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Communication Preferences of Pediatric Cancer Patients: Talking about Prognosis and Their Future Life

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Abstract

Purpose—The American Academy of Pediatrics recommends that healthcare providers communicate information to patients in a truthful and developmentally appropriate manner. However there is limited guidance about how to translate these recommendations into clinical practice. The aim of this study was to explore how young cancer patients experienced communication around their illness, especially communication about possible outcomes from disease or treatment.

Methods—Participants included young people ages 8 to under 18 years with cancer (N=16). Semi-structured interviews focused on their expectations about the future, the process of information exchange, and their preferences for communication within the pediatric oncology setting.

Results—Overall, participants wanted medical information to be provided to them by their healthcare providers and wanted to be direct participants in medical conversations. However, many participants displayed some ambivalence or conveyed conflicting wishes for prognostic information. For example, some participants reported that they were satisfied with what they knew, but later raised lingering questions. While not the focus of the study, almost every participant discussed social concerns as a key concern for their present and future life.

Conclusions—While most pediatric cancer patients want to be involved in conversations about their cancer care, including conversations about prognosis, this is an individual and sometimes fluctuating decision, and healthcare providers should be encouraged to discuss preferences for involvement with patients and families. This study highlights the importance of understanding the

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Conflict of Interest:

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developmental factors that make pediatric patients unique, especially with regards to their patterns of communication.

Keywords

Pediatrics; oncology; communication; child; adolescent; prognosis

INTRODUCTION

Communication skills and relational abilities are essential core competencies in patient-centered care and are associated with improved patient health outcomes, better patient adherence, fewer malpractice claims, and enhanced satisfaction with care [1]. In addition, communication is one way clinicians can promote healing and reduce suffering; however, they must have the skills and training to do so [1,2].

Communication with pediatric patients holds particular significance as well as challenges. Effective communication with pediatric patients and parents is critical to improving the disease outcome and emotional wellbeing of these vulnerable young people [3] and is central to their cancer experience [4]. Suboptimal doctor/patient/family communication is also one of the most important causes of medical noncompliance in adolescent patients [5]. However, when caring for young people, providers must not only find ways to effectively communicate with the patient, but also negotiate the triadic communication with the patient and the parent/caregiver, making communication with this population unique [4]. In the United States, parents have the legal authority to make medical decisions for a child under the age of 18. The American Academy of Pediatrics Committee on Bioethics recommends that health care providers communicate information to pediatric patients in a way that is truthful and developmentally appropriate, and include them in medical decision making to the greatest extent possible; however, there is limited guidance about how to translate these recommendations into clinical practice. In addition, although communication is the most common ‘procedure’ in medicine, the art of communicating with pediatric patients is rarely formally taught [6] and is an area in which health care providers feel poorly prepared [7].

Previous literature has evaluated child and adolescent preferences for learning about the cancer diagnosis [8], engaging in decision-making [9,10], receiving bad news [11] and making plans for end-of-life care [12,13]. We know little about their preferences for learning about possible outcomes of their illness, including whether cure is possible and what their future life may be like. However, parents of children with cancer consider learning about prognosis to be important for decision-making [14] and for their personal coping with the child’s illness[15], and adult patients similarly want this information [16]. In this study we therefore used semi-structured interviews with pediatric cancer patients, asking them to reflect on their own experiences and consider their communication needs, especially with respect to prognosis.

METHODS

Subjects

This study was conducted at the Dana-Farber Cancer Institute and Boston Children's Hospital. Participants were children of parents who had participated in a larger study about parent-clinician communication about prognosis. Young people were eligible to participate in this portion of the study if they were English-speaking and at least 8 years of age but under 18, reflecting ages at which a patient may be asked to provide assent to treatment [17]. Eligible children were approached in the clinic by the senior author or a research coordinator and given a letter describing the study along with information on confidentiality and an informed consent document. The purpose and structure of the interview were explained to the parent and consent was requested. Parents were asked if they thought the interview would be overly distressing for the child and were excluded if the parent answered yes to this question or they had other concerns. Parents were told that they could be present for the interview if they or the child wished. Informed consent was obtained from all parents of individual participants included in the study. After the parent consented to the child's participation, assent from the child was requested and a time for a private interview was set.

Data Collection

All of the interviews were conducted by a research coordinator trained by the senior author. The child was allowed to participate in the interview alone if both the child and the parent agreed. All but three children chose to participate in the interview alone. The interviews were audiotaped and transcribed in full. Questions were open-ended. Participants were asked "what do you think will happen to you because of your illness" and "how did you learn that (prior answer) could happen to you." Additional questions focused on a desire for additional information and preferences for communication and information delivery. The full interview script is provided in Table 1. The study was approved by the institutional review board at Dana-Farber Cancer Institute and all procedures performed in this study were in accordance with the ethical standards of the institution and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Analysis

Directed content analysis was used to analyze the interviews [18–21]. Analysis was performed using ETHNOGRAPH software (Qualis Research, Colorado Springs, CO). First the transcripts were read through by all authors for content familiarity and to abstract broad themes. They were then systematically coded using a detailed scheme based on questions of interest, developed by all three authors. Major categories of codes focused on the process of information exchange, affective results of information, information needs, values for communication, expectations about the future, specific comments about prognosis, decision-making, and the social impact of cancer treatment. Two authors (SRB and JWM) reviewed and coded all transcripts; the other author (KF) coded select transcripts and helped develop the coding scheme. After the development of the initial coding scheme, coding was performed independently and reviewed by all authors, using consensus to arrive at final code assignment but also using differences of opinion as an indicator that the coding scheme

required clarification [22]. After expansion and clarification of codes when needed, the coding scheme was finalized. We then continued independent coding and group review.

RESULTS

Sixteen young people participated in this study (80% of those approached, 16/20). Participants had a mean age of 13.7 years (range 8.3–17.8 years). Nine participants (56%) were female and seven (44%) were male. The majority of participants had a diagnosis of a hematologic malignancy (n=13, 81%), with the remainder having a diagnosis of a solid tumor (n=3, 19%). Data are discussed under three themes: participant expectations about what will happen because of the illness, affective response to this information, and the process of information exchange. Quotes are used for illustrative purposes and the participant's age is provided in parenthesis following the quote.

Expectations About the Future

Participants were first asked, “What do you think will happen to you because of your illness?” Responses covered a broad range of topics, including treatment and the immediate cancer experience, long-term effects of cancer therapy, and the expected outcome of the illness.

Treatment and Immediate Cancer Experience—Many participants focused their reflections about the future on treatment and the impact of treatment on their day-to-day life, especially the social impact. Several participants focused on restrictions and missed routines (for example, “I’ll miss school” (age 15) and “I will miss all my friends” (age 15)). Others referenced feelings of isolation (“My friends just kinda left” (age 13)) and a desire for a return to normalcy in the future (“I just liked the way my life was before. I was perfectly happy and I just want it to be that way” (age 12)).

Long-term Effects of Cancer Therapy—Other participants focused on the potential late effects of their cancer treatment. For example, one participant said, “it is easier for me to get skin cancer, so I use sunscreen now...but at first I didn’t really like the idea of having to put on sunscreen because I wanted to get tan” (age 16). Another said, “I know that I can’t smoke, ever, like even if I smoked like three cigarettes I would probably die...so when my friends are having a smoking party I can’t ever go” (age 13). Seemingly small and large concerns were sometimes juxtaposed; for example: “it’s irritating that I’m never going to have a perfect attendance record in school anymore, because I have to miss one day a year to go in [for check-ups]...And then the other thing, of course, is that they said I’m probably not going to be able to have kids” (age 13)

Outcome of Illness—Finally, some participants focused on cancer outcomes such as their chances of being cured. Some focused on getting better and trying not to consider other possible outcomes. For example, “I think I’m going to get a lot better from it [cancer] and I’m going to get lots of energy...I think the best thing to do is just to stay positive and happy with everything” (age 16) and “I have full confidence that I will get better. For me, I just like know that I am in a really good place and so, like not getting better, I’m just keeping in my mind, is not an option” (age 13) Only one participant acknowledged the possibility of death

directly in response to the main question, saying, “They told me there was no cure and they were going to send me home” (age 15). However, many participants brought up concerns about cancer recurrence or death later in the interview, often in an indirect way. For example, one participant said “I think I’m just really happy that everything’s just gone great, and they said that there’s a less than a ten percent chance of it coming [back].... I mean definitely whenever ... I get a stomach ache or something I get really worried” (age 13) Some participants acknowledged that these were issues they did not want to think about (for example, “[I feel] a little scared, but then I just drop it. I’m like, okay, time to change the subject” (age 16) and “I don’t think I would talk to my parents about the possibility of it coming back. Because I am not even ready to wrap my head around that” (age 16)).

Affect Associated with Cancer Communication, including Information about the Future

Although many participants described trying to be positive (for example, “I think the best thing to do is just to stay positive and happy with everything” age 16), most participants also described negative emotions as part of their cancer experience, either at diagnosis or when thinking about the future. Distress was the most commonly cited emotion (for example “I was terrified” (age 15)), and “scared” (age 9). Many participants also reported feelings of dissimulation or denial (for example “when they first told me, I was like, oh my gosh, this is so so crazy, like this isn’t happening” (age 13) “my mind is on another planet right now...it is like a universe where you just blank out and there you are fine. You are not sick” (age 15) and “I try not to think about the possibility of bad stuff...because if you don’t think about it, hey it is not there” (age 16)). Feelings of shock, loss and worry about others were also reported (for example, “that was the day that ruined my life” (age 15); “when I first discovered I was ill and I needed treatment, it was shocking because I never thought I could get cancer” (age 15) and “I wasn’t scared for me, I was scared for the people who knew me and loved me” (age 11). Distress was often focused on social concerns and changes in appearance, along with worry about how the cancer diagnosis would impact others, including friends and family (for example, “I was scared about my hair falling out” (age 11).

Process of Information Exchange

Desire for Information—When asked directly, almost all participants reported feeling that they had the information they wanted about their future. Example statements included “I know mostly about everything. There is not much more that I would want to [know]” (age 15) and “I knew I had the information, and my parents were behind me, and my doctors were all telling me they wouldn’t lie to me and they would tell me the whole truth and nothing but the truth” (age 13).

However, some participants noted that there was certain information they did not want (for example “I just wanted them to give me the simple things because I didn’t want to hear the whole conversation...because it is too much” (age 15) and “if something was going on, I would be curious about it but other than that, I did not want to learn more”(age 15)) or reported knowing information but pushing it away (“I try to brush [information] off as quick as I can”(age 12)). One participant noted a change in attitude regarding a desire for information: “At first you just don’t really want to know anything, but later on you do” (age 15)

Finally, although many participants reported feeling that they had the information they wanted, during the course of interviews, some later brought up a desire for additional information about their cancer and its prognosis. For example, one participant wanted to know more about “why my tumor is so tricky” (age 15) after previously stating she didn’t want any more information, and another wanted to know “what’s going to be the end result...if I’ll live or not,” (age 15), something he had never asked.

Sources of Information—All participants in the current study described receiving information about their future from a clinician (physician or nurse). Most also had received information from their parents, and many had sought additional information from other sources such as the internet (for example “I looked it up on the internet and everything and it ended up to be some other things too, so I had to look up even more” (age 15)) or obtained information from TV shows. While some participants found obtaining outside information helpful, others found it confusing and noted that they would rather hear the information directly from their clinician.

Values for Communication—During the interview, many of the participants referenced the importance of direct communication between them and their physician. One participant stated “they [the physician] had to make their choice whether to tell me right away [that I had cancer]...I was really glad they told me right away. I don’t like being in the dark” (age 13). A few participants referenced conversations between their parents and their doctors in which they were not included and while some noted that this was their preference (for example “I’d want the doctors to tell my parents, and then bring me back into the room and [tell me]”) (age 13) others viewed the experience less positively (for example “the doctors told my parents then and my parents waited until the next day to tell me [about my diagnosis]; I was overthrown by that”) (age 16).

DISCUSSION

We asked children and adolescents with cancer about their experiences with cancer communication, including communication about the future. In doing so, we were able gain a deeper understanding about areas of importance for young people undergoing cancer treatment. Several themes emerged.

First, we found that young people generally wanted prognostic information and wanted to be direct participants in medical conversations. These findings are in line with those from other areas of cancer-related communication research, including participation of adolescent patients in discussion about informed consent and medical decision making [23], and children/adolescent patient’s wishes about communication regarding bad news [11]. Most participants valued open and honest communication with their healthcare providers, who were their most frequent source of health information. Of note, some participants said that there was certain information they did not want to receive about their health status, and many had made their wishes about this known to their healthcare providers.

Participants also considered parents to be important communicators and holders of medical information. These findings support prior research and highlight the important role that

parents continue to play during an adolescent's cancer treatment and at the end-of-life [24,12]. While older children and adolescents are seeking autonomy from their parents, they also rely on their parents to filter information and free them from the burdens of hearing overly difficult information. Many young people reported seeking information from other sources, including the internet and television. While this has been reported previously among adolescent cancer patients [25], participants in the current study were often confused or distressed by information from outside sources, underscoring the importance of provision of critical information in the medical setting.

Second, participants often manifested some ambivalence about prognosis communication or conveyed conflicting wishes for information. For example, they often focused on the day-to-day impact of cancer when first asked about their understanding of the future, but later brought up worries about prognosis. Similarly, when asked directly, participants often said they were satisfied with the information they had about their future, but later in the conversation brought up issues they wished they understood better. While only one participant directly acknowledged the possibility of death in response to the main question, others mentioned it in more subtle ways during the interview. This pattern of responses suggests that, with children and adolescents, the direct answer to a question may not hold all the information, but the issue can arise again later in ways that are important and edifying, and allow for opportunities for active exploration by the provider.

In addition, some participants both expressed a desire for prognostic information and noted that they tried not to think about it. These findings are also consistent with normal child development, and have been particularly described among children and adolescents facing terminal illness [26]. Even adult patients have been characterized as simultaneously "knowing and not knowing" difficult information [27], suggesting that this is not solely an adolescent phenomenon, but a human one. This presents a special challenge for providers, who must learn how to balance information in the setting of ambivalence. Nonetheless, the fact that many patients had unresolved questions about prognosis is a reminder that ambivalence should not be considered a reason to withhold information; rather, providers should work with patients to meet their informational needs in the ways patients find most helpful and supportive.

Third, although we did not specifically ask about social concerns, the young people in our study brought them up frequently. Social concerns included the impact of cancer treatment on day-to-day life, feelings of isolation, a desire for normalcy (or for life to return to how it was prior to cancer), and the effects of their treatment on their appearance. These findings underscore the importance that adolescent patients place on "having a normal life," something providers often underestimate as they focus on curing the disease [28].

Our findings have several clinical implications. First, our data underscores the importance of providers' listening carefully for openings when working with young people, as many patients may not bring up concerns directly. Without careful listening and response by providers, however, young people may be left with unmet needs for information about their illness, including prognosis. Second, providers should be mindful that besides obtaining information from medical providers and parents, young people with cancer are seeking

additional information from other sources, including the internet. Patient-oriented websites are not always geared towards young people, and can be of poor quality [29]. Patients and families may therefore benefit from open conversations about where to find accurate information online. Third, it is important that providers assess the individual information needs of the patient rather than make assumptions about what they would like to hear. As young people may have different wishes for information at different times during their course of treatment, regular check-ins about information needs can help ensure that patients are receiving the information they want in the way they want to receive it. Finally, cancer treatment is extremely disruptive to a young person's life, and this should be acknowledged. By asking patients "what is important to you?" providers may be able to better understand the ways in which treatment is disrupting normal activities, and potentially identify ways of mitigating the disruption.

This study is not without limitations. The sample size was small and drawn from a single center, and most patients had hematologic malignancies, all of which may limit the generalizability of our findings. While we did not find clear thematic differences by age, we had a limited ability to detect such differences. However, most of our patients were teens, and our findings might be most representative of their perspectives. In addition, our final question "Do you wish you know more about what could happen because of your illness?" may have raised a new bias by prompting patients to raise new, but previously non-existing, questions. While we acknowledge that this is a limitation, we felt that this was an important topic to explore, and the responses provided a more in-depth understanding of the participant's experience. Finally, while we focused our questions on prognosis communication, many patients reflected broadly on communication experiences throughout care.

Young people can be extraordinarily thoughtful about their experience undergoing cancer treatment, and by listening to them and learning from them we can improve the care we provide. This study adds to existing literature by asking pediatric oncology patients to reflect on their experiences with communication about prognosis, both good and bad, which we described as "what could happen to you because of your illness." Although many patients expressed a desire for more information about prognosis, they often did so indirectly, a finding which reinforces the importance of understanding the developmental factors that make pediatric patients unique, including their patterns of communication. By keeping the pediatric patient at the center of our interactions, we are able to recognize and respect their information needs and desired level of engagement, and thus provide true patient and family centered care.

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TABLE I

Interview Script

Question:
1. Please describe for me when you first knew that you were ill and would need treatment
2. What do you think is likely to happen to you because of your illness?
3. What makes you think that [use participant’s words] could happen to you because of your illness?
4. How did you learn that [use participant’s words] could happen to you?
5. How do you feel when you think about what could happen to you?
6. Do you wish you know more about what could happen because of your illness? How would you like to learn about what could happen to you?

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