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Moving family-centered care forward: Bereaved fathers' perspectives

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Abstract

This paper describes the key behaviors of “excellent” pediatric healthcare providers – a term used by fathers of children with complex, life-threatening illness to describe providers who consistently and effectively engage in family-centered care for children and their families. Using interview data from a multi-site grounded theory study of 60 fathers with a deceased child, five behaviors were identified: getting to know the family as individuals, talking about non-healthcare related topics, connecting in a human-human relationship, including parents as team members, and applying specialized knowledge to help the family. These behaviors are consistent with the goals of family-centered care, but they are inconsistently practiced, resulting in less-than-optimal care for children and their families during periods of crisis and vulnerability. A renewed focus on relationship building and interactions with families is needed, as well as a re-evaluation of the training of pediatric healthcare providers.

Keywords

Family-centered care; Pediatric health care providers behaviors; bereaved fathers

Family-centered care (FCC), as endorsed by the American Academy of Pediatrics and the United States Maternal Child Health Bureau, is based on the premise that parents know their child best and should therefore be equal partners in the decision-making process for the child.¹⁻⁴ FCC has been embraced, in theory, by the field of pediatrics, with the goal that all families, and particularly those with children facing complex chronic illnesses or other life-limiting conditions, will benefit from this model of care. Successful FCC is dependent upon the creation of a partnership between the family and healthcare providers; this partnership must be nurtured and developed over time, providing consistency and support for family members as they deal with the child's development, disease progression, and/or acute health crises. Despite the widespread belief that FCC is an appropriate model of care for pediatrics,

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challenges to its implementation remain, particularly with regard to the development of trusting, supportive relationships between parents and healthcare providers (HCPs).³

Several investigators have documented the challenges that parents of children with special health care needs face as they interact with the healthcare system. These parents report difficulty navigating their roles as care provider and advocate within the healthcare system,^{5–7} particularly in the inpatient setting. When a child is hospitalized, parents say that HCPs are either reluctant to allow parent participation in care,⁵ or they expect that parents will provide all of the care.^{7–10} They also felt that HCPs were dismissive of the expertise that parents bring⁷ and had little understanding of the complexities of their role as parents of a child with a chronic illness.^{7,10} Kirk and colleagues¹¹ reported that parents believed they had both unique medical and experiential knowledge of their child. While some HCPs possessed the medical knowledge of their child's condition and the technical skills for providing care, they lacked the experiential knowledge necessary to detect subtle changes in the child's condition and assess overall well-being. Parents believed that both types of knowledge were necessary to effectively deliver care, but they found that their experiential knowledge was not valued by HCPs.¹¹ Parents also repeatedly express a desire to be fully informed about their child's care and to engage in discussion and negotiation about how best to meet their child's needs.^{6–10,12,13} They want an opportunity to express their opinions, share their expertise, and make known their limitations, including their desire to sometimes be 'just' a parent.^{7,11} Moreover, what parents desire is not just good communication but a sense of personal connection between themselves and their HCPs.^{14,15}

Unfortunately, but also not surprisingly, the majority of the data that has been collected about parenting a child with special needs within the healthcare system has come from mothers^{16,17}; it is therefore possible that what is represented as parents' opinions may, in fact, be more accurately described as mothers' opinions. A small, but growing, body of literature has begun to explore fathers' experiences parenting children with special healthcare needs and potentially life-limiting illnesses.^{16–19} Fathers identified both the emotional and practical impacts of their child's diagnosis upon individual and family life, and they discussed the need for information about the illness and the importance of having sources of support, both inside and outside of the family.^{16,18} Although the role of the healthcare team is frequently noted in these studies about fathers,^{16–19} no clear guidance is offered about the development of relationships and the provision of optimal FCC. This paper contributes to this literature by identifying, from the perspective of the father or father-figure, some of the key care practices of excellent HCPs – those who were most successful at building relationships and delivering FCC to the families of children who ultimately died from a serious illness.

Objective

Data are derived from a larger study on fathers' experiences as the parent of a seriously ill and dying child. The overall goal was to improve end-of-life care for children and their families by exploring these fathers' experiences. This particular analysis focused on describing fathers' perspectives of the care provided by HCPs to the ill child and the family as a whole, both during the illness and throughout the dying process.

Methods

A retrospective, cross-sectional qualitative study was conducted using a grounded theory approach. Fathers were recruited from four types of pediatric palliative care settings: (1) tertiary care hospitals; (2) a home care pediatric hospice program; (3) an in-house pediatric hospice; and (4) an adult hospice program that provides inpatient or home care to pediatric

patients. Recruitment occurred in three geographic regions of the United States (the West Coast, Midwest, and Southeast). Institutional review board approval was obtained at each of the sites prior to initiation of the study and guidelines for the ethical conduct of research were followed. To participate, fathers were at least 18 years of age, spoke English or Spanish, and had a child who received care for a life-limiting illness at a participating site. The child's death occurred between three months and three years prior to participation in the study. All children were 21 years old or younger at the time of death. A total of sixty fathers (55 biological fathers; 3 step-fathers; 1 uncle; 1 grandfather/adoptive father), ranging in age from 24–60 years, was interviewed. Most of the fathers were married to the deceased child's mother at the time of the interviews; the remainder were divorced (5), single (1) or widowed (1). Fathers were of diverse backgrounds. The majority (N=55) had at least a high school education. Average income was relatively high; thirty-seven of the fathers earned more than \$80,000 annually, likely reflecting the high income levels in the areas where the sample was recruited. Additional relevant demographic information can be found in Table 1.

Data collection consisted of two or three in-depth interviews with each father, field notes, genograms, reflexive journaling, and interviewer debriefing. The majority of interviews were conducted by a single interviewer, with assistance from two additional interviewers and one student and occurred over the course of three years. Interviewers used a semi-structured guide, open-ended questioning, and prompts to encourage fathers to share as much as they liked about their background and family history, their perceptions of fatherhood, experiences parenting a seriously ill child, the child's death, and the bereavement process. All interviews were digitally recorded, transcribed verbatim by a professional transcriptionist, and later verified by the interviewer. Field notes were recorded or written immediately before and after each interview to capture as much contextual information as possible, as well as to explore interviewer impressions and to document anything not readily apparent from the recordings. Reflexive journals were also particularly important, providing both an outlet for expression of interviewer thoughts and feelings.

Analysis started with open coding of the interviews by members of the core research team, which consisted of the principal investigator, the research coordinator, the primary research assistant, and graduate research assistants. Writing memos helped to explore and further explicate HCP-related codes and to create links between codes. Development of these codes and the grouping of codes within categories were done by members of the research team during weekly meetings. The use of constant comparative analysis, in which data is continuously compared both within and across cases for similarities and differences, helped to generate ideas and was central to the analytic process. Bi-monthly conference calls were conducted with the investigators at distant sites to discuss findings, share interpretations of the data, and explore developing conceptual models, in keeping with the standards of rigor in qualitative research.²⁰ The results reported here illustrate one component of the study's findings.

Findings

Fathers identified, through both positive and negative examples, several key care practices of HCPs. Fathers described most HCPs as *good*, but they reserved the terms *very good* and *excellent* for those HCPs who consistently provided a high level of care and who demonstrated most or all of these key care practices. These excellent providers were those held in highest regard by the fathers and from whom we can learn about how best to meet the needs of families with seriously ill children. The examples of less-than-optimal care provided by the fathers can also be instructive, as they help to clarify or more precisely describe the desired skills of an excellent HCP.

Fathers' descriptions included a wide range of providers, including nurses, physicians, chaplains, social workers, interpreters, and technicians. However, the majority of comments focused on nurses and physicians. The best of these providers facilitated the sharing of ideas between families and the healthcare team, encouraged questions about the child's care, allowed for the expression of concerns related both to the child's condition and the care being provided, and showed respect for each member of the family. Such interactions occurred because of a core set of care practices in which the providers engaged, all of which stemmed from the HCP's ability to demonstrate social adeptness. These care practices included: (1) listening to the child/parents and getting to know them as individuals; (2) talking about non-healthcare related topics; (3) connecting in a human-to-human relationship; (4) including father and mother as team members; and (5) applying their specialized knowledge to help each particular family.

Listening to the child/parent as individuals

HCPs who engaged in active listening to children and their parents developed a relationship with families that allowed them to know the family both as individuals and as a whole. Knowing the family took many forms, including understanding the family's ways of coping, accepting the family's strengths and weaknesses, and giving consideration to each member's unique needs and challenges.

They [health care providers] are very good listeners. They could listen to a child. They could listen to an adult. By good listeners I mean they heard the intent that was behind the words and they could even see beyond the intent or the hurt. In other words, they could see beyond that to the cause of the intent...from what I could see, these people were divested enough of their own self-interest that they could pick up somebody else's... they were empathic. They could pick up and, sometimes even- certainly without, hearing too much - they could see what's behind that. And at the same time they could disagree with that and just turn the person's hopes and attentions and to see it in a different way that was more correct, more healthy and just better for the person.

Once the healthcare provider came to know a particular family, it was easier for the provider to recognize and predict the family's way of coping with stressful or challenging situations, thereby allowing the provider to tailor his or her interventions to the specific needs of the family:

I would try be in tune with where [child] was and, you know, try to be her advocate but with most of the doctors and nurses it wasn't necessary. They have that. They could come in and very quickly find out where she was and work with it. If she was in a grumpy mood, they'd know how they could- if they could - you know, cheer her up. And they would sometimes know to just leave her alone.

The interventions used by HCPs varied widely from family to family, ranging from allowing a mother and father private space to argue about their child's care to connecting parents with other families in similar situations. On some occasions, healthcare providers established such strong relationships that they were able to help the family begin to think about alternatives to curative therapy. It was this level of relationship that was necessary to engage in effective conversation with families about a variety of topics, including disease progression and the possibility of the child's death.

Talking about non-healthcare related topics

Fathers valued those HCPs who recognized and honored the fact that life existed outside the hospital and that their child was more than just a patient. Providers frequently demonstrated this awareness by engaging families in conversation about non-healthcare related topics.

Such conversations helped families to put their child's illness into perspective and to take their mind off the severity of the situation, even if for a brief period of time. For example, one father discussed his experience with several nurses who came to his daughter's room to chat about a variety of topics, including their pets and upcoming wedding plans. These nurses made time to visit with his daughter, and they would use this time to discuss life outside the hospital and to engage in non-medical activities with the child, including coloring and craft-making. Such interactions brought a sense of normalcy to the situation. They also allowed the father to see that his daughter was valued as an individual and not just as another patient who required routinized medical and nursing care. Conversation about non-medical topics opened the door to connecting in more personal ways. One father of ill twins discovered a cultural connection with one of the nurses, and he appreciated her efforts to engage him in discussion about this culture:

Another note I wanna make here is ...there was just like a few people who knew that it wasn't just about the boys. It was about us as well. And that expressed itself in several ways...chit-chatting about the weirdest things. I remember one range of discussions with one nurse. She happened to be married- uh, engaged and about to marry a guy whose mother was Dutch. So he had Dutch family. And, "Well, we should go to Amsterdam. We're planning to see his [word said in Dutch]." She knew a little bit of Dutch words, and it was really nice to just chit-chat about silly stuff, but stuff that wasn't like 'His blood level is this,' and all that typical medical stuff.

Connecting in a human-to-human relationship

The HCPs who made the strongest impact upon fathers were those who made an effort to connect with the child and family in a human-to-human relationship. Acting graciously with parents facilitated the sharing of ideas, questions, concerns and information. To fathers, such behavior demonstrated respect, sensitivity and compassion:

HCPs who really care...have great empathy for the families who are going through what they are going through. I think that's what separates them from the rest. Someone could be very good at a job, but in terms of people skills, they can be severely lacking.

Establishing a meaningful connection also required the HCP to share information about him or herself, allowing the family to see the doctor or nurse as a person with interests and a life outside the hospital world. One father discovered that his child's physician had been a high school classmate of his wife's cousin; this created an immediate bond that put the family at ease. Another father was pleased to discover that the oncologist caring for one of his twin sons was himself a twin.

Sometimes it was the father who made an effort to connect with the providers. Two of the fathers, one a firefighter and another a police officer, reported feeling a bond with HCPs based on their mutual engagement in high-stakes, crisis-focused public service. Both fathers appreciated the demands of the HCPs' work and valued the care being given to their child. The father who was a police officer understood the challenges of working the night shift, so he brought food to the hospital for the night shift nurses, even going so far as to determine their likes and dislikes before preparing or purchasing the food. Such efforts created a special kind of connection; the HCPs were welcomed and embraced as a part of the family.

...[HCPs] were like family to us anyway...I knew everybody's- you know, their family, their kids' names, their wedding dates, who's gonna get married up in the ward, who's- you know, who's allergic to what. You know, so when we brought

food, we couldn't bring a certain type of food to everyone 'cause it's like, well, if we do, then we have to make something else for someone else...

Fathers believed that HCPs clearly welcomed this type of intimate connection with families; several fathers reported that some nurses and physicians would stop in their child's hospital room late in the evening or on their day off to check on the family, or they would call the parents to get progress updates, much as members of a family would do. This relationship often extended beyond the death of the child, with multiple fathers reporting continued contact with HCPs in the months and years following the death.

In contrast, some fathers reported encountering providers who lacked this willingness or ability to connect on a personal, human-to-human level. Fathers referred to these providers as *scientists* and *professionals*, indicating that their focus was on medical care and the disease process, rather than on caring for the fathers and their family members as individuals. Fathers' use of the term professional had a very specific meaning; it referred to a clinician who was qualified and capable in his or her role but who remained detached and impersonal, with little display of emotion. Professionals were the providers who did their job, but seldom went beyond it. Use of the term professional to describe these providers did not, however, imply that clinicians with whom the family did connect were *not* professional. The providers who became a part of the family were viewed as *professional-plus* – they were just as capable as the professionals, but they also had a level of compassion and caring that was absent from those who were seen as just professional.

Including father and mother as team members

Another critical skill was the inclusion of parents as members of the healthcare team. Fathers reported widely disparate experiences; some were welcomed as equal members of the team and appreciated for the unique knowledge that they brought to their child's care, while others were excluded from the process. Fathers who felt that they were incorporated into the team found providers receptive to ideas that they had about how to change or improve care for their child:

They always listened to everything we said. They always included [child] as much as they could and when she didn't wanna make a decision, she would delegate it to us...they would talk so she could hear what they were saying, and asking us and they let us help when we could.

One father described how his wife suggested that their daughter would do better with a bed in the hospital room and worked with a nurse to remove the existing crib and replace it with a bed. Another father realized that his daughter tended to regress and assume the 'sick patient' role whenever hospitalized, so he worked with the healthcare team to have her discharged as soon as possible, even if it meant assuming a larger burden of care at home. The team in this instance was willing to help father get the necessary equipment in the home and to expedite the discharge process because they valued father's input, acknowledged his expertise in caring for his daughter, and trusted the family's ability to care for her at home. Sometimes the father's participation on the team resulted in serious errors being avoided in his child's care, as in the case of a father who kept meticulous notes and was therefore able to catch an overdose of chemotherapy before it was administered. Because parents are focused solely on providing care to one patient – their child – and are not responsible for the large numbers of patients that the typical HCP sees, they can be an excellent source of information and a safeguard for the child, when clinicians allow them to assume that role.

Unfortunately, not all providers make inclusion of the family into the healthcare team a priority. Doing so requires providers to display their humanness and fallibility, and it allows parents to see that the process of medical diagnosis and treatment is at times disorganized

and imperfect. Providers who are focused on maintaining the traditional doctor-patient relationship or who may feel insecure about their practice are unlikely to welcome the additional scrutiny and oversight that parents bring. Many fathers reported encountering such providers, most of whom were physicians. One tattooed biker father reported feeling that his opinions did not matter to his child's physician because he felt his physician judged him as inadequate based on appearance. Another father expressed frustration with providers' lack of respect and their unwillingness to be forthcoming with information, noting that they would often enter the hospital room, offering no introductions or explanations, and proceed to conduct some test or intervention on his child. These interactions undermined fathers' trust in and respect for providers.

Applying specialized knowledge to help the family

Parents expect HCPs to be competent clinicians who are capable of providing excellent clinical care to their child. The fathers in this study were no different, and they identified situations in which such competence was demonstrated. They expected providers to recognize abnormal situations and to act promptly to address the concern. For example, one father reported taking his son to the doctor's office after noticing balance problems. The pediatrician was so concerned that he scheduled an immediate CT scan, denying the family's request to take the son home for a nap first. Although he did not understand the physician's sense of urgency at the time, this father was later able to appreciate the quality of care delivered. Another father recalled the excellent assessment skills of a hospital nurse; this nurse detected something wrong with their daughter's breathing shortly after birth and immediately contacted a physician to obtain x-ray films, leading to a diagnosis of diaphragmatic hernia.

Fathers expected providers to also provide information and advise families facing new or challenging situations. Nurses, for example, were often charged with teaching families how to care for their child at home by giving shots or gastrostomy tube medications and feedings. Parents learned how to provide this care both by observation of the providers in action and by direct practice in the hospital or the home. Fathers also expected providers to give accurate information and to help families see the larger picture, including, of course, the child's long-term prognosis. Failure to provide this type of information created confusion and misunderstandings for families, as in the case of a father who was sent home from the hospital believing his son was cancer-free. He was therefore shocked and entirely unprepared when he learned, just two months later, that his son had wide-spread metastases and faced imminent death. Such a dramatic reversal of prognosis was the result of poor communication between HCPs and the family and a failure to provide a big-picture analysis of the son's condition. In contrast, another father reported having weekly meetings with the healthcare team in which his daughter's fluctuating prognosis and ongoing challenges were openly discussed; although it was difficult for this father to hear the contradictory and often bad news, he appreciated the team's attempts to keep him apprised of the situation and realized that her constantly changing health status caused most of the confusion and contradiction that he was hearing.

HCPs were also a source of advice on a variety of topics, ranging from finances and sibling involvement to the grieving process and care of the spouse. Some of the most critically important advice was given as the child neared the end of life. One father reflected on the support and advice he received while his son was being maintained on life support. He felt that the HCPs gave him and his wife the time and space they needed to process the situation, but that they also reminded him that the child was being kept alive artificially, and they gently nudged mother and father to withdraw support

Discussion

HCPs who engaged in the care practices described above made a lasting impact on the father and the family as a whole. They helped the father to feel respected and listened to in a healthcare system that can, at times, marginalize the patient/family voice. They inspired trust in the care being given to the child, both by the individual provider and by the healthcare team as a whole. Such providers helped fathers to know that their family was being well cared for, resulting in satisfaction with that care, even when the ultimate outcome was the child's death.

Interestingly, the interactions with HCPs and the elements of care that fathers described as really good or excellent -- their highest commendation, reserved for extraordinary or exceptional care -- are those that have been identified as standards of care within the FCC model.^{2,3} HCPs engaged in FCC should consistently be listening to the family members as individuals, engaging in conversation to know the family both in and outside of the healthcare setting, including parents on the healthcare team, and using knowledge of the child's unique condition to provide personalized care. The fact that fathers identified HCPs who engaged in these activities as exceptional indicates that this level of care is not being consistently delivered and that the pediatric healthcare system is falling short of its goal in the delivery of FCC. The sensitive nature of work with children facing serious illness and their families requires that pediatric HCPs have a baseline level of social adeptness, an ability to engage, interact, and develop relationships with families in crisis and those facing a lifetime of care for their child with a chronic illness. Doing so is not just a "nice" thing to do or an added bonus when time permits, but rather a critical component of quality care for children and their families.

Engaging fully in FCC may also require a reevaluation of the concept of professional boundaries. In nearly every discipline, providers are taught to maintain strict boundaries and to avoid engagement in the very types of relationships that the fathers valued most.²¹⁻²⁴ Fathers reported welcoming providers into their 'family' and having relationships that lasted far beyond their child's discharge from the hospital or eventual death. Despite instruction to the contrary, many professionals do engage in some level of boundary-crossing, calling into question the relevancy of such boundaries, particularly in pediatric settings. While some level of guidance is needed regarding the limits of professional behavior, it is possible that the artificially-created boundaries around which practice is currently constructed hinder the development of therapeutic relationships that would benefit families.

Existing literature on interacting with children and families focuses largely on the acquisition of communication skills and the application of these skills to difficult conversations with the family.²⁵⁻²⁸ While these are undoubtedly important skills for HCPs to possess, the interviews with these fathers indicate that the delivery of FCC involves more than just communication between the parent and HCP; it involves the development of human-to-human connections and sustained relationships that demonstrate respect for the uniqueness of each child and family, emphasizing the concepts of relationship-based caring put forth by Browning¹⁴ and Kane and colleagues.¹⁵ Indeed, the focus on communication as a skill to be acquired or a procedure²⁷ to be performed runs the risk of minimizing the importance of relationship-building in pediatrics. Effective communication is a necessary, but not sufficient, component of quality FCC.

Study Limitations

The retrospective design of this study is a potential limitation, due to the likelihood of recall bias. A prospective design was, however, neither feasible nor respectful of the enormous burden that fathers facing the loss of a child must endure. Further, past research and clinical

experience has shown that parents are unlikely to quickly forget the details of such a monumental event²⁹; moreover, the fathers' experiences as they remember them is the focus of this study. As well, the reflective nature of the questions asked were, in some instances, therapeutic for the fathers who participated.

Implications for Practice and Research

As evidenced by this data from bereaved fathers, there is substantial room for improvement in the care provided to the families of seriously ill children. Fathers have high expectations for the care provided to their child, but they are also willing and able to work collaboratively with HCPs. They value the expertise that providers bring, but only inasmuch as that expertise is informed by personal knowledge of the child and family as individuals. HCPs across all disciplines must therefore invest time in getting to know each member of the family, time that the current healthcare system does not often allow. The standardization of care and the ubiquitous use of protocols, while necessary to ensure safety and consistency of outcomes, have resulted in a shift away from relationship-based caregiving. Within healthcare systems, individual providers must therefore rethink the current provision of care, placing renewed emphasis on the person-to-person connection between HCPs and families. A shift in the focus of care is needed such that time is allotted for *being with* families, rather than always *doing for* them. This time is critical for the development of relationships that enable HCPs to tailor their understanding, knowledge and interventions to the needs of each particular child and family.

Education is also a vitally important part of any effort to improve FCC for children and their families. It is time for a re-examination of the ways in which we teach HCPs to interact and establish relationships with patients and families. Curricular demands in healthcare training programs have created a task-oriented atmosphere that leaves insufficient time for the development of interpersonal and relationship-building skills. A renewed emphasis on these basic, foundational skills is needed; the focus for students and trainees should be not on how many patients they can care for, but rather on how well they care for each patient and family. A revisiting of the concept of professional boundaries is also in order; the emphasis should be on how HCPs can be professional in a personal way, rather than the creation of artificial, overly-strict separations between the personal and the professional.

It must also be recognized that in spite of the limitations on practice and the limited time in which HCPs have to work, many do an excellent job providing care to families facing a child's life-threatening illness. Further research is needed to explore in more detail how these HCPs interact so effectively with families and to examine any unique qualities that these providers possess, as well as other influential factors. The findings from such work could be used to better prepare future generations of HCPs for their work with children and families facing serious illnesses.

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Table 1

Demographic Info			
Age	Mean 42.4, range 24–60	Education	
Race		College degree or higher	33
White	40	Some college	
Asian	7	Technical school	10
Black	3	High school	4
American Indian	2	Less than high school	8
Pacific Islander	1		5
Mixed Race	7	Child's Age at Death	
Thereof: Hispanic	12	< 1 year	
		1–5 years	20
Marital Status		6–10 years	12
Married	53	11–15 years	7
Divorced	5	16–21 years	8
Single	1		14
Widowed	1	Causes of Death	
		Cancer	
Religion		Genetic disorders	25
	23	Heart disease	19
Protestant/Christian	23	Other	8
Catholic	10		9
None	4		
Other			
Income	25		
>\$100,000	12		
\$80–100,000	10		
\$40–80,000	13		
<\$40,000			

* The total number of children is 61 because one father lost twins.