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Development of the Day 100 Talk: Addressing Existing Communication Gaps during the Early Cancer Treatment Period in Childhood Cancer

Angela M. Feraco, MD, MMSc^{1,2,3,4}, Sarah R. Brand, PhD^{1,3}, Joshua Gagne, MA¹, Amy Sullivan, EdD^{3,5}, Susan D. Block, MD^{1,3,4}, and Joanne Wolfe, MD, MPH^{1,2,3}

¹Dana-Farber Cancer Institute, Boston, MA

²Boston Children's Hospital, Boston, MA

³Harvard Medical School, Boston, MA

⁴Ariadne Labs, Brigham and Women's Hospital and Harvard T.H. Chan School of Public Health, Boston MA

⁵Beth Israel Deaconess Medical Center, Boston, MA

Abstract

Background—Families' communication needs during the early cancer treatment period (ECTP) may not be optimally met by current practices. We sought to identify potential communication gaps and to ameliorate these by developing a novel in-depth conversation between families and their pediatric oncologists, the "Day 100 Talk" (D100), during the ECTP.

Procedure—We conducted semi-structured interviews with parents and patients undergoing childhood cancer treatment for <7 months. Interviews sought to elicit perceived communication gaps regarding cancer care and inform D100 development. Following qualitative analysis of interview responses, we developed a 3-part D100 conversation tool consisting of a preparatory family worksheet, a conversation guide, and a family summary sheet. We presented the tool during interviews and a focus group with pediatric oncology providers and revised it to incorporate provider input.

Results—Twenty-two stakeholders (6 parents, 5 adolescents, and 11 providers) participated in interviews or a focus group. Parents and patients perceived insufficient anticipatory guidance as the most important communication gap. They also reported sometimes withholding worries and cancer-related beliefs. Meanwhile, oncology providers worried about "opening Pandora's Box" and limited clinical time. Additionally, providers reported employing indirect methods, such as surmising, to determine families' needs, and relying on psychosocial clinicians to engage families around potentially "taboo" issues of emotional coping and spirituality.

Correspondence: Angela_Feraco@dfci.harvard.edu.

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Conclusion—Creating a communication occasion (D100), ensuring complementary disciplinary expertise through joint participation by oncologists and psychosocial clinicians, and providing a conversation tool to prompt disclosure by families and facilitate anticipatory guidance may ameliorate existing communication gaps during the ECTP.

Keywords

Conversation Guides; Childhood Cancer Communication; Communication Skills Training; Pediatric Oncology; Serious Illness Communication; Early Cancer Treatment Period

Introduction

Childhood cancer is a disruptive experience for children and their families.^{1,2} Initial diagnostic disclosure discussions and treatment decisions are distressing to parents, and deficits in parental understanding related to childhood cancer treatment are prominent.^{3,4} Important information is conveyed in the early days of a child's illness course,⁵ when distress may interfere with a parent's ability to ask questions or seek information.³

Several studies suggest a role for revisiting initial discussions regarding the cancer diagnosis and treatment decisions. Revisiting may reveal and clarify misunderstandings, repair prior insensitive communication, and equip parents to engage in shared decision-making.^{6–8} Notably, parents of children with cancer report wanting to revisit prognostic discussions during the year after diagnosis.⁹ Additionally, parents hold less active decision-making roles than they desire.¹⁰ In advanced childhood cancer, approximately one-third of parents report limited abilities to express hopes and worries during discussions of their child's medical condition.¹¹ These findings suggest a need to focus on fostering open communication and deepening the therapeutic relationship earlier in the illness trajectory. Specifically, revisiting initial discussions may facilitate parental illness understanding, agency, and trust during the ensuing months to years.

When and how to revisit initial discussions? Factors such as baseline mental health, health literacy and health-related beliefs, family structure and functioning, treatment intensity, and child symptomatology may all influence optimal timing and approach.¹² Acknowledging these mediating factors, the acute distress of the initial diagnostic period appears to lessen after approximately 4 to 16 weeks,^{12,13} and targeted interventions may “bend” the distress trajectory.¹⁴ Additionally, several common types of childhood cancer currently require six months or more of intensive, multimodal treatment, followed by a prolonged period of active surveillance.^{15–18} Thus, the early cancer treatment period (ECTP), which we define as at least one month but fewer than 7 months from initiation of antineoplastic treatment, may represent a pivotal phase of the illness trajectory across a range of diverse childhood cancers, as families adjust to a “new normal.”^{19,20} The ECTP presents timely opportunities for structured conversation between families and pediatric oncologists to consolidate key illness understanding, to enhance therapeutic alliance, and to assess and support family adaptation.

High-quality communication is a recognized route to strengthening therapeutic relationships in cancer care²¹ and evidence-based interventions to improve oncologists' communication exist.^{22–28} However, there is no standard framework to guide discussions during the ECTP.²⁹

The aims of this study were to elicit: (1) perceived communication gaps regarding cancer care among children with cancer and parents of such children currently in the ECTP, (2) conceptual acceptability of a novel in-depth conversation between families and their pediatric oncologists during the ECTP, (3) potential facilitators of and barriers to such a conversation, and (4) development and refinement of tools³⁰ to facilitate the conversation. Initial diagnostic disclosure and treatment discussions have been described as the “Day One Talk,”⁵ and so we tentatively titled this proposed new structured conversation the “Day 100 Talk” (D100). The name is not meant to imply a fixed date, but rather connectedness to the initial diagnostic disclosure and treatment discussions while invoking the passage of time.

Methods

Potential participants received printed information sheets that described the study. Participants indicated consent by participating in interviews or the provider focus group. For minor participants, parental permission and child assent were obtained. All participants received modest gift cards to an online retailer. This study was approved by the Dana-Farber/Harvard Cancer Center Office for Human Research Studies (institutional review board).

Participant Eligibility

Children, adolescents, and young adults (referred to collectively as “children” or “patients”) were eligible if they were undergoing cancer treatment for at least one month and less than seven months, were 13 years of age or older, spoke English, were not in foster care, and were cognitively able to engage in an in-depth interview. Eligible parents included English-speaking parents of any-aged child undergoing cancer treatment for at least one month and for fewer than seven months. Oncology providers, including junior oncologists (fellow physicians and first-year attending oncology physicians, hereafter JO), attending oncologists (AO), and oncology nurse practitioners (NP), were eligible if they cared for children with cancer at Dana-Farber/Boston Children’s Cancer and Blood Disorders Center. The clinical care model at the Center includes a multidisciplinary continuity cancer care team consisting of an attending oncologist, a fellow or NP, a psychosocial clinician and a nurse. This primary team is formally assigned after the child’s diagnosis has been established, and may or may not participate in initial diagnostic, prognostic and treatment discussions. Typically, attending oncologists, NPs, and psychosocial providers render care within a single disease center (hematologic malignancies, solid tumors, neuro-oncology), whereas fellows care for patients in all disease centers. Providers who care exclusively for patients undergoing stem cell transplantation were not eligible for participation, as stem cell transplant is more commonly undertaken beyond the ECTP.

Sampling Strategy

Purposive sampling was employed to incorporate potentially divergent perspectives.³¹ Initial characteristics of interest for both parent and child participants included gender of the child with cancer, cancer type (solid tumor, hematologic malignancy, or central nervous system (CNS) tumor), and time elapsed since start of treatment. For parent participants, we sought to sample fathers as well as mothers, as mothers’ perspectives are more prevalent in existing

research.³² Following initial analysis of the first three parent interviews and first patient interview, we refined our purposive sampling approach to pursue emerging characteristics of interest,³¹ such as hospitalization status. Provider sampling was likewise purposive to ensure representation of different disciplines and levels of experience, as well as different disease expertise within pediatric oncology. Our final sample size and composition was guided by a combination of *a priori* considerations (such as the wish to sample fathers) and the notion of “theoretical sufficiency.”^{31,33}

Interviews and Focus Group

Patient and parent interviews were conducted in-person or by telephone as desired by each participant, and were audio recorded. Interviews were semi-structured, conducted by a single interviewer (AMF) and lasted up to 60 minutes for parent participants and up to 45 minutes for child participants. Another researcher (JG) reviewed a subsample of early interviews to ensure integrity of the interview process. Oncology providers were invited to participate in a focus group conducted by a trained facilitator (JG) or an in-depth interview. Provider in-depth interviews followed the interview procedures described above, using the provider focus group guide. Audio recordings were subsequently transcribed, with identifying data removed. See Supplemental Material S1 for interview and focus group guides.

Conversation Tool Development

After preliminary analysis of patient and parent interview data, we developed a 3-part conversation tool to facilitate D100 including a preparatory family worksheet, a draft conversation guide, and a family summary sheet. Format and structure of the conversation tools were informed by the Serious Illness Care Program.³⁴ During provider interviews and the focus group, the draft guide was presented to providers (n=11) for feedback and refinement, and subsequently revised.

Data Analysis Plan

Data for analysis consisted of typed transcripts of interviews and a single focus group. Qualitative data analysis adhered to the constant comparative method³¹ and to standards for rigorous thematic analysis in a healthcare context.³⁵ Initial codes were developed through a process of line-by-line coding by a single investigator (AMF). These were refined to focused codes and compiled into a codebook, which was reviewed by a second researcher (JG) for adherence to the data. Computer-assisted qualitative analysis was conducted using Atlas.ti version 7.5.10 (Berlin, Germany). From focused codes, thematic categories were constructed, and links between emergent categories were explored.

Results

Parent interviews were conducted July 2015-October 2015. The provider focus group was conducted in November 2015 and provider interviews were conducted December 2015-February 2016. Seventeen parents and 16 children were screened for participation. Of these, 11 parents and 10 children were approached. Five parents declined, for a participation rate of 55%. Four children declined, and a fifth exited the eligibility period after being approached but before deciding, for a participation rate of 50%. Patient and parent participants came

from 11 distinct families. Thirty-four oncology providers (16 JOs, 10 AOs, and 8 NPs) were invited to participate, and 18 indicated willingness (53%). Ultimately, we conducted a focus group of four providers, and interviews with seven more. Characteristics of in-depth interview and focus group participants are shown in Table 1.

Content analysis highlighted several important themes that informed development of D100 and the three-part conversation tool. Themes are summarized in Tables 2–4.

Communication Needs During the ECTP

Parents and patients reported experiencing significant life changes during the ECTP, particularly changed roles within the family and an altered perspective that acknowledged a relative lack of control and significant uncertainty. Their expressed hopes and worries centered largely around the possibility of regaining health and a sense of normalcy. These hopes and worries were sometimes withheld from oncology providers, either because they were presumed to be known already, because of a wish not to be bothersome, to shield the ill child, or because of a sense of not yet having sufficient comfort in the cancer care relationship. Withholding emerged as a potential communication barrier, particularly in the context of oncology providers' communication practices. Communication and the oncologist's presence were identified as major mediators of the provider-patient-family (cancer care) relationship. The most prominent unmet communication need identified by patients and parents was insufficient anticipatory guidance. These themes shaped the 3 domains of D100: Current Questions/Concerns, Looking Ahead, and Family Context.

Current Communication Practices and Approaches to Communication Skill-Building

Oncology providers' current communication practices during ECTP included varying the “dosage” of communication and clinical contact as well as the content of communication in response to perceived patient and family needs. Notably, oncology providers reported employing indirect methods to determine family needs. This included “listening for” family concerns and waiting for families to raise or revisit issues such as overall prognosis or the role of spirituality. This surmising approach was particularly prominent for topics perceived as potentially taboo, such as emotional coping and spirituality. Additionally, oncologists focused their communication on perceived areas of expertise (e.g. chemotherapy side-effects) and emphasized their reliance on other members of the multidisciplinary cancer care team to assess and manage “non-medical” issues. Just as providers tended to rely on received cues and observation to gauge family needs, they tended to rely on observation and learning from experience—apprenticeship approaches³⁶—to build communication skills. NPs and JOs reported that they utilized their more senior colleagues as communication skills resources. None of the providers reported participating in dedicated communication skills workshops as oncology trainees or as practicing oncologists, though some had worked with standardized patients to learn communication skills as medical students.

Responses to D100 Proposal and Development of D100 Conversation Tools

Responses to the proposed D100 intervention and the conversation guide are summarized in Table 4. Parents and children with cancer saw the proposed D100 intervention as a chance for *regrouping*—bringing together care providers who may not be encountered together,

such as the oncology provider, primary nurse, and psychosocial clinician. In addition to the physical act of regrouping with the larger care team, parents and patients saw D100 as an opportunity to mentally and emotionally regroup: to reflect on their evolving illness understanding and the progress they have made in learning how to navigate cancer and its treatment, thereby boosting confidence. Furthermore, having gained new life experience with cancer and its treatment, some parents and patients wished to address new questions to their oncologists from their more seasoned perspective—now that they had their “sea legs.” Participants revealed unanswered questions that ranged from revisiting treatment decisions to anticipating future challenges and transitions.

Following review of the draft conversation guide, providers echoed the preference that D100 be an interdisciplinary conversation, particularly citing the value of drawing upon psychosocial clinician expertise to meet family support needs (both material and emotional) that may be identified during D100. Likewise, providers noted that D100 had the potential to augment current practice by facilitating greater mutual understanding between families and oncology providers, potentially deepening the therapeutic relationship or correcting the course of a faltering relationship.

Negative and mixed responses to the D100 proposal included concerns about redundancy, discomfort, and limited clinical time. Importantly, some parents and children felt that information and support needs were well met by current conversations with their oncologists. However, even these participants subsequently disclosed unshared hopes, worries, and circumstances. Furthermore, providers noted that the section of the conversation guide that queried current questions and concerns (see Supplemental Material S1) may overlap with existing communication during routine treatment visits, and that a conversation guide might feel overly prescriptive. When asked what might influence them to participate in a pilot test of D100, providers cited limited time and anticipated logistical complexities as potential deterrents. Providers recommended that D100 be flexible to account for disease-specific treatment plan characteristics, logistical considerations, and the needs of individual families. Although patients and parents indicated willingness to lengthen treatment visits or attend additional visits to participate in D100, providers preferred that D100 be fitted into existing work patterns. Provider time was described as a scarce resource, and the potential additional time required was seen as an important tradeoff of the proposed communication intervention. Additionally, parents occasionally expressed that engaging in D100 might increase their worries or anxiety. Likewise, providers indicated a fear of “opening Pandora’s Box” and suggested additional education about 1) available resources, and 2) how best to approach topics that may be considered sensitive or taboo—such as spirituality—in order to engage in D100 comfortably and successfully.

These responses shaped the revised communication intervention into an interdisciplinary communication occasion guided by a 3-part conversation tool and supported by focused provider training (Supplemental Figure S1). Joint participation by oncology providers and psychosocial clinicians ensures complementary expertise. The conversation tool provides 9 core questions across 3 domains to encourage disclosure of hopes and worries by families and prompt anticipatory guidance by providers and clinicians. To further address concerns about “opening Pandora’s Box” and the need to enhance provider knowledge and skills, a

companion training program was developed. Additionally, the family's completed preparatory family worksheet will be circulated to the care team prior to D100 to help the oncology provider and psychosocial clinician prepare.

Discussion

In summary, current communication during the ECTP is variable and shaped largely by providers' perceptions of families' needs, which may be insufficient when patients and parents withhold hopes, worries, and beliefs. Though parents and patients focused on anticipatory guidance when describing communication gaps, the combination of withholding and surmising emerged as a powerful potential barrier to open communication. Additionally, consistent with existing literature, providers' approaches to communication skill-building tended to rely on apprenticeship models, rather than more formal approaches, such as workshops and conversation guides.^{36–38} Finally, oncology providers perceived significant time pressures in their clinical work, and worried about "opening Pandora's Box." Thus, D100 was developed to encourage family disclosure and to prompt interdisciplinary anticipatory guidance within a structured, time-limited format.

The finding that providers may not ask and families may not share their concerns during the ECTP is not surprising, but it is worrisome. The implication is that providers are "listening for" cues that may not come, and missing opportunities to elicit and meet their patients' and parents' needs.^{11,29} Unfortunately, this reliance on surmising may hinder providers' stated strategy of tailoring their approach to each family. It may also set up the cancer care relationship for a rocky future course, if all parties expect the provider to intuit the patient's and family's needs.³⁹ Some providers indicated that discussing "non-medical" aspects of the cancer experience, such as emotional and spiritual coping, was outside their role, and therefore, a potential misuse of scarce provider time. As such, the original formulation of D100 as a conversation between family and oncologist was potentially at odds with providers' preferences and practices. Reconceptualizing D100 as an interdisciplinary conversation supports oncologists' preferred practice style, aligns with standards for psychosocial care,^{40,41} and may better address the communication gap created by withholding coupled with surmising.

This study has several limitations. While none of the children or parents interviewed were cared for primarily by any member of the study team, the study interviewer (AMF) practices pediatric oncology in the center at which the research was conducted. Answers directed to an individual actively working in the pediatric oncology setting may differ from answers given to an "outsider." Similarly, the disciplinary lens of pediatric oncology may have colored the qualitative analysis. However, the input of a second analyst (JG) with a different disciplinary frame—anthropology—should buffer this potential limitation of the analysis. Additionally, this study employed a limited sample of participants from a single academic pediatric cancer center in which the process of obtaining a diagnosis and selecting a treatment plan is directed by oncology providers who may not become members of the continuity cancer care team. Views captured here may not reflect the views of key stakeholders from cancer centers with different care models or formal communication skills training programs. Stakeholders who elected not to participate in the research study may

hold views that differ systematically from those who elected to participate. Adolescents' perspectives were represented to a greater extent than were those of families of young children. Finally, parents and patients at later phases of the illness trajectory may endorse differing needs and preferences when they think back to their ECTP experiences. As such, this study serves as a starting point from which to inform future prospective evaluations of the feasibility, acceptability, and efficacy of the proposed communication intervention.

High-quality communication has been recognized as central to the provision of optimal cancer care.²¹ By creating a structured conversation during the ECTP that explicitly probes family context and centers on families' concerns, D100 has the potential to ameliorate existing communication gaps and foster a culture of open interdisciplinary communication, with benefits to be reaped throughout the illness trajectory.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

AO	Attending Oncologist
CNS	Central Nervous System
D100	Day 100 Talk
ECTP	Early Cancer Treatment Period
JO	Junior Oncologist
NP	Oncology Nurse Practitioner
SD	Standard Deviation

References

1. Young B, Dixon-Woods M, Findlay M, Heney D. Parenting in a crisis: Conceptualising mothers of children with cancer. *Soc Sci Med*. 2002; 55(10):1835–1847. [PubMed: 12383468]
2. Patterson JM, Holm KE, Gurney JG. The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psychooncology*. 2004; 13(6):390–407. [PubMed: 15188446]
3. Kupst MJ, Patenaude AF, Walco GA, Sterling C. Clinical trials in pediatric cancer: Parental perspectives on informed consent. *J Pediatr Hematol Oncol*. 2003; 25(10):787–790. [PubMed: 14528101]
4. Greenley RN, Drotar D, Zyzanski SJ, Kodish E. Stability of parental understanding of random assignment in childhood leukemia trials: An empirical examination of informed consent. *J Clin Oncol*. 2006; 24(6):891–897. [PubMed: 16484698]

5. Mack JW, Grier HE. The day one talk. *J Clin Oncol*. 2004; 22(3):563–566. [PubMed: 14752081]
6. Mack JW, Ilowite M, Taddei S. Difficult relationships between parents and physicians of children with cancer: A qualitative study of parent and physician perspectives. *Cancer*. 2017; 123(4):675–681. DOI: 10.1002/cncr.30395 [PubMed: 27727442]
7. Clarke JN, Fletcher P. Communication issues faced by parents who have a child diagnosed with cancer. *J Pediatr Oncol Nurs*. 2003; 20(4):175–191. DOI: 10.1177/1043454203254040 [PubMed: 14567565]
8. Dixon-Woods M, Findlay M, Young B, Cox H, Heney D. Parents' accounts of obtaining a diagnosis of childhood cancer. *Lancet*. 2001; 357(9257):670–674. [PubMed: 11247550]
9. Sisk BA, Kang TI, Mack JW. Prognostic disclosures over time: Parental preferences and physician practices. *Cancer*. 2017
10. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Parents' roles in decision making for children with cancer in the first year of cancer treatment. *J Clin Oncol*. 2011; 29(15):2085–2090. [PubMed: 21464400]
11. Feraco AM, Dussel V, Orellana L, et al. Tumor talk and child well-being: Perceptions of “good” and “bad” news among parents of children with advanced cancer. *J Pain Symptom Manage*. 2017; 53(5):833–841. [PubMed: 28062345]
12. Kearney JA, Salley CG, Muriel AC. Standards of psychosocial care for parents of children with cancer. *Pediatr Blood Cancer*. 2015; 62(Suppl 5):632.doi: 10.1002/pbc.25761
13. Dolgin MJ, Phipps S, Fairclough DL, et al. Trajectories of adjustment in mothers of children with newly diagnosed cancer: A natural history investigation. *J Pediatr Psychol*. 2007; 32(7):771–782. [PubMed: 17403910]
14. Sahler OJ, Dolgin MJ, Phipps S, et al. Specificity of problem-solving skills training in mothers of children newly diagnosed with cancer: Results of a multisite randomized clinical trial. *J Clin Oncol*. 2013; 31(10):1329–1335. [PubMed: 23358975]
15. Sung L, Yanofsky R, Klaassen RJ, et al. Quality of life during active treatment for pediatric acute lymphoblastic leukemia. *Int J Cancer*. 2011; 128(5):1213–1220. [PubMed: 20473921]
16. Yu AL, Gilman AL, Ozkaynak MF, et al. Anti-GD2 antibody with GM-CSF, interleukin-2, and isotretinoin for neuroblastoma. *N Engl J Med*. 2010; 363(14):1324–1334. [PubMed: 20879881]
17. Bielack SS, Smeland S, Whelan JS, et al. Methotrexate, doxorubicin, and cisplatin (MAP) plus maintenance pegylated interferon alfa-2b versus MAP alone in patients with resectable high-grade osteosarcoma and good histologic response to preoperative MAP: First results of the EURAMOS-1 good response randomized controlled trial. *J Clin Oncol*. 2015; 33(20):2279–2287. [PubMed: 26033801]
18. Womer RB, West DC, Krailo MD, et al. Randomized controlled trial of interval-compressed chemotherapy for the treatment of localized ewing sarcoma: A report from the children's oncology group. *J Clin Oncol*. 2012; 30(33):4148–4154. [PubMed: 23091096]
19. Klassen A, Klaassen RJ, Dix D, Pritchard S, Yanofsky R, Sung L. Caregiving demands in parents of children with cancer: Psychometric validation of the care of my child with cancer questionnaire. *J Pediatr Nurs*. 2010; 25(4):258–263. [PubMed: 20620806]
20. Clarke-Steffen L. Reconstructing reality: Family strategies for managing childhood cancer. *J Pediatr Nurs*. 1997; 12(5):278–287. [PubMed: 9330503]
21. Street RL Jr, Makoul G, Arora NK, Epstein RM. How does communication heal? pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns*. 2009; 74(3):295–301. [PubMed: 19150199]
22. Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a cancer research UK communication skills training model for oncologists: A randomised controlled trial. *Lancet*. 2002; 359(9307):650–656. [PubMed: 11879860]
23. Baile WF, Kudelka AP, Beale EA, et al. Communication skills training in oncology. description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer*. 1999; 86(5):887–897. [PubMed: 10463990]
24. Back AL, Arnold RM, Baile WF, et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med*. 2007; 167(5):453–460. [PubMed: 17353492]

25. Fryer-Edwards K, Arnold RM, Baile W, Tulskey JA, Petracca F, Back A. Reflective teaching practices: An approach to teaching communication skills in a small-group setting. *Acad Med*. 2006; 81(7):638–644. [PubMed: 16799286]
26. Baile WF. Training oncology practitioners in communication skills. *J Pediatr Hematol Oncol*. 2011; 33(Suppl 2):115.
27. Kissane DW, Bylund CL, Banerjee SC, et al. Communication skills training for oncology professionals. *J Clin Oncol*. 2012; 30(11):1242–1247. [PubMed: 22412145]
28. Bylund CL, Brown R, Gueguen JA, Diamond C, Bianculli J, Kissane DW. The implementation and assessment of a comprehensive communication skills training curriculum for oncologists. *Psychooncology*. 2010; 19(6):583–593. [PubMed: 19484714]
29. Thompson AL, Young-Saleme TK. Anticipatory guidance and psychoeducation as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015; 62(Suppl 5):684.doi: 10.1002/pbc.25721
30. Bernacki RE, Block SD, American College of Physicians High Value Care Task Force. Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Intern Med*. 2014; 174(12):1994–2003. [PubMed: 25330167]
31. Charmaz, K. Constructing grounded theory: A practical guide through qualitative analysis. London; Thousand Oaks, Calif: Sage Publications; 2006. p. 208
32. Dixon-Woods M, Young B, Heney D. Childhood cancer and users' views: A critical perspective. *Eur J Cancer Care (Engl)*. 2002; 11(3):173–177. [PubMed: 12296833]
33. Dey, I. Grounding grounded theory: Guidelines for qualitative inquiry. San Diego: Academic Press; 1999. p. 282
34. Bernacki R, Hutchings M, Vick J, et al. Development of the serious illness care program: A randomised controlled trial of a palliative care communication intervention. *BMJ Open*. 2015; 5(10):009032.
35. Pope, C., Mays, N. Qualitative research in health care. 3rd. Malden, Mass.: Blackwell Pub/BMJ Books; 2006. p. 156
36. Feraco AM, Brand SR, Mack JW, Kesselheim JC, Block SD, Wolfe J. Communication skills training in pediatric oncology: Moving beyond role modeling. *Pediatr Blood Cancer*. 2016; 63(6): 966–972. [PubMed: 26822066]
37. Kersun L, Gyi L, Morrison WE. Training in difficult conversations: A national survey of pediatric hematology-oncology and pediatric critical care physicians. *J Palliat Med*. 2009; 12(6):525–530. [PubMed: 19508138]
38. File W, Bylund CL, Kesselheim J, Leonard D, Leavey P. Do pediatric hematology/oncology (PHO) fellows receive communication training? *Pediatr Blood Cancer*. 2014; 61(3):502–506. [PubMed: 24039096]
39. Tulskey JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*. 2005; 294(3):359–365. [PubMed: 16030281]
40. Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Interdisciplinary collaboration in standards of psychosocial care. *Pediatr Blood Cancer*. 2015; 62(Suppl 5):S425.doi: 10.1002/pbc.25718 [PubMed: 26700915]
41. Patenaude AF, Pelletier W, Bingen K. Communication, documentation, and training standards in pediatric psychosocial oncology. *Pediatr Blood Cancer*. 2015; 62(Suppl 5):870.doi: 10.1002/pbc.25725

TABLE 1

Characteristics of interview and focus group participants

	Parent Participants <i>N</i> =6	Child Participants <i>N</i> =5	Oncology Provider Participants <i>N</i> =11
Participant Characteristics			
Child age in years, mean (range)	9.9 (1.7-16)	17.8 (16-21)	–
Male sex, <i>n</i> (%)	2 (33)	2 (40)	2 (18.2)
Child hospitalized, <i>n</i> (%)	3 (50)	0 (0)	–
Weeks since treatment start, mean (range)	8.4 (5.1-15.0)	11.3 (7.9-17.4)	–
Primary residence outside of New England, <i>n</i> (%)	1 (16.7)	0 (0)	0 (0)
Disease Category, * <i>n</i> (%)			
Brain tumor	1 (16.7)	2 (40)	1 (14.2) **
Hematologic malignancy	2 (33)	1 (20)	3 (42.9) **
Solid tumor	3 (50)	2 (40)	3 (42.9) **
Provider Type, <i>n</i> (%)			
JO	–	–	4 (36.4)
AO	–	–	4 (36.4)
NP	–	–	3 (27.2)
Participation Type, <i>n</i> (%)			
Focus group	–	–	4 (36.4)
In-person interview	5 (83.3)	5 (100)	3 (27.2)
Telephone interview	1 (16.7)	0 (0)	4 (36.4)

* Brain tumors included primitive neuroectodermal tumors (2) and medulloblastoma (1). Hematologic malignancy diagnoses included acute lymphoblastic leukemia (1), Hodgkins disease (1), and non-Hodgkins lymphoma (1). Solid tumor diagnoses included Ewing sarcoma (1), osteosarcoma (1), neuroblastoma (1), and germ cell tumors (2).

** Fellows and first-year instructors do not have disease-specific affiliation

AO = Attending Oncologist; JO = Junior Oncologist (fellow physician or first-year attending physician); NP = Oncology Nurse Practitioner; SD = standard deviation

TABLE 2

Parent and patient themes

ECTP experiences		
Theme	Codes	Illustrative Quote
Experiencing life changes	Dividing/changing roles Family separation Illness and treatment take a toll Lacking control Living with uncertainty	<p>“[N]ot being able to go to school was hard, ‘cause I’ve been... one of the top students, so... at the beginning I DID try to go to school, and it just wasn’t working... I’d be the one that would stay up all night to do homework, so, we had to kind of stop that” (Patient #5).</p> <p>“We have ... kids, we haven’t seen ... we missed our second son’s birthday” (Parent #2).</p> <p>“And now we’re just kind of... like a boat in the waves... ‘cause there’s nothing else we can do right now. Just kind of... everyone’s like, ‘How do you do it?’ And it’s like, ‘Well, how <i>don’t</i> I do it? I don’t have a choice” (Parent #5).</p>
Cancer and Treatment Beliefs		
Theme	Codes	Illustrative Quote
Hopes	Beating cancer Getting back to normal Meaning-making	<p>“The statistics of people that don’t make it, they must be getting treatment elsewhere. That’s what I tell myself” (Parent #3).</p> <p>“Gonna go in and do the surgery, and just, you know, just praying that hopefully, it’s all over when they take it out” (Patient #4).</p>
Worries	Recurrence, progression, and death Impact on life Anticipating loss/Late effects	<p>“Well, we have... my mom has a friend that had cancer, and then got, like... got rid of it, and then, seven years later got it back? So we’re just scared of the cancer coming back. And, one of the ways we thought was by food... if we ate the wrong things, it could... get the cancer to grow again” (Patient #3).</p> <p>“What’s the chances that he may never have kids, because of this? ... [W]hat’s the chances that he’s gonna get a secondary cancer. You know what I mean? It’s not stuff you really want to think about” (Parent #6).</p>
Cancer Care Relationship and Communication Beliefs, Preferences, and Experiences		
Oncologist’s Role	Feeling oncologist’s presence Looking to providers to lead “Not my shoulder to cry on”/Don’t bother doctors Professionals know without being told Valuing/practicing truthfulness	<p>“[W]hat I said back to them was ... ‘As far as treatment goes, we’re just—we’re handing you guys the keys to the car here.’ ... [S]ome people’s way of coping I think, or dealing with some of this, is just to sort of like, become, like, an oncologist overnight, themselves? ... I couldn’t be any further from that ... I just, I had to hand it over to ‘em, say, ‘I’m trusting you guys to do... to do what you need to do’” (Parent #4).</p> <p>“[P]eople always asked me if I have questions, and I said... always said, ‘No,’ ‘cause it was still new, so, I would leave and not have asked any questions. But, ... before I even ask my questions, they usually answered them while they were explaining. So I... didn’t even have to ask my question and they already answered it.” (Patient #5).</p>
Unmet needs	Perceiving insufficient anticipatory guidance Withholding	<p>“[H]is first induction phase is six cycles of chemo. I thought that was all the chemo he was getting ... my expectation was, once he’s done with this induction phase, he’s done with chemo. But he’s not, because I wasn’t told that ... I want to be mentally prepared” (Parent #5).</p> <p>“Like, if they’re {the oncology team} still new to you and you’re not FULLY comfortable around them, um, you might not tell them things that you might, if you know them, for you know? Maybe... a longer amount of time?” (Patient #5).</p>

TABLE 3

Provider themes

Communication Beliefs/Attitudes		
Theme	Codes	Illustrative Quote
Oncologist's role	Being truthful Being responsible for decision-making Taboo subjects Taking over care after initial diagnostic discussions is challenging	"I don't usually talk about spirituality, a lot, um, because it's a, can be a very touchy subject. And in a family that's already in a very delicate place ... I ask if they want it, in some cases? But in a lot of cases, I don't discuss it very much, just because it's so, um, it's so variable from person to person" (AO #2). "Emotional coping, I probably don't specifically talk to the parents about? I might address it? But, um, nobody wants to be told that, 'You need to go see someone and take an antidepressant'" (NP #3). "... I have to work harder to build up my own relationship with that family when I wasn't there for the Day One talk" (JO #1).
Parental adjustment	Expectations may not match new reality Resiliency	"I think it also depends on what the family's expectations are? For some families, nausea is horrible! They just, they want their child never to be nauseous and to be eating the same way as they were, prior to the diagnosis. And, and that is an unrealistic expectation, um, that I don't know that we always communicate perfectly ... for us, those things are normal ... their 'new normal,' that the family doesn't necessarily understand" (JO #2).
Competing priorities/Constraints	Limited provider time	"Provider time. That, when you're a busy first year fellow and running around, and totally sleep deprived, the idea of planning a formal talk and, and getting the time to do it; or, maybe you have eleven patients scheduled in clinic that day... I think, time is just always something that's hard to carve out" (JO #1).
Communication Strategies and Practices		
Theme	Codes	Illustrative Quote
Tailoring: Varying communication "dosage" and content	Repeating illness information Intensifying family contact Choosing to omit	"I have had, repeatedly, patients who have been surprised, sometimes shocked, angry... that feeling, like, 'I didn't know this is what was coming?' And, so I feel like I've, I've... learned to incorporate sort of reviewing that plan at different time points" (NP #1). "I was just gonna say I feel like I rarely... maybe it's... something I should do more? But I rarely, directly would ask them, 'So, how... how's it going?' 'Cause I feel like the answer is usually, 'Why would you even ASK me that question? Of course it's not good'" (JO #4).
Tailoring: Methods of appraising family needs	Relying on listening, intuition and surmising, rather than direct inquiries "Reading" the family/ exercising professional judgment Taking cues from the family Asking questions/probing	"... I seldom probe them for values... I try to do that more with my ears than my questions, and listen to what they're telling me. And, through experience, sort of have my own view of what those values [are]" (AO #1). "So, I think it's... again, I think it... it's a matter of really... listening to how they frame their response to the information that you give them" (AO #4).
Focusing communication on areas of expertise/control	Emphasizing "medical things" Relying on multi-disciplinary team	"Because most of us feel like... for better or worse, I don't have the training or the time to really get into like, you know, your emotional coping with this because, you know, we have lots of other patients, and this could take hours ... that's why there's a specific ... psycho-social person who deals with that" (JO #4).
Communication Skill-Building		
Apprenticeship-model approaches	Utilizing other providers as communication skills resource Relying on experience Learning through observation Formal training methods unfamiliar Little feedback on communication skills after fellowship	"I'm definitely not as structured ... during that phase {the early cancer treatment period}, as I am... as I guess we're all trained on the Day One. Like I don't have a mental checklist to go through ... but it probably would be something useful, to sort of like, 'Over the next few months I want to make sure I've covered.' I think we end up doing it very ad hoc, you know? ... [W]e really talk about fever, the first time you get a fever; we really talk about, you know, uh... mental health, the first time they have a breakdown... I don't think I go through like a mental checklist of what have we talked about over the last three months" (AO #3). "[W]e don't give or get formal didactic feedback, specifically around communication, I would say. I think that the art of communicating... is... is not a highlighted part of our world. The Day One Talk, ...

Communication Beliefs/Attitudes		
Theme	Codes	Illustrative Quote
		<i>maybe ... but again, I think there's many different styles even to doing that... I think the <i>content</i> has been fairly well categorized, but ... the presentation of it, I think is something ... we don't spend a lot of time, explicitly discussing" (AO #4).</i>

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TABLE 4

Key stakeholder responses to proposed D100 intervention

Positive responses: Augmenting current practice	
Code	Illustrative Quote
Learning family context	“It seems like a good idea because some of the things that are on here that I would LIKE to know about families, there’s not a lot of time in the beginning to address them and maybe now that the medical issues have hopefully kind of become more routine and easier would be a good time to go back and kind of hash some of those things out” (JO #3). “You’re opening up this opportunity to ask you more questions. You’re also creating an opportunity for the physician to understand how to better take care of the family” (AO #4).
Allowing for regrouping	“I think it would do a lot to... give people a boost of confidence and feel like, ‘Okay, well, I remember when I had a conversation like this before, and I was completely scatter-brained ... and now I’m havin’ this conversation now. Look how much further we’ve come... we understand what’s going on” (Parent #4).
Engaging unanswered questions	“For the present, if the current chemotherapy I’m doing is right for me? Or, is it too much? Or, is there any way it could be better, or anything we improve right now or for the future. If there’s anything that we’re doing right now that could hurt me in the future, or, that... yeah, that we could prevent, and make sure it was better in the future” (Patient #3).
Negative responses: Potential redundancy	
Code	Illustrative Quote
Potential redundancy with current practice	“I think we have that now, ‘cause whenever [child name]’s here, um, Dr. [X2] knows he’s here, Dr. [X1] knows he’s here, if they’re not... you know, they can’t be at rounds, but they come here ... we see her at least once or twice a week” (Parent #6). “I think looking at the specific questions ... I think for me, for most of my families, the, ‘We’re still getting to know each other, can you tell me more about your family?’ I think would feel harder for me to ask at Day 100? I would have hoped that I would have asked that, gotten to know that about people, earlier?” (JO #1).
Mixed Responses: Opening Pandora’s Box	
Code	Illustrative Quote
Could increase family anxiety	“I think a lot of the questions I have to ask, I don’t really want to ask? ‘Cause they’re scary...” (Parent #6).
Could increase provider discomfort	“I think that probably the, one of the more challenging things is, is going to be to convince... physicians not just to spend the time, but to feel really comfortable to opening themselves up to this... kind of conversation, because it <i>is</i> a much more... sort of frank, and in some ways intimate conversation... than we typically have in a clinic day... it’s a different kind of business. Right?” (AO #4). “I think a big part of the reason we don’t <i>necessarily</i> ask some of these questions is because we don’t want to end up with a fireball that we can’t deal with. Right?” (AO #3).
Could be time consuming	“I think it’s gonna open up a lot of ... A LONG list of things to work on, I think that these families will have a lot... families will have a LOT to say. Um, and so, not only the meeting itself is gonna take a lot of time, but I think follow up of it will, also. But it’d be really nice to have it set, though, so that you have that availability to do it, and I think the families would appreciate it a lot” (NP #1).
Mixed Responses: Tradeoffs	
Code	Illustrative Quote
Anticipating logistical difficulties	“[It] would get complicated to, in the first one to three months, set up a new, um... family meeting that, say, isn’t... I don’t want to say ‘needed,’ but isn’t... called for... trying to really get the whole team there might be a little bit difficult? Having said that, I think it’s a... you know, it’s a great idea to have like a... 100 talk, just to kind of regroup” (NP #3).
Format too artificial?	“So I think these are questions that should be on our mind... as part of our relationship. And... I think for me, that sort of stopping it at some point and... it just feels like an artificial stop. I think it’s more important that we, in our OWN minds, know that we’re covering this, and that’s what I meant by an internal checklist. But, um, I don’t think that I would interrupt the natural flow of the doctor/patient relationship... with these specific questions” (AO #1).
Recommendations	
Code	Illustrative Quote

Positive responses: Augmenting current practice	
Code	Illustrative Quote
Empower families to tailor experience	"Maybe even giving families something to help them know what to expect in a conversation like this, um, give an opportunity to let them write down questions if they have them... basically just sort of going off and reading your patient... and what their needs are, sort of guide that conversation" (NP #1).
Clarify goals of D100	"I think the idea is a good one ... I would want to know what the ultimate goal of it is? ... Is it to help us? Is it to help the family?" (JO #2)
Enhance provider knowledge and skills	"I think people might ... need actual sort of training ... you know, a little bit of practice ... the buy-in into actually doing it {having a Day 100 Talk} will be harder, um, unless it comes as a little bit more of a package" (AO #3).
Make D100 timing flexible	"But, I think it would be difficult, because then every patient is going to, "Why haven't I had my Day 100 talk?" And then, you know, I think... it could be that the goal is to be around Day 100, but... I... make it a little bit more, um... flexible, I guess?" (NP #3).