Supportive Care in Cancer (2019) 27:1319–1324
https://doi.org/10.1007/s00520-019-4653-3

ORIGINAL ARTICLE

Inclusion of children in the initial conversation about their cancer diagnosis: impact on parent experiences of the communication process

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Received: 28 September 2018 / Accepted: 15 January 2019 / Published online: 23 January 2019

Abstract

Introduction Including children in medical conversations is considered the standard of care for children with cancer. However, previous qualitative research has raised concerns about how the child's presence impacts the parent's communication experience. The current study examines the frequency and impact of child presence during a serious medical conversation on the parent's communication experience in pediatric oncology.

Methods Three hundred sixty parents of children newly diagnosed with cancer completed questionnaires assessing the child's presence during the initial conversation with the oncologist about diagnosis and treatment and parental communication experiences. Primary oncologists completed a survey question about the child's prognosis.

Results Sixty-one percent of children were present during the initial conversation, with lowest rates among children aged 3–6 (44%) and 7–12 (44%). Child presence was not associated with parents' reports that they received prognostic information ($p = 0.20$), high-quality information ($p = 0.19$), or high-quality communication about the child's cancer ($p = 1.0$).

Discussion The parent's communication experience is not diminished by the choice to include the child. Given the bioethical imperative to include children in conversations about serious illness whenever possible, this concern should not be used to exclude children, but rather to give parents additional time of their own when needed to fully process decisions.

Keywords Pediatric hematology/oncology · Psychosocial · Communication · Parents

Introduction

Inclusion of children in medical conversations is considered the standard of care for pediatric oncology patients [1]. Appropriate communication of medical information between the physician and the pediatric patient at the time of diagnosis can serve as the foundation of a trusting relationship and can facilitate coping with illness, decrease stress, and improve adherence [2–5]. Open communication between parents and their children with advanced cancer at the time of diagnosis is predictive of lower child distress scores 1 year later [6]. However, inclusion of pediatric patients in serious medical conversations is not always straight forward to implement in clinical practice. This is especially true at the time of diagnosis when emotions run very high [7]. Providers must contend with their own feelings about the inclusion of the child, along with those of the parent and the patient [8]. Some studies have demonstrated that parents do not want their child to be present when they hear bad news [9, 10], raising questions about the impact of the child's presence on the parent's ability to get the information they need from the medical team with their child present [10]. However, others have found beneficial effects of the child's presence on the parent such as decreased parental distress [11].

The current study looks to extend the previous qualitative research by utilizing quantitative methodology to examine the frequency and impact of child presence during the initial conversation between the family and oncologist about the child's cancer diagnosis and treatment. Specifically, we sought to determine the frequency of child inclusion at two large cancer centers, examine the influence of child and disease-related factors on child inclusion, and evaluate differences in parent experiences of communication based on the child's presence.

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We hypothesized that parents experience with communication would not be adversely effected by the inclusion of the child.

Methods

The current study is part of a larger study designed to evaluate prognosis communication in pediatric oncology. Parents of children with cancer and physicians from the Dana-Farber Cancer Institute/Boston Children's Hospital and the Children's Hospital of Philadelphia were surveyed over a 6-year period, from November 2008 to April 2014. One parent per family was eligible to participate in the study if she or he could read English or Spanish, if the child was age 18 or younger, if the child was between 1 and 6 weeks from the date of cancer diagnosis, and if permission from the child's physician was given to contact the family. The parent who was primarily responsible for decision-making for the child was asked to participate; if both parents shared decision-making equally, parents could choose which parent participated. Eligible parents were mailed or given a letter inviting them to participate, the survey, and a postage-paid postcard to return if they did not wish to participate. All materials were available in English and Spanish. One subsequent contact was made with nonresponding parents. Return of the questionnaire was required within 12 weeks of diagnosis for inclusion in the study. Parents were offered a $10 gift card as a token of appreciation for participation. After the parent survey had been completed, the primary oncologist for each patient was given the physician survey, along with a $5 gift card. This study was approved by the Institutional Review Boards at the Dana-Farber Cancer Institute and Children's Hospital of Philadelphia.

Five hundred sixty-five parents were eligible for inclusion in the study. Three hundred eighty-two parents (68%) completed the survey, and 95 physicians completed matched surveys, corresponding to 95% (361/382) of parent surveys. One parent did not complete the survey item about whether the child was present for initial conversations about diagnosis and treatment, for a final analytic cohort of 360 parents.

Data collection

The questionnaires included items from surveys previously developed to assess communication in pediatric oncology [11, 12] as well as basic demographic information about the parent (gender, age, race, ethnicity, and highest level of education). All questionnaires were available in paper-and-pencil and electronic format, with participants able to pick which format they preferred at the time of enrollment. Parent questionnaires were available in English and in Spanish.

Child presence

The primary variable of interest for the current study was child presence during the initial conversation with the oncologist. Parents were asked to think about the time when the oncologist first sat down with them to discuss their child's cancer diagnosis and plans for treatment. They were then asked "was your child with you and the oncologist during these conversations? (yes/no)."

Child and disease-related factors

The child's age and cancer diagnosis were determined through review of medical records. The child's prognosis was evaluated as part of the physician survey; physicians were asked "how likely do you think it is that this child will be cured of cancer," with response categories of: "extremely likely (more than 90% chance of cure)"; "very likely (75–90%)"; "moderately likely (50–74%)"; "somewhat likely (25–49%)"; "unlikely (10–24%)"; "very unlikely (less than 10%)"; or "no chance of cure."

Communication process and outcomes

The primary outcomes of interest for the current study were parental communication experiences with prognostic disclosure, receipt of high-quality information, and receipt of high-quality communication. Prognosis disclosure was evaluated using a five-item index, previously developed and validated for use in pediatric oncology [13, 14]. Questions assessed whether prognosis was ever discussed, if the physician offered the information or the parent had asked for it, whether prognosis was discussed as a number or in general terms, whether written prognostic information was provided, and whether the parent still wanted additional information about prognosis.

To assess quality of information, parents were asked to rate the quality of the information they were given about the child's diagnosis, treatment and treatment choices available, prognosis, functional outcome, cause of cancer, and response to treatment. Response categories were "excellent," "good," "satisfactory," "fair," or "poor" [15]. Communication quality was assessed using a scale developed and validated for the purpose of the larger study, which included some previously validated items from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) [16, 17]. Domains assessed included physician sensitivity, time for questions, clarity of information provided, and if the parent felt listened to. Response categories were "always," "sometimes," "rarely," and "never."

Statistical analyses

Analyses were conducted using the SAS statistical package version 9.4 (SAS Institute, Inc., Cary, NC). Prognostic disclosure was dichotomized as 0–2 versus more than two elements [13].

Information and communication quality were dichotomized at the median for analysis, as described previously [11, 13].

We first examined the association of child and disease-related factors with child presence during the initial conversation utilizing bivariate logistic regression. We then utilized multivariable logistic regression and a backwards elimination method to further understand factors associated with the child's presence. We initially included variables for which bivariable associations were significant at the 0.10 level. Starting with the least significant variable in the multivariate model, variables were removed sequentially until all remaining independent variables were significant at the 0.05 level. Finally, parallel analyses were conducted for the possible impact of the child presence on the communication process (parental communication experiences with prognostic disclosure, receipt of high-quality information, and receipt of high-quality communication). Bivariable logistic regression was conducted between child presence and each outcome. We then repeated analyses, adjusting for the child's age. A final set of models assessed associations between child presence and each outcome, with and without adjusting for all factors that were associated with child presence.

Results

The majority of parent participants were female, Caucasian, English speaking, and married, with at least a college education (Table 1). Their children ranged in age from 0 to 18, with 25% older than 13. Forty-nine percent had a hematological malignancy, 39% had a solid tumor, and 12% had a brain tumor.

Sixty-one percent of parents reported that their child was present during the initial discussion with their child's oncologist, when details about the type of cancer and plans for treatment were discussed. As shown in Fig. 1, the majority of children under the age of two were present for the discussion (77%), as well as the majority of those between 13 and 15 (67%) and 16–18 (84%).

We first evaluated factors associated with child presence at the initial meeting (Table 2). In unadjusted analyses, child age was associated with the child's presence, with children ages 3–6 (OR 0.23, $p = 0.001$), and 7–12 (OR 0.23, $p = 0.001$) less likely to be present than infants (age 0–2). There was no difference in child presence between infants and early adolescents ages 13–15 (OR 0.6, 95% CI 0.29, 1.26, $p = 0.18$) or older adolescents (OR 1.52, 95% CI 0.56, 4.01, $p = 0.41$). In addition, children were more likely to be present if they had a diagnosis of a solid tumor (OR 1.82, 95% CI 1.14, 2.90, $p = 0.01$) relative to children with hematologic malignancies. Finally, children were less likely to be present if they had a physician-rated likelihood of cure of less than 90% (very likely OR 0.40, 95% CI 0.21, 0.74, $p = 0.004$; moderately likely OR 0.43, 95% CI 0.21, 0.85, $p = 0.02$; less than moderately likely OR 0.31, 95% CI 0.15, 0.64, $p = 0.002$). In multivariate analysis (Table 3), the child's diagnosis, the child's age at

Table 1 Characteristics of parents and children

Parent characteristics	*N* (%) (*n* = 360)
Parent age	
< 30	38 (11)
30–39	140 (40)
40–49	135 (38)
50+	39 (11)
Parent gender	
Female	288 (81)
Male	68 (19)
Parent race/ethnicity	
White	280 (79)
Black	23 (6)
Hispanic	29 (8)
Other	24 (7)
Parent education	
High school graduate or less	43 (12)
Some college/technical school	83 (24)
College graduate	139 (39)
Graduate/professional school	88 (25)
Parent marital status	
Married/living as married	296 (82)
Other	64 (18)
Language spoken at home	
English	338 (94)
Other	22 (6)
Child characteristics	
Child age at diagnosis	
0–2	97 (27)
3–6	73 (20)
7–12	98 (27)
13–15	55 (15)
16–18	37 (10)
Diagnosis	
Hematologic malignancies	176 (49)
Solid tumor	140 (39)
Brain tumor	44 (12)
Child present during discussion	
Yes	218 (61)
No	142 (39)
Other characteristics	
Physician-rated prognosis	
Extremely likely to be cured (> 90% chance)	78 (22)
Very likely (75–89% chance)	139 (39)
Moderately likely (50–74% chance)	80 (22)
Less than moderately likely	63 (18)
Site	
Boston	268 (74)
Philadelphia	92 (26)

*Missing values: parent age (8), parent gender (4), parent race/ethnicity (4), parent education (7)

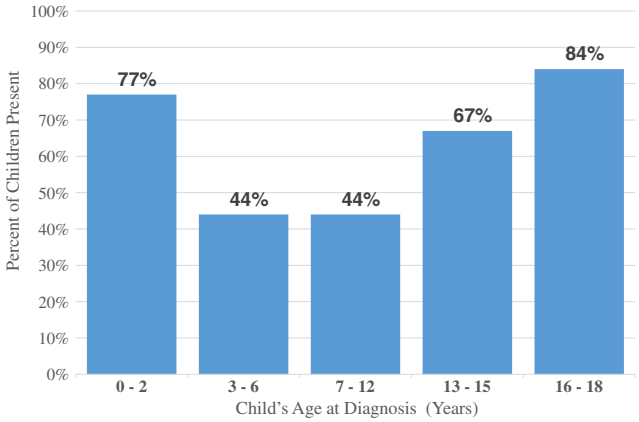

Fig. 1 Presence of child during initial conversation by child's age at diagnosis

diagnosis, and physician-rated prognosis all remained associated with child presence.

We then examined the extent to which the child's presence was associated with communication processes and outcomes (Table 4). In unadjusted analyses, the child's presence was not associated with prognostic disclosure (OR 1.38, 95% CI 0.84, 2.26, $p = 0.20$), receipt of high-quality information (OR 1.34, 95% CI 0.86, 2.08, $p = 0.19$), or receipt of high-quality communication (OR 1.0, 95% CI 0.65, 1.53, $p = 1.0$). Findings were similar after adjustment for child's age only, and after adjustment for the child's diagnosis, the child's age, and physician-rated prognosis (Table 4).

Discussion

More than 60% of parents of children with cancer treated at two large academic cancer centers reported that their children were present for the initial conversation with the oncologists about their cancer diagnosis and the plan for treatment. Adolescents were included in the majority of conversations, which is in line with the national and international recommendations [18, 19], although fewer than half of children aged 7–12 were present. Children with poorer prognoses and with hematologic malignancies were less likely to be present, perhaps reflecting a desire to protect children from difficult conversations about prognosis, and higher medical acuity at the time of diagnosis among children with leukemias.

While previous literature argues for inclusion of children, especially adolescents, with serious illness in medical conversations whenever possible [8], concerns have been raised that any benefit for children comes at the cost of parents' needs for open conversations at the time of diagnosis [10]. We therefore sought to examine parents' experiences and the extent to which perceived communication suffered when the child was included. For all communication outcomes measured, we found no difference in experiences between parents who did and did not have their child present for the initial discussion about the child's cancer diagnosis and treatment. This included the extent to which parents received prognostic information, the quality of information, and the quality of the communication process. While the child's age, their diagnosis, and their prognosis were all associated with whether or not the child was present, controlling for these factors did not impact the overall findings.

This study was observational, and while communication experiences were not inferior when the child was included, many factors may have played into the choice to include the child. We do not know whether communication experiences would have been similar if all children were included. Instead, it is possible that the best communication outcomes may occur when parents have the opportunity to make their best decisions for their

Table 2 Univariate factors associated with child presence during discussion

Child characteristics	OR (95% CI) odds of having child present	*P* value
Diagnosis		
Hematologic malignancies	Reference	
Solid tumor	1.82 (1.14, 2.90)	0.01
Brain tumor	0.71 (0.37, 1.38)	0.31
Child age at diagnosis		
0–2	Reference	
3–6	0.23 (0.12, 0.44)	< 0.0001
7–12	0.23 (0.12, 0.43)	< 0.0001
13–15	0.60 (0.29, 1.26)	0.18
16–18	1.52 (0.56, 4.01)	0.41
Other characteristics		
Physician-rated prognosis		
Extremely likely to be cured (> 90% chance)	Reference	
Very likely (75–89% chance)	0.40 (0.21, 0.74)	0.004
Moderately likely (50–74% chance)	0.43 (0.21, 0.85)	0.02
Less than moderately likely	0.31 (0.15, 0.64)	0.002

Table 3 Multivariable model: factors associated with child presence

	OR (95% CI) odds of having child present	*P* value
Child's diagnosis		
Hematologic malignancies	Reference	
Solid tumor	2.13 (1.21, 3.75)	0.01
Brain tumor	1.03 (0.47, 2.30)	0.94
Child age at diagnosis		
0–2	Reference	
3–6	0.24 (0.12, 0.49)	< 0.0001
7–12	0.26 (0.14, 0.51)	< 0.0001
13–15	0.79 (0.36, 1.73)	0.56
16–18	2.10 (0.75, 5.89)	0.16
Physician-rated prognosis		
Extremely likely to be cured (> 90% chance)	Reference	
Very likely (75–89% chance)	0.48 (0.24, 0.95)	0.03
Moderately likely (50–74% chance)	0.34 (0.16, 0.72)	0.005
Less than moderately likely	0.25 (0.11, 0.58)	0.001

children based on individual factors. In addition, the findings from this study should not be used to discount the qualitatively reported experience of parents that some felt having their child present during consultations inhibited the communication process [10]. Rather, they suggest that following the bioethical and developmental argument for including the child in important medical conversations is not detrimental to the parent experience of communication, while continuing to emphasize the importance of evaluating patients' and parents' preferences and needs around communication. Providers should be aware that some parents may require opportunities to meet with the medical team without their child present. While not a focus of this study, the same may be true for children and adolescents, who, as noted by others [20], may also need time to ask questions and process the meaning of the illness in their lives without parents in the room. This staged approach has been used in discussions about clinical trial enrollment in pediatric oncology [21, 22] and warrants further evaluation in future studies about its utility in other significant medical conversations.

There are several potential limitations of the current study which offer areas of future research. The evaluation of whether the child was present for the initial conversation about their illness and treatment was based on parental response to a single question. We did not have information about who made the decision to include or exclude the child from the conversation or why it was made. We did not have information on whether some families may have included the child for part, but not all, of the conversation or in subsequent conversations, or about the child's level of participation in the discussion. We also surveyed parents up to 12 weeks after diagnosis. Parents' feelings about inclusion of the child could have changed over time, especially after subsequent experiences with care and conversations with clinicians, and this was not captured in our data. In addition, this research focused solely on the potential impact of the child's presence on the parent's experience of the communication process. While our previous research has shown that children have a desire to hear information about their disease and treatment in a timely manner from their healthcare team [23], it would helpful to have a better understanding of the child's experience of the communication process alongside their parents. Finally, we cannot speak to the experiences of nonparticipating parents, who comprised 32% of those approached, and our focus on

Table 4 Possible outcomes of child presence

Parent communication experiences	% of parents with child present who had communication experience *N*/total(%)	% of parents without child present who had communication experience *N*/total(%)	Unadjusted		Adjusted for child's age		Adjusted for child's diagnosis, child's age, prognosis	
			OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Prognostic disclosure	154/202 (76)	93/133 (70)	1.38 (0.84, 2.26)	0.20	1.34 (0.79, 2.27)	0.27	1.19 (0.68, 2.09)	0.54
Receipt of high-quality information	126/207 (61)	72/134 (54)	1.34 (0.86, 2.08)	0.19	1.41 (0.88, 2.26)	0.15	1.14 (0.69, 1.88)	0.61
Receipt of high-quality communication	109/212 (51)	72/140 (51)	1.00 (0.65, 1.53)	1.00	0.96 (0.61, 1.51)	0.84	0.96 (0.59, 1.54)	0.85

two large academic centers with a sample of mainly female Caucasian mothers may also limit generalizability.

Communication in pediatrics is a complex process. While this study focused on the child's presence during the initial conversation about a cancer diagnosis, the findings are likely generalizable to other significant medical conversations such as at the time of relapse or transition to palliative care. The results of this study suggest that having a child present during a serious medical conversation is not uniformly harmful to the parent's experience of the communication process. As the time of diagnosis can be a crucial period for setting the stage for ongoing communication between the healthcare provider, patient, and parent [24], the decision about whether the child is present for the initial conversation should be one that is thoughtfully made and shared between the team and the parents, taking into account factors such as the child's desire for involvement, the child's current health status, family preferences, and cultural factors.

Compliance with ethical standards

This study was approved by the Institutional Review Boards at the Dana-Farber Cancer Institute and Children's Hospital of Philadelphia.

Conflict of interest The authors have no conflicts of interest relevant to this article to disclose. The study PIs have full control of all primary data. The data is not in a public repository, but that requests for data access will be considered individually and data made available if appropriate using processes consistent with those of our institution and IRB. We will consider requests for data access from reviewers if needed, again in compliance with institutional and IRB policy.

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