Let’s Talk Again, Now That We Have Our “Sea Legs”: A Qualitative Needs Assessment for a Novel Structured Conversation Targeting the Early Cancer Treatment Period

The Harvard community has made this article openly available. Please share how this access benefits you. Your story matters

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Citable link</td>
<td><a href="http://nrs.harvard.edu/urn-3:HUL.InstRepos:33840763">http://nrs.harvard.edu/urn-3:HUL.InstRepos:33840763</a></td>
</tr>
<tr>
<td>Terms of Use</td>
<td>This article was downloaded from Harvard University’s DASH repository, and is made available under the terms and conditions applicable to Other Posted Material, as set forth at <a href="http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA">http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA</a></td>
</tr>
</tbody>
</table>
LET’S TALK AGAIN, NOW THAT WE HAVE OUR “SEA LEGS”: A QUALITATIVE NEEDS ASSESSMENT FOR A NOVEL STRUCTURED CONVERSATION TARGETING THE EARLY CANCER TREATMENT PERIOD

ANGELA M. FERACO, MD

A Thesis Submitted to the Faculty of

The Harvard Medical School

in Partial Fulfillment of the Requirements

for the Degree of Master of Medical Sciences in Medical Education

Harvard University

Boston, Massachusetts.

May, 2016
Let’s Talk Again, Now That We Have Our “Sea Legs”: A qualitative needs assessment for a novel structured conversation targeting the early cancer treatment period

Abstract

Background: The initial months of childhood cancer treatment may occasion changed illness understanding and altered communication needs among families compared with those at diagnosis, but currently, there is no framework to guide communication in this early cancer treatment period (ECTP).

Objectives: To elicit (1) lived illness experiences during ECTP, (2) conceptual acceptability of a novel in-depth conversation between families and their pediatric oncologists, the “Day 100 Talk,” (D100) during this period, (3) preferred topics and goals for D100, and (4) potential barriers to D100.

Design/Method: We conducted semi-structured interviews with children aged ≥13 years and parents of all-aged children with non-relapsed cancer undergoing treatment for 4 weeks to <6 months, as well as in-depth interviews and focus group with pediatric oncologists. Sampling, interviews, and constant comparative qualitative analysis were informed by grounded theory.

Results: Five of 10 (50%) adolescents, 6/11 (55%) parents participated in interviews, and 11/34 (32%) oncology providers participated in interviews or a focus group. Emergent themes of the family experience of ECTP included being shell-shocked, seeking illness information, anticipating loss, settling in, and dividing/changing roles, as parents and children sought to meet the challenges of cancer and its treatment. Providers attempted to facilitate families’ adaptation by tailoring the approach to each family, which largely consisted of repeating illness
information, anticipating/deciding family needs, and presence during ECTP. Parent and adolescent participants suggested the D100 concept could facilitate regrouping, including reconvening the multidisciplinary cancer care team and reflecting on progress. D100 could also engage unanswered questions, such as revisiting treatment decisions and anticipating future challenges. Providers echoed the utility of the D100 concept, but expressed a commitment to maintaining professional autonomy to protect clinical time and tailor their approach to each family.

Conclusion: The D100 concept appears conceptually acceptable to this small cohort of children with cancer, parents, and providers. Limited clinical time and providers’ commitment to tailoring communication to each family may represent barriers to D100 implementation, despite perceptions that D100 could be a unique opportunity for families to set the conversational agenda. Future work should focus on piloting D100 and determining feasibility and acceptability to key stakeholders.
Table of Contents

1. Chapter 1: Background ............................................................................................................. 1

2. Chapter 2: Data and Methods ................................................................................................. 4
   2.1 Brief Introduction .................................................................................................................. 4
   2.2 Materials and Methods ....................................................................................................... 4
       2.2.1 Participant Eligibility ..................................................................................................... 5
       2.2.2 Sampling Strategy ......................................................................................................... 5
       2.2.3 Interviews .................................................................................................................... 6
       2.2.4 Focus Group .................................................................................................................. 7
       2.2.5 Data Analysis Plan ....................................................................................................... 7
   2.3 Results and Analysis ........................................................................................................... 8
       2.3.1 Thematic Analysis ........................................................................................................ 10

3. Chapter 3: Conclusions and Context .................................................................................... 37
   3.1 Limitations .......................................................................................................................... 38
   3.2 Context ................................................................................................................................ 39
   3.3 Future Research ............................................................................................................... 40

4. References .............................................................................................................................. 41

Appendices .................................................................................................................................. 45

Appendix A ................................................................................................................................... 46
Appendix B ................................................................................................................................... 47
Appendix C ................................................................................................................................... 48
Appendix D ................................................................................................................................... 52
Appendix E ................................................................................................................................... 57
Figures

Figure 1. Conceptual Framework of Family Adaptation as the Initial Diagnostic Period Gives Way to the Early Cancer Treatment Period (ECTP)…………………………………………2
Tables

Table 1. Characteristics of Interview and Focus Group Participants……………………………………9

Table 2. Organizing Thematic Categories and Key Subcategories: Patients and Parents…………11

Table 3. Organizing Thematic Categories and Key Subcategories: Providers……………………..18

Table 4. Organizing Thematic Categories and Key Subcategories: Parent and Patient
Relationship and Communication Experiences and Preferences………………………………………25

Table 5. Organizing Thematic Categories and Key Subcategories: Responses to Proposed D100
Intervention…………………………………………………………………………………………………31
Acknowledgements

I thank Susan D. Block, MD, Amy Sullivan, EdD, Chris Feudtner, MD, PhD, and Sarah R. Brand, PhD, for inspiration and guidance. I am grateful to the Pediatric Palliative Care Research Network (PPCRN) for helpful commentary and critique in the early phase of this work. I would also like to thank the Master’s students in Medical Education of 2016 and 2017, as well as the program leadership, Jennifer C. Kesselheim, MD, MBE, MEd, and Ayres Heller, MEd, for their enthusiasm, collegiality, and support. Thanks to Norma Ware, PhD, and Hannah Gilbert, PhD of Harvard Medical School, and to the University of California Advanced Training in Clinical Research program, I developed initial experience with qualitative research methods that enabled me to conduct this work. Joshua Gagne, MA, coached me in interview technique and contributed substantially to the trustworthiness of the final qualitative codebook. Finally, I am indebted to my research mentor, Joanne Wolfe, MD, MPH, for her dedication to fostering my professional, intellectual, and personal development. Any successes of this work are indebted to this group. Any failings are my own, alone.

This work was conducted with support from Students in the Master of Medical Sciences in Medical Education program of Harvard Medical School. The content is solely the responsibility of the authors and does not necessarily represent the official views of Harvard University and its affiliated academic health care centers.
Chapter 1: Background

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] Important information is conveyed in the early days of a child’s illness course,[4] when distress may interfere with a parent’s ability to ask questions or seek information.[3] Importantly, the early cancer treatment period (ECTP), which we define as 33 days to <6 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”[5] that includes frequent contact with the medical system, home medical caregiving,[6] and family separation. Although some children with cancer may receive curative treatment with surgery alone, or brief treatment of less than 6 months’ duration, several common types of childhood cancer currently require 6 months or more of intensive, multimodal treatment.[7-10]

Currently, there is no standard framework to guide discussions during ECTP, after initial diagnostic and treatment discussions. In ECTP, families may be better equipped to engage with information that was initially overwhelming. This greater capacity likely results from restructuring of the family’s understanding, identity, and meaning-making that begins to occur rapidly after the initial diagnosis of childhood cancer is delivered and treatment begins (see Figure 1). We hypothesize that ECTP is a missed opportunity to consolidate key illness understanding, to enhance therapeutic alliance, and to assess and support family adaptation through structured conversation. Initial diagnostic disclosure and treatment discussions have been described as the “Day One Talk,”[4] and so we tentatively titled this proposed new
structured conversation the “Day 100 Talk” (D100) to imply a sense of the passage of time, but also connectedness to the initial diagnostic disclosure and treatment discussions.

In proposing the addition of a new structured conversation, targeted to a particular phase of cancer treatment, we are proposing a change in our communication practices, and by extension, a potential change to the process by which the relationship develops between oncology providers, patients, and families.[11,12] We are also proposing a change in practice that would require practitioner guidance and education. As such, important initial steps in the development of this proposed new structured conversation are problem identification and needs assessment.[13] The problem, as we see it, is a potential mismatch between the timing of when we provide important information to families and solicit their preferences (at diagnosis), and when families may be most equipped to engage with us about this information and about their preferences (after they have lived experience with their child’s cancer and its treatment). In terms of needs assessment, we sought to understand 1) current communication practices during
ECTP, 2) which factors might influence these current practices, such as family preferences and provider perspectives, 3) perceived communication needs, and 4) factors which might facilitate or hinder proposed changes to current practices. To examine whether our formulation of the problem and potential solution were borne out by patients’, parents’, and providers’ experiences with cancer communication during ECTP, we undertook the present study, a qualitative needs assessment among key stakeholders.
Chapter 2: Data and Methods

2.1 Brief Introduction

We elected to utilize a qualitative approach to needs assessment. Qualitative data can capture nuances of current experiences of children with cancer, parents of such children, and oncology providers, and may delineate whether and how these key stakeholders might accept and benefit from the proposed communication intervention. There is substantial precedent for this approach. Nearly thirty years ago, qualitative research contributed importantly to our conceptualization and understanding of how dying children with leukemia came to understand that they were dying, and how they showed this understanding.[14] Soon after, seminal work explored the psychological impact of surviving childhood cancer through in-depth interviews with survivors of childhood cancer and their parents.[15] Our aim, in addition to gauging the reception of our proposed D100 intervention, was to build and refine the substance and format of the intervention from the input of key stakeholders.[16] This required the flexibility and iterative nature of qualitative inquiry, as opposed to the hypothesis-driven, deductive approach more typically characteristic of quantitative inquiry.[17,18]

2.2 Materials and Methods

This study was approved by the Dana-Farber/Harvard Cancer Center Office for Human Research Studies (institutional review board). A request to waive documentation of informed consent was granted. All potential participants were provided printed information sheets that described the study, indicated that participation was voluntary and confidential, and provided contact information for study investigators and for psychosocial resources in case of unexpected feelings elicited during study participation. Participants indicated consent by participating in interviews
or the provider focus group. For minor participants, parental permission and child assent were obtained prior to interviews. All participants received modest gift cards to an online retailer.

2.2.1 Participant Eligibility

Eligible children, adolescents, and young adults (referred to collectively as “children” or “patients”) had received a diagnosis of cancer, had been undergoing cancer treatment for at least one month and less than six months, were 13 years of age or older, spoke English, were not in foster care, and were cognitively developed sufficiently to engage in an in-depth interview. Eligible parents were parents of children who met eligibility criteria, with the addition that parents of any-aged child were eligible. Eligible parents also spoke English and were deemed cognitively developed sufficiently to engage in an in-depth interview. Oncology providers, including fellow physicians, attending physicians, and nurse practitioners, were eligible if they cared for children with cancer at Boston Children’s/Dana-Farber Cancer and Blood Disorders Center. Providers who cared exclusively for patients undergoing stem cell transplantation were not eligible for participation, as their clinical experience is less relevant to the early cancer treatment period.

2.2.2 Sampling Strategy

i. Parent and Child Participants

Purposive sampling was employed to incorporate potentially divergent perspectives. Participant characteristics of interest for both potential parent and child participants included gender of the child with cancer, type of cancer, and time 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.[19] Prospective participants were identified as potentially eligible if they met eligibility criteria and the sample contained fewer than three participants of both the same type (parent, child) and diagnosis group (solid tumor, hematologic malignancy, central nervous system (CNS) tumor). We pursued theoretical sampling,[17] interviewing additional participants as analysis of existing interviews suggested potential characteristics of interest, such as hospitalization status, with a goal of achieving thematic saturation. Due to feasibility concerns, purposive sampling of other characteristics hypothesized to be of interest, such as family structure, household income, or self-identification as spiritual/religious, were not included in our sampling strategy. Nonetheless, our sample did demonstrate diversity in these realms as disclosed by participants during in-depth interviews.

ii. Provider Participants

Provider sampling was likewise purposive to ensure representation of different disciplines and levels of experience, as well as different disease expertise within pediatric oncology. In addition to eligibility criteria, we aimed to sample at least three participants from each relevant discipline and training level (nurse practitioner, fellow physician/first-year instructor, attending physician) and each disease center (solid tumor, hematologic malignancy, neuro-oncology).

2.2.3 Interviews

Interviews were conducted in-person or by telephone as desired by each participant (see Table 1), and were audio recorded. Interviews were semi-structured and lasted up to 60 minutes for parent participants and up to 45 minutes for child participants. Interview guides (see Appendices C, D) developed for these interviews contained four sections: 1. Understanding of Illness and
Impact on Life, 2. Communication with Oncology Provider and Perceived Needs, 3. Therapeutic Alliance (provider-patient-family relationship), and 4. Day 100 Talk Proposed Intervention. Interviews were conducted by a single interviewer (AMF). Another researcher (Joshua Gagne, MA, hereafter, “JG”) reviewed a subsample of early interviews to ensure integrity of the interview process. Audio recordings were subsequently transcribed, with identifying data removed.

2.2.4 Focus Group

Oncology providers were invited to participate in a focus group or an in-depth interview. The focus group was conducted by a researcher and trained focus group facilitator (JG) from the Dana-Farber Survey and Data Management Core, audio recorded, and subsequently transcribed, with identifying data removed. A focus group guide (see Appendix E) developed for this focus group contained four sections: 1. Impressions of Patients’ and Families’ Experiences and Communication During Initial Cancer-Directed Therapy, 2. Patient/Provider Relationship or Therapeutic Alliance, 3. Introduction of the Day 100 Talk Pilot, and 4. Personal Experiences with Building Communication Skills. Provider in-depth interviews followed the interview procedures described above, but the interview content followed the provider focus group guide.

2.2.5 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 method, as outlined by Charmaz.[17] We adhered to standards for rigorous thematic analysis in a healthcare context, as outlined by Pope and Mays.[20] Initial codes were developed through a process of line-by-line
coding of the complete transcript documents by a single investigator (AMF). These were refined to focused codes and compiled into a codebook, which was reviewed by a second researcher (JG) from the Dana-Farber Survey and Data Management Core for adherence to the data. Computer-assisted qualitative analysis was conducted using Atlas.ti version 7.5.10 (Berlin, Germany; AMF) and NVivo version 10 (QSR International, London, UK & Burlington, MA; JG). From focused codes, thematic categories were constructed, and links between these emergent categories explored, in order to investigate the current lived experiences of children with cancer, their parents, and their oncology providers, as well as the potential utility and acceptability of the Day 100 Talk concept in the context of these current experiences.

2.3 Results and Analysis

Parent interviews were conducted July 2015-October 2015. The provider focus group was conducted in November 2015. Provider interviews were conducted December 2015-February 2016. Seventeen parents and sixteen children were screened for participation. Of these, eleven parents and ten children were approached. Five parents declined, for a parent participation rate of 55%. Four children declined, and a fifth exited the eligibility period after being approached but before deciding, for a child participation rate of 50%. Thirty-four oncology providers (16 fellows/first-year instructors, 10 attending physicians, and 8 nurse practitioners) were invited to participate, and 18 indicated willingness to participate (53%). Ultimately, we were able to schedule a focus group of four providers, and conduct interviews with seven more (32%).

Characteristics of in-depth interview and focus group participants are shown in Table 1. 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” as described by
Dey, who notes that the term “saturation” may imply undue certainty about the dataset.[21] Charmaz likewise notes that the standard for achieving “saturation” may vary depending on the research aims.[17] Briefly, between parent and child participants, there were at least three participants whose diagnosis (or whose child’s diagnosis) fell into each of the major disease categories of hematologic malignancies, solid tumors, and CNS tumors.

Table 1. Characteristics of Interview and Focus Group Participants

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>Parent Participants</th>
<th>Child Participants</th>
<th>Oncology Provider Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Participant Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child age in years, mean (standard deviation)</td>
<td>9.9 (6.4)</td>
<td>17.8 (2.5)</td>
<td>-</td>
</tr>
<tr>
<td>Primary residence outside of New England</td>
<td>1 (16.7)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Male gender</td>
<td>2 (33)</td>
<td>2 (40)</td>
<td>2 (18.2)</td>
</tr>
<tr>
<td>Child hospitalized</td>
<td>3 (50)</td>
<td>0 (0)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Disease Category/Affiliation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNS tumor</td>
<td>1 (16.7)</td>
<td>2 (40)</td>
<td>1 (14.2)*</td>
</tr>
<tr>
<td>Hematologic malignancy</td>
<td>2 (33)</td>
<td>1 (20)</td>
<td>3 (42.9)*</td>
</tr>
<tr>
<td>Solid tumor</td>
<td>3 (50)</td>
<td>2 (40)</td>
<td>3 (42.9)*</td>
</tr>
<tr>
<td><strong>Provider Type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fellow physician/first-year instructor</td>
<td>-</td>
<td>-</td>
<td>4 (36.4)</td>
</tr>
<tr>
<td>Attending physician</td>
<td>-</td>
<td>-</td>
<td>4 (36.4)</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>-</td>
<td>-</td>
<td>3 (27.2)</td>
</tr>
<tr>
<td><strong>Participation Type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group</td>
<td>-</td>
<td>-</td>
<td>4 (36.4)**</td>
</tr>
<tr>
<td>In-person interview</td>
<td>5 (83.3)</td>
<td>5 (100)</td>
<td>3 (27.2)</td>
</tr>
<tr>
<td>Telephone interview</td>
<td>1 (16.7)</td>
<td>0 (0)</td>
<td>4 (36.4)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>6 (100)</td>
<td>5 (100)</td>
<td>11 (100)</td>
</tr>
</tbody>
</table>

*for providers, fellows and first-year instructors do not have disease-specific affiliation, so percentile is based on n=7, versus total n=11
**all focus group participants were fellow physicians/first-year instructors
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). CNS tumors included primitive neuroectodermal tumors (PNET) (2) and medulloblastoma (1). Participants included 4 mothers, 2 fathers, 3 adolescent/young adult females, and 2 adolescent/young adult males, from eleven distinct families. We achieved the a priori desired sampling frequency of at least three providers from each discipline and disease center with the exception of neuro-oncology, which is a smaller clinical group than the other two disease centers (see Table 1). Two of the four attending physicians were male, while all of the fellow physicians, first-year instructors, and nurse practitioners were female. Ten of the eleven families who consented to participate resided in New England.

After completing the patient and parent interviews, we undertook preliminary data analysis, and developed an initial draft conversation guide (see Appendix A). This draft guide was subsequently presented to providers for feedback and refinement during provider interviews and the focus group. We then revised the draft conversation guide in February 2016 based on provider feedback (see Appendix B).

2.3.1 Thematic Analysis

Thematic analysis of the data led to the inductive development of several organizing thematic categories, including illness-engendered family experiences, family communication experiences and preferences, provider communication strategies, provider values/priorities, and reception of the proposed D100 intervention. Organizing thematic categories and key subcategories are summarized in Tables 2-5.
<table>
<thead>
<tr>
<th>Organizing Category</th>
<th>Subcategory</th>
<th>Code</th>
<th>Illustrative Quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness-engendered Family Experiences</td>
<td>Learning the Diagnosis</td>
<td>Being shell-shocked</td>
<td>“I wasn’t expecting them to say that I had a brain tumor. And, same thing when they told me it was malignant... I wasn’t expecting that, either. So. It... both times... it didn’t hit me right away? ... [M]y mom said I looked like a deer in the headlights when they told me.” (Patient #5).</td>
</tr>
<tr>
<td>Feeling overwhelmed</td>
<td></td>
<td></td>
<td>“[Y]our daughter’s in getting a lumbar puncture and bone marrow biopsy, and you’re sitting here – and just hours before this all happened – right? Like, this diagnosis happened just hours before, and it happened overnight, and it was just very ... chaotic. And then, now you’re in a room talking to them about the next two years of life and what’s going to happen... all the mouth sores and the nausea, the vomiting, the... you know, the 2% chance of mortality at this stage and whatever else... just a lot of information to take in.” (Parent #4)</td>
</tr>
<tr>
<td>Anticipating loss</td>
<td></td>
<td></td>
<td>“Before I was gonna graduate, and hopefully go to med school and be a pediatrician. And, now ... I don’t... I don’t really have the time for that. You know, and I, I basically have to decide whether I risk it, and don’t have a family before thirty; or, I have a family” (Patient #2).</td>
</tr>
<tr>
<td>Experiencing life changes</td>
<td>Dividing/changing roles</td>
<td></td>
<td>“We basically [gave] up our jobs – I was a mailman ... they weren’t so friendly with givin’ me the time off I needed ... I didn’t qualify for Family Medical Leave Act, and neither did my wife... I basically resigned” (Parent #2).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“After I put them to bed, I, you know, do things like the laundry and clean up the house, and pay the bills... ‘Cause I really just want my wife to be able to ... focus on just being ... here [in the hospital] and be there for [child name]’” (Parent #4).</td>
</tr>
<tr>
<td>Family separation</td>
<td></td>
<td></td>
<td>“[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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“It affects everybody in a family. My wife and I have been apart for a month, pretty much, and kids, too? We have... [ill child] has a younger brother and sister that, they’ve all been... they’re all split, you know? ... [A]s a rule, we always spend time together. So, I—I never would have known going in ... it’s very long separation of our family to do this” (Parent #4).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“We have five kids, we haven’t seen... we’ve seen them... like, before we flew out... we missed our second son’s birthday, he... he had turned six” (Parent #2).</td>
</tr>
<tr>
<td>Organizing Category</td>
<td>Subcategory</td>
<td>Code</td>
<td>Illustrative Quotation</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
<td>------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Illness and treatment take a toll</td>
<td></td>
<td>“We’re … puttin’ all this stuff inside his body, that’s breakin’ down his … good AND bad cells, and he’s… not healthy enough” (Parent #2).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I think [about] how tough this is on everybody else who loves the person who has cancer. You know? … [I]t’s tough on the person who has cancer, that’s horrible: to see your child go through this? …[E]ven when you’re making progress… you just don’t want to see your child suffer and feel bad” (Parent #4).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I feel like my education’s been put back … because I can’t do anything during those periods of chemotherapy. And then, during the weeks we break, see, I feel like I try to get back to it, but then, as soon as I am back to it, then I have another cycle. So, it feels like I keep getting chopped off” (Patient #3).</td>
<td></td>
</tr>
<tr>
<td>Lacking control</td>
<td></td>
<td>“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 DON’T I do it? I don’t have a choice. You know? This is what I have to do for my kid.’ And, you kind of wake up and… do what he needs to do, and then go to sleep and hope the next day is as good or better than the day before. That’s what I’ve gotta do” (Parent #5).</td>
<td></td>
</tr>
<tr>
<td>Living with uncertainty</td>
<td></td>
<td>“He woke up with the sweats and I’m like, ‘Oh, god,’ ‘cause that’s what he had before, you know” (Parent #6).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“And… but not knowing is… like, the waiting is the hardest part, like… when we’re waiting on pathology, they told us it could be like a week … after the tumor was removed? And then, that week turned into two, and then, three, and I’m still waiting now” (Patient #5).</td>
<td></td>
</tr>
<tr>
<td>Coping strategies</td>
<td>Gaining new knowledge</td>
<td></td>
<td>“Um, well, I’m a biochemistry major, so I felt like I understood a lot of [what cancer was]? But, through a textbook. I don’t think I understood everything that cancer meant… until I’ve been here, so I think… I didn’t know that treatment can be a year or more, you know, I thought it was maybe like a month or two? Um, I didn’t realize … it’s changed in the sense that I didn’t realize everything that was involved…” (Patient #2).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“[I’ve learned how] to flush a line? (Chuckles lightly) How to spend a month in a hospital (chuckles). Just… it’s just been a crazy experience – stuff you never thought you’d HAVE to know, so” (Parent #6).</td>
<td></td>
</tr>
<tr>
<td>Seeking illness information</td>
<td></td>
<td>“So now, of course, we’re thinking, ‘Okay, so he’s the rarest of the rare, and, you know, what else could possibly go wrong?’ So then we were just like… just reading everything… trying to prepare ourselves for what the next year could be” (Parent #5).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I didn’t really find much, since my cancer … they still can’t really define it? They’re just calling it a PNET tumor? … I really don’t have a definition of what my cancer is? So there’s nothing I can really look online for, but …. I did Google PNET, and … I did Google chemo and radiation, you know, just to get a feel for it…” (Patient #5).</td>
<td></td>
</tr>
<tr>
<td>Organizing Category</td>
<td>Subcategory</td>
<td>Code</td>
<td>Illustrative Quotation</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
<td>------</td>
<td>------------------------</td>
</tr>
<tr>
<td></td>
<td>Still trying to do things</td>
<td>“...I still went to school and like did my homework ...I still hang out with friends and everything, so, like, I just basically have to like deal with like coming here and like doing chemo and stuff like that... the appointments and everything, but like, I basically have a normal life around it” (Patient #1).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Putting faith in medicine</td>
<td>“I just believe in the power of good, um, the power of positive thinking, um, the power... the power of medicine and research” (Parent #3).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Trusting providers</td>
<td>“Like, you know, some people do die from surgeries, but... it’s like a plane crashing. Like, what are the odds? ... [T]his is Boston, and they have some of the... most greatest surgeons and doctors that are with you every step of the way in surgery. So, I know they’re gonna do great, I trust them...” (Patient #4).</td>
<td></td>
</tr>
<tr>
<td>Transformation</td>
<td>Having lived it, we get it</td>
<td>“But I feel like now ... I’m a little more comfortable with having conversations with the doctors, because we’ve LIVED it. ...[W]hen you are waiting between diagnosis and starting treatment, you just don’t know what it’s gonna be like. You have, you know, all these ideas of what it MIGHT be like, but until you get through it, you don’t KNOW” (Parent #5).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Settling in</td>
<td>“...[I]’s a lot more normal now than it used to be. Like at first, it was like kind of weird, being like hooked up to machines and stuff, but like now it’s pretty normal? ... I’m used to it now (chuckles)” (Parent #1).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Learning to get through things</td>
<td>“[T]hey seem to GET it ... they’ll say, “Oh, we know now. We give this med now, we give this med now, we sort of figured out their pattern,” which is what I tell families: it’ll get easier with time – we learn your child, they learn themselves ... that happens within the, you know, first two cycles usually” (Nurse Practitioner #2).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“She’s been in a situation where she needed to get treatment, or perish. ...I’ve never been in that situation. ...I think just, you know, knowing that, at a young age ... if you stick through it, you stay strong ... then you can get through some pretty tough stuff ... I think that’s incredibly valuable?” (Parent #4).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“[Y]ou definitely look at things differently... like, when I was in school, you know, and just listening to some of the things that people complain about? ... [I]t’s not really a big deal, so...you just learn to get through little things that don’t really matter, that you shouldn’t get upset over, because there are bigger things to worry about” (Patient #5).</td>
<td></td>
</tr>
<tr>
<td>Organizing Category</td>
<td>Subcategory</td>
<td>Code</td>
<td>Illustrative Quotation</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
<td>------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Family beliefs/context</td>
<td>Cancer beliefs</td>
<td></td>
<td>“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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I mean, I have a great marriage. I can’t imagine how a regular marriage ... would deal with this... there’s a saying... ‘cancer kills more marriages than people.’” (Parent #1).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I was given this because I can... I can handle this, and maybe do something that I’m meant to do in my life with this? I’m... I’m gonna help others, you know?” (Parent #3).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Well, you know... my, my wife’s mother has cancer, has a form of cancer. Um, she’s been fight... it’s terminal, it’s, um... she’s gone well beyond her life expectancy with that, so it’s great, you know ... you think of a cancer diagnosis, you think about things you’ve seen that person go through” (Parent #4).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“The statistics of people that don’t make it, they must be getting treatment elsewhere. That’s what I tell myself” (Parent #3).</td>
</tr>
<tr>
<td>Co-cancer relationships</td>
<td></td>
<td></td>
<td>“I know someone that had what I have now, and they’ve been cured for about a year... she’s around my age, so like, we get along really well and we’ve hung out a few times, and like, she always like tells me... what it was like, and like, prepares me for stuff” (Patient #1).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“That’s... that’s whose been supporting me – a mother who’s about, who’s going, who’s right now with her daughter in a thoracotomy” (Parent #1).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“[R]ight down the hall, I saw this guy that I recognized ... and his daughter is, is here. Um, she’s older, but the downer is that... it came back. And so, she, she had a recurrence... just before, she hit the five-year mark” (Parent #4).</td>
</tr>
<tr>
<td>Spirituality</td>
<td></td>
<td></td>
<td>“I don’t know how to explain it, but it just... I just kind of felt like I needed to go to a Catholic Church in a weird way? ... It’s very, it’s hopeful to just... be in a room with people ... I don’t know, it’s a good feeling. So it’s not really so much spiritual, where, like, I can go read the Bible, or anything like that. But just knowing that I have this group of people that are willing to help, even though they have no idea who I am, it’s nice and they sing a lot of ... Like, I don’t know, just singing and... and, um, even on the days that I can’t sing,... just knowing that I’m part of a choir, in a sense, this is comforting” (Patient #2).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“We’re probably way more family-centered than we are church-centered” (Parent #6).</td>
</tr>
</tbody>
</table>
i. Illness-engendered family experiences

A major organizing category was that of illness-engendered family experiences. These summarize families’ reports of the transformation of their lives from before childhood cancer to the early cancer treatment period (Table 2).

a. Learning the diagnosis and experiencing life changes

Parents of children with cancer described feeling overwhelmed by the initial discussions they participated in, during which they frequently learned both their child’s diagnosis and the plan for treatment. Some patients and parents described being almost unable to comprehend the substance of these initial conversations—as though in a state of suspended animation, preoccupation, or shellshock: “I was the one taking notes. He couldn’t process, he was... his mind is, was frozen, you know, he wasn’t able...” (Parent #3). Life changes occasioned by the diagnosis and the ensuing treatment were swift and sweeping: “I say it’s like I gave birth to a disabled child, overnight” (Parent #1). While current disruptions were highlighted, anticipating loss frequently encompassed the future, altering even the patient’s previously emerging identity, such as career aspirations or expectations of future parenthood.

b. Settling in, but with ongoing worries

The subsequent early cancer treatment period was characterized by settling in, in which families’ understanding and coping capacity grew. Parents and patients note that their providers reassured them that this transition/transformation would occur: “... and you just figure out a way to do it, and you just get through it. You know? Like they said we would. ‘You’ll figure it out, and this will become your new normal’ ” (Parent #6). However, families also developed greater firsthand understanding that illness and treatment take a toll as they experienced ongoing disruptions to
their lives, physical suffering, and emotional suffering. Thus, in addition to ongoing anticipation of loss, actual losses accrued during ECTP. Likewise, worries persisted, and these worries reached back to past decisions and forward to the unknown future. Pervasive life changes were profound stressors for patients and parents, but were also embraced as opportunities to reassert values, such as savoring family time, that had been previously hard to prioritize. Patients and parents also spoke of a growing sense that they would benefit from the cancer experience, gaining new perspectives through which they were learning to get through things. At times, parents and children negotiated life changes by still trying to do things that had been important fixtures of their pre-cancer lives. Families’ settling in experiences were mediated in part by their unique family contexts and beliefs, including beliefs about why cancer had touched their lives. Importantly, parents and patients derived increasing satisfaction from their growing sense of mastery of previously bewildering aspects of childhood cancer and its treatment, and meaning from their experiences.

ii. Provider communication strategies

Providers expressed awareness of families’ experiences of suddenly finding their lives changed and subsequently adapting to these new conditions:

... I think that reality takes awhile to set in … during that first three months … they get an education on all sorts of things that, uh, they wished they’d never had to learn about. So, there’s a lot of involuntary, ‘there is no choice’ type of life-changing experience that they go through, and I think it probably impacts every single other aspect of their own life.  

(Attending Physician #1)
Frequently, providers gave a sense of passively watching this transformation during ECTP, as opposed to actively facilitating it. However, providers sought to meet perceived family needs during ECTP through several strategies (Table 3).

a. Tailoring the approach to each family

In describing their communication with patients and families, providers noted tailoring their approach to each family. For some, this meant first listening for a family’s meaning-making, and proceeding based on these perceptions. For others, this took the form of selectively engaging particular topics, typically waiting for the family to raise issues first. This was particularly true for discussions of spirituality: “I wait more for the family, to see if there is some indication that they want to, to touch on spirituality, or... or the impact of family life, because those are considered such... kind of... even... MORE difficult subjects ... So, I don’t, I wouldn’t say that I bring it up, unless I hear it from the family” (Focus Group Participant #2, a fellow physician). A common strategy to tailoring communication was repeating illness information. Some providers even tailored the number of clinical visits to meet perceived family communication needs, scheduling more visits for families who seemed to need more reinforcement of illness information.

b. Relying on intuition, listening, and surmising rather than direct queries

Despite the emphasis providers placed on tailoring their approach to each patient, few providers actively queried their patients’ and parents’ cancer-related beliefs, core values, or unique struggles, presuming that this could be anticipated, or would emerge organically if listened for: “I think that ‘what causes cancer,’ thing... is one thing that also was drilled into me, early on, just sort of without people even asking to tell them, like, ‘You didn’t cause this. You didn’t do
Table 3. Organizing Thematic Categories and Key Subcategories: Providers

<table>
<thead>
<tr>
<th>Organizing Category</th>
<th>Subcategory</th>
<th>Code</th>
<th>Illustrative Quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider communication strategies</td>
<td>Tailoring approach to each family</td>
<td>Tailoring approach to each family</td>
<td>“So, the one time I don’t usually discuss [late effects of cancer treatment] much is with, uh, diffuse pontine gliomas, um... because, unfortunately, those patients DON’T survive, uh, so, I, uh... I don’t really talk a lot about late effects in that respect?” (Attending Physician #2).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Uh, prognosis is something that’s huge, I feel like, in the patients that we take care of. And there was sort of moments of checking in about plan, and moving forward, and, um, scans... we always sort of tend to touch on that. Usually, it’s... um, based on the family’s bringing that up” (Nurse Practitioner #1).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Um... we made daily phone calls for about two months, um... which I think was helpful in... in the moment, helping anxiety, and then probably alleviating some of the phone calls to other team members, I mean in triage and other services? But, I’m not sure, overall, if it’s really changed how they’re coping” (Nurse Practitioner #2).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“We just meet with them, and some families, you know, you might need them to come back once or twice a week. So, for instance, this family I’m talking about, once they’re discharged, after consolidation I (a phase of treatment), I’m gonna have outside labs done weeks 2 and 3, ‘cause they’re holding it together. Whereas, other families, I would have come back that week. You know? You just have to kind of... oh, I know a perfect family that I have … [T]hey’re coming twice a week for Erwinia (a chemotherapy agent), and thank God … because they absolutely need reinforcement and teaching” (Nurse Practitioner #3).</td>
</tr>
<tr>
<td></td>
<td>Repeating illness information</td>
<td></td>
<td>“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, to make sure everybody knows that, “then comes this, and then we do this, and...” (Nurse Practitioner #1).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I like to go over as much as I can with them, even if it’s repetitive, to Day One (the initial diagnostic and treatment discussion) – side effects, medications, long-term effects, as well as make sure that the plan, the full plan is reviewed at the beginning, when we meet them, and do talk about prognosis things at some point, so that it’s clear that if there’s something that maybe you’ve said a little bit different, how their primary team now feels” (Nurse Practitioner #2).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I’ve found that for a lot of my patients, when they came off therapy is when I like went back and sort of reviewed the late effects of treatment… I also have tried to make a point of telling them certain things like, ‘You know, this, just so you know, and maybe we, you know, you might remember, you might not, that we discussed that, like, their fertility is NOT gonna be affected by the treatment’ that they got, because I think a lot of people just sort of, in their head they think that, ‘Of course, that’s gonna be affected.’ Even if you kind of told them at the beginning” (Focus Group Participant #4, a first-year instructor physician).</td>
</tr>
<tr>
<td>Organizing Category</td>
<td>Subcategory</td>
<td>Code</td>
<td>Illustrative Quotation</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
<td>------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Valuing/practicing truthfulness</td>
<td></td>
<td></td>
<td>“I think the one thing I like to establish with people 100% of the time is, uh, that from me and us, they’ll always get the truth. And I think establishing a truthful relationship is probably the one single thing that, uh... that is always sort of pivotal in my relationship with, uh... with any patient and their family” (Attending Physician #1).</td>
</tr>
<tr>
<td>Relying on listening, intuition and surmising, rather than direct inquiries</td>
<td></td>
<td></td>
<td>“... I’ve always felt that you have to be honest with families in terms of prognosis, so like I... just to bring up the DIPG (diffuse pontine glioma), you know, we walk into a room and someone who has a DIPG, and basically that... their child is going to die, um, from this tumor. And, it’s very unfortunate. But to say, ‘Yeah, you know, we still have hope that we’re gonna treat... cure them,’ um... that’s not really that fair to that family because they have to recognize the fact that unfortunately within a year, their child’s probably not gonna be with them. I don’t go in and say, ‘Your child’s gonna die.’ Most families kind of have an idea and they ask, they’ll ask you, ‘What’s the outcome?’ And I’ll say that the outcome is very poor, and I’ll explain what that means by saying, you know, ‘Most children are dead within a year’ (Attending Physician #2).</td>
</tr>
<tr>
<td>Strained therapeutic relationships</td>
<td>Directly querying family beliefs/context</td>
<td></td>
<td>“I think just because of the nature of how frequently they have to come, some things will just come out... even if you don’t ask them, because if people are not coming to the visits or not taking their medication, or being admitted all the time, there’s so much... or, very little that you can actually hide... um, because we just, we just see them all the time” (Focus Group Participant #2, a fellow physician).</td>
</tr>
<tr>
<td>Organizing Category</td>
<td>Subcategory</td>
<td>Code</td>
<td>Illustrative Quotation</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
<td>------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Communication</td>
<td>skill-building</td>
<td>Utilizing other providers as communication skills resource</td>
<td>“I think as fellows, we have our attendings as resources, and we can check in with them after a conversation, say, ‘How did that go?’ But, I don’t know, once you reach the faculty level what you have for anyone, hearing or giving feedback or…” (Focus Group Participant #1, a fellow physician).</td>
</tr>
<tr>
<td>Relying on experience</td>
<td></td>
<td></td>
<td>“And then, usually... um, so I learned the hard way, um, after, when I was a fellow, of giving bad news, uh, two or three weeks into treatment, as more results came back – either cytogenetics (genetic information about the tumor), or response to therapy, or things like that? So I usually warn my patients about those milestones? So then, of course, I sort of create a little bit of an anxiety? ... I make it very clear that we have... some milestones” (Attending Physician #3).</td>
</tr>
<tr>
<td>Learning through observation</td>
<td></td>
<td></td>
<td>“Um... I guess, most comfortable [topics to discuss]: acute symptoms. I feel like, you know, we see that every day, we deal with it every day and so we have, I think, most providers that have worked in this field for any length of time get very comfortable with these symptoms and can help families, and have lots of different ideas, and medicines, and techniques” (Nurse Practitioner #2).</td>
</tr>
<tr>
<td>Provider values/priorities</td>
<td>Maintaining professional identity as medical doer</td>
<td>Focusing communication on areas of expertise/control</td>
<td>“I feel less comfortable a lot of times talking about, um... the things I don’t know how to address as well? So, for me, those would be spirituality and sort of the financial... impact? Um, because I know WHO I can access as help? But I don’t... personally feel like I have the skill set to directly address those things?” (Focus Group Participant #1, a fellow physician).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I think because we have such dedicated teams to do certain things, for example, the impact, financial, job loss, and then, the kind of emotional and maybe the spiritual goes into the psycho-social provider? We kind of concentrate on (chuckles lightly) what’s supposed to be the... the ‘medical things,’ if you will” (Focus Group Participant #2, a fellow physician).</td>
</tr>
<tr>
<td>Organizing Category</td>
<td>Subcategory</td>
<td>Code</td>
<td>Illustrative Quotation</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
<td>------</td>
<td>------------------------</td>
</tr>
<tr>
<td></td>
<td>Working with multidisciplinary team</td>
<td>“You know, I think I’m good at understanding psychologic issues in families with cancer, but I’m not, that’s not my area of expertise, and so I have, again, two excellent psychologists who I know can help them with a lot of those things, and, and make sure that they get that. So I think my job, in terms of some of the emotional issues that can occur not just with the patient, but the patient’s family and the siblings, is to recognize when it’s very important that they, um... get the help they need from our psycho-social group, as well” (Attending Physician #2).</td>
<td></td>
</tr>
<tr>
<td>Maintaining professional autonomy</td>
<td>Exercising professional judgment to decide/anticipate family needs</td>
<td>“I don’t know if I get... um, I would say, just empower them the best way that they need support, um... I don’t know if I look for it, or I just sort of decide, ‘This is where they need help’” (Nurse Practitioner #3). “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, like, ‘So, how... how’s it going?’ ‘Cause I feel like the answer is usually, like, ‘Why would you even ASK me that question? Of course it’s not good’” (Focus Group Participant #4, a first-year instructor physician). “Hm... I think personally most challenging is, uh... because we’re strangers when we have to have this intimate conversation, uh... one of the greatest challenges is just getting a good READ on... on one another. Who they are, and... how... based on my perception, and guess about what they can hear and how they cope; how I can best, um... shape or tailor the communication so that they can hear it and learn it and accept it” (Attending Physician #1).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Protecting provider time</td>
<td>“Provider time. That, when you’re a busy first year fellow and running around, and like, totally sleep deprived, the idea of like planning a formal talk and, and getting the time to do it; or, maybe you have eleven patients scheduled in clinic that day. Like, I think you’d actually need to have, perhaps, a different, like, clinic scheduling thing where you get an HOUR to do this for your patient, instead of half an hour, the way your normal clinic visit [is]... I think, time is just always something that’s hard to carve out” (Focus Group Participant #1, a fellow physician).</td>
<td></td>
</tr>
</tbody>
</table>
anything wrong. This is not your fault.’ … [I]t WOULD be good to kind of find that out, but I feel like as a blanket statement, we just try to sort of say that” (Focus Group Participant #4, a first-year instructor physician). A similar approach was described by more experienced oncologists: “I ... don’t think I ask, directly? I think I just intuit ... what’s important, sort of, in terms of how much information they want; what their kind of understanding of causation is” (Faculty #4). Still other providers expressed that they reserved discussion of beliefs and values for occasions when it became clear that the therapeutic relationship was strained, or that presumed shared goals could no longer be met: “[W]e might not necessarily have time for, or even... um... feel that [spirituality and effects on the family] are important enough to change treatment decisions for, in the upfront setting, when you’re really just sort of, we’re gonna go for a cure, at the cost that we need to take, and that’s sort of everybody’s feeling in that initial setting? But, that changes, your priorities change, when you’re talking about relapse” (Nurse Practitioner #1).

Although active querying to seek out families’ cancer-related beliefs or core values was uncommon, the importance of family context was frequently acknowledged: “Sometimes … a lot of cultural things play into it … sometimes they really feel like, you know, if you speak negative... into the world, and you kind of create it, so, the less that’s said about the negative things, the better? So, I think, kind of understanding … that situation really dictates for me, ongoing conversations in the future.” (Focus Group Participant #3, a fellow physician). Given the recognized importance of family beliefs and context but the rarity of active querying, providers’ approaches suggest that gauging family needs and perspectives without relying on direct questioning is an expected professional skill.
iii. Provider values/priorities

Provider values/priorities that emerged from the data included commitments to maintaining the professional identity of “medical doer” and to maintaining professional autonomy. These were expressed in providers’ preferred communication content and in how oncology providers defined their role in relationship to the roles of other multidisciplinary healthcare team members.

a. Commitment to staying within bounds of perceived expertise

Although providers frequently adapted their practice significantly in response to perceived family needs, limits to the notion of tailoring emerged. Providers largely restricted their communication to topics on which they felt they had expertise, and on which they thought they could intervene. The role of conversation to produce subsequent action was an implicit value of many providers. Some providers also indicated that discussing “non-medical” aspects of the cancer experience, such as emotional coping, was outside their role, and therefore, a potential misuse of scarce provider time. In explaining why discussing symptoms was most comfortable, one fellow physician noted, “I think it’s the stuff that is the easiest for us to feel like we can do something ABOUT, also? … Because most of us feel like... for better or worse, I, I don’t have the training or the time to really get into … your emotional coping with this because … we have lots of other patients, and this could take hours to sort of sort that part out, and that’s why there’s a specific, like, psychosocial person who deals with that.” (Focus Group Participant #4). This commitment by oncology providers to provisioning tasks to those seen as most expert was accompanied by respect for the expertise of other members of the healthcare team, particularly nurses and psychosocial providers.

b. Provider approaches to building communication skills
Reliance on received cues and observation to gauge family needs, communication strategies that oncology providers frequently employed, mirrored the approaches providers took to building communication skills. Overwhelmingly, oncology providers cited learning through observation and subsequently relying on experience as the primary modes by which they built communication skills. This is consistent with existing literature on communication skill-building in pediatric oncology.[22-24] Nurse practitioners and fellow physicians also reported that they utilized their more senior colleagues as communication skills resources. None reported participating in dedicated communication skills workshops as training or practicing oncologists. Some had worked with standardized patients to learn communication skills as medical students. Thus, providers relied largely on observational skills to learn to communicate as well as to learn—or “read”—each family.

iv. Parent and patient communication experiences and preferences

Communication was seen by all participant types (patient, parent, and provider) as the major mediator of the provider-patient-family relationship, with the oncologist’s presence a close second (Table 4). Many parents and patients commented on how much they valued the presence of their oncology provider, and both parents and patients were usually highly satisfied with their perceptions of the quality and quantity of time spent with their oncology provider. While some parents sensed and disagreed with oncology providers’ preference for “medical” communication, others agreed that the role of the oncologist was not to provide emotional support to families, and that this role was adequately filled by existing psychosocial resources. Although most parent and patient participants indicated high satisfaction with their communication and relationship
Table 4. Organizing Thematic Categories and Key Subcategories: Parent and Parent Relationship and Communication Experiences and Preferences

<table>
<thead>
<tr>
<th>Organizing Category</th>
<th>Subcategory</th>
<th>Code</th>
<th>Illustrative Quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family therapeutic relationship and communication experiences and preferences</td>
<td>Feeling oncologist’s presence</td>
<td></td>
<td>“When I was inpatient, they would come almost every day, if not every day. And, update me about how things are going” (Patient #3).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“[Provider] was just always… She would listen and she would… answer your questions, and she would, just, if you needed her, if you called from home and she’d call you right back, you know … Didn’t matter… I don’t think it would matter where she is now, if you called her. She might not come here but she’d answer your phone call, you know? Um, she just… maybe it’s because she’s been with us since that day that… you know, you what, feel like you form a relationship with her” (Parent #6).</td>
</tr>
<tr>
<td></td>
<td>Looking to providers to lead</td>
<td></td>
<td>“[W]hat I said back to them was that, you know, ‘As far as treatment goes, we’re just—we’re handing you guys the keys to the car here.’ You know … [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? You know, study up. Um, that’s … you know, I couldn’t be any further from that -- from an oncologist! (chuckles), so… um, 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).</td>
</tr>
<tr>
<td></td>
<td>Perceiving insufficient anticipatory guidance</td>
<td></td>
<td>“[Y]ou know, I think that the, the place where… your role as an attending is heightened is when there’s badness that happens and, you know, you really… you know you have, you really have to decide on next steps and, um, you know… what, what the next right thing to do is? Um, and I… I think that both the nurse practitioners and the families look to you for that, um… the decision-making at that time” (Attending Physician #4).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I think, um, I think it’d be important for families to comment on the emotional stages that you go through, when you go through finding out your kid has cancer? Like, you know, is it like… like, death? Like when you find out someone died, the grieving stages … And do a check-in and be like, ‘Okay, a visual. Like, here, this is where you were… And, this is where we think you are now. And you’re where you’re supposed to be.’ … You know, ‘This is where you’re gonna be probably a year from now. But, you know? It’s different for different families. You may be HERE.’ You know? I think that is missing?” (Parent #3).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I think the hardest one for me was the tattoos. And so, um, I, I never considered getting a tattoo before and I know that they’re just dots, but, it was a big deal because it was all over my head and all through my spine. And um, I had no idea until I was going in. They were like, drawing on me, and I was like, “Oh, what is this… what is this for?” And they were like, “Oh, we’re going to tattoo you now,” and I was like, “WHAT?” … I cried and everything … and I was a little bitter” (Patient #2).</td>
</tr>
<tr>
<td>Valuing/practicing truthfulness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“[Our provider is] straightforward and doesn’t beat around the bush, and if we really needed to know somethin’, he’s not gonna say otherwise. And that they’ve told us many times, you know, that they’re... they’re not gonna... they’re gonna let us know when... when somethin’ happens, when we need to... to write the new chapter, or... or start a new page kind of deal, so we’re... definitely feel comfortable asking them and, and communicating with them” (Parent #2).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“You’ve gotta tell ‘em the full truth, and the fact that...for instance, she asked once, “Is it gonna go away?” You know? When... when we first told her, with the doctor, that she has cancer. You know? And she was scared, she’s like, “Is it gonna go away?” You know, and I said... “PROBABLY. But it might not.” You know? Because... I don’t believe in... lying to, to the kids” (Parent #4).</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
with their oncology providers, some noted *feeling unheard*: “[Y]ou know, we go through his whole appointment and then, ‘Oh, do you have any other questions?’ … that never feels like the time to say, ‘Well, yeah, I’m really worried that X, Y, Z is gonna happen in six weeks’” (Parent #5). A few others wished for specific changes to current communication dynamics, such as time to speak to the treating oncology provider without the ill child present.

a. *Just-in-time communication interpreted as insufficient anticipatory guidance*

The most common negative communication experience shared by patients and parents was perceived *insufficient anticipatory guidance*. For many providers, the tailoring strategy included discussing issues at the time they arose, such as initiating detailed discussions of the implications of fever in the setting of immune compromise once a child experienced fever. Patients and parents sometimes interpreted this just-in-time approach to communication as intentional withholding, perhaps with the goal of avoiding influencing patients’ experiences: “I feel like a lot of the team, they don’t tell you everything? ‘Cause they don’t want you – I think – they don’t want you to feel like, “This is gonna happen,” so, it’s gonna happen. So I feel like, for me, finding things out BECAUSE it’s happening was harder for me, ‘cause I like to know things” (Patient #2). Providers were occasionally aware of not meeting families’ expectations for anticipatory guidance, but attributed this not to a desire to withhold or mislead, but rather as their own failure to realize families’ frames and perspectives: “I think it also depends on what the family’s expectations are? For some families … 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, because they … for us, those things are normal? … [T]heir ‘new normal,’ that the family doesn’t necessarily
understand” (Focus Group Participant #2, a fellow physician). Thus, parents and providers suspected that their understandings and expectations were not entirely shared.

b. Mutually enforced silence: Provider as speaker, family as listener

Providers’ assumptions that they need not ask directly about their patients’ and parents’ cancer beliefs and core values were matched by several patients’ and parents’ beliefs that they need not tell. Patients and parents frequently assumed their personal worries, experiences, and beliefs to be universal and automatically understood. Often, they did not share relevant experiences or beliefs with their treating oncologists if not explicitly asked:

Patient #3: I was scared of cancer because there was a student at my school who died of cancer, a few years ago. But, after talking to the whole team, they assured me that I could be cured, and that most likely, it wouldn’t be fatal.

Interviewer: And... can you tell me when you had that, that conversation?

Patient #3: Just at the beginning when they were making all the choices, they told me that... if I went with chemotherapy, the success rate would be pretty high.

Interviewer: Thank you, and did... when they were having that conversation with you, did they know that you would have known a classmate who’d died of cancer?

Patient #3: I don’t think so.

Interviewer: Do they know now?

Patient #3: I don’t think so.

Interviewer: And, can you... can you tell me why... why they don’t know?

Patient #3: Well, it’s never really come up, as a topic.
Interviewer: I mean, is it something you feel private about that you wouldn’t want to talk about? Or...? 

Patient #3: Not really. Just never really came up as a conversation.

Arguably, the patient’s needs were met by the interaction with his oncologist – his worries about death were directly addressed, even though the source of them was never queried. This patient later expressed that he believed his oncologist knew his worries without being told, because he thought it “... would be the same for everyone; that you don’t want it to come back.” The faith in medicine and trust in providers that may underlie this instinct not to share are likely adaptive for families facing life-threatening illnesses. Perceived oncologist expertise can be a deep source of comfort to families.[25] But the assumption implied by patients who don’t tell and providers who don’t ask is that it is the job of providers to know and tell, and the job of patients to listen. Despite shifting concepts of the patient-provider relationship and a new emphasis on shared decision-making,[26] given the power dynamics inherent in the provider-family relationship, particularly in the setting of rare diseases like childhood cancer, this reality is not so surprising. Unfortunately, this arrangement may hinder providers’ stated value of tailoring their approach to each family—how can one tailor to unknown proportions? It may also set up the therapeutic relationship for a rocky future course, if all parties expect the provider to intuit the patient’s and families’ needs.[27]

v. Responses to the proposed D100 intervention and D100 development

As noted above, initial drafts of the proposed D100 Conversation Guide (Appendix A) were developed based on a review of the literature and from themes elaborated from interviews
conducted with patients and parents (Tables 2 and 4). The Conversation Guide was further refined (Appendix B) based on analysis of provider interviews and focus groups (Table 3). The most notable changes following provider review of the Conversation Guide were addition of a stated goal of D100 at the top of the Guide and re-ordering of the sections to assure that the conversations first addressed families’ perceived needs, prior to eliciting additional family context that might enable providers to render more tailored care. Responses to the proposed D100 intervention and the Conversation Guide are summarized in Table 5.

a. *Valuing an opportunity for a family-directed in-depth conversation*

Parents and children with cancer saw the proposed D100 intervention as a chance for *regrouping*—bringing together care providers who might otherwise all be working for the child and family, but may not be encountered together, such as the oncology provider, primary nurse, and psychosocial provider. Many providers echoed this preference for a multidisciplinary meeting, particularly citing the value of having the psychosocial provider present to ensure that key family context was known to both the oncology provider and the psychosocial provider, and to draw upon the expertise of the psychosocial provider in meeting family needs that may be identified during D100.

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 as a family in learning how to navigate cancer and its treatment, thereby boosting confidence. Furthermore, having settled in and gained new life experience with their child’s cancer and its treatment, some parents and patients expressed a wish to be able to address new questions to their oncologists from their
### Table 5. Organizing Thematic Categories and Key Subcategories: Responses to Proposed D100 Intervention

<table>
<thead>
<tr>
<th>Organizing Category</th>
<th>Subcategory</th>
<th>Code</th>
<th>Illustrative Quotation</th>
</tr>
</thead>
</table>
| Responses to proposed D100 intervention | Positive responses | Augmenting current practice | “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” (Focus Group Participant #3, a fellow physician).  
“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” (Faculty #4). |
<p>|                     |                       |                           | “I think that would be key because you see everybody in the beginning? … I would say to them at this point, ‘Okay, well… when does the psychologist come into play?’ … [A]nd then my husband could just get… an opportunity to get … clarification, which, ‘cause I’m doin’ all of it right now? ‘Cause he, he’s… working. And, I just think three months is a good time to kind of come back and any of those questions that you may be pondering in the back of your head, you could just kind of just catch up.” (Parent #3)                                                                                      |
|                     |                       |                           | “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).                                                                                                      |
|                     |                       |                           | “I would say that beyond that, then, the second conversation be, yeah, now that you’ve gotten a feel for things, you’ve got your sea legs under you about this whole situation that you’re now in, and, then you can talk about, very methodically, the next steps” (Parent #4).                                                                 |</p>
<table>
<thead>
<tr>
<th>Organizing Category</th>
<th>Subcategory</th>
<th>Code</th>
<th>Illustrative Quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaging unanswered questions</td>
<td></td>
<td></td>
<td>“... I have had limited interactions with them, just because … he’s in the hospital so much because of the fevers that he’s had... I don’t feel like we’ve really had that... conversation where the practitioners have said, “How can we alleviate any of your anxiety with... what questions can we help you answer... or, what... you know, now you’ve had time to process the full scenario...” like I feel like... a check-in, for like after... you’ve lived it for a little bit and... let’s have a meeting where we sit down and we say, “Okay... now that you’ve lived it, what questions can we answer, what are your expectations, how can we help support you as best we can?” Now that you know what you’re getting into... I think that would be really helpful.” (Parent #5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Just, like... if there’s anything I’m gonna have to watch out for in the future? Um, you know, how often I have to come back, and do follow up appointments. Um... if there’s gonna be any lasting side effects of this that... I’ll have to live with? ‘Cause, um, right now, um, after the surgery to remove the tumor, I lost my left peripheral vision in both eyes, um, which is getting better. Um, I had an ophthalmology appointment and they said it is improving. But, um, I don’t know, I still don’t have full vision? (Coughs) Excuse me. Um, so, if you know, if this doesn’t go away, something that I have to... live with, learn to live with, um...” (Patient #5).</td>
</tr>
<tr>
<td>Negative responses</td>
<td>Potential redundancy with current practice</td>
<td></td>
<td>“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).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I think looking at the specific questions, um... 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?” (Focus Group Participant #1, a fellow physician).</td>
</tr>
<tr>
<td>Could increase family anxiety</td>
<td></td>
<td></td>
<td>“I think a lot of the questions I have to ask, I don’t really want to ask? (Chuckles) ‘cause they’re scary...” (Parent #6).</td>
</tr>
<tr>
<td>Organizing Category</td>
<td>Subcategory</td>
<td>Code</td>
<td>Illustrative Quotation</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------------</td>
<td>-----------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Could increase provider discomfort</td>
<td></td>
<td>“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 IS 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?” (Attending Physician #4).</td>
</tr>
<tr>
<td></td>
<td>Anticipating logistical difficulties</td>
<td></td>
<td>“I think the thing that would, uh, encourage me to do it is, uh, if I knew that... that as I found things, there would be either someone to ask for resources – like if, if finding these things would be even helpful or easy, like if they bring a lot of, you know, spiritual things that I would actually know what to do about it? Uh, who to refer, or what the best options? Uh, THAT kind of thing? That support for... because I think a big part of the reason we don’t NECESSARILY ask some of these questions is because (chuckles lightly) we don’t want to end up with a fireball that we can’t deal with. Right?” (Attending Physician #3).</td>
</tr>
<tr>
<td></td>
<td>Format too artificial</td>
<td></td>
<td>“[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 ... it may get a little difficult, um, because we have multiple patients on multiple days, with multiple attendings, um, who are very busy doing a lot of things and 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” (Nurse Practitioner #3).</td>
</tr>
<tr>
<td></td>
<td>Time consuming</td>
<td></td>
<td>“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” (Attending Physician #1).</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Organizing Category</th>
<th>Subcategory</th>
<th>Code</th>
<th>Illustrative Quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendations</td>
<td>Tailor to individual family needs</td>
<td></td>
<td>“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” (Nurse practitioner #1). “Just thinking about being a parent and sitting there, this [conversation guide] might feel a little bit... not prying, that’s... that’s too strong a word, but I think again, it’s... really making them feel like you’re there for THEM right now, you know? ...[A]nd then I DO think that’s all of this conversation, once you’ve developed their trust and alliance around really helping them deal with what it is that THEY perceive as the problems? And I think asking these questions is ... really good and really helpful” (Attending Physician #4).</td>
</tr>
<tr>
<td></td>
<td>Make D100 timing flexible</td>
<td></td>
<td>“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?” (Nurse practitioner #3). “[M]aybe it should be more like, uh, you have this talk like, at a certain point when you’re done with this phase of treatment; rather than this day?” (Focus Group Participant #4, a first-year instructor physician).</td>
</tr>
</tbody>
</table>
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. Often, one parent was less informed than the other, due to the necessity of *dividing roles*, and their unanswered questions differed. Thus, an additional benefit that emerged was the opportunity to ensure that all members of a family felt involved and informed in the child’s cancer care. 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.

b. *Potential redundancy with existing practices, potential anxiety/discomfort*

However, some parents and many children felt that their informational needs were well met by current conversations with their oncologists. Several noted that their communication needs were anticipated and met almost before they became aware of them. However, even these participants often subsequently disclosed hopes, worries, and circumstances that they had never shared with their oncology providers, often because participants did not consider them relevant to their cancer care. Likewise, providers noted that the section of the Conversation Guide that queried current questions and concerns may overlap with existing communication during routine treatment visits. Additionally, parents occasionally expressed that engaging in D100 might increase their worries or anxiety. Providers likewise indicated that they would require support in the form of 1) education about 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.

c. *Potential logistical difficulties and provider time consumption*
When providers were asked about what might influence them to participate in a pilot test of D100, provider time and logistical complexities were cited as potential deterrents. Although patients and parents indicated overwhelming willingness to lengthen treatment visits or attend additional visits in order to participate in D100, providers preferred that D100 be fitted as much as possible into existing work patterns. For those who specifically mentioned the duration of conversation, thirty minutes was preferred. Provider time was described as a scarce resource, and the potential requirement for additional provider time was seen as the major weakness of the proposed communication intervention. Fellow physicians and nurse practitioners, who serve as “frontline” primary oncology providers, were most likely to discuss concerns about finding time for D100. Several providers noted concerns that the requirement for additional time might extend beyond the bounds of the proposed talk, citing the potential for families to raise issues that might consume further provider time through needed follow up. Interestingly, this suggested a second motivation for promoting a dynamic in which providers talk and families listen—a worry that if families begin to talk openly, the fallout will be unpredictable.
Chapter 3: Conclusions and Context

Based on our thematic analysis, we conclude that children and parents would likely value a structured conversation during the early cancer treatment period to discuss unanswered questions and regroup. Potential unanswered questions to be addressed by D100 ranged widely: some participants wished to revisit treatment decisions while others were most interested in preparing for transitions in treatment, such as changing from hospital-based to clinic-based treatments, and still others wished to discuss questions about the more distant future. Although individual questions varied, thematic analysis allowed us to generate a flexible Conversation Guide that permits providers and families to tailor D100 to their perceived needs. However, despite endorsing D100, a few patient and parent participants noted that D100 could reignite anxiety by recalling the initial diagnostic discussion and reiterating information that may be distressing, such as the potential for long term adverse effects.

Likewise, providers cited benefits of introducing a structured conversation into the early cancer treatment period, including better meeting families’ needs and potentially shoring up therapeutic relationships. However, D100 was potentially at odds with providers’ values, namely, the importance of exercising clinical judgment to anticipate family needs, protecting time, and limiting communication to personal areas of expertise (Table 3). These values might be collectively described as maintaining professional identity and autonomy. Providers recommended that the timing of D100 be flexible to account for disease-specific treatment plan characteristics, logistical considerations, and the needs of individual families. Several providers predicted that orchestrating such a conversation might be logistically cumbersome and worried that the conversation itself had the potential to be too time-consuming. Finally, in keeping with the elaborated value of tailoring communication to each family, one senior attending physician
suggested that mandating a partially-scripted conversation might be too artificial, interfering with the natural development and flow of the provider-patient relationship. Thus, although the current study suggests a clear role for D100 during ECTP, it also demonstrates potential challenges to D100 implementation.

3.1 Limitations

This study has several important limitations. Notably, the study interviewer (AMF) is a practicing pediatric oncology fellow in the center at which the research was conducted. While none of the children or parents interviewed were cared for primarily by any member of the study team, answers directed to an individual actively working in the pediatric oncology setting in which these families were undergoing treatment may differ from answers given to an individual who was truly an “outsider.” Likewise, the interviewer was a colleague or trainee of the oncology providers interviewed, and as such, their responses to questions regarding the proposed communication intervention may have been more positive than they truly felt, motivated by a desire to support the work of a colleague/trainee. Similarly, the disciplinary lens of pediatric oncology may have colored the qualitative analysis, leading to less rigorous unpacking of language that may be shared between the interviewer and participants. This is likely to be particularly true for those participants who were pediatric oncology providers. However, the input of a second analyst (JG) with a different disciplinary frame—anthropology—should buffer this potential limitation of the analysis.

Finally, this study employed a limited sample of participants from a single academic pediatric cancer center. The provider participation rate was particularly low (32%), despite initial provider interest (58%) that more closely resembled the participation rate among parents.
(55%) and children (50%). Providers who did not participate in interviews or the focus group may have had more negative views of the D100 concept than those who elected to participate. Furthermore, the views captured here may not reflect the views of key stakeholders from similar but distinct settings, or even of stakeholders from this same setting who elected not to participate in the research study. The perspectives of adolescents and young adults were represented to a greater extent than were those of families of young children. As such, this needs assessment, while helpful exploratory research, cannot definitively predict how such a communication intervention would ultimately be received, whether at the Dana-Farber/Boston Children’s Cancer and Blood Disorders Center or at other pediatric cancer centers. Rather, it serves as a starting point from which to inform future feasibility and acceptability trials of the proposed communication intervention.

3.2 Context

Despite the limited sample utilized in this study, the design and number of families represented are comparable to other works that have produced important theories of family coping following the diagnosis of childhood cancer, such as Clarke-Steffen’s work on “Reconstructing Reality.”[5] From a sample of seven families of children with leukemia and lymphoma, Clarke-Steffen identified six key strategies that families utilize to manage a diagnosis of childhood cancer: Managing Flow of Information, Reorganizing Roles, Evaluating and Shifting Priorities, Changing Future Orientation, Assigning Meaning to the Illness, and Managing Therapeutic Regimen. The settling in process identified from the current dataset encompasses each of these aspects of adjusting to childhood cancer. As such, this current work confirms Clarke-Steffen’s conceptual framework, and extends this work by demonstrating that,
as families settle in during ECTP, new communication needs and preferences arise, which are unmet by our current emphasis on an intensive, upfront diagnostic discussion.

3.3 Future Research

Future research should follow two avenues: firstly, feasibility and acceptability of D100 should be appraised through pilot testing, utilizing the Conversation Guide and a supportive educational curriculum. Given relatively low provider participation in the current needs assessment, additional acceptability assessment is particularly important. Feasibility endpoints of interest include provider willingness to participate in the educational curriculum and number of D100 conversations completed, as proxies for logistical feasibility and provisional acceptability. Secondly, the results of this qualitative research can be used to inform the design of surveys to assess knowledge, attitudes, and behaviors of key stakeholders. In future comparative studies, such tools would facilitate evaluation of patient-, parent-, and provider-level outcomes, and the impact on these of exposure to D100.
References


Appendices
Appendix A. The Day 100 Talk Draft Conversation Guide

### The Day 100 Talk Conversation Guide

#### Before beginning, establish:
- **Key players**
  - Who does family want to participate?
- **Readiness/agenda**
  - Are family and multi-disciplinary team aware conversation will happen?
  - Has family agreed to conversation?
  - Does family know what to expect?
- **Preferred communication style**
  - Examples: small chunks of info; note-taking while talking; having a trusted other in the room; (not) numbers-oriented

#### Closing:
- Summarize discussion; offer to provide a written summary
- Negotiate timing of next substantive conversation
- Follow up any issues raised

#### Right Now
- **Lead in:** Families tell us life is very different now compared to before cancer, or even compared to when they first got the news.
- What is most on your mind today?
- What is going well? (e.g. strengths, supports)
- Where or from whom are you finding support?
- What has been hardest/scariest?
- We are still getting to know each other. Can you tell me a little more about your family? (e.g. culture, spirituality, parents’ jobs, child talents/hobbies)

#### Looking Back
- **Lead in:** Families often tell us that there was so much information and shock at the beginning that they couldn’t absorb very much.
- What is your understanding about your child’s illness and likely disease course?
- What questions can we answer now? (e.g. about cancer type, treatments, expected outcome, treatment effects, how clinic works)

#### Looking Forward
- **Lead in:** We would like to talk about what may lie ahead—
  - What questions do you have about what’s coming up?
  - As you think ahead, what do you worry about/hope for?
  - Provide anticipatory guidance about next steps in treatment and/or surveillance
  - Briefly review counseling related to issues such as fertility, expected school functioning if not covered above
Appendix B. The Day 100 Talk Draft Conversation Guide Following Provider Input

The Day 100 Talk Conversation Guide

Before beginning, establish:
• Key players
  • Who does family want to participate?
• Readiness/agenda
  • Are family and multi-disciplinary team aware conversation will happen?
  • Has family agreed to conversation?
  • Does family know what to expect?
• Preferred communication style
  • Examples: small chunks of info; note-taking while talking; having a trusted other in the room; (not) numbers-oriented

Closing:
• Summarize discussion; offer to provide a written summary
• Negotiate timing of next substantive conversation
• Follow up any issues raised

Goals
• The goals of today’s talk are
  • To address any questions about your child’s illness and treatment
  • To help us understand how things are going for your family

Current Questions/Concerns
• Lead in: Often there is so much information and shock at the beginning that it’s hard to absorb very much. Also, your questions and worries may change.
  • What is most on your mind today?
  • What is your understanding of your child’s illness and its treatment?
  • What questions can we answer now?

Looking Ahead
• Lead in: We would like to talk about what may lie ahead –
  • What questions do you have about what’s coming up?
  • As you think ahead, what do you hope for/worry about?
  • Provide anticipatory guidance about next steps in treatment and/or surveillance
  • Briefly review issues such as fertility, expected school functioning, etc. if not covered above

Family Context
• Lead in: Families tell us life is very different now compared to before cancer, or even compared to when they first got the news.
  • What is going well? (e.g. strengths, supports)
  • Where or from whom are you finding support?
  • What has been hardest/scariest?
  • Can you tell me a little more about what’s important to your family? (e.g. culture, spirituality, parents’ jobs, child talents/hobbies)
Appendix C

IN-DEPTH INTERVIEW GUIDELINE – Children/Adolescents aged 13+

In all cases, remember to adapt your language to that of the interviewee. When appropriate, consider adapting the way in which questions are posed to elicit input from all interviewees.

INTRODUCTION AND OPENING (5 min)
This is a sample introductory paragraph:

➢ “Thank you for agreeing to participate in this study by talking with me today. I’m [interviewer will introduce herself]. The purpose of this research project is to understand how children and their families here at the Jimmy Fund Clinic and Boston Children’s experience childhood cancer treatment. In particular, we are interested in conversations between you and your oncology team and your relationship with your oncology doctor or nurse practitioner. The results of this research will help us think about how to have better conversations, and perhaps improve the cancer experience.

The interview will take 30-45 minutes, but if you get tired of talking, we can stop sooner. We will use a recorder to make sure we get everything you say to us. Please let me know if you would like to take a break, or if you would like to stop. [Explain incentives, including that incentive (Amazon gift card) will be given even if the participant wishes to stop the interview early]

I would also like to remind you that only members of the research team will see and hear your answers. They will not be shared with your oncology team. When the research is shared more broadly, information from multiple interviews will be presented together and without names or details that could identify you as you.

SECTION 1. UNDERSTANDING OF ILLNESS AND IMPACT ON LIFE (6-8 min)

Q1. How are things going with your cancer and your health right now?
   Probes:
   - How are you feeling about your health right now?
   - How is your family feeling about your health right now?

Q2. How has your understanding of your cancer changed over the past 3 or so months?
   Probes: What do you know now that you didn’t or couldn’t know at the beginning?

Q3. Were there certain conversations or events that shaped how you think about your cancer? If so, please describe these.
Probes [as needed]:
- Talking with your oncology team?
- Talking with other kids/teenagers/families who have experience with (your) cancer?
- Knowing/remembering someone else with cancer?
- Reading about your cancer in books or online?

Q4. How has life changed since you were diagnosed with cancer and began treatment?
   Probes:
   - What have been some of the hardest things you’ve dealt with since you’ve started treatment?
   - What have been some of the best things to happen to you since you were diagnosed/started treatment?
   - Are you in school?
   - What is the daily routine like now?

Q5. Sometimes people need to relax, laugh, or find support. Is this something you’ve needed/experienced? Tell me more about what you needed and how you got it?
   Probes: [as needed, probe individually regarding potential sources of relaxation/humor/support, e.g. friends, siblings, extended family, religious or youth group]

Q6. What does the phrase “the big picture” mean to you when it comes to your cancer?

SECTION 2. COMMUNICATION WITH ONCOLOGY PROVIDER AND PERCEIVED NEEDS (6 min)

Q7. How well do you feel like you can communicate with your oncology team (doctors and nurses)?
   Probes:
   - Do you feel comfortable asking them questions?
   - What hopes and worries have you shared with them, if any? If not shared with them, with whom have you shared hopes and worries? With whom are you most comfortable sharing your hopes and worries?

Q8. Can you tell me about the most serious or important conversation you’ve had with your oncology team so far?
   Probes:
   - What made it serious or important?
-Did you know what to expect beforehand? If yes, how did you know what to expect?
-How did it go?

Q9. When you think back to your most recent treatment visit, what did you want or need to talk about with your doctor or nurse? [ask open ended and see what the organic responses are, then consider going through the list].
   Probes:
   - Information (e.g. about your symptoms now, about what is coming next for treatment)
   - Hopes/worries (e.g. about what symptoms mean, about what this means for you in the future)
   - Emotional support (e.g. for you, for your parents)
   - Something Else

Q10. How good a job is your team doing talking about these things? [referencing answers to the above question]

SECTION 3. THERAPEUTIC ALLIANCE (6 min)

Q11. Overall, how is your relationship with your oncologist or oncology nurse practitioner?
   Probes:
   - What's going well with the relationship and what could be better?
   - What is the “right” amount for an oncologist to know or be involved with you and your family?
   - What, if anything, has helped you and your oncologist get to know each other?

Q12. Sometimes we talk about priorities and values, meaning things that are important to us. We also all have hopes and worries. How well does your oncologist understand what's important to you? How well does your oncologist understand your hopes and worries?
   Probes:
   - How do they show that they understand? Can you share any examples?

SECTION 4. DAY 100 TALK PROPOSED INTERVENTION (6-8 min)
Now I would like to shift gears. We are considering creating a planned conversation or “talk” that would take place about 3 months into cancer treatment. This would be a time for you and your oncology team to sit down together to talk in depth about how things are going.

Q13. How does this idea sound to you?
Probes: strengths/weaknesses

Q14. What would you want to/what would be important to talk about during such a talk, and who should be there?
   Probes:
   About yourselves as a family (who you are, what is special about your family)
   Hopes/Worries
   Physical Symptoms
   Emotional/Spiritual Coping
   Your future
   Effects on Daily Life
   Anything Else?

Q15. When would be a good time to have this kind of talk?
   [Can probe times, e.g. 4 weeks, 6 weeks, 9 weeks, etc. or probe on events, e.g. before surgery if not offered]
   Probe: Would you consider coming to a separate clinic visit or having a longer clinic visit in order to have this talk?

Q16. What would you name this talk, so that families could understand what it would be?

Wrap Up/Closing remarks: Ask for further comments/closing remarks, and give incentives.

Sample Wrap Up

➢ "Thank you again for taking time to talk with me about your experience with your cancer treatment, and conversations and relationships with your primary oncology team. Can I answer any questions for you about the conversation we have had here today? [give incentive]"
Appendix D

IN-DEPTH INTERVIEW GUIDELINE – Parents of Children with Cancer

In all cases, remember to adapt your language to that of the interviewee. When appropriate, consider adapting the way in which questions are posed to elicit input from all interviewees.

INTRODUCTION AND OPENING (5 min)
This is a sample introductory paragraph:

➢ “Thank you for agreeing to participate in this study by talking with me today. I’m [interviewer will introduce herself]. The purpose of this research project is to understand how children and their families here at the Jimmy Fund Clinic and Boston Children’s experience childhood cancer treatment. In particular, we are interested in conversations between you and your child’s oncology team and your relationship with your child’s oncology doctor or nurse practitioner. The results of this research will help us think about how to have better conversations, and perhaps improve the cancer experience. The interview will take about 45 minutes to an hour, but if you get tired of talking, we can stop sooner. We will use a recorder to make sure we get everything you say to us. Please let me know if you would like to take a break, or if you would like to stop. [Explain incentives] I would also like to remind you that only members of the research team will see and hear your answers. They will not be shared with your child’s oncology team. When the research is shared more broadly, information from multiple interviews will be presented together and without names or details that could identify you as you.

SECTION 1. UNDERSTANDING OF ILLNESS AND IMPACT ON LIFE (10-12 min)

Q1. What is your understanding of how things are going with your child’s cancer right now?
   Probes:
   - How are you feeling about your child’s health right now?
   - How is he/she feeling about his/her health right now?

Q2. How has your understanding of your child’s cancer changed over the past 3 or so months?
   Probes:
   - What do you know now that you didn’t or couldn’t have known at the beginning?

Q3. Were there certain conversations or events that shaped how you think about your son’s/daughter’s cancer?
Probes [as needed]:
- Talking with your oncology team?
- Hospitalizations/surgeries?
- Talking with other parents/kids/families who have experience with (your child’s) cancer?
- Knowing/remembering someone else with cancer?
- Reading about your child’s cancer in books or online?

Q4. How has life changed [for your family?] since your child was diagnosed with cancer and began treatment?
   Probes:
   - What have been some of the hardest moments/things you’ve dealt with?
   - What have been some of the best moments/things that have happened?
   - What is the daily routine like now? (e.g. work, children’s routines, life with partner, community participation)

Q5. Who/what has supported you during this time?
   Probes:
   - Emotional/spiritual support
   - Logistical or material support (e.g. walking pets, cooking meals, helping with driving or childcare, money for rent/mortgage/groceries/medical bills)

Q6. What else is going on in your life right now?
   Probes [as needed]:
   - Your own health/health of other family members
   - Job/home/school/financial worries

Q7. What is the “big picture” for you right now?

SECTION 2. COMMUNICATION WITH ONCOLOGY PROVIDER AND PERCEIVED NEEDS
(10-12 min)

Q8. How well do you feel like you can communicate with your child’s oncology team (doctors and nurses)?
   Probes:
   - Do you feel comfortable asking them questions?
   - What hopes and worries have you shared with them, if any? If not shared with them, with whom have you shared hopes and worries? With whom are you most comfortable sharing your hopes and worries?
Q9. Can you tell me about the most serious or important conversation you’ve had with your child’s oncology team so far?

Probes:
- What were you hoping to get from that conversation?
- What made it serious or important?
- Did you know what to expect beforehand? If yes, how so?
- Were key decisions made during that conversation? If so, please describe these.
- Was your child present for this conversation? How did you feel about their presence/absence?

Q10. When you think back to your most recent treatment visit [if inpatient, discussion with your primary team], what did you want or need to talk about with your child’s doctor or nurse practitioner during treatment visits? [ask open ended and see what the organic responses are, then consider going through the list].

Probes:
- Information (e.g. about common side effects, about what is coming next for treatment)
- Hopes/worries (e.g. about what symptoms means, about the future)
- Emotional support (e.g. for me and/or my spouse, for my child)
- Something else

Q11. How well were your needs met at that visit/during that discussion? [referencing answers to the above question]

Q12. How much have you talked about each of these things with your child’s doctor or nurse practitioner?
- Side effects of treatments
- How to manage symptoms
- Hopes/worries
- Prognosis
- Late effects of treatment
- Spiritual and emotional coping
- Jobs, school, transportation, childcare
- Anything else?

Q13. How satisfied are you with how you have talked about each of these things?
SECTION 3. THERAPEUTIC ALLIANCE (8-10 min)

Q14. How is your relationship with your child’s oncologist or oncology nurse practitioner?
   Probes:
   - What’s going well with the relationship and what could be better?
   - What is the “right” amount for an oncologist to know or be involved with you and your family?
   - What if anything has helped you and your child’s oncologist get to know each other?

Q15. How is your child’s relationship with his/her oncologist or oncology nurse practitioner?

Q16. We’ve talked a little bit about sharing hopes and worries with your oncology team. How well does your oncologist seem to understand your hopes and worries?
   Probes: How do they show that understanding? Can you share any examples?

Q17. In your opinion, how much does your oncologist take your hopes and worries into account?

SECTION 4. DAY 100 TALK PROPOSED INTERVENTION (6-8 min)
Now I would like to shift gears. We are considering creating a planned conversation or “talk” that would take place after you as a family have started to become more familiar with what going through treatment is really like. This would be a time for you and your child’s oncology team to sit down together to talk in depth about how things are going and think ahead about the future.

Q18. How does this idea sound to you?
   Probes: Strengths/Drawbacks or downsides

Q19. What would you want to/what would be important to talk about during the talk, and who should be there?
   Probes:
   - About yourselves as a family (who you are, what is special about your family)
   - Hopes/Worries
   - Physical Symptoms
   - Emotional/Spiritual Coping
   - Prognosis
   - Effects on Daily Life
   - Something Else
[Probe on participants as needed, e.g. psychosocial, nursing, surgeon, etc.]

Q20. When would be a good time to have this kind of a talk?
   [Can probe times, e.g. 4 weeks, 6 weeks, 9 weeks, etc. or probe on events, e.g. before surgery if not offered]
   Probe: Would you consider coming to a separate clinic visit or having a longer clinic visit in order to have this talk?

Q21. What would you name this talk, so that families could understand what it would be?

Wrap Up/Closing remarks: Ask for further comments/closing remarks, and give incentives.

Sample Wrap Up

➢ “Thank you again for taking time to talk with me about your experience with your cancer treatment, and conversations and relationships with your primary oncology team. Can I answer any questions for you about the conversation we have had here today? [give incentive]”
Appendix E

FOCUS GROUP GUIDE – Oncology Providers (ATTENDINGS)

Time: 45-60 min
Registration Method: Audio recording and note taking
Date: ___________________
Name of note taker: ___________________

In all cases, remember to adapt your language to that of the interviewee. When appropriate, consider adapting the way in which questions are posed to elicit input from all interviewees.

INTRODUCTION AND WARM UP (5 min)

➢ Thank you for agreeing to participate in this focus group today. Let’s start by introducing ourselves. [Facilitator will introduce self and then introductions go around the table]. The purpose of this research project is to understand how and when oncology providers and families here at DF/BCH discuss the experiences of cancer treatment, and how these conversations may shape families’ experiences and the relationships that develop between patients, families, and providers. We ask that each of you keep what we say here confidential. Please do not discuss anything said here outside of this room. Recordings will not be shared with your colleagues, patients or families, or with anyone else outside the research team. You will see that a member of our team is taking notes during our focus group. This will help us to transcribe the audio recording faithfully. We will not include any names or other identifiable information in the transcription of this session.

SECTION 1: IMPRESSIONS OF PATIENTS’ and FAMILIES’ EXPERIENCES and COMMUNICATION DURING INITIAL CANCER-DIRECTED THERAPY (15 min)

Intro to Section:

➢ First, I would like to focus on your impressions of patients’ and families’ experiences during the first three months of cancer-directed treatment [initial cancer-directed therapy]. If there is a particular disease with which you have most experience, please consider this disease context.

➢ QUESTION 1. In your experience, what is most difficult or troubling for patients and their families during this period?

➢ QUESTION 2. For your context, what is most challenging about communication with patients and families during this period?
QUESTION 3. Apart from the Day One Talk, when else might you have in-depth discussions with patients and families, if ever, during the first few months of treatment?

Probes:
- What prompts these discussions?
- Who usually initiates (e.g. provider or family)?
- Are these generally planned beforehand, or do they more often arise in the course of routine visits?
- What do you cover during these conversations (what is their purpose)?

I’m going to pass around a handout now that lists some aspects of the cancer experience.

Handout:

- Emotional coping
- Spirituality
- Acute symptoms (e.g. fatigue, nausea) and management
- Potential late effects of cancer treatment
- Impact on family life such as job loss, financial concerns, altered daily routines
- Prognosis

QUESTION 4. Of the aspects listed on the sheet, which areas are you most and least likely to address with patients and families, and why?

Probes:
- Are there aspects on the sheet you rarely or never discuss?
- Always discuss (with every family)?
- In your opinion, what should be covered by the attending oncology provider versus other members of the care team, such as fellows/nurse practitioners, resource specialists, nurses, or psychosocial clinicians?

SECTION 2: PATIENT/PROVIDER RELATIONSHIP or THERAPEUTIC ALLIANCE (10 min)

Intro to Section:

- Now I would like to talk with you about your relationships with patients and families in your care.

QUESTION 5. How do you approach building relationships with patients and families, and how is your role in the relationship distinct from that of the fellow or nurse practitioner who may also care for the patient?

Probes:
What does the term “therapeutic alliance” mean to you?

→ QUESTION 6. When you are developing a relationship with a patient and his/her family in the early months of cancer treatment, what do you need to know to best care for them? Are there beliefs, values, or circumstances about which you routinely ask?
  Probes:
  Cancer-related beliefs (e.g. what causes cancer)?
  Family structure?
  Religious or spiritual beliefs?
  Sources of strength?

→ QUESTION 7. What role, if any, does the Day One Talk have in forming your relationships with your patients and their families?

SECTION 3: INTRODUCTION OF THE DAY 100 TALK PILOT (15 min)

Intro to Section:
  ➢ We are interested in piloting a Day 100 Talk in our program. The idea is that the family and the primary oncology team would have a scheduled in-depth conversation after families have acclimated somewhat to the cancer diagnosis and cancer care, (about 5 weeks to 4 months into active cancer treatment), with the goal to get to know each other better, address current patient and family concerns, and strengthen communication around topics that may not be well-covered right now. We have developed a draft conversation guide for this proposed talk, which I will pass out now. I will give you a few minutes to look at the guide.

→ QUESTION 8. What do you think of this Day 100 Talk proposal, and how might it fit with your clinical practice?
  Probes:
  What do you see as strengths of the proposal?
  What do you see as weaknesses of this proposal?

→ QUESTION 9. What are your reactions to the Conversation Guide in front of you?

→ QUESTION 10. What would be helpful to include in the Day 100 Talk?
  Probes:
  Time to get to know each other better?
  Emotional/Spiritual considerations?
Review information discussed previously?
Focus on aspects not previously discussed in-depth (e.g. fertility and other late effects)?

→ QUESTION 11. What would influence your decision to participate in a Day 100 Talk pilot with your patients and their families?
   Probes:
   * Elicit worries/interests
   * Elicit time and setting factors, other barriers/facilitators

→ QUESTION 12. What do you think of calling this conversation the “Day 100 Talk?” What do you think of when you hear that name?

SECTION 4: PERSONAL EXPERIENCES WITH BUILDING COMMUNICATION SKILLS (10 min)

Intro to Section:

➢ *Finally, I would like to change gears again and talk about developing communication skills as a pediatric oncologist and teaching others to communicate.*

→ QUESTION 13. Looking back on your own training, how did you learn to talk with patients and families about issues that arise during cancer treatment?

   Probes:
   Did you learn primarily through modeling and subsequent direct experience, or did you have other experiences (e.g. formal workshop or training course, working with standardized patients)?
   In learning this way, what went well, what was difficult/challenging?
   When did you develop the approach(es) that you now use?

→ QUESTION 14. As a teaching attending, how do you approach helping fellows to build their communication skills? What role, if any, is there for conversation guides, like the one proposed?

→ QUESTION 15. What do you think of the resources available for faculty and staff interested in building on their communication skills?
→ QUESTION 16. Before we wrap up, has this discussion prompted any other thoughts that would be important to consider as we think about the potential merits or problems of designing a conversation guide for use during this early treatment period?

WRAP UP and INCENTIVES (5 min)

Sample Wrap Up:

➢ Thank you again for taking time to participate in this focus group today. Your participation has been so helpful. Please accept this gift card as a token of our appreciation for your time and thoughts. Can I answer any questions for you about the conversation we had today, or your participation in this study?