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Bereaved Caregivers as Educators in Pediatric Palliative Care: Their Experiences and Impact

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Abstract

Background: With the continuing growth of pediatric palliative care, there is an increasing need to develop effective training for health care professionals. Bereaved parents have participated in the training of health care professionals utilizing curriculum from the Initiative for Pediatric Palliative Care (IPPC), but the experience of bereaved parents as educators has not been studied.
Objectives: This qualitative research examined the experience of bereaved parents involved in pediatric palliative care education of health care professionals and the challenges and possible benefits for the health care professionals.
Methods: Nine bereaved parents and eleven health care professionals were interviewed about their experiences in a pediatric palliative care education program utilizing the IPPC curriculum. The interviews were recorded, transcribed, coded and analyzed for themes and subthemes.
Results: Major themes found were a sense of purpose for the parents and benefits and challenges for both parents and professionals. The experience for parents contributed to their meaning-making for both their children's lives and deaths. Parents and professionals identified mutual learning and increased mutual understanding. Some professionals noted that the presence of parents may have limited the openness of discussion of the professionals and parents acknowledged challenges of emotional management in their participation in the educational program. Both parents and professionals recognized and described challenges involved in working sensitively with patients and families without being overwhelmed by the intensity of situations where children die.
Conclusion: More benefits than burdens were experienced by both parents and health care professionals from the participation of bereaved parents in the palliative care trainings.

Introduction

With the increasing interest in and acceptance of palliative care in pediatrics, there is a growing need to develop effective training approaches for health care professionals in the concepts and practice of pediatric palliative care. One such effort has been the Initiative for Pediatric Palliative Care (IPPC), introduced in 1998 as a research, quality improvement, and education effort to enhance family-centered care for children with life-limiting illnesses and conditions.[1] Along with the goal of having interdisciplinary educational experiences, integral to the family-centered nature of the IPPC educational approach is the use of family members who actively take part in facilitated discussions. Most participating family members are parents or grandparents who experienced the death of a child.[1,2]

Beginning in 2006, the pediatric palliative care program at our tertiary care facility utilized the IPPC curriculum and educational model for a seven- and now eight-week luncheon training series offered three times per year (see Table 1). An interdisciplinary group of ten health care professionals is represented. Each time the series is offered, two family members of deceased patients, a parent, grandparent, or other primary caregiver attend. (For the purposes of this study, "parent" will refer to the patient's primary caregiver even in cases where the primary caregiver is not the biological parent of the patient.) Parents take an active role in the facilitated discussions surrounding topics relating to communication, family support, end-of-life support and care, and death.

Bereaved parents have been utilized in educating health care professionals in other settings, but generally these experiences are limited, as a parent panel or small, single session group discussions.[3–7] Additionally, there have been efforts to measure the impact of the IPPC curriculum[8] and the increased focus on the voices and perspectives of parents of seriously ill children.[1,2] Solomon and colleagues sought to measure the impact of IPPC educational retreats for pediatric palliative care teams and found that learning from parent involvement

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Table 1. Training Series Topics

Session 1	Speaking the Same Language: Values and Principles of Pediatric Palliative Care
Session 2	Big Choices, Little Choices: Family-Centered Options for Children and Families
Session 3	Knowing Who We Are: Learning from Families about their Needs
Session 4	Difficult Conversations: Talking with Parents in a Crisis
Session 5	Difficult Conversations: Ideas for Family Conferences
Session 6	Supporting an Adolescent Facing Death
Session 7	The Experience of Professional Caregivers in Pediatric Palliative Care
Session 8	What Next: Putting Palliative Care into Practice

was identified as the most important pedagogical element of the educational experience and that parents also experienced benefits as they "came to appreciate the depth of caring and commitment that clinicians feel toward the children and families they serve."[8] However, no research focuses on the experience of bereaved parents as educators of health care professionals, and efforts to examine health care professionals' perspectives concerning the participation of bereaved parents in palliative care education have been limited.[3–7] The question of negative impact or harm for bereaved parents in research was examined by Hynson and colleagues, and findings suggested that a careful and thoughtful approach can acceptably minimize possible harm and the research experience can even be experienced as a positive one for some parents.[9]

The purpose of this qualitative research was to study motivations, expectations, challenges, benefits, and meaning-making for bereaved parents involved in pediatric palliative care education of health care professionals and to learn about the challenges and possible benefits for the health care professionals.

Methods

Design

Focused ethnography with its attention to the cultures of particular groups[10] was used to explore perceptions and experiences of bereaved parents and experiences of health care professionals participating in palliative care education. Health care professionals also have their own culture, including language, rituals, expected behaviors, and assumptive worldviews; and bereaved parents bring their family's culture and the culture of bereavement to the health care setting. Demographic forms and interview guides were developed in consultation with the palliative care team and a pediatric nurse researcher with expertise in qualitative research.

The contacts, meetings, consent process, and interviews of both parents and health care professionals were completed by a research assistant (RA) who received training in qualitative research interviews from both the principle investigator (PI) and staff in the hospital nursing research department. Each parent and health care professional completed a corresponding demographic form (see Tables 2 and 3).

Initial contact of the 10 parents (the total population of parent participants) and 11 hospital health care professionals who completed the IPPC training was by e-mail and phone in one instance where e-mail was unavailable. Purposive sampling was used to recruit the 11 hospital health care professionals. If they agreed to participate, a description of the study and a consent form was mailed to the participants for reference and an appointment was made for them to meet at the hospital where the study and consent were reviewed and explained. If the parent consented and completed the demographic form, the interview was conducted using a corresponding interview guide designed especially for the study (see Table 4). The interviews were recorded using a digital recording device and then transcribed verbatim by the RA for analysis.

All interviews were conducted in a private conference room in the hospital. The RA dictated field notes into a recorder immediately after each interview with parents and health care professionals. The field notes, transcribed for review and reference, included observations, impressions, and reactions during the interview.

Subjects were assigned a unique numerical identifier. Data were collected on all forms using only this identifier and then transferred into a secure database accessible only to the study staff. The study staff members were the palliative care director and the research assistant. A master list of these ID numbers linked to subjects' names was maintained in the PI's file and kept in a secure location accessible only to the study team for purposes of data verification and validation of results.

The data from the forms and measurement tools, transcripts, and analysis were entered in an electronic or computer database without identifying information. Hardcopies of the forms and measurement tools were kept in a locked file cabinet in the RA office.

The risks to the parents and health care professionals in this study were the risks of a breach of privacy and confidentiality if the information gathered with the measurement tools were to be handled improperly and without due concern for confidentiality. Due to the emotional nature of the content of the interviews, there was also a risk of feeling distraught or

Table 2. Demographic Information for Child and Caregiver

Child's age (*n*)	<1 year (6)	1–4 years (1)	5–10 years (1)	16–20 years (1)	
Gender	Female (8)	Male (1)			
Place of death (*n*)	Hospital (4)	Home (5)			
Ethnicity (*n*)	White (6)	African American (3)			
Caregiver (*n*)	Parent (6)	Grandparent (2)	Other relative (1)		
Caregiver age (*n*)	20–29 years (1)	40–49 years (5)	50–59 years (3)		
Caregiver education (*n*)	High school or GED (1)	Some college or vocational (1)	College (3)	Postgraduate work (3)	Doctorate (1)

Table 3. Demographic Information for Health Care Professionals

Age (*n*)	20–29 (2)	30–39 (3)	40–49 (4)	50–59 (1)	60–69 (1)	
Gender (*n*)	Female (7)	Male (4)				
Ethnicity (*n*)	White (8)	African American (2)	Latino (1)			
Years of experience (*n*)	0–2 (1)	3–5 (2)	6–10 (2)	11–15 (3)	16–20 (2)	>20 (1)

overwhelmed by emotion. Care was taken to offer breaks to the participants, as needed, as well as the option to terminate or reschedule the interview. As the parents had experience with being exposed to similar emotional content in the palliative care trainings, the risk of unacceptable distress in the interview was thought to be slight.

Setting and subjects

The palliative care program operates in the only pediatric hospital in the state. Designated staff for the team includes two physicians, specialty nurse, social worker, and director, and the team collaborates closely with pastoral care and child life representatives. The program follows a consultation model[11] and can serve patients and families in both inpatient and outpatient settings.

All 10 parents who had participated in the IPPC trainings were invited to participate in the study and most of these parents had participated in multiple trainings. One parent was unable to be contacted and thus did not participate. The remaining 9 parents participated in the study. Causes of death of their children included cancer, genetic disorders, neurologic conditions, and consequences of child abuse.

Purposive sampling of the hospital professionals who had participated in the IPPC trainings was used to choose 11 participating staff members of the approximately 130 who had completed IPPC training. Theoretical saturation was achieved as determined by repetition of information, such that it became apparent that new conceptual information was not added with additional participants.[12,13] Diversity of discipline, gender, ethnicity, and length of experience in pediatric health care settings were considerations in the purposive sampling. The diversity of disciplines was similar to the diversity of disciplines in an IPPC training series (see Table 5). The strategy of purposive sampling and theoretical saturation was not utilized in the parent sample, as all available parents participated in the study.

Measurements

Each interview transcript was checked for accuracy before being entered into Ethnograph software (Qualis Research, Colorado Springs, CO), which assists with qualitative data management by numbering lines and permitting searching and sorting data by multiple codes.[14] After entering three sets of interviews into Ethnograph, the PI and RA used content analysis to interpret the meaning and assign labels or codes to passages of text.[15] The team carefully read the transcribed interviews, individually identified codes, and then compared and discussed codes to develop a codebook based on the first three sets of interviews. Using the codebook, each recoded the initial interview and compared coding decisions until 90% agreement was reached. All subsequent interviews were then coded using the developed codes and their precise definitions. The PI coded subsequent interviews in Ethnograph with the RA checking for consistency with every fourth interview. Two additional codes were added in the coding process requiring review of all transcripts to insure coding consistency.

Table 4. Interview Guide for Parents and Health Care Professionals

Interview guide for parents
- What motivated you to accept the invitation to participate in the IPPC trainings?
- How did your expectations of the training experience compare with the reality of the training experience for you?
- What have you found to be the different challenges in participating in the trainings?
- What different things have you found to be meaningful in your training experiences?
- How has the hospital staff responded to your presence and sharing in the trainings?
- What are your thoughts about having staff present in the training with whom you are familiar from your child's treatment?
- What would you say to a parent considering participation in an IPPC training for the first time?
- What would you say to health care educators about the possible inclusion of parents in future education efforts for hospital staff?
- How has your participation in the training affected your experience of grieving for your child?
- What have you learned in your training experiences about health care professionals and about yourself?

Interview guide for health care professionals
- What motivated you to accept the invitation to participate in the IPPC trainings?
- What were your initial thoughts and concerns when you learned that parents would be involved in the training?
- What challenges were presented by having parents present and participating in the trainings?
- What was meaningful and helpful about having parents present and participating in the trainings?
- How were you and your work affected by the presence and sharing of parents in the training?
- What are your thoughts about having a parent involved with whom you are familiar because of your involvement in his or her child's treatment?
- What are your thoughts about parents being involved in other staff education and trainings here at the hospital?

IPPC, Initiative for Pediatric Palliative Care.

Table 5. Professional Discipline or Role in Hospital for Health Care Professional Participants for Research Study

Position	*Number*
Advance practice nurse	1
Child life specialist	1
Family services	1
Language interpreter	1
Nurse	2
Pastoral care	1
Physician	2
Respiratory therapist	1
Social worker	1

After the interviews were coded in Ethnograph, data were segregated by code. The team used constant comparison, an iterative process of comparing and contrasting each piece of datum with all other data to yield conceptual understanding.[14] In this process, data were compared within and across codes, within and across individual participants, within and across parent participants and health care professional participants to identify similarities, differences, and relationships. As data collection and analysis were concurrent,[10,16,17] data collection continued until theoretical saturation was reached in the case of transcripts for health care professionals.[12,13] Observations and transcribed field notes were used to assist with data analysis and interpretation.

Results

Three major themes—sense of purpose, benefits, and challenges—were found in the analysis of the interviews of parents and health care professionals. Most but not all themes were common for both parents and staff as described below and shown in Table 6.

Sense of purpose

Parents. For parents, purposes ranged from giving additional meaning to their children's lives, helping other families, helping staff understand families better, and giving back to the hospital for the care they and their children received.

One of the things I really wanted to emphasize is that I wanted her life to mean something…. I didn't want to just have this child…forgot about.

Staff. *I think that they were very passionate about wanting to share their experiences with other people…so that other parents would be supported appropriately.*

Benefits

A theme for both parents and staff was that of benefits related to the involvement of the parents in the trainings, including a subtheme of "you still learn."

Parents. Being able to share family stories with health care professionals seemed an affirming, empowering, and sometimes healing experience for the parents. It also helped keep the memories of their children alive and added layers of meaning and value to the memories—their children's lives continue to touch and influence others, and parents gain a better understanding of themselves and of the emotional challenges of palliative care situations:

I learned that I'm a lot stronger than I thought because I would never have thought I would come back and talk about it.

It helped me a lot because it helped me to understand…the doctors, the nurses, what they did, what they didn't do, how they did it. I understood a lot better.

Both parents and health care professionals made multiple comments about "you still learn" concerning insights gained and increased sensitivity. Comments suggested mutual learning and insights between professionals and families, and this subtheme had more combined comments than any other.

Staff. Professionals with experience saw the learning experience as a validation and helpful reminder:

I think this training makes you think in a whole different way if…you weren't already thinking that way. And even if you were or you thought you were, you still learn.

Comments from one of the professionals were especially poignant in expression of the insight into how palliative care can be a healing experience in a very difficult time:

The child is the one that has to, in this case, be the one that has to die, but you can have some dignity. You can feel love. So it's bad, but it's not that bad…by how the situation is handled.

Parents. In a second subtheme of benefits, both parents and staff expressed statements about the opportunity to "see it from another side." Most comments referred to the helpfulness of having the parent perspective included, but there were also comments affirming various staff perspectives and parents receiving a better understanding of the staff experience.

… probably the opportunity to participate with a group of people from different disciplines and all talk together about something to get each other's perspective…I'm talking not only doctors and nurses, but social workers and…child life specialist and anyone who's in here…is going to look at things differently for having participated and listening to parents or grandparents talk about what it is from the family viewpoint.

Staff. One particular comment seemed a powerful validation for the health care professional:

I really could see some clarity in her eyes that she had a different perspective when she thought about it like that.

Parents. In a third subtheme of benefits, both parents and staff affirmed that the presence of parents made the learning experience more "real." In response to a question regarding health care professionals, one parent stated, *They're real people…caring, compassionate people.*

Staff. A staff member affirmed that *[family involvement] makes it more real.*

Challenges

Both parents and health care professionals were aware of the challenge for professionals to be emotionally open with families without becoming overwhelmed by the intensity of situations where children's lives are threatened and some children die:

Table 6. Responses from Participants

Theme	*Subthemes*	*Quotes*
"Sense of… purpose"	**For child's life and death**	"One of the things I really wanted to emphasize is that I wanted her life to mean something, I didn't want to go, I didn't want it to be quickly forgotten nor did I want it to be wasted, didn't think her life, per say, was wasted, but I didn't want to just have this child…forgot about." **–Parent**
	Helping others	"If I could help, you know, somebody else, you know, what they're going to go through later or you know a physician or a nurse or any other health care provider, you know, with a patient or a family if I could help in any way that would be a make a little more sense to what happened…and you kind of keep, you know, to keep his memory alive." **–Parent**
	Paying back	"…and I thought about what [hospital] had meant to our family and the care that Michael received and so I thought it could pay back a little bit." **–Parent**
Benefits	**Telling my child's story and feeling stronger**	"I learned that I'm a lot stronger than I thought [laughing] because I would never have thought I would come back and talk about it; it would be something I didn't want to do. But in the process of coming back and talking about it and talking about it I've gotten a lot stronger and I can talk about it because now I'm past my, um, sadness to an extent." **–Parent**
	"You still learn" …insights, increased sensitivity	"…has given me the knowledge that it's more than just you live, you die and that's it, it's about a process of healing…so I think I learned a lot." **–Staff**
		"…class, it was kind of a softer side of death. You know it's more of, um, I guess when you go to church and you learned about religion, you've learned about God or whatever it teaches you go through the stages and what…didn't make it seem like it was, it was just doomsday, you know." **–Staff**
		"I mean I've got that much out of the training that, you know, I couldn't understand that even though I grieved, they grieved too." **–Parent**
		"People are who they are regardless of what walk of life they're in, everyone has feelings, everyone has their own way of dealing with things…it was more like after a child had passed, you know, some of them didn't want to go to the room or the memorial service or really go and visit a parent or they were afraid they would say the wrong thing. So it lets me know that they had feelings but they didn't know how to express them." **–Parent**
	"See it from another side"	"I thought it was great. Um, you get to see it from another side not just as a worker, but also know what the families go through by having parents being present." **–Staff**
		What would you say has been the most meaningful things you've walked away with? "I, gosh, probably the opportunity to participate with a group of people from different disciplines and all talk together about something to get each other's perspective and feel like maybe, maybe health care professionals and I'm talking not only doctors and nurses, but social workers and…child life specialist and anyone who's in here can is going to look at things differently for having participated and listening to parents or grandparents talk about what it is from the family viewpoint." **–Parent**
	"Makes it more real"	"You still learn and it's nice to hear the perspectives, I mean I really enjoyed hearing the physicians speak, like to see where they were coming from because there's, you know, it makes them real people too…to say I was uncomfortable talking about this or this was a hard conversation for me and I can see why that on the video blah, blah, blah. You know it was nice to, I love how it was so multidisciplinary–I think that was the best part of it and family aspect is really good even though it is a little intimidating at first." *Right, it wouldn't be the same without that piece obviously, you know.* "No, because it makes it more real." **–Staff**

(*continued*)

Table 6. (Continued)

Theme	*Subthemes*	*Quotes*
Challenges	**"The emotional factor" for parents**	"I guess the biggest challenge was the emotional factor." **–Parent** "There were some tearful moments along the way…then my heart went out to this grandmother because it brought out fresh memories for her and but this is a different setting and I didn't know how much to reach out and try and comfort her during that discussion or just let it go because she's part of the team instead of, I had to distinguish between her being part of the team which she was and she had made a lot of good contributions to the team instead of remembering her as a grandmother." **–Staff**
	Staff discomfort with parents present	"and they were like, you could ask anything and you can express and view because we've been through this; they were far enough removed from the time that they had to deal with the whole situation in person that they were able to talk more freely about it and be more candid." **–Staff**
	"Not so hard professional" in staff relationships with patients/ families	"Yeah, I remember going back in my own care and how you know one of the things we talked about was, um, becoming emotionally detached because you know this person's going to die. And I remember going back and it was real hard time for me because I was treating someone with a brain tumor, and watching him die and it was so hard because I just wanted to emotionally detach and after that seminar I realized, you know, hearing that how harmful that is for the parent because they think you don't care. And so I think that was something they all were sort of expressing, you know, where is that fine line because I detach because I don't want to get hurt, but then I want the family to know I do deeply care." **–Parent who is also a health care professional with adults** "Oh yeah, I mean it's impossible not to have an emotional attachment to patients that are dying." **–Staff** "I will remember that little girl for the rest of my life and I'll remember what her body felt like under my hands for the rest of my life." **–Staff**

Parents. *Doctors, nurses, they're just so professional…and you can help them to be professional, but not so hard professional that you never see a human emotion.*

Staff. *I think just time was one thing that was important and people not being afraid to show emotion…. They (parents) didn't want people to try and be too stoic. Like they wanted people to feel free to say things, but also I think not forcing things.*

Parents. Challenges included "the emotional factor" for parents. Every parent made a comment about the challenge of sharing, although none indicated regret at being a part of the training. Some of the challenge seemed to be reexperiencing pain and managing the upsurge of intense emotion without being overwhelmed.

I think one of the biggest challenges for me was there were a lot of things I hadn't expressed and so figuring out a way to express it without becoming overly emotional.

Staff. Some staff members felt discomfort with the parents' presence and participation in this discussion-oriented training. Staff expressed concerns that something they could say might be upsetting to the parents and that the presence of the parents limited their frankness to some extent:

I think some people would have participated more and expressed their views more had parents not been there.

Comments affirmed the need to have parents participate who could balance the demands of the role, share without being overwhelmed, and be able and willing to consider other perspectives—and they affirmed the parents who participated as meeting these expectations.

Conclusions

Parents experienced more benefits than burdens from their participation in the palliative care education trainings. Part of the challenge for bereaved parents is finding ways to make sense of and tell the story of their children's lives and deaths in a constructive and resilient narrative.[18] A major benefit was a reinforced and sometimes expanded sense of meaning for their children's lives and deaths and for the parents' lives. This enhanced sense of purpose contributed to the task of meaning-making and thus contributed to a positive adjustment to loss and grief. Telling the story to and having it validated by health care professionals was an important and positive experience. This experience was complemented by increased understanding and appreciation of the roles, motivations, and experiences of health care professionals, which also contributed to greater insights into their children's treatment experiences. An additional benefit was the understanding that their sharing contributed to increased quality of service to other families in similar situations.

Health care professionals identified more benefits than burdens from the participation of bereaved parents in the palliative care trainings. Parents brought depth and reality to the educational experience and contributed insights about family perspectives that would not otherwise have been present. Another benefit was that parents provided validation and affirmation for health care professionals, as parents expressed greater comprehension of the complexities of health care decision making, the emotional burden for staff, and the challenge of maintaining a balance of caring and distance with chronic exposure to children and families in life-and-death situations.

Having parents present for vulnerable "off stage" discussions, however, was uncomfortable at times and may have limited staff openness and frankness. Another limitation of the research is that this small study focused on parents and health care professionals participating in a palliative care training program at a single pediatric hospital. In addition, there were emotional challenges and costs in the midst of the benefits described above. Not all memories and emotions raised were burdensome; those that were could sometimes be intense but did not dissuade participants from contributing or being open to participating in the future.

The experience of bereaved parents as educators has not been the focus of investigation previously. The results of this study are consistent with the finding of Solomon and colleagues[8] in that parent participants gained a greater understanding and appreciation of the perspectives and emotional investments of health care providers. In addition, this study suggested that not only can the participation of bereaved parents expand and deepen the educational experience for health care professionals, parent participation can also contribute to positive grief adjustment, especially in the area of meaning-making, for the parents.

Study results suggest that expanded efforts to include the voices and perspectives of bereaved parents in pediatric palliative care education, and perhaps bereaved family members in palliative care education in general, would provide benefits for both staff and family members with reasonable and acceptable costs for each. The positive potential of the contributions of bereaved parents as educators has been underutilized and perhaps underestimated in pediatric palliative care education efforts. This study supports expanded efforts to include family voices in palliative care education.

Selection of and orientation for participating parents were areas not examined and these topics would benefit from greater study and exploration.

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Author Disclosure Statement

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