Parental Perspectives of Communication at the End of Life at a Pediatric Oncology Institution

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Abstract

Background: The interaction of health care providers and hospital staff with patients and families at the end of life affects the parental grief experience. Both verbal and nonverbal communication are key components of this interaction.

Objective: The study objective was to explore the communication between hospital staff members and patients and families at the time of patients' health decline near the end of life.

Methods: Twelve bereaved parents participated in a focus group. Semantic content analysis was used to analyze the transcript.

Results: Parents' responses to the prompt about typical ways the medical team communicated yielded 109 codes, which were grouped into 12 themes. The most common themes were ''patient inclusion'' and ''explanation of medical plan,'' both used in 17% of responses. Responses to the prompt about positive and negative aspects of communication generated 208 codes, yielding 15 different themes. The most common theme about positive communication was the ''strong relationship between family and staff.'' The theme ''variations in care with a negative impact'' was used most frequently in describing negative communication.

Conclusion: This study helps to identify techniques that should be used by clinicians as they work with children with cancer and their families, particularly including patients in treatment decisions, ongoing relationship building, communicating with caring and empathy, using an interdisciplinary team for additional support, and pairing bad news with a plan of action.

Introduction

DESPITE THE CONSENSUS that poor communication is a significant barrier to effective pediatric palliative care,[1–6] few studies have examined palliative care communication between physicians and families of children with progressive incurable cancer. Despite studies showing that parents of children with advanced cancer rate the quality of care higher when they feel that they receive clear information, including anticipatory guidance about what to expect in the end-of-life period delivered in a sensitive and caring manner,[7,8] there remain barriers to this type of communication. When treating patients with a life-limiting disease, many physicians are hesitant to be the bearers of bad news, because they see ''disclosure of a poor prognosis and provision of hope as conflicting obligations.''[9] The end result of this selective communication by health care providers may be a false sense of parental hope, which may not allow the patient and family to adequately prepare for the possibility of a poor outcome.[10]

Studies involving bereaved parents were recently identified as a research priority in palliative care.[11] With the aim of determining the communication needs of parents of children with progressive cancer, we used a focus group consisting of bereaved parents to explore the perceptions of communication between staff members, patients, and patients' families that occurred when patients were still receiving cancer-directed treatment and experienced health decline near the end of life. A focus group was used to explore broad themes and topics with a goal to move to individual interviews to further characterize important aspects of communication.

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Methods

The institutional review board of St. Jude Children's Research Hospital reviewed this study and waived the requirement for written consent (IRB no. Pro00003702). Eligible participants were parents whose child had died at our hospital; there were no exclusion criteria. Participants were recruited from the institutional family advisory council. The focus group was tape-recorded. The facilitator of the group was a psychology doctoral student without clinical responsibilities at the institution. The two other members of the study group that were present for the focus group were not involved in the clinical care of any of the children of the participating parents. Tape recordings were transcribed by an independent group; personal identifiers were removed.

The transcript was analyzed, and responses to each prompt underwent qualitative semantic content analysis[12] using MaxQDA software (Version 11, Berlin, Germany). The unit of response was the response to each prompt, and the unit of analysis within each response was the phrase. Two study team members with experience in this method jointly reviewed the transcript and generated codes from each key phrase to capture its meaning. A third team member analyzed the transcripts and applied previously defined codes to the transcript. Responses to each prompt were analyzed independently and the frequency of the codes was tallied for both prompts. To compensate for multiple appearances of the codes within a single answer to a prompt, we also tallied the total number and percentage of parents for whom the code appeared. For both prompts, multiple codes frequently overlapped in meaning: these codes were grouped and identified as a theme capturing the shared meaning.

Results

Twelve bereaved parents participated in the focus group; 10 of them met in a room with a facilitator and 2 other study staff members, with the other 2 parents calling in on a conference line, given limitations in ability of these parents to travel. Participants had experienced the death of their child an average of 5 years prior to participation in the focus group, with a range of 1.5 to 14 years. Observation of the group and analysis of the transcript revealed the majority (10) of parents were Caucasian; 2 were African American. One of the parents lived in the local community; the other 11 parents lived in communities outside the local area. No other demographic data was collected. The mean inter-rater reliability between the first two and the third study team members was 83% for prompt 1 and 86% for prompt 2.

Focus group prompt: Please tell me about the typical ways your child's care team communicated with you

Parents' responses generated 109 codes, which were grouped into 12 themes (see Table 1). "Affirmation" was used for segments of the transcript in which parents praised the team for nonspecific good care. ("I thought it was really admirable that he just helped us understand those things.") This code was used 12 times but was not included in the final analysis as it did not directly relate to the prompt. Of the remaining 97 codes, the most common theme was "patient inclusion" and "explanation of medical plan," both used in 17% of codes and by the majority of parents. The next most common theme was "not given all information," with a frequency of 15%.

Focus group prompt: Please tell me what kinds of things were said or done when good communication occurred and, conversely, what kinds of things were said or done when bad communication occurred

Responses to this prompt generated 208 codes, yielding 15 different themes. The code "affirmation" was used three times and was removed from the analysis. The code "apology" (describing times at which a team member apologized to the parent) was used two times and was directly linked to both positive and negative aspects of communication: "Well, he said that it was a mistake made but they tried…but they did everything they did to correct it. And he apologized to me for that." And, "The guy just got obnoxious. And he finally, when it was all done he apologized."

The remaining 203 codes were subdivided into those describing either positive (109 codes; see Table 2) or negative (94 codes; see Table 3) communication. The most common theme about positive communication was the "strong relationship between family and staff" (24% of codes). The next most common themes were "empathetic explanation and reassurance of medical care/plan" (20% of codes) and "medical team involvement/individualized interaction" (14% of codes). These three themes were used by the majority of parents. Although used less frequently, the themes "show of emotion by the medical team" (9% of codes) and "continued care/connection with staff" (7% of codes) were used by a large number of parents. Of the themes describing negative communication, "variations in care with a negative impact" was used most often (24% of codes). The themes "required parental advocacy" and "required parental vigilance" were also used frequently (18% and 13%, respectively) but represented distinctly different results of negative communication. See tables for full definitions of themes and example statement(s).

Discussion

This study provides new insights into and emphasizes previously described aspects of communication. One of the key findings was the effect of including the patient in the communication process: "[Our doctor] let him know whatever he was going to do, what to expect, from day 1. And he had a conversation with him like he was a grown child." Literature on communication at the end of life has mainly focused on parents and health care providers with underdocumentation of inclusion of children[13] and adolescents[14] in decision making discussions. However, the vast majority of chronically ill teenagers want to share medical decision making, with most preferring to discuss their wishes earlier in the course of the illness.[15] There is a focus of newer literature to "enable and empower"[16] adolescents in medical decision making. Inclusion of children with life-limiting illness in medical discussions should be considered for all patients, because even very young children may have an advanced understanding that may facilitate participation in discussions about future treatment options and end-of-life decisions.[17–19] Additionally, inclusion of child siblings in the exchange of information has been found to be important in adjustment to the illness experience and may be important in anticipatory grief[20] and should be considered.

Table 1. Themes Generated from Responses to the Prompt, "Please Tell Me about Typical Ways in Which Your Team Communicated with You"

Theme	Definition	Frequency, n=97 (%)	No. of parents using theme, n=7 (%)	Example statement
Patient inclusion	Patient deciding about inclusion in discussion, treatment plans, team giving patient age-appropriate information	17 (17.5)	5 (71)	"[My son] was always included in the conversation and the other doctors, whoever was on rounds up on the second floor, if we were in ICU, they knew [he] wanted to be included. And he would ask questions just like my husband and I would."
Explanation of medical plan	Team giving updates, explaining steps of treatment, reinforcing information, giving anticipatory guidance; always one step ahead	17 (17.5)	5 (71)	"Assuring us everything they could do and giving us every option and every insight and every bit of education that you could have as a parent."
Not given all information	Patient/family not given all medical information, including prognosis or available treatment options; hard time obtaining info after transition of care; parents not understanding severity of the situation; questioning info exchange later	15 (15.5)	3 (43)	"We had a really horrific time sometimes getting answers when something didn't look right."
Descriptions of ways in which communication was done poorly	Bad information given abruptly, without compassion; too much information seen as a burden; primary physician not being available or comfortable communicating bad news	11 (11.3)	2 (29)	"But I think the type of doctor he had and the compassion he had, I think that he actually dreaded saying certain words. He did not stay here very long after that and you see a lot of turnover. Because I think he just actually hated to be the one to bear that type of news."
Compassionate delivery of information	Caring delivery of information to patient/family by members of interdisciplinary team; team respecting decision about where exchange of information would take place	7 (7.2)	4 (57)	"And [our doctor] was always really good to, as kindly and as compassionately as he could, give us the news without sugarcoating it, without giving false hope."
Presence/ vigilance of medical team	Doctor/nurses physically being with patient/family, remaining attentive and involved with care of patient; establishing trust	9 (9.2)	5 (71)	"But [my son's] doctor was so great because every day he came over and he was watching his labs."
Parental vigilance/ advocacy	Parents needing to carefully watch and explain things to new providers not familiar with patient/family; parental activism on behalf of child for his or her best care	9 (9.2)	3 (43)	"I felt like I had to advocate for him and watch every move and everything that went on because we'd had that emergent situation."
Negative aspects of variations in care	Other/new staff not knowing patient/ family or medical history/plan, difference in care provided at other locations	4 (4.1)	3 (43)	"There had been a couple of physicians around but they weren't familiar with what was going on with [my son]."
Goals of care	Patient/family involved in decision about medical treatment/end of life, team respecting wishes of patient/family	4 (4.1)	4 (57)	"He was able to come over and talk to us about what our wishes were as far as where we wanted [my son] to be."
Emotional connection with team	Good rapport between patient/family and members of interdisciplinary team, creating a trusting relationship, medical team showing emotion	4 (4.1)	4 (57)	"We had such a team of support between the social worker and chaplains and child life and the nurses and doctors and staff just handled everything great, explained everything in great detail and made my son understand what he needed to and gave him all the support he needed."
Recommendations for improvement	Parents suggesting ways to improve care/communication	2 (2.1)	1 (14)	"So that may be something to look at, that different areas of the hospital, the staff handled things a little bit better than others."

TABLE 2. PARENTS' RESPONSES ABOUT POSITIVE OR HELPFUL ASPECTS OF COMMUNICATION

Theme	Definition	Frequency, n = 109 (%)	No. of parents using theme, n = 11 (%)	Example statement
Strong relationship between family and staff	Caring and love between all members of the medical team and patient/family, deep bond	27 (24.8)	8 (72.7)	"Having a connection with the family and the patient, not just treating them as a record number or just a statistic."
Empathetic explanation and reassurance of medical care/plan	Team giving updates, recommendations, anticipatory guidance; confirming and supporting decisions; explaining steps of treatment/plan	22 (20.2)	6 (54.5)	"And she said…'they're doing exactly what I would do.' I needed reassurance that we were taking care of him like we should be."
Medical team involvement/individualized interaction	Team members physically being present/attentive/interactive; remaining attentive; providing flexible, individualized care	16 (14.7)	7 (63.6)	"Before they would get to anything they would sit down with him and just talk with him and play with him and laugh with him and ask him questions, like, about his cars…or Legos…. Just getting to know him and his personality and, you know, what he was like as a child."
Patient involvement	Patient having a role in information exchange, treatment plan/decisions, delivery of care	13 (11.9)	6 (54.5)	"[Our doctor] let him know whatever he was going to do, what to expect, from day 1. And he had a conversation with him like he was a grown child."
Show of emotion by medical team	Members of team showing caring, crying; expressing exasperation at situation	10 (9.2)	7 (63.6)	"He cried in front of me, himself, I think, in trying to explain…I think he wanted to explain…he wanted to explain the gravity of the situation or that he'd done all he could do."
Continued care/connection with staff	Loss of patient felt by all members of team; staff continued to be involved with family after leaving the hospital; follow-up with families after death	8 (7.3)	5 (45.5)	"It was everyone's loss, it wasn't just ours and it was just heavy, that so many people loved him so much and came to support us."
Compassionate delivery of information	Information delivered in a caring manner, humanizing; bad news immediately followed by plan for future, open to new (treatment) ideas	7 (6.4)	5 (45.5)	"If you know the person that's coming in there and they're telling the truth, as hard as it is, but you know they care about you and they love your child, it's okay. As hard as it is, it's okay and it makes all the difference."
Families wanting to care for staff	Parents desire to check in with and support staff after child's death	6 (5.5)	2 (18.2)	"I just wanted to see [my son's nurse] again so I could tell her that it was okay, that we didn't…. You know, she did the best she could for him and to express that to her."

Both passive actions, such as the act of being physically present at a difficult time, and active behaviors, such as empathetic listening and showing emotions, were identified as being aspects of positive communication. The collaborative bond between the physician and patient forms a therapeutic alliance.[21] Many themes that we identified as positive aspects of communications are components of a therapeutic alliance (e.g., showing emotions, physical presence, and development of individualized care). A caring bond between the patient, family, and medical staff may aid in difficult discussions about goals of care at the end of life[21] while still promoting hope.[9] The importance of the therapeutic alliance is exemplified by the following parental quote: "If you know the person that's coming in there and they're telling the truth, as hard as it is, but you know they care about you and they love your child, it's okay. As hard as it is, it's okay and it makes all the difference."

Physicians are often pressed for time, and patients and family members are not in the best emotional state to listen to and comprehend the information provided during brief encounters primarily focused on medical information exchange. An interdisciplinary approach to communicating bad

TABLE 3. PARENTS' RESPONSES ABOUT NEGATIVE ASPECTS OF COMMUNICATION

Theme	Definition	Frequency, n=94 (%)	No. of parents using theme, n=11 (%)	Example statement(s)	
Variations in care with a negative impact	Negative interactions with staff; unsure whether medical treatment is correct and/or safe; contrast between care given in other locations/ by other teams	23 (24.5)	6 (54.5)	"Difference between what was the expectation from [our hospital] perspective and what was actually delivered when it's not a [hospital] person doing it was stark in its contrast."	"The person who brought the morphine pump had never seen the pump before. And it was an hour and half on the phone talking to their support staff, trying to get it set up and it just didn't give you any sense at all that they had a clue of what was going on."
Not given all information	Parents/patients not involved in information exchange; not given all information or treatment options; team not comfortable giving bad news, not truthful	17 (18.1)	5 (45.5)	"You're not including me and telling me, explaining to me what's going on with my son."	
Required parental advocacy	Parents needing to take initiative, imploring medical staff to do what is best for their child	17 (18.1)	5 (45.5)	"I then said, 'You know, we need you to do all that you can do for [my son].'"	"He's [our] responsibility. I know [the hospital] cares about him but I need to know that I'm doing everything as a parent."
Required parental vigilance	Parents needing to carefully watch and explain things to new providers not familiar with patient/family	13 (13.8)	3 (27.3)	"You really feel like you have to watch everything and kind of explain it to them."	
Lack of continuity of care	Issues with staff who are not primary team members understanding patient, plan, correct way to do things for the patient; family not knowing the team members	11 (11.7)	5 (45.5)	"I've always found that very difficult when there was someone else that wasn't used to taking care of my son on a regular basis."	
Poor ways in which medical information was delivered	Bad information given without hesitation; lack of compassion; too much information as burdensome; team sharing bad news without presenting plan for future; nonverbal expressions of abandonment	9 (9.6)	3 (27.3)	"That was the truth. But the way she delivered it made me feel like she didn't really care about my child."	"But I just saw the tears as a nonverbal expression of, 'I've done all I can do.' You know, kind of throwing the hands up."
Not understanding severity	Parents/patients not knowing the seriousness of the situation, not knowing about impending death	4 (4.3)	1 (9.1)	"We didn't know he was that ill.… We knew he was sick but not *that* sick."	

news can help to overcome these difficulties and has been shown to improve communication of sensitive information.[22,23] Members of an interdisciplinary team may know or connect with the patient and family in a different way (e.g., nurses, social workers, chaplains) and may have more time to spend with the family to help reiterate information and allow them to have all questions answered. Involvement of psychosocial team members may not only help to improve communication around end-of-life issues[22,23] and decision making but may facilitate earlier referral to hospice,[24] and has been associated with greater use of comfort medications (opioids and sedatives) in the last 24 hours of life.[25]

As in other studies, parents note that communication between the physician, patient, and family must be honest and complete,[10,26,27] especially at the end of life. However, they note that too much information can lead to more confusion and stress. Medical team members must balance the families' needs for information with the desire to protect patients and families from information overload. Parents noted that bad news was easier to handle if it was immediately paired with a plan of action: ''Just what we personally needed to hear because even though the 'yep, it's back' was kind of abrupt, he went straight into 'and this is what we're going to do.''' However, there may not always be a treatment plan that can be offered. The medical team must be aware that the family's expectation to have 'a plan' presented when bad news is delivered may represent the need for reassurance that the team knows what they may face and will continue to be with them. Both of these themes, involvement of the interdisciplinary team as well as pairing bad news with a plan for action, suggest that a two-step approach to these conversations may be most helpful to patients and families, similar to an approach that was recently outlined for phase I informed consent discussions.[28]

There are several limitations to this current study. The analysis includes only one focus group with a small number of parent participants, although qualitative methodology may help to overcome some of these issues. Recall bias or reframing of the communication around the time of death must be considered, as some parents were many years out from the death of their child. Additionally, there is wide variability in time from the death of the child of the parents in this focus group. This study includes parents from a single, oncology-based institution; and these parents were self-selected so may not represent the entire population and experiences at our institution. Finally, demographic and cultural data were limited to observation and review of the transcript, and no other demographic data were collected from the parents. Despite these limitations, this study highlights important aspects of communication near the end of life using bereaved parents in an open, focus group setting.

In conclusion, this study affirmed certain techniques that should be used by clinicians as they work with children with cancer and their families, specifically patient inclusion in medical discussions and treatment decisions, relationship building, communication indicating caring and empathy, additional support by an interdisciplinary team, and pairing bad news with a plan of action. Palliative care employs an interdisciplinary approach to patient and family care and has been associated with improved end-of-life communication, including overall advanced care planning in pediatrics,[4] patient inclusion in discussions of death and dying, and providing anticipatory guidance around death.[8] Integration of key palliative care concepts and early involvement of the palliative care team will allow for development of a therapeutic alliance and strong relationship that can provide high-quality communication and supportive care for the patient and family.

Author Disclosure Statement

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