, 1976; Schafer & Graham, 2002), with $\alpha = .05$ for each analysis. Due to limited research in this area and recent debate on best practices for error control (Cribbie, 2003; Keselman, Cribbie, & Holland, 2002), corrections for multiple comparisons were not calculated, and effect sizes were included to guide future work.

Results

Parent–Child Communication Over Time

Descriptive statistics for communication and adjustment variables are in Table I. Because child age was unrelated to communication, with the exception of problems in communication with mothers at T2, $r = .257$, $p = .004$, it was not included as a covariate in any models. Mother openness in communication did not differ between children with advanced cancer, children with non-advanced cancer, and comparison children at either time point. Additionally, mother openness did not change over time (Figure 1a). Father openness did not differ between groups at T1 or T2, but declined across all groups over time, $F(1, 174) = 4.87$, $p = .029$ (Figure 1b).

Children's reports of problems in communication with mothers and fathers were similar between groups at T1 (Table I). Different patterns of change were found for problems in communication with mothers and fathers, such that comparison children reported declines in problems with both parents, children with non-advanced cancer reported increased problems, and problems remained stable for children with advanced cancer (Figure 1c and d). Pairwise comparisons revealed that these changes in problems in communication with mothers significantly differed between children with non-advanced cancer and comparison children, $t(182) = 3.25$, $p = .001$. Additionally, changes in problems in communication with fathers differed between children with advanced cancer, $t(174) = 2.23$, $p = .027$, and non-advanced cancer, $t(174) = 3.53$, $p = .001$, relative to comparison children. At T2, there were group differences for problems in communication with fathers, such that scores were significantly higher in children with non-advanced cancer relative to comparison children, $t(174) = 2.33$, $p = .021$, $d = 0.41$ (Table I).

Parent–Child Communication at T1 and Child Adjustment at T2

Anxious/depressed scores changed from T1 to T2, such that scores increased for children with non-advanced cancer relative to comparison children, $t(167) = 2.21$, $p = .029$. However, no differences were observed for withdrawn/depressed scores over time. We then examined the contributions of parent–child communication at T1 in predicting child adjustment at T2 and whether the strength of this association varied by group. Higher mother openness in communication predicted lower withdrawn/depressed scores for children with advanced cancer at $b = -.140$, $t(172) = 2.82$, $p = .005$ (Table II), but not for children with non-

Table I. *Group Differences in Parent–Child Communication and Child Adjustment at T1 and T2*

Variable	T1						T2					
	Adv (A)	Non-Adv (N)	Comp (C)	Pairwise tests	*p*	*d*	Adv (A)	Non-Adv (N)	Comp (C)	Pairwise tests	*p*	d
Mother–child communication												
Openness	43.68 (7.07)	41.58 (7.31)	41.42 (6.92)	A > C	.092	.32	41.73 (8.01)	40.49 (7.21)	41.36 (7.61)	–	–	–
Problems	23.15 (8.76)	23.51 (7.10)	25.92 (7.45)	A < C	.056	.34	22.93 (7.33)	26.53 (8.26)	24.69 (7.04)	–	–	–
				N < C	.078	.33						
Father–child communication												
Openness	38.77 (9.60)	37.01 (9.82)	38.47 (8.69)	–	–	–	38.98 (8.69)	33.87 (11.04)	35.86 (10.13)	–	–	–
Problems	23.33 (8.18)	24.60 (7.20)	25.78 (6.83)	A < C	.067	.33	23.04 (8.03)	27.80 (9.25)	24.39 (7.20)	**N > C**	**.021**	**.41**
Child adjustment												
Anx/Dep	54.31 (5.34)	52.95 (5.61)	56.33 (7.15)	**A < C**	**.042**	**.35**	52.79 (4.55)	55.11 (7.90)	55.33 (6.12)	–	–	–
				N < C	**.004**	**.49**						
Wd/Dep	55.10 (6.03)	55.58 (6.21)	55.68 (8.42)	–	–	–	55.48 (7.43)	55.89 (7.10)	54.42 (5.78)	–	–	–

Note: Adv/A = advanced cancer; Non-Adv/N = non-advanced cancer; Comp/C = comparison children. Anx/Dep = anxious/depressed scores; Wd/Dep = withdrawn/depressed scores. Means, standard deviations, and Cohen's d values reflect raw data. Pairwise tests are based on data derived from models using MLE. Significant (and marginally significant) results are displayed, with effects reaching the criterion of $p < .05$ shown in bold.

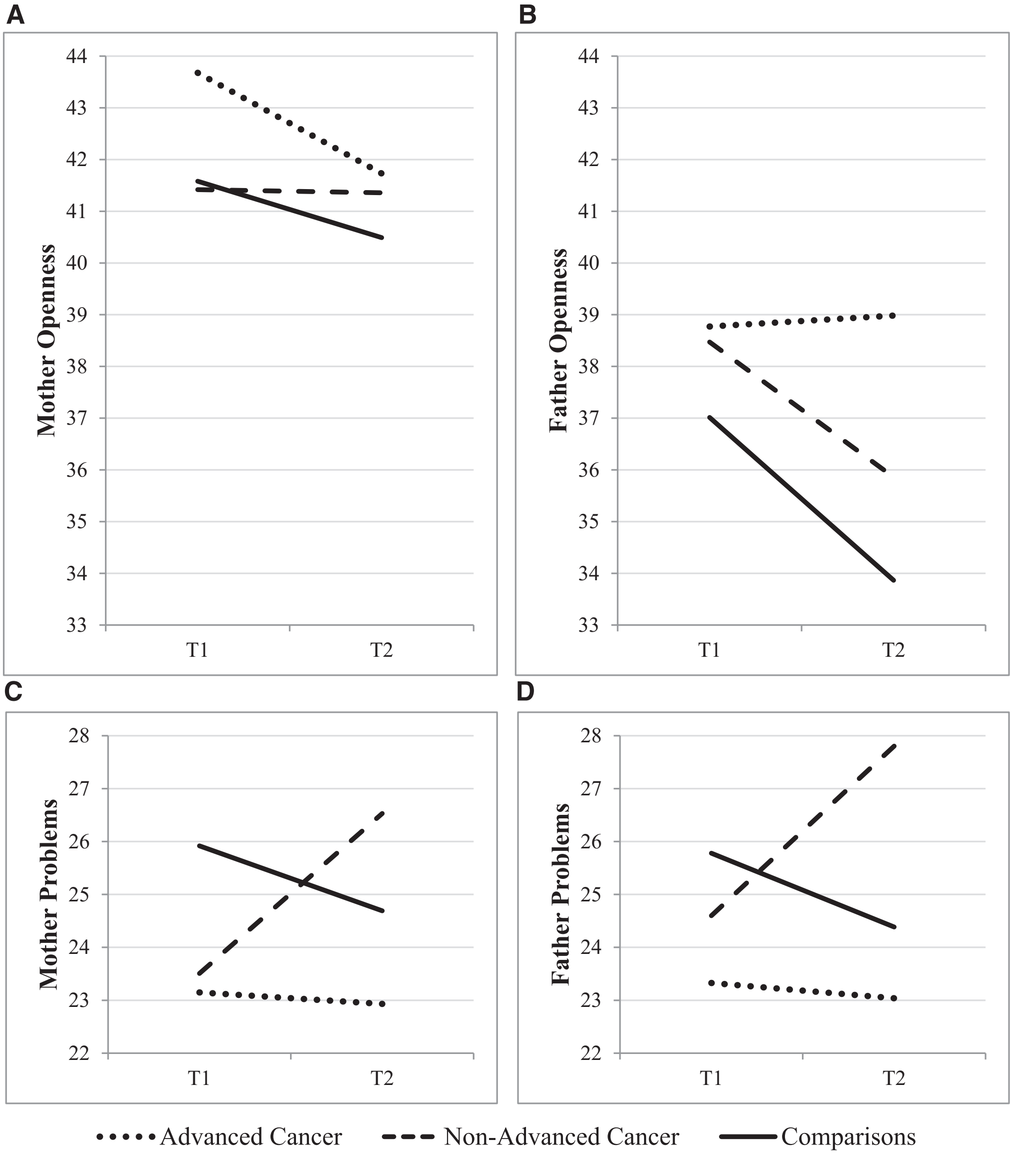

Figure 1.(A–D) Openness and problems in parent–child communication at T1 and T2. Raw means displayed. Refer to Table 1 for analysis of group differences by time point and text results for analysis of differences in change over time.

Table II. *Regression Coefficients (b) for T1 Parent–Child Communication Predicting T2 Child Adjustment*

Predictor	Anxious/Depressed problems						Withdrawn/Depressed problems					
	Adv (A)	Non-Adv (N)	Comp (C)	Pairwise tests	*t*	*p*	Adv (A)	Non-Adv (N)	Comp (C)	Pairwise tests	*t*	*p*
Mother–child communication												
Openness	−.079	.027	−.036	–	–	–	−.140	.016	−.034	**A, N**	**2.64**	**.009**
										A, C	1.69	.092
Problems	.036	−.003	.048	–	–	–	.140	.045	.073	A, N	1.82	.070
Father–child communication												
Openness	−.116	.006	.026	**A, N**	**2.24**	**.027**	−.102	−.004	−.002	**A, N**	**2.19**	**.030**
				A, C	**2.40**	**.018**				**A, C**	**2.05**	**.042**
Problems	.047	.117	.052	–	–	–	.125	.110	.061	–	–	–

Note: Adv/A = advanced cancer; Non-Adv/N = non-advanced cancer; Comp/C = comparison children. Unstandardized beta weights (b) reflect simple effects for each group and pairwise tests are based on data derived from models using MLE. Pairwise tests examine differences in the strength of associations between communication and adjustment between groups. Significant (and marginally significant) results are displayed, with comparisons reaching the criterion of $p < .05$ shown in bold.

advanced cancer or comparison children. Similarly, fewer problems in communication with mothers at T1 predicted lower withdrawn/depressed scores for children with advanced cancer at T2, $b = .140$, $t(172) = 3.47$, $p < .001$, but not for children with non-advanced cancer or comparison children (Table II). Significant pairwise comparisons between children with advanced and non-advanced cancer, $t(172) = 2.64$, $p = .009$, confirmed the differential importance of mother openness in communication at T1 in predicting withdrawn/depressed scores at T2 between these two groups specifically.

Similarly, higher openness in communication with fathers at T1 predicted lower anxious/depressed, $b = -.116$, $t(161) = 2.51$, $p = .013$, and withdrawn/depressed scores at T2, $b = -.102$, $t(161) = 2.80$, $p = .006$, in children with advanced cancer, but not in children with non-advanced cancer or comparison children. Pairwise comparisons in the association between father openness at T1 and adjustment problems at T2 were significant for children with advanced cancer relative to each of the other two groups (Table II).

Discussion

This is the first study to examine parent–child communication and adjustment in children with advanced and non-advanced cancer over the first year after diagnosis or relapse relative to comparison children. This approach provided an opportunity to determine whether the quality and patterns of parent–child communication varied in the context of a life-threatening illness relative to typical development. Despite concerns that advanced cancer in childhood may create unique challenges for families, children with advanced cancer did not report less openness or more problems in communication with parents than children with non-advanced cancer or comparison children. Mother and father openness was similar across groups, but problems in communication with fathers were actually higher for children with non-advanced cancer relative to comparison children at T2. Openness with fathers declined over time across all groups, while problems in communication changed differently across the groups. Specifically, problems with both mothers and fathers decreased for comparison children, increased for children with non-advanced cancer, and stayed relatively stable and low for children with advanced cancer. Importantly, we found that the quality of communication near diagnosis or relapse was more strongly predictive of future adjustment for children with advanced cancer than children with non-advanced cancer or comparison children.

We were surprised that the groups changed differently over time with respect to problems in communication, but not openness. The problems in communication scale includes items related to giving too little or too much information, avoiding certain topics of conversation, lack of trust, and inappropriate reactions to conflict. In contrast, the openness scale assesses the degree to which communication is natural, unrestrained, warm, and helpful. Thus, in the context of cancer communication, the problems in communication scale may more closely reflect challenges with sharing information, particularly of a sensitive nature, compared with the openness scale. Interestingly, both children with cancer and comparisons reported higher-quality communication, particularly with regard to problems, than measure norms or a similar study of Dutch families adjusting to parental cancer and comparisons, but work is limited (Barnes & Olson, 1985; Huizinga et al., 2005).

Although parents of children with cancer must navigate significant challenges, this does not mean that the quality of their communication with ill children is negatively affected. As in other pediatric illness populations, it is likely that some children with cancer may experience heightened closeness or “extraordinary parenting” (Anderson, Riesch, Pridham, Lutz, & Becker, 2010; Rempel & Harrison, 2007). This can manifest as increased attentiveness, patience, emotional availability, and other aspects of care that protect child survival. While children with advanced cancer experienced stable patterns of problems in communication over one year, children with non-advanced cancer noted increases in problems, particularly relative to comparison children, who noted decreased problems. Following heightened attentiveness at diagnosis, parents who realize that their child is likely to recover may return to parenting as normal, or they may allow practical barriers (i.e., lack of time, other obligations) to hinder communication, with the expectation of reestablishing normal family life after treatment. This change may be particularly salient to children with non-advanced cancer after a period of “extraordinary parenting.” Likewise, decreased problems in communication reported by comparison children may be consistent with a meta-analysis finding that parent–child conflict typically declines across adolescence, particularly with mothers (Laursen, Coy, & Collins, 1998).

Considering the distinct roles parents assume in childcare, children may view the quality of father communication less favorably than with mothers. After diagnosis, mothers often take responsibility for medical care, while fathers uphold life outside of the hospital, including maintaining the household, finances, and sibling care (McGrath, 2001; Nicholas et al., 2009). During this time, fathers report a sense of responsibility to preserve stability, even at the expense of emotional expressiveness and intimacy (Nicholas, Beaune, Barerra, Blumberg, & Belletrutti, 2016; Nicholas et al., 2009; Reay, Bignold, Ball, & Cribb, 1998).

Perhaps this explains why father openness was generally lower than mother openness and significantly declined for all groups. These findings are also consistent with gender differences and general developmental trends in parent–adolescent closeness and communication across adolescence (Laursen & Collins, 2004). However, the decline in father communication appeared less pronounced within the advanced cancer group, where mean scores stayed stable and relatively favorable for both dimensions of father communication. Again, advanced disease may motivate fathers to stay more engaged in the life of the ill child relative to non-advanced cancer or healthy comparisons.

Although testing differences in adjustment was not a primary aim of the study, we found that children with advanced and non-advanced cancer had significantly lower anxious/depressed scores, but not withdrawn/depressed scores, than comparison children at T1. Anxious/depressed scores also increased over time for children with non-advanced cancer, suggesting that clinical attention may be warranted for these children over the disease course. Further analyses indicated significant elevations for all three groups when compared with established norms (i.e., T-scores = 50). However, raw scores indicated only a 1–1.5 point mean difference between groups, and the proportion of children exceeding clinical cutoffs on both scales was also similar across groups. This raises important considerations about the selection of comparison samples in research and interpretation of potential differences based on demographically matched peers or large normative samples. Caution in over-interpretation of low scores on the CBCL has been noted, and certain items (e.g., “Fears going to school”) on the anxious/depressed scale may not apply to children on treatment (Achenbach & Rescorla, 2001). Because anxiety and sadness often occur near the end of life (Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2010), it also may be beneficial to follow children with advanced cancer more closely and extend assessments to better understand this trajectory.

Our results should be interpreted in light of several limitations. First, our classification of children with advanced cancer and non-advanced cancer was guided by previous work and SEER data (National Cancer Institute, 2011; Peppercorn et al., 2011; Wolfe et al., 2002), but may be imprecise. A prognosis of 65% was chosen as a cutoff to preserve sample size in the advanced cancer group, and findings were virtually identical using slightly lower prognosis cutoffs. This is consistent with numerous studies indicating that physicians consistently overestimate prognosis relative to the actual disease course (Glare et al., 2003). Identifying other reliable and valid methods to identify this high-risk group is an important direction for future work. Further, attrition among children with advanced cancer and the unique pattern of findings suggest our approach provided meaningful distinctions across groups. We also focused on child perspectives of parent communication, which may contain less response bias than parent report and have inherent validity for predicting child outcomes (Hartos & Power, 2000; Xiao, Li, & Stanton, 2011). However, this limited our sample to children above age 10 who were well enough to provide self-report, which was a particular challenge for our advanced cancer group. Given the lack of prospective research with families of children with advanced cancer, we include statistics on effects that approached significance ($p < .10$) in the tables along with effect sizes to guide future work. More research is needed with larger samples of children with advanced cancer to ensure adequate power for detecting significant effects. In addition, we made a concerted effort to recruit fathers but had to rely on mother report of child adjustment. Future work should use methods such as flexible home visits, electronic data collection, or mailed questionnaires to accommodate participation from fathers or secondary caregivers who are less frequently in the hospital. Research that includes larger, more diverse samples is essential to examining differences based on same-sex or mixed-sex dyads (e.g., mother–daughter, father–daughter; Orbuch, Parry, Chesler, Fritz, & Repetto, 2005; Phares & Compas, 1992). Finally, we relied on paper-and-pencil measures, but mixed methods should be used and include assessments at meaningful intervals that are sensitive to the trajectories of children with declining health. In particular, observations of parents and children in semi-structured problem-solving situations or obtaining ecological momentary time samples may provide richer data (Barakat & Alderfer, 2011).

Despite these limitations, results provide valuable direction for future research and clinical care for families of children with life-limiting conditions. Families of children with advanced cancer are an understudied, often inaccessible population, but one that has potentially high need for intervention. Clinicians should encourage and teach skills to promote open and warm communication from diagnosis, particularly for those with advanced disease or a poor prognosis, as early communication may have significant implications for later adjustment. This can include aiding difficult conversations among family members as the child’s health declines. For example, novel tools and interventions have proven useful in supporting conversations about advance directives, which allow children the opportunity to articulate their preferences regarding future care (Lyon, Jacobs, Briggs, Cheng, & Wang, 2013; Zadeh, Pao, & Wiener, 2014). High-quality communication in these circumstances is critical for both minimizing distress and promoting dimensions of resilience, like meaning-making and reappraising priorities/hopes (Cataudella et al., 2014). Furthermore, clinicians may play an important role in facilitating the transition to survivorship and assuming normal family roles for those children with non-advanced disease. With additional research and support to identify families at high risk for difficulties, we can provide more effective care to promote resilience even in the most challenging end-of-life circumstances.

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