



Published in final edited form as:

*Pediatr Blood Cancer*. 2018 January ; 65(1): . doi:10.1002/pbc.26760.

## Longitudinal parental preferences for late effects communication during cancer treatment

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### Abstract

Few studies have investigated parent preferences for late effects communication during pediatric cancer treatment. We used questionnaire data to assess whether parental preferences for late effects information change over the year after diagnosis. Most parents found this information to be very/extremely important at baseline, assessed soon after diagnosis, (94%, 153/162), 4 months (91%, 147/162), and 12 months (96%, 156/163). Similarly, most parents wanted as much detail as possible about late effects at baseline (85%, 141/165), 4 months (87%, 144/165), and 12 months (83%, 137/165). Parents of children with favorable prognoses preferred more details at baseline (OR 2.94, 1.18–7.31,  $P = 0.02$ ) than parents whose children had less favorable prognoses.

### Keywords

communication; late effects; parent; pediatric oncology; survivorship

## 1 | INTRODUCTION

While a diagnosis of cancer was previously uniformly fatal, over 80% of current pediatric cancer patients will become long-term survivors.<sup>1</sup> However, the majority of survivors experience at least one chronic health condition as a result of cancer or its treatment, and the prevalence of late effects increases as survivors age.<sup>2,3</sup> Most previous studies of late effects communication have focused on information needs during survivorship and long-

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#### AUTHORS' CONTRIBUTION

B.A.S. participated in conceptualization and writing the original draft; K.A.G. participated in conceptualization, writing, reviewing, and editing; T.I.K. participated in investigation and writing, reviewing, and editing; J.W.M. participated in conceptualization, formal analysis, writing, reviewing, and editing.

#### CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

term follow-up, and showed that most survivors of pediatric cancer have unmet information needs that persist for years.<sup>4-9</sup>

Few studies, however, have focused on communication about late effects during cancer treatment. These studies have shown that many parents want information regarding late effects early in treatment,<sup>10</sup> yet this topic is discussed less frequently than acute side effects of cancer therapy in informed consent discussions.<sup>11</sup> Possibly as a result, many parents believe themselves to be less prepared for survivorship than for treatment.<sup>12</sup> We are not aware of any study that has assessed these preferences longitudinally after diagnosis. Providing information regarding late effects prior to survivorship is important to support informed decision making, and could potentially impact health-related quality of life and sense of control.<sup>13</sup> Understanding times of highest information need during treatment can inform clinician strategies for addressing this crucial topic. In the following study, we performed secondary analysis of questionnaire data to assess whether parental preferences for late effects information change over the year following a diagnosis of cancer in their child.

## 2 | METHODS

As previously described,<sup>14</sup> we surveyed parents and physicians of children with cancer at the Dana-Farber Cancer Institute/Boston Children's Hospital, Boston, Massachusetts, and the Children's Hospital of Philadelphia, Pennsylvania, between November 2008 and April 2014. Parents were approached for baseline questionnaires between 1 and 6 weeks after diagnosis; those who completed baseline questionnaires were contacted 4 months and 12 months after diagnosis to complete follow-up questionnaires, so long as they agreed to be contacted and their child was still living. Additionally, primary oncologists for each patient were given the physician survey at each time point. Of 565 eligible parents, 382 (68%) completed the baseline questionnaire, 211 (69%) completed the 4-month questionnaire, and 168 (82%) completed the 12-month questionnaire. Of these 168 parents, three were excluded because of missing values for our primary questions of interest at any time point for a final analytic cohort of 165 parents.

Survey development has been described previously.<sup>14</sup> Briefly, parent and physician questionnaires included items from previously developed surveys,<sup>15,16</sup> select new items that are not included in the current analysis, and select items from existing validated instruments. We asked parents about their preference for details of information about their child's likelihood of "limitations in the future, after treatment is finished" with three response options ("I prefer not to hear a lot of details"; "I want to hear details only in certain situations, such as when the information is important for a decision that needs to be made"; "I want to hear as many details as possible in all situations relating to my child's future limitations"). We also asked parents, "How important is it to you to know about how cancer or its treatment may affect your child's life in the future?" with response options of "extremely," "very," "somewhat," "a little," or "not at all" important. Child's prognosis was evaluated using physician report at each time point, as previously described.<sup>16-18</sup> A "favorable prognosis" was considered 75% chance of cure. The institutional review boards

of the Dana-Farber Cancer Institute and Children's Hospital of Philadelphia approved this study.

We used McNemar's test to compare parents' desire for detail ("as much detail as possible" versus all other responses) and the importance of late effects information ("extremely" or "very" important versus all other responses) at baseline to their reports at 4 and 12 months. We then used bivariable logistic regression to evaluate factors associated with parental report of wanting "as many details as possible" about late effects at baseline, relative to parents who wanted limited details. Factors tested based on a priori hypotheses included parent race/ethnicity, education, and gender; physician-rated prognosis, and likelihood of future intellectual or physical limitations. Given the small sample size, multivariable analysis was not performed. Analyses were conducted using the SAS statistical package, version 9.4 (SAS Institute, Inc., Cary, NC).

### 3 | RESULTS

Participating parents were predominantly white (80%), female (83%), and well educated (Table 1). Children were diagnosed mostly with hematologic malignancies (51%), followed by solid tumors (38%) and brain tumors (12%). Physicians generally reported favorable prognoses for children, with 61% of children having at least a 75% likelihood of cure at baseline.

Most parents found information related to late effects of cancer therapy to be very or extremely important at baseline (94%, 153/162), 4 months (91%, 147/162), and 12 months (96%, 156/163). Similarly, most parents preferred to receive as many details as possible related to late effects at baseline (85%, 141/165), 4 months (87%, 144/165), and 12 months (83%, 137/165) (Table 2). On bivariable analysis, wanting as many details as possible about late effects at baseline was associated with having a favorable prognosis (OR 2.94, 1.18–7.31,  $P=0.02$ ), but this relationship did not reach significance at 4 months (OR 2.20, 1.18–7.31,  $P=0.12$ ) or 12 months (OR 1.94, 0.82–4.59,  $P=0.13$ ). No other variables were associated with wanting as many details as possible, including parent race/ethnicity, education, and gender, and physician-rated likelihood of future intellectual or physical limitations (data not shown).

### 4 | DISCUSSION

To our knowledge, this is the first study to assess parental communication preferences regarding late effects longitudinally. Our results show that the large majority of parents of children with cancer find late effects information to be very or extremely important throughout the first year after a diagnosis of cancer, and most prefer detailed late effects information at each time point. Parents who participated in the longitudinal study were generally similar to the baseline cohort of parents, who represented 68% of those eligible and also wanted late effects information. Given prior evidence that parents feel under-informed about late effects, this study further reinforces the need to incorporate late effects discussions into communication practices.<sup>11</sup> These discussions should recur over time, not only at diagnosis or end of treatment.

However, assuredly there are times when parents may prefer not to focus on late effects. Our results suggest that parents of children with less favorable prognoses are less likely to prefer detailed discussions of late effects, at least at diagnosis. Notably, we utilized physician-rated prognosis rather than parental prognostic estimate, because we believe physician-rated prognosis largely influences the way conversations unfold.<sup>19–21</sup> Also, clinicians can use their understanding of the prognosis to develop communication strategies, and when clinicians recognize a poor prognosis, we need to be especially careful to assess information needs about future limitations. However, parent perceptions of prognosis are another important element worthy of consideration in future work.

This brief report provides important information, but it also raises additional questions. How should late effects information be communicated? How can physicians best assess parental learning style and preferences for receipt of information? When should late effects information not be emphasized, and how can healthcare providers meet the needs of individual families? Gestalt and common sense are helpful, but insufficient guides to navigating complex communication situations. Further evidence is needed to support effective communication strategies and practices.

## ACKNOWLEDGMENTS

This study was supported by American Cancer Society Mentored Research Scholar Grant MRSG-08-010-01-CPPB (to J.W.M.) and 2007 American Society of Clinical Oncology Career Development Award (to J.W.M.).

### Grant sponsor:

American Cancer Society Mentored Research Scholar; Grant number: MRSG-08-010-01-CPPB; Grant sponsor: 2007 American Society of Clinical Oncology Career Development Award.

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## Patient and parent characteristics

TABLE 1

	Full baseline cohort, N = 382	Longitudinal cohort for analysis, N = 165	P value, longitudinal cohort versus all others in full baseline cohort
Parent age	N (%)	N (%)	0.64
<30	39 (11)	16 (10)	
30–39	146 (39)	57 (35)	
40–49	147 (40)	71 (44)	
50+	39 (11)	17 (11)	
Parent gender			0.56
Female	305 (81)	136 (83)	
Male	70 (19)	28 (17)	
Parent race/ethnicity			0.79
White	298 (78)	132 (80)	
Black	25 (7)	11 (7)	
Hispanic	28 (8)	12 (7)	
Other	29 (8)	10 (6)	
Parent education			<0.01
High school graduate or less	47 (12)	14 (9)	
Some college	88 (24)	25 (15)	
College graduate or technical school	147 (40)	76 (47)	
Graduate/professional school	90 (24)	47 (29)	
Parent marital status			0.02
Married/living as married	309 (83)	143 (88)	
Other	63 (17)	19 (12)	
Child age at diagnosis			0.56
0–2	101 (26)	43 (26)	
3–6	78 (20)	37 (22)	
7–12	102 (27)	42 (25)	
13–18	101 (26)	43 (26)	
Child gender			0.84
Male	210 (55)	91 (55)	
Female	171 (45)	73 (45)	

Diagnosis	Full baseline cohort, N = 382	Longitudinal cohort for analysis, N = 165	P value, longitudinal cohort versus all others in full baseline cohort
Hematologic malignancy	188 (49)	84 (51)	0.37
Solid tumor	143 (37)	62 (38)	
Brain tumor	51 (13)	19 (12)	
Physician-rated prognosis			0.36
Extremely likely (>90% chance of cure)	78 (22)	36 (23)	
Very likely (75–90%)	140 (39)	60 (38)	
Moderately likely (50–74%)	80 (22)	39 (25)	
Less than moderately likely (<50%)	63 (17)	21 (13)	
Site			0.87
Boston	279 (73)	122 (74)	
Philadelphia	103 (27)	43 (26)	

Missing data: Full baseline cohort: parent age (11); parent gender (N = 7); parent race/ethnicity (2); parent education (10); parent marital status (10); child gender (1); physician-rated prognosis (21).  
 Longitudinal cohort: parent age (N = 4); parent education (3); parent marital status (3); physician-rated prognosis (9).

**TABLE 2**

Desire for information about late effects over the first year after diagnosis

	Full baseline cohort <sup>a</sup>	Longitudinal cohort: baseline	Longitudinal cohort: 4 months	Longitudinal cohort: 12 months
As many details as possible	322 (86)	141 (85)	144 (87) <sup>b</sup>	137 (83) <sup>c</sup>
Limited details	51 (14)	24 (15)	21 (13)	28 (17)
How important is it to you to know how cancer or its treatment may affect your child's life in the future?				
Extremely or very important	350 (92)	153 (94)	147 (91) <sup>d</sup>	156 (96) <sup>e</sup>
Somewhat, a little, or not at all important	29 (8)	9 (6)	15 (9)	7 (4)

<sup>a</sup>Missing data for the full baseline cohort: preference for detail (N = 9); importance of information (N = 3). Numbers are shown as N (%).

<sup>b</sup>Test for symmetry with longitudinal cohort at baseline:  $P = 0.41$ .

<sup>c</sup>Test for symmetry with longitudinal cohort at baseline:  $P = 0.61$ .

<sup>d</sup>Test for symmetry with longitudinal cohort at baseline:  $P = 0.20$ .

<sup>e</sup>Test for symmetry with longitudinal cohort at baseline:  $P = 0.59$ .