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Family Communication Practices about Death in the Setting of  
Pediatric Malignancy Relapse:  
A Qualitative Study

A Thesis Submitted to the  
Yale University School of Medicine  
in Partial Fulfillment of the Requirements for the  
Degree of Doctor of Medicine

by

Caitlin Koerber

2012

FAMILY COMMUNICATION PRACTICES ABOUT DEATH IN THE SETTING OF PEDIATRIC MALIGNANCY RELAPSE: A QUALITATIVE STUDY.

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ABSTRACT: This qualitative study was undertaken to describe adolescent and parent thoughts and fears about the adolescent patient's possible death following relapse of a pediatric malignancy. Other aims were to characterize the range of communication styles used by families to talk about death with one another, and to identify contexts in which communication about their thoughts and fears takes place. Semi-structured, one-on-one interviews were conducted with four patients and seven parents by a single interviewer. Interviews were recorded and transcribed. Multiple coders used NVivo9 software to identify emerging themes through inductive qualitative analysis. This study found that families used a range of communication practices to share information about their experiences living with cancer. These communication practices include open communication that discloses all information, avoidant communication that restricts information exchange, and honest communication that consists of sharing information upon request. Communications about the patient's possible death occurred in the context of discussions of fears about the patient's death, fears of the patient's relapse, the patient's near death experiences, experiences with the deaths of other patients, and patient's thoughts about stopping treatment. In general, family feelings about communication align such that parents and patients share a common communication style across a range of contexts for communication about death. However, families may change their communication style from one context to another. In all, greater differences exist between families than within them. Physicians must identify which communication

style may be helpful to families in discussing death in order to assist them in meeting their information needs with this stressful topic.

## ACKNOWLEDGEMENTS

This thesis is dedicated to the six families who shared their stories with me.

Their words will stay with me always.

I would like to thank my advisor, Dr. Megan McCabe, whose generosity in taking on this project, and whose patience and perseverance in overcoming its challenges has ensured its success.

I would like to thank Dr. Joseph McNamara, who acted as the pediatric oncologist affiliated with the project, and who lent his expertise to the study design.

I would like to thank the faculty of the Section of Pediatric Hematology and Oncology at Yale for welcoming me into their clinics and for supporting subject enrollment.

I would like to thank the Yale Pediatric Hematology and Oncology social work and counseling staff for their help in ensuring the emotional and psychological well being of the families who participated in this study.

Support for this research was provided by  
The Yale University School of Medicine Office of Student Research via  
Short-term research funding (2011-2012)

Thank you to Donna Carranzo, Mae Geter, and Dr. John Forrest.

Financial and administrative support was also generously provided  
the Yale School of Medicine Department of Pediatrics.

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## I. INTRODUCTION

Communication between patients and parents is an important aspect of coping with the inherent stress of receiving a pediatric cancer diagnosis and undergoing treatment. Communication with adolescent patients poses a particular challenge to parents as these patients are often mature enough to understand the life-threatening nature of their illness (1). When adolescent patients with cancer experience relapse, patients and parents face increasing concerns for the patient's survival. Some families may avoid candid communication about the possibility of the patient's death out of a concern for the patient's loss of hope (2). However, a lack of communication about death may isolate patients who recognize that they may die from their disease (3). In order to help families navigate the emotionally challenging experience of living with cancer, physicians must understand how patients and parents communicate with one another about the possibility of the patient's death.

### **Communication in the Pediatric Oncology Triad**

Pediatric medicine revolves around the triad of the physician, the patient and his or her parents. As in other areas of pediatrics, pediatric oncologists must work closely with parents to care for their children. Many pediatric oncology patients lack the developmental maturity to participate in detailed communication about their illness with physicians. Parents play a vital role in mediating the exchange of information between the oncologist and the child. Much of what children learn about life-threatening diagnoses depends upon what their parents tell them. Pediatric oncologists seek to maximize patients' involvement in their care by communicating openly about diagnosis



and treatment in a developmentally-appropriate manner and by encouraging parents to do the same (4). Parents may or may not emulate that openness when sharing illness-related information with their children.

Parents may withhold different kinds of information about cancer from their children for different reasons (5). Some parents choose to withhold information because of the uncertainty of the prognosis (6). Other parents are reluctant to disclose information because of their concerns that their children are too young to understand information about their disease (7). Some parents avoid sharing information in order to protect their children from additional psychological suffering or from loss of hope (5, 6). Parents may resist talking about some sensitive topics because of their lack of experience in doing so, or because of the stressful nature of such communications (6, 8-11).

The literature is full of anecdotal evidence that families display different degrees of openness when they share information (12). However openly parents share information with their children about cancer, many parents must face the difficult question of how they and their children will cope with the fact that their children may not survive the disease.

### **Factors Affecting Communication about Death in Pediatric Oncology**

Death and dying are especially challenging topics for families and physicians to discuss together. While the majority of pediatric oncology patients survive, 25% of patients die from the disease despite treatment (13). Different factors influence communication about death between physicians, patients and parents. These factors include physician communication practices, family readiness for communication,

adolescent participation in care, and the presence of discordance in adolescent and parental information needs.

When families are confronted with a poor or worsening prognosis, physicians must find ways to communicate about end-of-life (EOL) issues with families. The majority of pediatric oncologists agree that children should be informed about the possibility of their death through open communication (10, 14-16). However, pediatric oncologists report anxiety about disclosing the likelihood of a patient's death to families despite the fact that those physicians otherwise feel "very competent" in communicating with dying patients and their parents (17).

Physician communication is an essential component of care for families facing a child's death from cancer. In one survey, parents of children who died of cancer report that sensitive communication from physicians is the principal determinant of high-quality care (7). While many parents have positive experiences with providers in communicating about the possibility of their child's death, the communication needs of some families are not met by current physician practices. Another study found that some parents experienced the delivery of a bad prognosis for their child as insufficient, confusing, or uncaring (18, 19).

Even though parents place a high value on compassionate communication about their child's prognosis, physicians report that a lack of patient and parent "readiness" is one of the primary barriers to the initiation of discussions about EOL issues (17). In one study, this lack of family readiness was associated with unrealistic parent expectations for the patient's outcome, and with differences between physician understanding and patient/parent understanding of the prognosis (20). Parental concerns about patients'

emotional distress and loss of hope, may cause some families to avoid candid communications about the possibility of death (2, 3, 21, 22). However, the withholding of information from adolescent patients may constrain their ability to participate in their own care.

It is widely recognized that some adolescent patients can attain the cognitive and experiential maturity needed to express personal values regarding care for a terminal condition (1, 10). Professional guidelines encourage physicians to insure the developmentally-appropriate inclusion of adolescent patients in shared decision-making about their care (23, 24). Research has shown that adolescents are interested in and capable of participating in EOL discussions (25). In one survey, 88% of healthy teens and 96% of chronically ill teens reported that they would want to share decision-making about their care if they became very ill (26). These patients wanted their physician to initiate discussion about EOL issues, and they wanted to share decision-making power with their families. Another study interviewed adolescents with advanced cancer, shortly after they had participated in an EOL decision such as enrollment in a phase I trial, adoption of a Do Not Resuscitate order, or initiation of terminal care (27). The patients in this study understood their own death as a consequence of their decisions.

In order to express their preferences for EOL care, different patients may desire different levels of disclosure of information about their prognosis (9). Physicians do not always understand what their patients want to know either. While the majority of patients and physicians in one study agreed on the extreme importance of an adolescent knowing how serious her illness is, 84% of adolescents believed that it is extremely important to know what to expect if cancer spreads. By contrast, 55% of physicians thought it slightly

important or unimportant for them to know this (28). What is more, patients and parents do not always agree on how or when patients' prognosis should be shared with them. One survey showed that a majority of children with cancer wanted to be told a percent chance for cure, no matter what it is, while only a minority of parents wanted their children to be given this information (22). Some parents may seek to protect their children from prognostic information which they believe threatens their child's sense of hope (2). However, parental silence on the possibility of the patient's death is not without consequences for patients and parents alike (3).

### **Repercussions of Avoiding Communication about Death**

Ill children are often aware of their risk of dying (1, 14, 29). Signs that a child wants to talk about death may be subtle, and these signs can be missed by parents. Parents may believe their child is unaware of death, or may be afraid to confront their own fears about their child's possible death (23). In turn, patients may hide their emotions or remain silent in order to protect their parents from distress (6, 30, 31). As a result, patients may feel isolated when parents and physicians limit or postpone communication about the possibility of death (8, 29, 32).

Parents as well as patients may suffer when families avoid discussing the likelihood of the patient's death (33). In a study surveying parents of children who died of cancer, none of the parents who talked to their child about death regretted their decision to do so. Almost one third of parents who refrained from talking to their child about death did regret the fact that they had not talked about it. Parents who sensed that their child was aware of his or her impending death were significantly more likely to

regret not having talked about it compared to those parents who did not sense this awareness in their child.

Physician-patient-parent communication is a key factor in a family's psychosocial adjustment following a patient's diagnosis with cancer (19, 29, 32, 34). Communication about the possibility of death is an especially difficult, but none the less important, issue for families of adolescents with cancer. Different studies have examined physician-family communication practices in hopes of improving communication within the pediatric oncology triad, and some studies have looked at communication of prognosis to better understand how physicians can support family communication about the possibility of the patient's death.

### **Previous Studies of Physician-Family Communication**

A range of studies have described different facets of physician-parent (20, 30, 35-38) or physician-patient communication (30, 38) to assess family information needs about cancer diagnosis and treatment. Some studies have examined information content exchanged between patients or parents and physicians (22), while other studies have solicited patient or parent views on important qualities in physician communication style (7, 18, 19). Such studies have helped to establish ways in which physicians can share information about cancer with patients or parents in the most effective manner.

Several studies have looked at parent preferences for physician-patient communication (30, 39) and found intrafamilial variability in the degree of openness desired by patients and their parents. In one study, some parents reported that they wanted physicians to be open and straightforward with the child (30). However, a few parents reported that they preferred to be the first to receive any bad news from the

physician without their child present, so that they could later serve as the filter for the information when presenting it to the child. By contrast, their children wanted to receive information, including “bad news,” directly from the physician without their parents filtering it.

Another study looked at patient preference for participation in physician-parent consultations (38). Some patients wanted to be present for all such consultations, while other patients preferred to receive information from their parents who acted as communication buffers between patients and physicians. When patients were not present for physician-parent consultations, some patients believed that important information about their illness may have been held back from them. These studies confirm that physicians must tailor their information sharing with patients and parents based on a patient’s preferred source for receiving information.

Various studies have explored physician-family communication about a patient’s poor or worsening prognosis to better understand information needs surrounding this sensitive topic (8, 36, 37, 40). Some studies found that parents’ estimates of their child’s chance for cure were more optimistic than the physicians’ estimates (37, 40, 41). Another study found that a majority of patients did not receive any prognostic information at the time of diagnosis (8). Some patients in this study were told about their prognosis later when their illness worsened while others “figured it out” themselves. Physicians served as the primary source of prognostic information, and adolescent patients received more specific prognostic information than younger patients. It is clear from these studies that parents do not always understand their child’s prognosis, and that patients’ access to prognostic information varies widely. While physician-family communication in

pediatric oncology has been well studied, less is known about patient-parent communication about cancer distinct from physician-family discussions.

### **Communication about Cancer between Patients and Parents**

Patients and parents communicate together apart from their discussions with physicians in order to address concerns about illness with one another. This intrafamilial communication plays an important role in how families cope with their cancer experiences. Pediatric oncologists must take patient-parent communication into account when assessing a family's information needs about the patient's illness.

Family members play different roles in giving and receiving communication. One qualitative study asked adolescents and their parents about communication management in their family regarding the child's cancer diagnosis (9). Many parents identified themselves as "communication executives" who controlled information boundaries for their children. Patients described different ways in which their parents facilitated communication, though they sometimes felt marginalized or constrained when their parents imposed limitations on information sharing. Some families reported a shift in their communication management over the course of illness to a partnership style with open and equal exchange of information. All families reported that patients use their parents as communication resources.

Some researchers have proposed specific frameworks to characterize the spectrum of patient-parent communication practices about cancer. These frameworks commonly compare communication styles in which parents share all information with their children with styles that involve the withholding of information. One review referred to these contrasting approaches as the "open" approach and the "protective" approach to

communication (5). How families communicated about the possibility of death proved to be a key factor in distinguishing these two broad approaches.

Some studies assigned families to different categories of communication, which ranged in degree of “openness” from no communication to full communication (6, 42, 43). Minimal information sharing acknowledged illness without specific diagnosis. Ambiguous information sharing acknowledged the diagnosis (leukemia, Hodgkin’s lymphoma) without identifying it as cancer. Factual information sharing disclosed the diagnosis as cancer without mentioning the severity of illness. Full information sharing acknowledged the patient’s cancer as life-threatening. In all of these studies, acknowledgement of the possibility of the patient’s death determined whether parents and patients communicated with complete openness.

Glaser and Strauss discussed family communication practices about death in terms of “awareness contexts” which may motivate families to share more or less information (44). These contexts include closed awareness, suspected awareness, mutual pretense awareness and open awareness. In the closed awareness context, parents recognize the possibility of the patient’s death but hide it from the patient who is unaware of the possibility. In the suspected awareness context, the patient suspects that he might die and tries to confirm or deny his parents’ awareness of this possibility. In the mutual pretense context, hereafter referred to as mutual pretense, both patient and parent recognize the possibility of the patient’s death but neither acknowledges it. In the open awareness context, the patient and parent are both aware, and they share their awareness with one another. Depending on which awareness context exists in a family, parents and



patients may communicate openly about the possibility of the patient's death, mutually acknowledge the issue without discussion, or avoid discussion of the issue.

### **A Qualitative Approach to Patient-Parent Communication about Death**

A better understanding of the range of family communication practices about death may help pediatric oncologists to support family coping with the possibility of the patient's death. Qualitative research methods are useful for describing a phenomenon like family communication about death from the perspective of the individuals experiencing the phenomenon (45). The rich details of patients' and parents' personal experiences may be captured as data through the use of open-ended interviews which allow the participant to determine the content of the information that best represents his or her experience (46). This study seeks to describe family communication about death through an analysis of patient and parent thoughts and fears about death, focusing on the contexts in which communication about death occurs, and on the range of communication styles used to express these thoughts about death.

This study proposes a framework for family communication based on three communication styles used by participating families to talk with one another about diagnosis, prognosis and treatment. Open communication indicates a patient's or parent's full disclosure of all information. Avoidant communication reduces information sharing by minimizing general communication or by withholding specific information. Honest communication by parents conveys accurate information but only at a patient's request. With this framework in mind, physicians caring for children with malignancy may better support family concerns about the patient's prognosis whatever it might be.

## **II. STATEMENT OF PURPOSE and SPECIFIC AIMS**

This thesis aims to qualitatively describe the experiences of adolescent patients and their parents in communicating about issues of death and dying in the setting of pediatric malignancy relapse.

Specifically, this thesis aims to:

- Expand current understanding about how adolescent patients and their parents think about the possibility of the patient's death in the setting of malignancy and relapse
- Identify key contexts in which patients and parents share their thoughts and feelings about the possibility of the patient's death
- Describe the range of styles in which patients and parents communicate their thoughts about death

### III. METHODS<sup>1</sup>

This qualitative study involved the analysis of one-on-one, semi-structured interviews of patients and parents performed by a single interviewer. The open-ended questions prepared for the interview guide addressed the experiences of each family with a child's initial diagnosis with cancer and subsequent relapse, focusing on communication about issues of death and dying. Interviews were performed in person, recorded, and transcribed. Multiple coders used a constant comparative method of analysis to identify emerging themes.

#### **Subject Population**

The goal of the study was to explore family communication practices about issues of death and dying. Purposive sampling was used to select a specific subset of patients from a larger population of patients in order to maximize the likelihood of capturing the desired phenomenon (45). Subjects were recruited from families with children diagnosed with pediatric malignancy who had been given a poorer prognosis and so were believed to be more likely to think about death. Eligibility criteria were used to select patients with poorer prognosis. To be eligible for participation in this study, patients must have had a history of relapse or primary diagnosis of a malignancy carrying a survival rate of less than 50% as estimated by the primary pediatric oncologist.

Patients and parents had to be English-speaking, and patients had to be between the ages of 13 and 25. This age criterion for participation was selected to ensure that patients had developed a mature understanding of death (14). Parents and patients were

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<sup>1</sup> All stages of this study were completed by Caitlin E. Koerber (CEK). Input from others is credited where appropriate.

permitted to enroll independently, though patients under age 18 required parental informed consent for their participation.

Families were referred to the study by faculty from the Section of Hematology and Oncology in the Department of Pediatrics at Yale. Eligible families were recruited from the clinical practices of faculty at the Yale Pediatric Hematology Oncology Clinic (Guilford, CT) and from the Pediatric Oncology Program at Smilow Cancer Hospital (New Haven, CT).

### **Procedure**

Once a family was identified as eligible, permission to approach the family was solicited from the primary pediatric oncologist. If permission to approach the family was granted, a letter of introduction to the study was provided to the family, either by mail or at their next clinic appointment. Families interested in participating gave informed consent following an in-depth explanation of the study's purpose, risks and benefits (CEK). Parents provided written informed consent themselves and for patients under age 18, while the patient provided written assent. Patients who were age 18 or older provided written informed consent to participate. Consent and assent documents were later signed by the primary pediatric oncologist.

All interviews were conducted by a fourth year medical student (CEK), who had participated in the Yale School of Medicine clinical skills program, which strongly emphasizes patient-centered interviewing. The interviewer received additional training prior to the interview process from Yale Department of Pediatrics faculty with expertise in addressing difficult issues for pediatric patients and their families. The interviewer had

not provided care to the participating families, and she was first introduced to patient and parent subjects at their recruitment to the study.

Interviews took place in person in a private room, either in the clinic or hospital where the family received care. A one-on-one approach was chosen to maximize subject comfort in discussing the potentially distressing interview questions. During the consent process, each subject was informed that the interview was voluntary and confidential, and that he or she could end the interview at anytime or refuse to answer any question. These rights were reviewed once more at the start of each interview. The interview guide developed for the study relied on a subject-centered approach with open-ended questions. The researcher generated the interview guide questions from the literature with input from the faculty advisor and from pediatric and child psychology faculty. In order to put subjects at ease, introductory questions were asked about subject demographics and current pursuits. These questions were followed by the main interview (See Appendix A for complete interview guide.) Closing questions asked subjects to identify personal strengths, coping skills and helpful resources so that interviews might end on a positive note. Additional prompts were used as needed to clarify concepts, elicit detail, and extend narrative (47). These included questions such as, “What was that like?” or “Can you tell me about that?,” as well as echoes of the subject’s words to focus attention on what he or she had said.

All interviews were digitally recorded with an Olympus DS 3400 audio recorder. The interviews were then securely uploaded to ASP.MD, an independent, confidential medical transcription service (CEK). The completed transcripts were electronically received, and reviewed for accuracy (CEK). The study design received expedited

approval by the Human Subjects Committee of Yale University, IRB Protocol # 1105008534.

### **Ethical Considerations**

Special procedures were put in place to safeguard subjects from undue distress because of the vulnerable status of the subject population. The primary oncologist had to give permission for the researcher to approach eligible families. Subjects had access to social work, psychiatric, and spiritual support services during their interviews. The interviewer used predetermined cues for subject distress to offer access to additional support or to pause the interview while subjects recovered from their distress. At the end of his or her interview, the subject received written contact information for psychiatric and social work services in anticipation of his or her possible need or desire to speak further with a counseling professional after the interview.

The faculty advisor was present as a silent observer during the second interview and provided feedback to the interviewer on her interview technique. The faculty advisor also reviewed audio recordings of two subsequent interviews to ensure that the interviewer's interviewing style was appropriately subject-centered and sensitive to subject expression of emotion.

### **Data Analysis**

This study utilized the constant comparative method (CCM) for data analysis which is derived from a grounded theory approach to qualitative research (48). Grounded theory seeks to generate theory that is grounded in the data to ensure the relevance and applicability of that theory. With CCM, the process of comparing allows the analyst to

recognize conceptual patterns as she generates categories and assigns data segments to those categories (49).

A systematic approach to CCM was based on the step-by-step guidelines published by Boeije (49). Fragmenting and connecting steps played a key role in the comparison process (49). Fragmenting allowed the analyst to generalize data segments by separating them from the context of the interview from which they came. Connecting created relationships between data segments as they were restored to the context of their respective interviews. Comparisons were made within each individual interview, within the patient group, within the parent group, and between the patient group and the parent group. When a patient and at least one parent were interviewed from a family, comparisons were made at the level of the family and between families.

At the onset of analysis, the transcribed interviews were uploaded in NVivo 9, a workbench for qualitative data analysis. As a first step, the two researchers read the interviews to familiarize themselves with the data (CEK, MEM). They independently formulated initial categories across the data by identifying key phrases and applying labels to capture their meaning. They shared these provisional code labels for categories until consensus was reached on a provisional code tree. Then, each interview underwent open coding where each data segment was reviewed and assigned to the appropriate category or categories (CEK, MEM). As new data segments were added to existing code categories, they were compared to the segments that were already coded for that category to determine how their inclusion contributed to the definition of the category. Codes for the individual interviews were reviewed jointly to reach consensus on interpretation of the coded segments and evolving categories (CEK, MEM). This process led to a final

code tree of categories in which several codes were renamed or merged to better reflect the patterns emerging from the data (CEK, MEM). Memos were kept throughout the coding process to document relationships between categories as well as preliminary theories about these relationships (CEK).

Once the final code tree was established, comparisons were made between interviews within the patient group. These comparisons allowed for expansion of code words until all relevant themes were covered and concepts represented by each code were described (49). Patterns in which several related categories combined were identified to establish profiles. This process was repeated for interviews within the parent group. Triangulation through comparison of interviews from the patient group with interviews from the parent group helped to enrich the information for each group and to complete the picture of the family experience from the perspective of each (49). Triangulation also took place in the comparison of patients to their parents within families when possible. Final comparisons were made between family units.



## IV. RESULTS

### Study Enrollment

Primary oncologists gave permission for recruitment of thirteen eligible families who were provided with the letter of introduction to the study. Two families who received the letter of introduction by mail did not respond and were unavailable for contact. Two families who received the letter of introduction from their oncologist during a clinic appointment declined participation in the study with that information alone. One family declined participation following explanation of the study during a clinic appointment (CEK). This family agreed to follow-up contact one month later, and declined participation again at that contact, at which point their participation was complete.

Of the eight families who consented for participation, one patient-parent dyad withdrew prior to scheduling an interview. This family agreed to follow-up contact one month later, and declined participation again at that contact. This family was the only family recruited on the basis of the patient's initial prognosis of < 50% chance for cure. As a result, no families recruited on the basis of this eligibility criterion were included in the study.

One patient who consented for participation withdrew prior to scheduling an interview, though her mother continued participation and completed an interview. One patient-parent dyad consented for participation but was unable to make the interview appointment prior to the close of the study despite maintaining interest in participation. For one family, the primary oncologist recommended recruitment only for the mother since knowledge of the study would be distressing for her child. This mother completed

participation though her daughter was not approached for recruitment to the study. Six consented families completed interviews for the study. These families were represented as three patient-parent dyads, two individual parents, and one family with the patient and both parents participating.

Reasons for declining participation or withdrawing from the study included feeling overwhelmed by current treatment experience, not feeling well, changing one's mind, or the timing of the invitation to participate coming too soon after relapse diagnosis. Interviews lasted between 30 and 170 minutes, with a mean of 82 minutes (SD 49 minutes). No incidents of undue distress occurred, and no subject required access to additional support services during his or her interview.

## Subjects

Eleven interviews were completed with four patients and seven parents. Subject demographics are shown in Table 1.

Table 1. Subject Demographics. Parentheses indicate that a family member did not participate in the study. Ages are given in years. ALL (Acute Lymphoblastic Leukemia). Rx (completion of treatment for relapse).

Family #	Age	Race	Education Level	Diagnosis	Age at Diagnosis, Relapse	Treatment phase
Father 1	71	Caucasian	College Graduate	-	-	-
Mother 1	65	Caucasian	College Graduate	-	-	-
Son 1	25	Caucasian	College Graduate	ALL	15, 19	6 yrs since Rx
Mother 2	54	Caucasian	High School Graduate	-	-	-
Son 2	19	Caucasian	High School graduate	Osteosarcoma	17, 18	Active Treatment
Mother 3	42	Puerto Rican	Associate's Degree	-	-	-
Son 3	22	Puerto Rican	Some High School	Hodgkin's lymphoma	12, 16	3 yrs since Rx
Mother 4	47	Caucasian	College Graduate	-	-	-
(Daughter 4)	16	Caucasian	High School Sophomore	Osteosarcoma	12, 13	Active Treatment
Mother 5	57	Caucasian	High School Graduate	-	-	-
(Daughter 5)	15	Caucasian	High School Sophomore	Hodgkin's lymphoma	13, 14	2 months since Rx
Mother 6	49	Caucasian	Master's Degree	-	-	-
Son 6	18	Caucasian	High School Senior	Rhabdomyosarcoma	16, 16	1 yr since Rx

## Communicating with Children about Cancer

### Openness, Avoidance & Honesty

Parents found themselves weighing openness, avoidance, and honesty in communicating with their children about their cancer experience. Parents' openness in communication indicated willingness to volunteer negative information as well as positive information in the spirit of full disclosure. When asked if there was anything he didn't talk about with his son, one father replied:

*No. Not at all. Everything was open for discussion. I can't think of anything that I say, "We will talk about later," to put something off. There may have been a reason not to talk about this instant but within a short period of time, we will discuss it. You have to be open with your kids. Kids know when you are lying. They know their parents.*

Parents practicing open communication discussed the full spectrum of cancer experiences from interactions with providers and community members to treatment decisions to emotions associated with treatment. "We would always like talk about like everything—anything that just happened." One parent identified her open communication style as an established part of her parenting before her child was diagnosed. She described this style as supporting her family's well-being and strengthening her relationships with her children. "For me as a parent, having that open and honest relationship has been really healthy and it's kind of been my guiding philosophy all along."

Patients whose parents communicated openly also reported communicating openly about their experiences with cancer. Openness allowed patients to express emotions, share needs, and obtain information about their care.

*I think that was just my way of coping, being open with it and letting people know. Instead of maybe holding all the thoughts of what I'm going through in, just out.*

One patient reported that he was uncomfortable with sharing his experiences at first, although later he became open with his family about his experiences when he recognized that they were comfortable hearing about them.

*When I first felt it, and, like, I told my parents about it, I didn't even want to tell [my sister] because it was paratesticular. It's like not really something you talk about with your sister. Once we talked about it, it was more—it was open like—that's how I feel about everything now because like it's going through this whole thing has made me like, "Okay, doctors are used to seeing all this and hearing about all this." Like there's nothing to be ashamed of or anything and so we—like at my dinner table we would talk about like [am I] having diarrhea today.*

Not all families shared positive and negative information about their cancer experience with one another openly. Parents avoided communication with their children in several ways. One mother reported minimized communication about her family's cancer experience to provide a sense of normalcy.

*We don't really talk. I mean we talked about [my daughter's cancer diagnosis] at the time, but it is not something that we dwell on at home. We try to make home as normal as possible and just go about our daily activities. You get ready for school. You go to school. You come home. You do your homework.*

Some parents withheld specific information from their children to protect them from additional stress. One mother avoided raising the question of her son's fertility, although she believed he was aware of some complications of his treatment.

*At one point my husband said, "Do you want to sit down and talk to him about the fact that, you know, we don't know if he'll be able to have children." I said, "Not yet." ... At some point we will sit down, but I just felt like there was too much he had to deal with at that point, and I also think that we talked about that, you know, radiation there will be some permanent scarring, and I think [my son] knows that already. I don't want to hide it from him but I just was kind of like, there was like so much. I was like, "Why?," you know? It's a possibility but it's not a definite thing, you know? So do we need to bring it up right now?*

Patients sometimes minimized communication to get a break from being surrounded by constant conversations about their diagnosis and treatment. One patient sought normalcy by avoiding such conversations while spending time with his sister in the hospital and at home. He continued to communicate openly with his parents because of their direct involvement in his care.

*I think, like, in the hospital, I didn't really want to talk about any of that stuff because I was—you're kind of living it already. Yeah, and so like [my sister and I] just kind of watched movies and stuff, and then, out of the hospital, it was the same way. Like, I was out of it. I was done with it so I didn't really want to talk about it that much. But like we—my parents obviously talked about it a lot because they—were taking care of everything.*

Another patient avoided communication with his mother out of a sense of futility. When asked if he talked to his mother, he replied:

*No. I keep to myself, most of the time... Honestly, I really keep to myself. I don't, like, complain, yeah... Not worth it. Too much energy to complain. It's not really going to fix nothing so...*

Some parents described their communication style as “honest.” In this study, honest communication implied a willingness to share information with a child who had asked about a particular issue. This kind of honest communication represents a combination of openness and avoidance in which families share limited information based on the patient's information seeking behaviors such as asking questions. One parent represented this communication style as patient-driven, and she based her communication practices on her daughter's preferences for receiving information.

*I will tell her anything that she asked me. It's—and if I don't know the answer I will find out for her. Because she does do that sometimes. She'll say, “Well, what about this Mom?” And I'll say, “Well, I'm not sure.” So I will find out, and she will hold me to it until I get that answer... If she wants an answer, she wants it.*

Some parents struggled with the openness required for honest communication. For one mother, communicating with honesty meant confronting her own discomfort with the word “cancer” when her daughter asked directly about her diagnosis.

*She's not one to just say, "I've got cancer." You know? I don't think she's ever even said the word. No, actually she has because at first I was being—I was saying, "You have Hodgkin's disease." I didn't want to say the cancer word myself, and she's like, "Well what is Hodgkin's?" and I said, "Well, you know," and I explained how the cells and all this and everything. She goes, "Mom, is that cancer?" And I'm like, "Yeah." And that was like, you know, I have to be honest. I really learned that right there that, you know, you can't sugar coat it.*

No patients described their communication style as “honest,” or discussed questions their parents had asked them which they answered through an honest communication style.

Different families used different communication styles based on their comfort with and value of openness, avoidance and honesty in sharing their cancer experiences with one another.

### **Positivity, Emotional Interdependence and Mutual Pretense**

Communicating negative information about illness posed a special challenge for patients and parents alike, and positivity played an important role for all families in discussing stressful subjects. Positivity played a different role in family communications depending on the style that each family used to share illness-related information. Parents with honest or open communication styles used positivity to balance stressful information, as when they discussed their uncertainty or fears. For parents using avoidance as their primary communication style, positivity served as a substitute for stressful information, either to mask or deny the possibility of problems. Some parents avoided negative information by communicating in a strictly positive light or sharing only positive information. Positive attitudes allowed parents of all communication styles

to take an active stance in confronting the challenges of illness or to model an acceptance of uncertainty for their children in a spirit of perseverance.

*I think basically his main question that he would ask me and say out loud was, "I don't understand why this has got to happen to me." "Well, I don't have that answer. Nobody knows why any of these kids have to go through any of this stuff. We just got to look at the other aspect of everything and just be grateful that we have a chance to be able to overcome it because way back when, that's it."*

*I am sure he must have asked, "Are you scared?" and I'm sure there were times when I told him, "Sure I am, but this is what we are going to do."... There's always a way of doing something.*

*I explained things a little bit but not on the negative side. All positive.*

*So, I said, "I am only telling one person. So, you choose to tell everybody else, and if anybody's ready to have a funeral, stay away, and if you want to think that I am living in denial, let me be in denial over here by myself but here it's going to be nothing but positivity and 'the glass is half full' and 'everybody has their number'."*

*There were some very painful and stressful times and scary times obviously, but I think I look at my parents. The three of us just got together. My mom's comment years ago, I'll never forget it, but it was "Don't try to be too stiff and try to be strong but think yourself as a tree. In the wind, they go back and forth, and it's to get through it and afterwards they are still standing but if you are brittle, it is going to crack."*

Some parents hid their distress behind positivity in order to protect their children from additional suffering.

*I realized, There's no time for you at all. What you feel, you have to feel by yourself at another time but never again in front of him, because the minute he saw my tears, and he saw me break— I don't know if you've ever seen anybody's spirit break in their eyes, but his broke and the fear in his eyes, "Ok, if Mom doesn't have control of this, I am done."*

Some parents perceived that their positivity contributed to their children's emotional well being. These perceptions can be described through a process of emotional interdependence in which the emotional state of one affects that of the other. Some parents described an emotional exchange from parent to child: "By my keeping it



together, [my son] is keeping it together.” Some described an exchange from child to parent: “Parents will get better when their child is better.” One mother described both kinds of emotional exchange with her daughter. “I think [my daughter] realizes I’m okay, and she’s okay with everything too,” and “[My daughter]... really had a hard time with it... I think I had a hard time too.”

Few patients spoke about communicating positivity to their parents. One patient mirrored his mother in protecting her from suffering by substituting positivity for his true distress.

*So, when [my mom and doctors] asked questions, I would say, ‘Yeah,’ but sometimes I would know I was off a little bit, not feel myself, but I wouldn’t say nothing, just kept on going.*

This family appeared to communicate based on a mutual pretense. When the patient learned after treatment about his mother’s withholding emotion during treatment, he identified it as a positive support. “She kept it together in front of me at least, so that was cool.”

### **Thoughts and Feelings about the Possibility of the Patient’s Death**

Death and dying are some of the most challenging issues that come up for families of adolescents with cancer. Patients and parents described their thoughts about the possibility of death in several ways. Some parents reported feelings of disbelief at the thought of their children’s deaths, which represented a pain they could not imagine. “I just shudder because the thought of losing child is unthinkable, and I know it happens.” When asked how he felt about the issue that his son might not survive, one father used a metaphor of war.

*Nothing. Just something, you know. I don't know. I have never been in the service so I don't know what it is like being shot at. I don't know what it's like to be injured in service, but I think the same thing. You get up. You do what you have to do. Afterwards, you may sit back and say, "My god, we went through this. We did this. We're here." You do what you have to do.*

For one parent, thoughts of death came up in the context of stressful treatment decisions, described as "life and death decisions." Within the parent group, treatment was seen as both necessary for survival and a form of death in and of itself.

*[My son] in bed looked like death warmed over, and he was. They tried to kill him basically. That was what they were trying to do, with this procedure, same way here. When they gave the radiation and chemo, you are really bringing a person down to a level, hopefully, where you get rid of all of the cancer cells and leave good cells behind, and it's a balancing act.*

Though parents hoped treatment would cure their children of a deadly disease, receiving treatment also brought a necessary risk of death from complications.

*You don't get off scot free. Whether kidneys, whether it be liver, whether it be some other kind of internal something, I'm praying to God that nothing happens. I'm praying to God that [my son gets] off scot free but the reality is that stuff is poison, but it is needed poison.*

Similar to parents, patients thought about death as unfamiliar or strange, describing it as "unreal," "unfathomable," and "weird." One patient recognized the life-threatening nature of cancer through a description of its chronicity.

*It's like a chronic disease I guess, not like the flu or a cough... you can die from it or... you can have it for a long time. Forever, I guess. Yeah.*

Most patients reported thinking about death with their initial diagnosis while one patient first thought about death at relapse. Some patients noted that their thoughts about dying increased greatly following relapse and attributed this to their mature age and improved cognitive grasp of the concept of death.

*Mostly on the second time, when I relapsed. Because I was older. I mentally understood it. I was really scared.*

Despite the cognitive development and emotional maturity that came with age and illness, patients still struggled to process the meaning of death in their existences years after treatment had ended. “I still don’t understand everything I went through.” This struggle to recognize the significance of one’s experience parallels the father’s metaphor for war above.

Parents perceived their children’s fears about death to different degrees. One mother was more distressed by her child’s awareness of death than her own fears about losing her child.

*You can’t even say, “I know what you are going through,” because you have no idea and even though it is terrible to think that your child may die, I can’t even imagine what it must be for them to think that they have to even think about that.*

However, parents were not always so attuned to their children’s thoughts about death. One parent reported being unaware of her son’s feelings of hopelessness, which were instead recognized by his oncologist. She attributed this lapse in recognition to the pace and pressure of the treatment experience.

*This was just after it had come back and [my son] thought he was going to be done and [his doctor] said to him, “You know, giving up isn’t an option,” and [my son] told us afterwards that he said that and... [my son] said, “It that was good for me to hear that from him.” And he said, “Mom, did you notice I wasn’t wearing my bracelet?” I was like he wore this bracelet like, you know, since they—it was a great thing. Like the team sold them and we could wear it. I was like, “I didn’t notice.” He goes, “I wasn’t wearing my bracelet that day Mom. I was kind of like—I was giving up a little bit.”... I knew he was down but I didn’t realize until he told me that story like how down he was...because you’re kind of just like going.*

Her confidence that her child would survive may have masked her ability to see her son’s diminishing hope. “I always felt he would beat it.” Despite such moments of disconnect between parent and child, patients and parents confirmed that death was on their minds

during treatment and after relapse. Families varied in the communication styles they used to communicate their thoughts about death.

### **Communicating about the Possibility of the Patient's Death**

Patients and parents utilized openness, avoidance, and honesty to communicate about the possibility of the patient's death. However, the communication styles for discussing this topic did not always align with the general communication style used by patients or parents. Families reported that communications about the patient's possible death occurred in the context of fears about a patient's death or relapse, a patient's near death experiences, experiences with the deaths of other patients, and patient thoughts about stopping treatment. Parents and patients used positivity either to supplement or to supplant communication about death just as they used positivity to serve these roles in communication about other sensitive topics.

### **Fears of the Patient's Death**

Patients often expressed their fears about dying to their parents through specific questions about death. A majority of parents reported their child asking "Am I going to die?," either at initial diagnosis or relapse. Parents varied in their need to acknowledge the uncertainty of survival for their children. Some parents avoided the topic of the possibility of death with absolute positivity.

*You are not going to die. We will do whatever has to be done.*

*Not on my watch. Not if I can help it.*

One parent described this approach as misleading, and she communicated honestly with positivity.

*I think the hardest question is to answer when your kids says, “Am I going to die?” You know, how do...? You can’t say, “Well, no. You are not going to die.” Just say, “I hope not... There is treatment out there and we are going to try, and, God willing, it is going to work.”*

One mother relied on physicians to address the possibility of death, and, after a treatment plan was established, she described the family’s avoidance of a discussion of death.

*We never really talked about like when [my son] said, “Am I going to live?” Like that’s the only time that that question ever came up. Like I think once we heard, “Yes,” and once we had that plan, like I’ve never had any doubt.*

However, in the only case of disagreement within a family about the nature of family communication about death, her son reported open communication with his parents as a way to process the unfamiliarity of death.

*I talked to my parents about it because just—when it was happening, it was so unreal, and I just wanted to like bounce ideas off them and just be like, “I’ve never felt like this... I might not make it through.” And I think that was very scary for them but I wanted them—and I’m sure they were thinking the same thing like, “We’ve never felt like our son could ever die.”*

He described his parents’ reactions to these communications about death as exhibiting positive attitudes that offered affirmation and sympathy.

*They were supportive. My dad was kind of—I think he was more just like, “Let’s just focus on the fact that you might make it through...” He said he didn’t want me to worry, but I think my mom was being a little more- like she was empathizing with me and just saying like, “It is. It’s so unreal but let’s hope for the best.”*

Not all children openly expressed a fear of dying, and parents responded in different ways to this avoidance. When asked if her daughter had talked about death, one mother described her honest approach to the subject. “No. She probably won’t. If she does, I will be honest. That’s the best thing I can do for her.” Otherwise, this parent had only discussed her own fears of her daughter’s death with her spouse.

Another mother emphasized her son's avoidance of the topic, and she denied the possibility of his death herself.

*He doesn't talk about death or anything like that. I mean, he's not going to. That's the first time I said the word. But it's ok because it's not going to happen.*

She also used avoidance in communicating about the possibility of the patient's death with his sibling.

*[His sister] looked at me and said "But if he won't get the chemo..." I said, "He will." I wouldn't answer the question because I didn't have to. She knew by me not answering.*

By talking around death instead of about death, this mother substituted positivity for honesty, and she avoided any stressful acknowledgement of her family's fears about death. Like his mother, this patient avoided the thought of his death, and instead of positivity, he used pain as a distraction. "I try not to think about it. It's easy because I'm in pain. The pain, yeah from my knee, my leg hurts."

### **Fears of the Patient's Relapse**

Half of patients described their fears of dying in terms of fears of relapse. In one patient's words, "I think every cancer kid's worst fear...is that it will come back." These fears were often triggered by the discovery of a new mass or symptoms suggestive of another relapse. Each new episode caused the same extreme distress for the patient that a recurrence would cause. "My heart would drop." One patient experienced these episodes of distress only during treatment while another patient experienced episodes after treatment as well.

All patients who talked about fears of relapse communicated openly with their parents about these fears. They relied on physician expertise and medical evaluation to

regain confidence that they were healthy, and their parents supported them in this approach.

*A couple of times, [my son] has felt badly and would wake up feeling extremely tired, with a sore throat, like anybody else would but been nervous about feeling tired for a protracted time or whatever. So, when that happens, he immediately is on the phone. He goes out to [the clinic]. He gets a blood test. Everything comes back normal, and he says, "Okay, great."*

The one patient who did not have fears of relapse after completing treatment identified his belief in his physicians and in himself as sources of support.

*I've never been like really, really worried about it because I just have trust in my doctors and that I'm going to make it through and I trust in—I had faith in myself that I will push through this...and maybe it's me wanting to have that faith and so I don't have to just be like, "Oh my God. What am I going to?" But I have it. So that's a good thing.*

Another patient coped with his fears through an attitude of acceptance.

*I think we all have it in the back of our heads, the what-ifs in a way, but it is something that we have been able to move on, say, "Okay. We know it," but if you do what-ifs about everything, it's going to drive you insane.*

Parents responded to their children's distress by asserting a protective stance when physicians displayed insensitivity to a patient's fears about relapse, exacerbating those fears.

*So [my son] had like a pimple I guess, like in his nose, right? So the doctors come in and they're doing the exam...so [my son] says something about, you know, "I feel something here," and he's very, very sensitive to changes in his body. So the doctor looks at it kind of like—didn't really like seriously look at it, you know?...and then he leaves and [my son's] just like, "He didn't even look at it, and you didn't even say anything. He didn't take it seriously." So I run down the hallway after this team that just comes in, and they're like looking at me like, you know... They were not expecting that, and I just said, "I need you to go back and like look at my son's nose." I said, "I realize that you looked at it but he is upset and he feels like you didn't take him seriously and you need to do that."*

Most parents echoed their children's attitudes toward the possibility of relapse and denied their own fears of their children's relapse. One mother thought that her daughter did not understand the possibility of relapse, and this mother used an honest communication style to wait for her daughter to raise the issue. Another mother reported personal fears of her son's relapse as well as her sense of his fear of relapse. He had not acknowledged such fears openly with her, and she withheld her own fears from him in accordance with their mutual pretense.

*He's picked up a lot of things, you know, as far as his outlook. He is ready to live but, at the same time, he is afraid to really whole-heartedly enjoy because of always having that fear, and I know he doesn't tell me, and I don't ever tell him that there's not a day that doesn't go by that I don't wonder what's going through his body.*

### **Patients' Near Death Experiences**

When families experienced the near death of the patient, this stressful event provided a personal context for family communication about death. Parents responded to the stress of near death experiences with varying coping strategies, including humor and faith. One mother avoided expressing her emotion to protect her son with positivity, and she discussed this approach with his physicians.

*Having to put myself and everything for me on the back burner, I don't know if [his doctors] thought I was in denial but they were like, "Do you understand what is going on and do you understand the severity?" I said, "I understand it all completely, and I'm well aware what's going on, and I'm well aware that he may not be here tomorrow so my question to you is, if I become hysterical like I would like to be and cry, is that going to help him? Is that going to make any of this better?" and the doctor just looked at me, and he said, "It is not going to help him."*

She was the only parent to describe her anticipated reaction to the death of her child that might have followed the near death experience. She expected that the need to take care of



the patient's sibling would negate the possibility of acting upon anticipated feelings of grief.

*“If something happens to this kid, what am I going to do?” And the only thing I can think of is get in my car, throw my cell phone out the window and just drive until my car dies. Where? I didn't know. And then I thought, “You can't do that because you have another child.”*

Another parent recalled her prior experience with her acceptance of her mother's death from old age in contrast to her feelings at the moment of crisis for her young son.

*[My son's] blood pressure started to drop so badly, and I really thought he was dying because... I knew what it was to see a blood pressure just drop and continue to drop, and someone dies, but [my mother had been] 88, and she had had a wonderful life... I am quite sure that had [the doctor] not come in when he did or had he not known what to do, we would have lost [my son] that night. I still, when I think of it, I just shudder.*

Patients did not elaborate on their emotional experiences, but sometimes alluded to the surreal nature of the communication about danger during these experiences. One patient implied that the physicians caring for him spoke to his mother about the severity of his illness instead of to him, though he was almost 18 years old at the time.

*I remember I was in intensive care, and had a collapsed lung, pneumonia, temperature 103 or 104. They told my mom I had 24 hours or something like that. It was crazy because I remember that, and I felt perfectly fine. That's the crazy part. They tried to put on a mask and I was like, “What's this? I am fine. I feel fine.” “No, you are not fine.” “Yes I am.” Nope. They showed me a picture of my lung. I guess it was collapsed.*

When talking about their near death experiences, patients focused on the contrast between the seriousness of their illness and their physical sense of calm and comfort. One patient felt that his near death experience allayed his subsequent fears of dying.

*Ever since then the idea of death, it did not really bother me because I knew that if it comes to that point, it would probably be painless, which to me still is a little weird.*

## Experiences with the Deaths of Other Patients

When parents and patients experienced the deaths of other patients, these events provided an opportunity for communication about the emotional impact of these deaths. Several families spoke openly about the pain of deaths of young children whom they had befriended during treatment. These experiences contributed to some patients' advanced sense of maturity.

*We of course [talked about them] because [my son] was close to [the baby who died]. He was close to him. He grew up in one way more than most people do but in a hurry. He even said to me one day after one of these, one more baby, usually the little ones who didn't make it, and we cried together, and he said to me one day, he said, "You know Mom... I feel like my friends, in one way, I have got one foot being their same age but the other foot of me is about 40," because he had seen things that most people that age don't ever have to see.*

For one father, the experience of the deaths of other patients was more affecting than any discussion with a physician about the risk of death for his own child.

*[Seeing other patients die] bothered me. Doctor telling me something, that is fine. The way it's going to be or the way things could happen, that is fine. Didn't bother me at all. What bothered me was some of these children did not make it.*

Patients who were aware of pediatric oncology deaths in the hospital were affected in different ways, depending on the degree of personal contact with the patients who died. One patient reported that he heard only indirectly from staff about the deaths of patients with whom he had no personal contact. He reacted to these deaths with confusion when he did not see those patients anymore.

*[A nurse] was talking about a kid who used to go there, and I had seen him and—but he had passed away and that was like—even though I didn't even know him. I had never spoken a word. It was just like the idea that it was so strange that he was there, and he was sick, but he was walking around. Like he's still a living human being, and then a certain time period passed, and he was just not like—I don't understand how that happens.*

In contrast, another patient directly experienced the events and communications surrounding the death of a patient in the room next door. This experience was particularly stressful because he had no control over his exposure to the death. He did not talk about it with anyone afterward, in keeping with his general communication style of avoidance. He also reported an ongoing fear of the chaplains in the hospital, because after his experience with the dying patient, he associated the presence of chaplains with death.

*I was in, like, a far room, like, that they share with the PICU. So the chaplain went to the PICU, and this girl who is right next to me, she was like passing away, I guess. It was weird... That was kind of scary, knowing what was going to happen to her... I heard from, like, some nurses and stuff. I just heard them talking. So it was kind of weird. I didn't like that. It was weird. And then you hear all the family crying and stuff... and even the door is closed you can't. They were standing right outside my door with like the chaplain.*

Regardless of the communication style used by parents and patients to discuss death, patients and parents often experience the real possibility of death directly as a result of the patient's treatment or close proximity to other seriously ill patients.

### **Patient's Thoughts about Stopping Treatment**

When patients thought about stopping treatment, this experience played an important role in allowing them to recognize the possibility of their death. All of the patients who had completed treatment spoke about their desire to stop treatment, although these desires were manifested in different ways and with different levels of intention. Some patients thought about stopping treatment during initial treatment when they were first diagnosed with cancer and with treatment for relapse or with treatment for relapse alone. One patient thought about stopping treatment in order to focus on his life goals, as his motivation to fight his illness waned.

*I clearly remember when I relapsed, once the initial shock wore off, I really did not have any motivation to go through treatment. I was ready to throw in the towel, and just do things that I had always wanted to do.*

Other patients spoke about their desire to stop treatment because of the stress of the treatment itself. “That’s what made me want to not do it anymore, because it was so draining.” Several patients recognized that their disease would worsen without treatment. One patient reported wanting to stop treatment in order to die and escape the stress of treatment. Another patient did not focus on the fact that stopping treatment would mean dying. “I [wasn’t] thinking about... ‘Then I would be dead’... just the immediate.”

The seriousness of intention behind the desire to stop treatment also varied among patients. The patient who felt like he wanted to die described his desires to stop treatment as sincere. The patient who only thought about stopping treatment as a way to feel better temporarily was not serious about his desire to stop.

*I told doctors like one time when I was almost dead serious about it. “I don’t want to do it no more.”*

*It wasn’t a real—I wasn’t planning on acting on it.*

Some patients maintained their open or avoidant communication styles with their thoughts about stopping treatment. Other patients modified their general communication style, and became more or less open when communicating about such thoughts. One patient communicated openly with his parents and physicians about his desire to end treatment if the likelihood of cure became obscure. He spoke openly to ensure that his parents understood his wishes so that they would be able to make decisions on his behalf if he were incapacitated. This openness was consistent with his general style of openness.

*I told them that, “If it ever gets to a point where the odds are really against me, you tell me because I will pull out all the IVs, and I am going out and living whatever life I could and just doing things that I always wanted to do.”*

*I was open with them because I felt if I wasn't and it came to that point that they wouldn't understand... "No. You've got to keep going on. Push." Obviously, they would do anything in their power to help get me better. It's a stressful situation for everyone involved, and, when I was going through both treatments, I told them what was on my mind. I think maybe subconsciously I said to myself, "If they especially don't know what is going through my mind, they can't fight for me in the best way, and if I am asleep or something goes wrong, I want them to know what I would want to do."*

Another patient openly expressed his desire to stop treatment, but he avoided sharing his thoughts about his desire to die. Those thoughts stayed "back in my head... because I know I couldn't have done it because, or I couldn't stop treatment because I wouldn't want to." This mix of openness and avoidance demonstrates a departure from his general avoidance of communication, suggesting that the issue of stopping treatment was important enough to overcome his tendency to withhold feelings. Even so, he did not communicate his desire to die with his mother, his doctors or the hospital psychologist who met with him. Looking back, this patient believed that communicating openly would have helped more.

*One day I would want to talk to [the psychologist] but when I would come in for clinic, what I was feeling that day is not here this day. I wouldn't need to talk to her... It would have been a little bit smarter idea to talk. Probably, it would have helped out a little bit, but I handled it pretty good, because I'm still here.*

Another patient departed from his general communication style of openness by withholding thoughts about stopping treatment from his mother. In contrast to the previous patient, he communicated openly with the hospital psychiatrist and felt this resource was sufficient to help him process thoughts about stopping treatment.

*I didn't really want to scare my mom and obviously I think she would wish—would want me to tell her but... it was just a thought that I was having... It was a scary thought, and I felt like [my psychiatrist] took care of it with me.*

All of these patients continued treatment in order to protect their loved ones from

suffering. Some also attributed their success in completing treatment to support from physicians, who provided direct communication about the certainty of death without treatment, as well as positivity in coping with the stress of treatment.

*The only thing that pulled me through was knowing that, if I [stopped treatment], I would cause my parents, my friends so much pain and, literally, that was the only reason that I went through the treatment, and, looking back on, I am so happy I did.*

*I think they actually broke it down for me. Either you do it or you die.*

*I wouldn't want to do treatment, and they would just keep on, "You got to do this." While I was doing it, not telling me that I had to do it, just "It's best if you do it." Always got a positive attitude so that's why I just do it.*

Few parents spoke to the question of their child's participation in treatment.

However, one mother described the anxiety her husband shared with her when discussing the possibility that their son might want to stop treatment.

*My husband, would also say, you know, "I think when we bring him to the hospital, I think to myself, he could be fighting us on this. Like he could be literally saying, 'I'm not going back in there.' Because he knows, 'I'm going to go back in that room and within two hours I'm going to be nauseous and it's going to be like that for six days.' You know?" ... and I was like, "Yeah. I realize that."*

For one patient who communicated openly with his parents and physicians about his desire to stop treatment, his mother expressed gratitude that his physicians addressed the issue with him. She did not describe any direct communication with him about his desire to stop treatment, and she hid her own fears from his concerning his expressed desire to stop. These communication practices were in keeping with her generally avoidant style.

*When he was turning close to 18, he gave me a heads up saying, "When I turn 18, you know I'm stopping my treatment." I thought, "Oh God. Alright. Well, he is not 18 yet. We'll deal with that when that day comes" ... then he turned 18, and then he started knowing, "I have control" and thank God for [his doctor].*

One mother described conversations with her spouse about their gratitude that their son had complied with treatment. When she talked to her son about it, he mentioned his strategies to mentally prepare for treatment, but he did not share his thoughts about stopping treatment with her. She interpreted his motivation for continuing treatment as a personal interest in maintaining positive relationships with friends and family.

*[My son] talks about, you know, realizing like how much he— how important his friends and his family, you know, were, and, like, he recognized it like, “I want to get through it to be with them and for them.” You know? Like feeling really low but then like realizing like, “I can’t give up because I’ve got all these good people around me.”*

### **Patient’s Age as a Factor in Parent Communication about Death**

Parents spoke differently about how their child’s age affected the way in which they communicated with their children. One mother emphasized her belief in honesty about the possibility of relapse irrespective of her daughter’s age.

*I will be honest with her and up front because at this age—even if she was littler, even if she was younger, I would still be honest because there’s no sense sugar coating things and this is something—I mean this is serious. [She]has to be watching herself for the rest of her life. I mean she might not get a lump in her elbow next time. It might be something else. So, you know, and we all have to be that way too.*

By contrast, another parent with a child the same age chose to withhold poor prognostic information based on her daughter’s age of 16.

*I have never told her what her prognosis is. I just don’t think she needs to know that... at this point, you know... and she has never asked, so... This last time, she said, “Oh this is bad, isn’t it?” and I said, “Well, it is bad but not hopeless,” and that was the end of that... I just think it is too much of a burden for a kid her age to have.*

This parent even modified her honest communication style to avoid communication about prognosis. When her daughter asked a question about prognosis, the mother interpreted

her daughter's question as a general inquiry, and then responded to it with general honesty and positivity. She did not disclose specific prognostic information despite her suspicion that her daughter had already received this information from other sources. In keeping with her honest communication style, she justified this communication practice based on her daughter's perceived silence on the issue.

*I am sure she probably understands more than I want her to but yeah. Like I have a feeling that she has probably researched osteosarcoma and probably seen the statistics, but she has not mentioned them to me, so you know.*

It is clear that a parent's perceptions of patient maturity vary from one parent to another, as do parental attitudes about the age at which a patient is mature enough to receive information about the possibility of his or her death. Other factors can influence a parent's decision to communicate openly or honestly about prognosis with a younger child. For example, these two patients of the same age differed in two respects. First, the patient from whom information was withheld was described as asking direct and indirect questions about death and prognosis. The other patient had not yet asked such questions, and her mother described the honest response that she was prepared to provide, not a response that had been provided. Also, the patient from whom prognostic information was withheld was in active treatment with limited therapy options, while the other patient had completed treatment and was doing well.

The mother who withheld prognostic information from her daughter commented specifically on her experiences concerning the differences in communicating about death based on the patient's age at diagnosis. Her daughter had been diagnosed as an infant and again as an adolescent. Her daughter had not been able to ask questions about cancer as



an infant but reached this stage of maturity as an adolescent. This mother struggled with the openness required by her investment in an honest approach to communication.

*[Adolescents] understand a lot more now than they do as babies. It's just their life and... you don't have to answer the tough questions because [babies] don't know to ask them.*

*In the end, it is much easier that I found for a child to have cancer as a baby because they don't know anything else. Then, now you got a teenager who is going to go through with the whole gamut of emotions like, "Am I going to die? What is going to happen?" You know, "I don't want to do this. I want to do that." So, I think it is a lot harder. Cause they understand, you know, what is going on and you can't really hold back, you know. You have to kind of tell them.*

This mother was torn between her awareness that her daughter was too old to be oblivious to the possibility of death, and her feelings that were daughter was still too young to bear the burden of it. Her daughter's awareness of death was more stressful to her than her own awareness of this possibility.

## V. DISCUSSION

This qualitative study of adolescent patients and their parents compares the experiences of their families with thinking about and communicating about death in the setting of pediatric malignancy relapse. This study aimed to explore adolescent patient and parental thoughts about death, to describe the different styles of communication that families used to talk about death, and to identify the contexts in which death was discussed between parent and patient.

Families used a range of communication practices to share information about their thoughts about death. This study describes a framework for family communication practices which include open communication that discloses all information, avoidant communication that restricts communication, and honest communication that consists of sharing information upon request. Positivity played different roles in intrafamilial communications depending on the style of communication that was used. Positivity could support open or honest communication about the possibility of death, or it could reinforce avoidance of communication about the possibility of death.

This study found that family communications about death occurred in the context of discussions of fears about the patient's death or relapse, the patient's near death experience, experiences with the deaths of other patients, and patient's thoughts about stopping treatment. Several parents mentioned the age of the patient as a relevant factor in their decisions to disclose or withhold information with their children in the contexts of future relapse and current prognosis. Patient-parent communication proved to be an important process in which families renegotiated their relationships with one another

when faced with the challenge of coping with an adolescent's cancer diagnosis and relapse.

### **Styles for Communicating about Cancer with Children**

Families adopted a variety of communication styles in sharing information and expressing feelings about illness with one another. Primary styles include openness to discussing all issues and avoidance of stressful topics. Some parents combined both styles into an honest approach in which information was discussed only when explicitly sought by the patient. Openness emphasized an upfront grappling with difficult issues as well as simple ones. Avoidance served to support normalcy and to minimize stress for oneself and others, despite one's immersion in a cancer-centric environment. Honesty put the onus on patients to communicate with their parents, supporting their independent power to control information exchange, while leaving them to advocate for their own information needs concerning issues that were challenging even for parents to face.

Interestingly, no patients reported using honest communication. This phenomenon suggests that the privilege of information sharing may be weighted toward parents, who typically have a greater level of access to information, and, thus, more control over the style of communication that will be adopted by a family. Even when parents seek to give adolescents control over family communication about death, parents retain the option to withhold information or to represent it in a biased way. This feature of patient-parent communication comes into play with special force in the sharing of prognostic information or information about risks related to treatment. By contrast, adolescent patients may act independently in sharing their own personal thoughts and feelings about death with their parents, or in seeking information outside of the patient-parent context.

Patients and parents tended to adopt the same style of communication in a cooperative fashion. Open exchange in one direction encouraged open exchange in the other, as did avoidance. Some patients described a gradual acceptance of openness once it was modeled by their parents, while others felt comfortable with openness from the outset. Notable exceptions typically occurred when a new or unusual level of stress was introduced to either the parent or the patient, shifting the established paradigm for the communication style that was used in other circumstances. In most cases, patients and parents construed their dominant method of communication as a positive element in their coping resources, regardless of which style they used.

### **Positivity, Emotional Interdependence and Mutual Pretense**

Families used positivity in open and honest communication to balance negative information. In avoidant communication, positivity acted as a substitute for negative information. Parents incorporated positivity in their attitudes toward illness, either by actively engaging in their children's care or by passively accepting the uncertainty of prognosis by making the best of things. Each group of parents framed their positivity in accordance to their views.

Emotional interdependence between parents and patients reinforced parents' beliefs that positivity could protect their children from suffering. This dynamic sometimes influenced families to avoid communication in a style of mutual pretense, which some patients identified as a positive support. Recognizing emotional interdependence may help families to reconcile their desires to protect one another from stress with their needs for communicating about the possibility of the patient's death.

### **Thoughts and Feelings about the Possibility of the Patient's Death**

The majority of patients and parents described thoughts about death in terms of fears of the patient dying. Both parents and patients struggled to comprehend the possibility of the patient's death, introduced into their lives by his or her malignant diagnosis and relapse. Patients thought about the possibility of death at initial diagnosis and to a greater degree with relapse. They attributed this increase in their concern to their advancing maturity and cognitive development.

Parents reported a range of experiences when it came to recognizing their children's thoughts about death. Their awareness of their children's thoughts related to their communication styles. Parents who communicated openly with children sometimes missed the cues that signaled a child's diminishing hope, while parents who practiced honest or avoidant communication felt additional stress in thinking about a child's awareness of death. In such cases, openness may lead to a false sense of confidence in knowing what one's child is thinking. Avoidance or honesty may exaggerate emotional burdens for the parent in the absence of any communication about a child's suffering.

### **Contexts for Communicating about Death**

Families communicated about death in the context of fears about the patient's death or relapse, patients' near-death experiences, experiences with the deaths of other patients, and patients' thoughts about stopping treatment. Parents also considered their child's age in deciding how much information to share with their children in the contexts of future relapse and current chance of survival.

Patients expressed their recognition of the possibility of death by asking if they were going to die. Parents answered such questions based on the values they placed on

openness or avoidance in communication. Some parents who communicated openly in general did not do so when asked about death by their children. One such parent denied the possibility of death based on his investment in an active attitude of overcoming cancer, while another parent allowed physicians to answer the child's question about death without feeling a need to answer it herself based on her confidence in cure. By contrast, her son reported speaking about death with her often and receiving positive encouragement from her to accept the uncertainty of survival. Contradictions such as this one support the idea that open communication does not guarantee that parents and patients understand one another's perspectives. Parents who practiced avoidance or honesty in general approached communication about death in the same way, citing their child's avoidance of the topic as a motivation for doing so. For one family, avoidance of communication about death extended into communication with a patient's sibling, and reinforced the system of mutual pretense surrounding the patient.

All patients participating in this study had experienced relapse, confirming for them the real possibility of disease progression despite treatment. Some patients were plagued by fears of relapse during treatment or afterward. These fears included a general awareness of the possible risk of disease progression as well as acute episodes of fear triggered by suspicious symptoms. Patients maintained their open communication with their parents about these fears, and parents supported patients' preferences for seeking medical evaluation as reassurance of their continued remission. Patients coped with fears of relapse through a belief in themselves or through acceptance of uncertainty. Most parents did not report fears of relapse themselves, although they sought to protect their children from insensitivity of others to these fears. Like their children, parents maintained

their general communication style in addressing fears of relapse. Parents who avoided communication about future relapse did so based on their child's failure to discuss the topic. Such situations represented either honest communication or avoidance of communication for mutual pretense.

Families described two kinds of experiences with death, personal near death experiences and witnessing the deaths of other patients. Avoidance acted as a common communication style during near-death experiences, when the focus remained on the physical experience instead of the emotional experience for patients. With regard to the deaths of other patients, patients and parents who chose to communicate openly reported a positive experience of sharing grief. Other patients and parents continued to avoid communication despite the extreme stress associated with these encounters with the deaths of others. Some patients and parents did not feel a personal connection with these deaths, although these deaths heightened their awareness of death in general.

Patients also thought about death in the context of stopping treatment. Patients gave a range of reasons for thinking about stopping treatment, from wanting to pursue life dreams if cure were not possible, to wanting to die in order to escape from the suffering experiences of treatment. One patient expressed complete seriousness in his intention to stop treatment. Another described his thoughts as not at all serious. One patient utilized open communication about his desire to stop treatment, in order to make his wishes known to his parents and providers. Other patients used avoidant communication styles to protect their family members from grief. Opportunities to talk to counseling professionals allowed patients to process their thoughts outside the family and its emotionally interdependent relationships, although not all patients utilized this

resource. Patients endorsed open communication and avoidance as effective ways to cope with thoughts about stopping treatment, although one patient who avoided communication believed open communication would have been better.

Parents reported different attitudes toward sharing information based on their children's age in the context of relapse and current prognosis. In these different contexts, one parent stressed the importance of communicating honestly regardless of her child's age, while another parent reported she avoided communication because her child was too young to bear the burden of such knowledge. Beliefs about a child's ability to cope with different kinds of information influenced these parents to be more or less open in communicating, respectively. Other factors that may have influenced communication included the patient's current health status and the patient's information seeking behavior.

Some families also experienced the changes in communication style which occur when a child is diagnosed with cancer as an infant, and later diagnosed again as an adolescent. One parent struggled with the question of whether to discuss possibility of death with her adolescent daughter, who had not understood the possibility of death as a baby. This mother used an honest approach to communication about death in general but avoided communication about the patient's specific prognosis. She withheld this information to protect her daughter who she believed was too young to hear it despite her value of truthfulness in other communications about the possibility of death.



## VI. CONCLUSION

This study demonstrates that many factors affect communication about death between adolescent patients and their parents in the setting of cancer relapse. Factors such as communication style and the context for communication influence the ways in which families share thoughts and feelings about the possibility of the patient's death. Communication about death is often stressful whether the family uses an open or avoidant style of communication, and positivity may serve to alleviate that stress.

More often than not, family feelings about communication are aligned, so that parents and patients share a common communication style across a range of contexts for communication about death. However, the exceptions described here illustrate how families may change their communication style from one context to another, or may disagree about the level of communication required by a particular context. This phenomenon holds true, irrespective of the family's communication style. Never-the-less, greater differences exist between families than within them.

Communication between patients and parents was intimately related to their perceptions of how disclosure would affect the suffering of the patient or the parents and to their beliefs about the types of communications that would maximize trust and minimize stress for one another. By exploring family beliefs about the best ways to provide support to one another through communication, physicians can help patients and parents to clarify the nature of their own communication needs, and thereby enhance the ability of patients and parents to share those needs with each other.

### Limitations of the Study

This study was limited by its small sample size of four patients and seven parents with a relatively uniform demographic make-up. The majority of the participating patients were Caucasian males, and the majority of participating parents were Caucasian females. Only one patient was in active treatment, while the others had completed treatment between one and four years previously. It would be useful to interview a larger number of patients and parents, in order to ensure that saturation is reached for the perspectives of female patients, male parents, and families of different ethnic backgrounds and socioeconomic status. The inclusion of patients at different stages of treatment would make it possible to further characterize how patients' communication needs evolve over the course of illness. Only four of the six families had patient and parent perspectives represented, and the results of this study would be strengthened by including both perspectives for all families.

Recall bias may have been introduced as patients and parents remembered past conversations and experiences. This is particularly relevant for the participating families whose experiences occurred more than five years ago. However, the focus of the study was on the families' experiences, and so their recollections of the experiences are a logical subject of study. One patient reported difficulty remembering experiences as a side effect of the treatment he received. Other patients cited their young age at initial diagnosis as sources of difficulty when attempting to recall relevant events. It would be useful to conduct interviews of young patients closer to the time of initial diagnosis or relapse, but such interviews would be more challenging due to ethical concerns about the vulnerability of those patients.

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## **Future Studies**

Direct observation of intrafamilial communication represents the most faithful source of data for this topic of study. Recording patient and parent interactions in real time would allow researchers to identify themes in intrafamilial communication with a high level of fidelity to the original interaction. This method of data collection is prohibitively labor intensive in many cases, however, and may be considered invasive of a family's privacy, limiting its utility.

Two parents described their experiences with children who had cancer as babies and again as adolescents. Studies of families with this experience would be helpful in illuminating the ways in which family communication styles evolve as patients age and advance in their own communication skills and cognitive abilities.

Every family participating in this study described a history of significant psychosocial stressors unrelated to the patient's diagnosis of cancer. One family had experienced the deaths of close family members. Another family had a history of an abusive parent. Multiple families reported siblings or parents with significant mental health illness. Half of the families who participated represented single-parent homes. Future studies may examine how these kinds of psychosocial stressors affect family communication style, both before and after a child's diagnosis with cancer.

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## **Appendix A: Interview Guide**

### **Parent Interview**

Tell me about yourself as a parent.

What has it been like to have a child with cancer?

How have things been since the cancer came back?

What is on your mind?

What is hard for you?

How has your child responded to being ill?

What kinds of things do you talk about with your child?

What questions have come up?

How do you and your child usually talk about things related to his or her cancer?

Some parents think about their child dying. Have you?

What have you thought about?

What have you talked to other people about?

What have you talked to your family about?

Who do you go to for support?

What helps you stay positive?

What are your strengths in coping with your child being sick?

### **Patient Interview**

Tell me about yourself.

What has it been like having had cancer?

What was it like when the cancer came back?

What was on your mind?

What was hard for you?

How did your mom or dad respond to you being sick?

What kinds of things did you talk about with your mom or dad?

What questions came up?

Some people who get cancer think about dying. Have you had any thoughts like that?

What have you thought about?

What have you talked about to other people?

What have you talked about to your family?

Who do you go to for support?

What has helped you to remain positive?

What are your strengths in coping with being sick?

## Appendix B: Final Coding Tree

1. Family Relationship
  - a. Protection
  - b. Expressing emotion to others
  - c. Recognizing stress in others
  - d. Closeness
  - e. Distance
2. Dying
  - a. Fears about
  - b. Talking about
  - c. Stopping Treatment
3. Social Factors
  - a. Disruption
  - b. Isolation
  - c. Interactions with Professionals
  - d. Interactions with Other Patients
  - e. Interactions with Community Members
  - f. Information Sharing
4. Psychological Factors
  - a. Importance of Attitude
  - b. Description of Attitudes
  - c. Stressors
  - d. Coping Mechanisms
  - e. My Role
5. Emotional Factors
  - a. Fears
  - b. Source of comfort
  - c. Other
6. Physical Factors
  - a. Symptoms
  - b. Physical Limitations
7. Life After Treatment
  - a. Reflection on Experience
  - b. Hopes for Future
  - c. Advice to Other Families
  - d. Fear of Relapse

### **Appendix C: Reflexivity**

Early in the recruitment phase of this project, I sat at the end of the clinic hallway, waiting for my chance to speak with a family that had been identified as eligible for participation in my study. A door opened to one of the examination rooms on the other end of the hall, and I watched as a boy about 12 years old walked toward me with his father. This was not the family I had come to see, but I saw them none the less. I saw the boy with his head thrown back, eyes squeezed tight, and mouth gasping in a silent, wrenching sob. He leaned heavily on his father, whose own silence heightened the grim determination on his face as he stared straight ahead. The image of this father and son has stayed with me as an emblem of the moment of suffering that I wish to enter into as a pediatrician offering comfort.

I have learned more about the meaning of patient comfort from this project than any lecture or bedside demonstration could offer. For a physician in training like me, it is not enough to see an experienced physician provide comfort to a family in need because what I see is colored by my own perceptions of what is comforting. When I heard patients and parents share the details about what made their darkest moments bearable, they imparted to me a profound sense of awe and humility. I listened to the interviews to ensure the transcripts were accurate, but this opportunity for active listening did more than verify fidelity between talk and text. It took my breath away to hear the emotion pouring out in these voices, the fear and pain, the frustration and relief. Many others had provided care to these families whose lives were changed irrevocably by disease. But I was the stranger who came to hear what is so often missed in the medical history. Their stories will remain etched in my heart.