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Review Article

Parent Communication Strategies for Facilitating Children's Coping with Pediatric Advanced Diseases

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Abstract

CIn pediatric palliative care, parents are main sources of support for children and often influence the quality of life their children experience. In related research of parent-child dyads in pediatric oncology, it is known that parents play a crucial role in how children adapt and battle their disease; however, when disease advances and there is less chance for cure, little is known about parents' perception of their communication style on their child's coping with disease progression. This qualitative study reports on interviews with 29 parents (mean age=38 years, range 32-54 years) of pediatric oncology and cardiology patients (mean age=14.7 years, range 9-21 years) with a poor prognosis (physician reported likely <20% chance of survival beyond 3 years) from two children's hospitals and one pediatric hospice in Los Angeles, California. Perspectives on parent communication from parents' individual narratives were recorded, coded, and analyzed using qualitative grounded theory methodology. Across interviews, parents identified six communication strategies they deemed to be highly salient and influential in helping their children confront advanced disease. These included facilitating communication between the child and others, promotion of family understanding, showing awareness, discussion of stressors, redirecting the child, and demonstrating protection and comfort. Findings from this qualitative study can be used by clinicians to recognize and monitor communication patterns between parents and their children with advanced disease. In turn, knowledge of these communication domains can be used as a step-stone toward improving interventions aimed at maximizing pediatric quality of life, especially as disease progression occurs.

Introduction

Battling a life threatening illness inevitably presents a child with a multitude of stressors that increase in nature as disease progresses [1,2]. A primary goal of pediatric palliative care is to foster the highest level of comfort and quality of life for pediatric patients facing life-threatening illness. Communication becomes the cornerstone to learning about the child's experience and needs as they face changes associated with their illness [3]. Parents are woven intimately into the child's illness experience as they typically become their child's primary care-provider and proxy-reporter of symptoms [4]. They may struggle to balance their personal fears and anxiety regarding their child's disease along with a sense of responsibility to help empower their child's coping with the hardships of disease [5]. Open parent-child communication regarding changes to physical abilities and limitations, social interactions and relationships, and the child's various manifestations of stress can prove powerful in learning to cope with a child's "new normal" when first diagnosed with a life-limiting disease [6]; however, little has been documented regarding parents' communication strategies that can assist children coping with advanced disease.

Methods

This study is part of a larger project assessing communication in pediatric palliative care [7]. Qualitative research methodology was used to assess parent-child communication for children with advancing disease. The current study examines parent interviews focusing on their perceptions regarding communication with their child [8,9]. Pediatric health care professionals conducted interviews with parents and their children, ages 7- 22 years. Qualifications for being interviewed included physician determined life-limiting

conditions, defined as having <20% chance of survival beyond 3 years. Exclusion criteria included inability to speak English at a level suitable for participation and parents not mentally competent. This qualitative aspect of the study recruited patients and parents from all subspecialty divisions at one children's hospital, the hematology/ oncology division of another children's hospital, and an in-ho me children's hospice. Each of the institutions granted International Review Board approval for the study. Health care providers affiliated with each of the institutions referred potential patients for participation and this report examines the interviews of 29 parents (mean parent age=38 years, range 32-54 years; mean child age 14.7 years, ranging 9-21 years). Fourteen (70%) of participating patients were female, 65% Caucasian, 35% Hispanic, 5% Asian. The response rate for invited participants was 57%. Some reasons for refraining from participating included "being too tired to participate," "not a good time," not returning phone calls, and child passing away before meeting time was rescheduled (1 family). All subjects enrolled completed the study. Additional demographic characteristics of the patients and parents are described in (Table 1).

Variable	Number (%)	Mean (SD)	Range
Dyads	29		
Child Characteristics			
Gender			
Male	12 (41%)		
Female	17 (59%)		
Age (years)		14.7 (3.90)	9-21
Education/ grade		8.39(3.43)	3-13
Ethnicity			
Caucasian	17 (58.6%)		
Asian/Pacific Is	1(3.4%)		
Hispanic	9(31.0%)		
Other	1(3.4%)		
Missing Values	1(3.4%)		
Birthplace			
USA	26(89.7%)		
Other	1 (3.4%)		
Missing Values	2 (6.9%)		
Religion			
Christian	23 (79.1%)		
Jewish	1(3.4%)		

None	3 (10.3%)		
Missing Values	2 (6.9%)		
Medical Grouping			
Cardiology	14 (48.3%)		
Oncology	13 (44.8%)		
GI	1 (3.4%)		
Missing Values	1 (3.4%)		
Disease Stage			
Post-BMT	2 (6.9%)		
Multiple Relapse End Stage	11 (37.9%)		
End Stage	4 (13.8%)		
Pre-transplant	3 (10.3%)		
Post-transplant	3 (10.3%)		
Congenital Heart Disease	4 (13.8%)		
Missing Values	2 (6.9%)		

Table 1: Demographic characteristics of pediatric participants.

Semi-structured interviews were used as a means to guide participants telling their individual narratives to include responses to particular questions regarding communication. Topics included asking the children about their experience being sick and asking parents their perspective on their child's experience with the illness (Table 2). Parents and children were interviewed separately and both were given the opportunity to tell their story with minimal interruption; although the interviewer remained engaged in the conversation, asking follow up questions and guiding the participants if they had not yet answered the intended questions. This methodology enabled children and parents to share their individual experiences, while ensuring to include a common set of issues across all participants. The focus of the study portion described here is on parent interview responses [10].

1	What do you think has bothered (name) the most?
2	How do you know _ bothered (name) the most?
3	Tell me about how you responded to (the above)? Did you think that helped?
4	To whom on the health care team do you talk to most about your child? Whom do you feel most connected with?
5	What it made it easier or more difficult to talk about your child's symptoms?
6	Did you feel you received the help that you wanted?

Table 2: Parent Interview Prompts.

Qualitative Data Analysis

Each interview was audiotaped and videotaped, followed by verbatim transcription. At least one person tested the reliability on each transcript and corrected any errors if necessary [11]. The lengths of each transcript were compared and found to be on average 16.5 pages for parents. Reasons for differences in transcript length include cognitive deficits that influenced the child's ability to respond and individual differences in communication tendencies [12].

Following transcription, the transcripts were analyzed for various themes using the grounded theory approach, a method used to allow concepts and theories to emerge from data itself. Qualitative analysis revealed specific trends and enhanced understanding of the child's experience with illness from the parent's perspective. The research assistant and project coordinator analyzed a subset of transcripts individually and discussed the findings to create an initial list of themes and trends based on the interviews and additional literature findings regarding pediatric palliative care and parent-child communication. The observed themes were grouped into a set of codes used as a guide to analyze interviews.

They established an initial codebook with definitions of each code to encourage consistent analysis among coders and minimize the influence of individual biases when coding [13]. The size of transcript text coded ranged from key phrases to several sentences regarding the same theme.

Some parts of the text were coded into more than one aspect and were marked if double-coded. Two research assistants trained in qualitative analysis used this codebook to individually code a set of transcripts provided by the project coordinator. The research assistants then met to discuss differences and make adjustments to codes or code definitions where necessary. By comparing the coding of the interviews by each research assistant they were able to determine interrater reliability in terms of how consistently the codes were applied to the same transcripts. Once an interrater reliability of .80 or higher was achieved for three consecutive interviews, the final set of codes was used to analyze all the transcripts. Some interviews were randomly selected to double-code to ensure interrater agreement remained constant. Coding meetings were held periodically to maintain consistent focus.

Results

From review and analysis of parent interview transcripts, six communication strategies emerged that parents deemed helpful in assisting their children confront advanced disease. These included facilitating communication between the child and others, promotion of family understanding, showing awareness, discussion of stressors, redirecting the child, and demonstrating protection and comfort. (Table 3) shows the different categories of communication strategies along with the frequency of endorsement across all interviews.

	Parent n	%
Providing Comfort and Protection	25	86.2
Discussing Stressors	23	79.3
Parental Awareness	22	75.9
Facilitating Communication	10	34.5
Promoting Family Understanding	7	24.1
Redirecting Child	6	20.7

Table 3: Communication strategies identified by parents N = 29.

Providing Protection and Comfort

The majority of parents endorsed that they used communication strategies which let the child know that s/he can consistently depend on parent(s) for protection and fostering a sense of security.

Parent (P): "Just like I gotta promise her to come back. And I'm always gonna have her assured that I'm going to be there. And every time when I assure her, it gives her a lot more way of knowing that no matter what she goes through, we're gonna survive it together. We're a team."

Parents also emphasized the nature of their role as advocate and the importance of additional treatment or therapeutic activities in order to provide reassurance to their children. (P): "I have the luxury of being with her whenever she needs support and to be her advocate and all these things so…But umm, you know and you try to help - you don't want to - you don't want to be overly protective."

Showing Awareness

Parents expressed their desire to show their children they were aware of potential sources for their child's distress as well as how and when their child demonstrated distress. Parents tended to describe their awareness of their child's explicit expressions of distress, such as when their child had arguments with siblings.

P: "Sometimes after school I can tell that she's been under a lot of stress because she'll yell at her brother or yell at her sister and take it out that way but I can tell that she's sort of trying to deal with all this stuff going on."

Parents also described more implicit expressions of their child's distress (e.g. cues related to their child's individual personality), such as the "look on their child's face" that they notice on a recurring basis when their child is distressed or in pain.

P: "I sort of try to um tune in to reading her signals you know as far as if I catch her being out on a walk (to get away) and try to um intervene and make her feel more comfortable."

Discussing Stressors

Across interviews, parents commonly talked about their methods for discussing stress with their child in one of two

capacities: either how they initiated discussions regarding stress or how they responded to discussions regarding stress. Parent initiation. In these instances, parents initiated discussion with their child regarding the child's stress by asking questions like: "Are you too tired?" "Are you in pain?" P: (When my child is in pain, I say) it's okay, you know, um, don't hold your feelings inside, you know, you want to let people know what you're feeling, how you're feeling in a respectful manner." Parent responsiveness. Parents explained how they responded to the child's initiation of discussions regarding stress. P: I wait for my child to ask "Can you talk to my teacher?" about not being able to walk between classes on time. I listen for "Mommy I need this, I'm feeling this, or I'm upset, this helps, can you do it?"

Facilitating Communication

On several instances parents endorsed how they would facilitate their child's communication with others, which included help accessing professional guidance from counselors and other resources. P: "she would actually benefit by um talking with someone, with a child psychologist, psychiatrist, someone who's aware of children who have severe medical problems or um you know um so that she can cut I know the frustrations that she's probably doesn't voice to us and I think that was hard for her" P: "I didn't want to upset her and force it on her so I couldn't find a way to like, be gentle and let her feel free to communicate with me. I was just paralyzed. And um, when we came here, the Child Life, um people. Oh, they were tremendous, you know. They were a tremendous help because, um, they helped, they helped a lot"

Promoting Family Understanding

Parents also indicated how they promoted others in the family to understand what their child was undergoing. They spoke of how they tried to promote, specifically, (1) sibling understanding of the patient's circumstances as well as encouraging the (2) overall family's understanding and empathy of the pediatric patient. In one instance, a mother describes how she needed to tell her own mother and uncles that they should not cry or show their worries and concerns in front of her ill child, in order to maintain a positive environment for her child: P: "And I feel that he won't fight if he sees us breaking down and I need him to be strong. I go, I'm sorry mom, you may be my mom and you may be his grandson but I will kick you out of his life if you do that."

Redirecting the Child

In interviews, parents emphasized that they redirected their child's focus to more positive thinking and/or helped them reframe their attention on their strengths and abilities rather than weaknesses and inabilities.

P: "But at the same time she's dealing with it emotionally, psychologically, it's just, you know, and that part, um, I tell (name of child), you know, "You want to be optimistic, you want to be you know, um, have a good attitude! And, you know, you send good energy, you'll get good energy back." And, you know, um, we talk about what the good points are and she knows what the bad points are."

Limitations

Some study limitations may affect the generalizability of our findings. Non-English speaking parents were excluded from the study sample. Thus, families speaking a primary language other than English may utilize different strategies for communication based on language and cultural differences. Other limitations related to the sample include the limited ethnic, geographical and religious diversity of the sample. Self-selection bias may have also restricted generalizability, such that those parents who are more open apt to practicing various communication strategies with their children volunteered participation the study.

Application of Qualitative Findings in Clinical Practice

Qualitative analyses of parent interviews identified six communication strategies parents perceived as being useful in helping their children confront advanced diseases. These communication strategies included facilitating communication between the child and others, promotion of family understanding, showing awareness, discussion of stressors, redirecting the child, and demonstrating protection and comfort. Parents most frequently endorsed that they used strategies which provided their children with a sense protection and comfort as well as strategies that provided opportunities for discussion of stressors in their children's lives.

Parents often feel responsible for easing their child's suffering throughout the course of an uncontrollable illness [14]. The strategies summarized above suggest that effective parent communication be a combination of providing security for the child through parental presence while facilitating communication and not intruding or projecting one's own distress. This recipe for the ideal blend of helpful communication strategies could be considered a reflection of the bi-product of Ainsworth's (1978) [15] "securely attached" child, where as long as the mother is present in a strange or "stressful" situation, the child can exist comfortably [16].

Clinical care for children facing advanced diseases can be improved by helping parents recognize their children's various cues of distress and when to appropriately aid the child by utilizing the most effective forms of communication. For example, when disease progresses to a stage where curative treatments are no longer possible and symptoms become less controllable, parents can be taught to redirect their child to focus on their current abilities

rather than on the skills or mobility lost. Similarly, when a child realizes s/he is at an end-of-life stage, his/her focus of time may not be on researching various clinical trials, but rather on creating memory- making (e.g. crafting a family tree with photographs and handprints) opportunities with family members. Parents can facilitate communication with other family members and promote an understanding with family that the most appropriate way to empower their ill child is to make themselves available to crafting and memory-making activities rather than by bringing journal articles on clinical trials to the child's attention.

Future Directions

Along the same lines of learning about effective parent communication strategies from the parent's perspective, it would then be beneficial to explore what children valued as effective parent communication as they face advanced disease. An important component that would also need investigation is how cultural differences play a role in what is deemed effective communication from both the parent and child's experiences. Longitudinal follow-up, even as some parents might be grieving the loss of their child, would be an important next step. In other words, does effective parent communication while the child is confronting advanced illness help prevent complicated grief and regret after the child's death.

Acknowledgement

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