

The Long Road to Farewell: The Needs of Families With Dying Children

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Abstract

Families of dying children are profoundly impacted by numerous interactions with health-care providers before, during, and after their child's death. However, there is a dearth of research on these families' direct, qualitative experiences with health-care providers. This study presents findings from interviews with 18 family members, predominantly parents, regarding their experiences with health-care providers during a child's terminal illness, from diagnosis to death. The importance of compassion emerged as a salient theme, manifested in myriad ways, and connected to participants' perception of caregiver *presence* in multiple domains. Families were likewise negatively affected by a wide variety of situations and behaviors that represented individual or institutional *abandonment* or *nonpresence*, and thus compounded the experience of loss. Specifics and implications for practice are explored.

Keywords

pediatric palliative care, bereavement, trauma, cancer, bereaved parents

When a child has a terminal condition, parents must bear witness to the trajectory of the illness and sometimes excruciating treatments in perinatal or

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pediatric settings. As that child begins his or her progression into death, parents must watch helplessly as their child's health deteriorates, on the long road to farewell.

Both researchers and clinicians acknowledge "attention and investment" deficits in the advancement of perinatal and pediatric palliative care (Powell, Mwangi-Powell, & Radbruch, 2015, p. 131). Overall, palliative care and hospice services are underutilized for many families (Rodgers et al., 2011). The Committee on Bioethics and the Committee on Hospital Care of the American Academy of Pediatrics have recommended integrative palliative care teams for all dying children and their families (Brosig, Pierucci, Kupst, & Leuthner, 2007); however, the implementation of care teams is still in the early stages. The need for comprehensive improvements in the delivery of palliative care to children and their families has been recognized from a variety of perspectives, including care professionals, patients, and their families (Browning & Solomon, 2005; Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Contro & Sourkes, 2012; Liben, Papadatou, & Wolfe, 2008). Browning and Solomon (2005) described the need for multifaceted improvement that would address provider education, health-care financing and regulatory efforts, quality improvement within hospitals, and broader societal views surrounding child death. Areas commonly cited in the literature as needing improvement are communication and interpersonal issues related to families' interactions with health-care providers (Aschenbrenner, Winters, & Belknap, 2012; Gold, 2007; Liben et al., 2008); the need for greater follow-up bereavement care and continuity of care across all system levels, including coordination between primary care centers such as hospitals and community hospice/bereavement resources (Contro & Sourkes, 2012); pain and symptom management in children receiving care (Browning & Solomon, 2005; Contro et al., 2002; Solomon & Browning, 2005); and bereavement support for siblings and family members (Contro et al., 2002).

Conversations surrounding diagnosis, treatment, and prognosis of the dying or terminally ill child hold great importance for parents, and the manner in which these conversations are held has lasting consequences. Interpersonal issues such as communication, perceived emotional support, and empathy/sensitivity of health-care providers (HCPs) play a critical role—both positive and negative—in how parents experience and cope with the death of a child; these are among the most salient means of assessing the quality of end-of-life care delivery (Aschenbrenner et al., 2012; Pullen, Golden, & Cacciatore, 2012). Notably, several articles discuss the impact that even a single interaction can have on the long-term abilities of parents and families to cope with and make meaning out of their loved one's death (Browning & Solomon, 2005; Contro et al., 2002; Gold, 2007; Pullen et al., 2012). Despite evidence suggesting the lasting positive effects of empathy, humility, and compassion toward grieving families and attempts to teach these skills in medical training, neither this evidence nor the current pedagogy has translated into improved psychosocial care

as perceived by bereaved parents (Gallagher, Cass, Black, & Norridge, 2012; Pullen et al., 2012).

Another commonly addressed topic in the literature is the perception of parents that their ill or dying child suffered from physical pain and distressing symptoms during his or her care (Browning & Solomon, 2005; Contro et al., 2002; Solomon & Browning, 2005). This is a salient finding considering the deep anguish and fear parents have reported both before and after their child's death if they felt he or she suffered (Hoeldtke & Calhoun, 2001).

HCPs, too, experience significant distress because of their own deep attachment to patients and families (Contro & Sourkes, 2012). Many studies illuminate the need for increased emotional support, mentoring, and provider education. For example, providers report a need for training in issues of cultural competency surrounding grief, death, and dying (Browning & Solomon, 2005; Contro & Sourkes, 2012; Gold, 2007). On a related note, providers also report disparities in the interpersonal/psychosocial aspects of care delivery to cultural minority families (Contro et al., 2002; Contro & Sourkes, 2012), including lack of provision of Spanish language interpreters during critical events (e.g., during surgeries; Contro et al., 2002). High levels of guilt, self- and other-blame, fear of litigation, risk of burnout, and emotional distress in care professionals are also noted in the research (Contro & Sourkes, 2012; Gold, 2007).

There exists a dearth of research on parents' lived experiences of the continuum of end-of-life *and* bereavement care with HCPs and other care providers. This study aims to qualitatively evaluate parents' perceptions of their experiences with HCPs before and after the death of their child in a variety of settings and geographic locations.

Methodology

A qualitative descriptive methodology with phenomenological overtones informed the present study (Sandelowski, 2000, p. 337). The primary research question asked what in the health-care system was especially helpful or unhelpful to the family during and after the illness and death of their child. In a series of open-ended interviews, parents were encouraged to describe as much as they wanted of their experience during these times. Minimal direction was supplied. Follow-up questions were asked as needed to obtain a full understanding of the participants' perspectives. Data were then transcribed verbatim and inductively analyzed employing conventional content analysis techniques (Hsieh & Shannon, 2005) to topically group statements as pertinent themes emerged.

Participants. Respondents were recruited through a national children's cancer advocacy organization and a bereavement organization. Each participant was informed and signed written consent. They consisted of 19 family members:

13 mothers, 4 fathers, and 2 grandparents who narrated their experiences surrounding the terminal illnesses and deaths of 16 children. Children ranged from 4 months to 22 years at their time of death, with various types of cancer being the most frequent cause of death. Family members identified as White/Caucasian, with one parent identifying as White and Hispanic. All but one of the families self-identified as middle class socioeconomically. Families lived in nine states and a mix of rural or urban areas in the United States. Thirteen interviews were conducted by phone; three interviews were conducted using Skype; one interview took place in person at a counseling center; and one interview took place in a participant's home. Most interviews lasted between 2 and 4 hours. Interviews were conducted by three of the authors, who then transcribed the recorded interviews.

Results

Data were retained from 18 family members. In an interview with three family members, one grandparent did not make substantively independent statements pertaining to the themes that emerged in the data analysis. All but one respondent in the retained data set indicated that helpful or unhelpful interactions with professionals and organizations strongly colored their subjective experience of distress during the illness and death of their child. No respondent offered exclusively positive observations of their child's care; however, problems or transgressions were identified by all 18 respondents. Many family members reported multiple negative experiences and 14 stated these experiences increased their subjective distress. For several parents, hurtful experiences dominated the memory narrative. The majority of respondents reported a mix of helpful and unhelpful experiences, with 10 clearly expressing that helpful experiences alleviated distress and offered solace.

Variations on a Theme: "Presence" as a Core Concept

In respondent narratives describing what was especially helpful or unhelpful during and after the illness and death of their child, two concrete topic areas emerged: (a) attitudes and behaviors of specific professionals; and (b) characteristics, policies, and offerings of facilities or organizations. Spanning across these concrete subdivisions a number of deeper psychological themes repeatedly emerged in these data. To a greater or lesser extent, all the themes analyzed express various aspects of a primary dichotomy: presence/witnessing/joining vs. absence/abandonment/distancing. Subthemes included warmth/engagement vs. objectification/detachment; honesty/disclosure vs. withholding/misrepresentation; competence vs. incompetence; empowerment/egalitarianism vs. paternalism/coercion; flexibility/individualized care vs. inflexibility/rule-bound uniformity; continuity of care/trust vs. isolation/mistrust. How these themes

represent manifold faces of compassion by representing the core theme of presence versus abandonment will be explored. The presentation of data below will be organized according to these deeper meanings with informal subgroupings of the concrete themes.¹

Compassion: Warmth/Engagement Versus Objectification/Detachment

The most common complaint about professional care during the illness and death of respondents' children was a lack of compassion, including HCPs behaving in a "rude," "cold," "sterile," or "curt" manner. Likewise, perceived overt compassion was by far the most noted characteristic of individual interaction. "We had really good care . . . the whole team . . . personable, and loving, and supportive, and very emotionally available, and empathetic, and all those things." "He told me horrible news, but he did it with such grace and such compassion that I knew he cared, and you can't fake that." Thoughtful words had lasting positive impact on respondents: "Hearing . . . 'I'm sorry' from a doctor that never even treated my child was very helpful. It just went a long way . . . you honestly felt like she cared." "He told me that day something that I've thought about a thousand times: 'I'm a dad and a doctor, and I watched you make heart-wrenching decisions. And I want you to know that I would have done it no differently.'" Compassionate presence was also noted in attentive body language "He was the most gentle, kind-hearted person, who told me some of the worst news of my life . . . But he sat down in a chair, and he looked me in the eye . . . and he answered every question." The following parent's subjective experience of compassionate presence emerges clearly: "He was the only one that we liked because he would sit on the couch and he'd just talk to us . . . how are your healthy kids doing at home and who's taking care of them, and, um, have you eaten dinner yet, and um, do you think you'll take [child] home, would you like to take him home? . . . So he was really the only one who spent time talking to us and everyone else just seemed very far removed that we didn't bond with anyone else."

Respondents remembered vividly the manner and circumstances in which bad news was presented to them. The flavors of nonpresence and abandonment run strongly through these statements: "He couldn't look me in the eyes, he just kept like pacing back and forth, and, um, very nonchalantly just said 'well, it didn't work.'" "We weren't sitting, we weren't sitting, we were standing up. We were just standing there . . . And he said, 'Mmmm, the baby has a brain tumor, okay? . . . Doctor W-'s gonna be here tomorrow to tell you more about it, mmmkay?' And he just like ran away. He wanted out of that room as fast as possible. That initial diagnosis day is probably one of the most traumatic days of my entire life. It was way worse than the, the day he died." "The guy put us in this room, and I'm like 'all right, is there something wrong?' and your anxiety is like, just building and like it was literally maybe an hour and a half before the doctor came in there."

Acknowledgment of family members' needs was a critical part of presence. Eight participants specifically commented on whether or not their emotional needs as caregivers were directly addressed by any provider. "Even after receiving the diagnosis, they . . . never asked me how I was. I felt like because I didn't have anyone reaching out to me, that I shouldn't—like I didn't—need it." "The medical director is amazing there. She would sit with us. She would check in with us, to see how we were doing emotionally." "So just, we're really blessed to have a good network of medical professionals that were able to treat us, um, not only [child] but also help take care of us as we were going through that." Respondents also noticed when HCPs seemed directly present with their child, including the child as an active participant in treatment. "He always smiled at [child], and he interacted with him." "She is a phenomenal nurse. He valued that she let him own some of his own treatment. Like she let him do some of his own things to himself, like, 'do you want to hold the flush?'" "If she and I were talking near [child] about her care, about medication or whatever, she always would keep addressing [child] as well as me. I really appreciated that, so that allowed me to then feel I could trust her."

Often, acts that exceeded minimum care standards or made allowances within reason for specific needs outside the norm were portrayed as indications of compassionate presence. Professionals who visited the child at home, visited the child or family off duty, attended funerals, or in any other manner went out of their way to improve the child's or family's experience were greatly appreciated: "So much compassion . . . he stood in the line at [child's] viewing—and understand, this line was out the door." "She came to the house the day he died. It really means a lot." "They'd get up in the middle of the night to get him strawberry ice cream. Yes, yes, they loved him."

Honesty and Disclosure Versus Withholding and Misrepresentation

Families appreciated the truth, yet diplomatically presented. "He said, 'Childhood cancer is highly treatable.' He did not say, 'Oh no, honey, he won't die. . . . And he said, 'I'm going to do everything in my power to make sure you get the best of care.'" She's like, 'there's no way for me to tell you how much longer she has, you know, we'll try to treat the symptoms the best we can.' By saying it gently like that, it just, I don't know, it was so much easier on us. We definitely liked the softer approach—because at the same time, she wouldn't lie to us." Several participants acknowledged that the right presentation is hard to achieve. "I don't know how you find that balance of honesty and at the same time, allowing people to have hope." "I don't know how you tell people with a terminal child all the things—I think everybody's gonna be different about what they want to hear when."

Multiple respondents were upset at not being given all available information or at evidence that HCPs may have been untruthful with them. "The whole room goes silent and everybody looks at us, because everybody knew, but

nobody had told us yet.” Families were clearly upset by HCPs who were seen as not admitting mistakes. “They wanted to give as small a dose as possible clearly because they were afraid something like this would happen. And it did anyway. But they wouldn’t admit it, which really pisses me off still.” A sense of a lack of caregiving presence emerges when families describe such perceived lapses in authentic communication. “He wouldn’t look at me...he never looked up. He never communicated with us again, not once after that. He wasn’t the kind of guy who’d admit to a mistake. He was not a good man.” “I didn’t expect everybody to be perfect in providing healthcare. And I know it’s complicated. But I think just saying—even after he died—to say, ‘I’m sorry, this could have gone differently. We could have done something better.’”

Empowerment/Egalitarianism Versus Paternalism/Coercion

Empowerment was supported by egalitarian rapport: “When [hospice nurse] came it didn’t feel like she was teaching me anything. It’s like she was working together with us to make sure that, that he had the best care.” Discontent was elicited by providers who behaved in what was perceived as a “patronizing” or “condescending” manner. “He had a problem with being a doctor, felt like he was smarter than anyone else... It was all about him, arrogance, and we were so aware of it.” “It was just not an egalitarian relationship at all. There was always this, ‘I’m the nurse and you’re the family,’ and ‘I’m here to teach you something, and you need to learn.’”

Many respondents emphasized the importance of making their own decisions whether to continue treatment or enter palliative care. “I didn’t want to live the rest of my life questioning whether this or that could have saved him. I feel good knowing the rest of my life that we did everything we could.” “I just think it’s important that everybody make their own choices. You’re the one who has to live with your decisions.” “I knew that forever I would have to look back on the decisions I made that day and tell myself that I did the best I could with what I had, with the knowledge that I had, with the, with resources that I had.” Respondents appreciated HCPs who respected these choices. “He said, ‘What matters is that you make a decision you can live with for the rest of your life. And that’s the decision to either treat him or not treat him.’” They were upset by perceptions that providers were pushy regarding particular agendas, or disrespectful of parental decisions. “I had a problem with [doctors] saying I was wrong in my opinion. One doctor in particular... was just more pushy about it. I couldn’t get her to stop, no matter what I’d say... [They kept] asking me the same questions over and over... I just said, ‘you know, they’re driving me nuts with this.’ They need to respect what you decide and back off and leave you alone about it.” “I think sometimes the children’s hospital is a little anti-hospice. I let them make me feel a little guilty about the decision that we made to put him on hospice.”

Several respondents addressed the importance of HCPs empowering the whole family as a functional unit. “He didn’t tell me that it was gonna—that it’s like, bad news, or, do you want your husband to be here when you find out.” This same parent reported of another occasion: “We, we had to make the decision right there, basically. I wish they would have told us more about it before the meeting, so we could decide together rather than in front of the doctors.”

Respondents who perceived domination/paternalism/coercion in their experiences with HCPs did not feel that they had allies in these HCPs. In this, the disempowerment entails a sort of distancing or abandonment. Respondents expressed the need for alternate allies to stand by them. “I finally went to Child Life and asked them to have the doctors back off.” “The social workers and support staff are tremendous; would show up every day, help you any way, so when we did have these issues and problems, we were able to talk to them to help mediate.”

Of concern, the majority of participants reported HCPs who acted dismissive of their questions or concerns. “She [nurse practitioner] wanted you to take everything that she said as the gospel and never question anything . . . She was probably the least favorite person . . . we interacted with at the hospital.” “At first they didn’t listen to me . . . They said, ‘he’s fine.’” “She wasn’t listening . . . when I told her things weren’t going well . . . she just didn’t seem to care.” The lived experience of disempowerment is palpable in the following narrative: “Yet another horrible experience at that hospital . . . we’re like ‘we’re not going to let you risk (a treatment or procedure)’ . . . and then they say ‘no we have to,’ and then they do a bad job . . . [Child] was just completely screaming and upset.” In an extreme case, one physician’s instance on a choice that flagrantly contradicted the wishes of parents resulted in the child’s death. “We all said no. But he did it anyway because he thought he knew what was right. We felt terrible guilt that we left [child], when he was so vulnerable, with such a monster.”

For family members who feel disempowered by HCP behaviors, providers have voided their role as ally. Such HCP behaviors contributed to respondents feeling that they in some respects abandoned their own child. Conversely, respondents who perceived allies in HCPs expressed egalitarian and empowerment themes.

Flexibility and Individualized Care Versus Inflexibility and Rule-Bound Uniformity

Families noticed when providers offered individualized attention, rather than following mechanized formulas: “There’s probably a lot of circumstances where she should’ve or could’ve come in and taken his vitals, but we were cuddling with our son. She gave us that privacy.” They noticed this trait in whole treatment teams as well: “They would ask me before we would go to

sleep ‘do you want us to come and check in on you or not?’ They really got it, you know, in terms of what a family needs and doesn’t need.” “I think that they do a really good job there of giving parents the leeway that they want if they want it, or the guidance that they need if they need it.” Sometimes such flexibility even meant someone bent rules: “They gave us private rooms so that we could sleep together as a family when [child] was close to death. They broke the rules for us. That means the world to me even today.”

Flexibility allowed respondents to feel they had allies. Inflexible protocols insisted upon by institutions led respondents to feel alone with their individualized needs. One area this emerged was that respondents appreciated being allowed to move at their own pace immediately after the death of their child. “The [children’s palliative care facility] was great . . . No rushing me out of there afterwards . . . you know, it was just take—take your time, do what you need to do.” Several felt things moved too quickly. “I stayed holding [him] in the room for a few hours, by the time I got downstairs everything was gone . . . Can you just give me a minute here? He just died!”

Families noticed institutions or policies that offered perceived nonchalant, rote, or mechanical care, and their language in these areas strongly portrayed nonpresence. “The surgical hospital is like a Jiffy Lube . . . they were very mechanical.” “They were just cranking the people out of these treatments. And so there was just not very much personal interaction at all. And there wasn’t a lot of making [child] comfortable at the radiation center.” “There was never any kind of ‘we’re gonna do what is absolutely best for [child].’ It was always, ‘this is what hospice does, and so this is what we’re going to do.’” “I feel like we were thrown out of the hospital like we were a piece of garbage, like, you know, my son was a lab rat to [doctor] and it didn’t work, and so on to the next kid.”

Continuity of Care/Trust Versus Isolation/Mistrust

For some respondents the ability to maintain contact with trusted providers when transitioning to or from hospitals or to hospice care was very important. “They let us keep our oncologist . . . as our doctor. So I never had to break a new doctor in. You should write in your study: no one should ever have to break a new doctor in, period.” “We still wanted his oncologist in [city] to be making the decisions . . . because she is a pediatric oncologist. Hospice did not like that, they didn’t like that their doctor couldn’t just be in charge of his care.”

Thirteen respondents mentioned appreciating a professional who functioned as an advocate or main point of contact. “I was still very much confused by everything . . . from diagnosis to the end we very much felt like we were the ones having to make all these decisions by ourselves. I think to have somebody there to kind of guide you through this and explain to you exactly what’s going on, I feel like that would have saved me a lot of posttraumatic stress. Nobody should

go through this alone.” “He said, ‘I’m your advocate here.’ And that was probably one of the best things that happened to us . . . he would help us take all that information and sort through it and say, this is true and this is where the nucleus is instead of all this other stuff . . . he was a really good voice for us.” “Child Life is there for the kids but they’re also there for the families . . . kind of your go-between . . . if you don’t like something that’s going on.”

Respondents discussed the availability and quality of follow-up bereavement care. Experiences varied greatly, but again, themes of presence and abandonment emerged. “I’ve been really amazed and appreciative of how much hospice pays attention to bereavement and grief, that they really continue their work after their patient dies.” “Hospice I haven’t seen or talked to at all. I got one lousy Happy New Year card from them. But no contact. They offered nothing. Just completely dropped us.” “After [hospice nurse] came and we got rid of the meds, that was really the last we heard from them. Nobody even told us that, that there was websites that you could go to for support.” Several respondents mentioned the importance of peer support groups. “They’ve done so much for me. I don’t know where I would be in this whole process without that support.” “The [peer support] meetings—that was really helpful, for me that was extremely helpful.” Overall, families expressed that “the aftercare of all this is so crucial.”

Issues of Competence Versus Incompetence

Issues of perceived competence and incompetence manifested variously. HCPs demonstrating efficiency, promptness, and familiarity with care needs were appreciated. “PICU is so high tech and they deal with children’s illnesses every day and so they were very accustomed to dealing with parents and very sick kids. So they inspired a lot of confidence.” In several cases, HCPs did not know how to use crucial equipment or acted at a loss during crises, failing to lead. “He [child] was panicking and she was just staring at me and I said, ‘What do I do?’ and she just kept staring . . . I just wanted to smack her. Get out of here, you’re not helpful! You’re just standing there.” “They look at the feeding tube, they’re like ‘well we don’t know how to use it.’ We’re like, ‘well you’re the doctors.’ It was just a completely crazy situation.” This last parent encountered more HCP incompetence with other equipment: “So he’s looking through the pages of the manual . . . again, we’re in the ICU, it was just a bad taste . . . that kinda puts us in a tough position, because you want to be able to be the parent, you don’t want to be the doctor.”

Respondents noticed and appreciated good interdisciplinary communication, good staffing patterns, and efficient chain of command. “In [city], like I said, you literally walked over to a desk and thirty seconds later the doctor was at your daughter’s bedside.” “At our hospital, when you’re on compassionate care they put a butterfly sign on your doorway so that everybody knows, so that nobody says something stupid.” Likewise, poor staffing, poor communication between

providers, and bureaucratic difficulties with patient transfer protocols or implementation of treatment plans negatively affected families' palliative care and hospital experiences, creating an inherent incompetence. The sense of abandonment is obvious in this area in participant responses. "I tried to call the 24/7 number on the weekend before he passed. I called and I called and I called and I called but nobody answered the phone . . . what am I supposed to do? We need help!" "The neurologist was hard to work with . . . she just was really busy, never would call us back." "Here we were in intensive care, but they all seemed like maybe they had four minutes to talk to you and they needed to like rush down the hallway. And so you felt like if you asked them one more question you were taking them away from some other patient." "The trouble . . . is the whole chain of command between who can sign off on what orders . . . the hospice workers felt bad about . . . how long it took to try to make [child] comfortable." "Just that hospital thing of having different doctors different days, and residents, that whole thing, um, lack of communication." In one case, a family waited needlessly for emergency service due to rigid protocol. "That type of thing was very difficult to take, to, you know, watch your daughter suffer. Eventually the doctor finally showed up, and they were like oh we're so sorry, you know, blah blah blah."

The infrequency or inadequacy of nursing visits while enrolled in home hospice care was a theme discussed by eight respondents. "Hospice said they wouldn't come sit with us as he was dying. I didn't have a fear of him dying at home, but I did have a fear of, um, being alone with him when he died." Six felt their visit schedule was inadequate. "Hospice care . . . was really fairly minimal. I thought they'd be there every day." "I thought she [hospice nurse] was going to come on a daily basis. She only ended up coming about twice a week. . . nobody really helped us, I mean, it really falls on your shoulders . . . it's overwhelming." For several, the lack created great distress. "The last few days when things were changing rapidly, I'd call and say 'Are you coming? Are you coming? The color is changing,' but she said 'No, we have our scheduled appointments.' I said 'Scheduled appointments, he is DYING, what are you talking about?'"

Respondents appreciated hospitals and hospice programs that specialized in children's care. They sensed not only greater competence but also more compassion at these facilities. "At the children's hospital I definitely always got the feeling that [child] was really really loved and cared for, and I never got that feeling from [other hospital]." They were negatively affected by HCPs with little or no training in working with sick or dying children and organizational policies that were not designed with children's unique needs in mind. "At the proton center, you could tell that taking care of these kids was really taxing on the nurses, and very difficult, and they didn't have the skills and the training to take care of them the same." "They [hospice workers] had never seen a child. The nurse, what she was used to seeing in elderly just didn't apply to him—at all." "He got really anxious and nervous sitting there. We asked him, finally, do you

want to just leave? He was the social worker for the hospice—he wasn't able to handle what we were going through.” One parent explained a key difference: “I chalk it up to that it's very difficult for adults to see dying children, obviously. And so there is some training that needs to take place when they're dealing with a child that is very ill or dying. And I think in a children's hospital they get that training, or they come into contact with families that are losing a child more often. At these other centers, they're not as accustomed to it, or they're not trained in it.”

Overall HCP experience was noted as a factor possibly affecting personal competence. Multiple respondents noted compassion was compromised because tragic news was poorly delivered by interns, residents, or very inexperienced HCPs. “When that doctor came and told me that he was dying—he was a young doctor. I don't know if he was an intern, but he was a young doctor. It was pretty abrupt.” “You could tell he didn't know what to say; he was really nervous and upset.”

The theme of competence versus incompetence also manifested in family members' personal sense of preparedness or unpreparedness. Several respondents addressed whether anyone prepared them for crucial transitions, such as from hospital to home hospice, the physical particulars of the death experience, or the closing of the casket during the child's funeral. “Before they let us bring him home, the nurses made (us) do all of his meds for like 2 days.” One parent was shocked: “It was like a horror movie—gasping, like the last couple of hours, it was so disturbing. I was totally unprepared for that. I felt like he was suffering, and I wish someone would have explained this all to me.” Other respondents described fears about the transitions. “I thought, oh my God, you can't send him home with me, I'll kill him! Because he had all these [needs] and I was totally freaked out.” A specialty program that helped parents prepare for the birth of a child with a fatal condition was appreciated and discussed by one respondent.

Repeatedly in the data, narratives about perceived incompetence—whether individual, team, or organizational—not only left families feeling alone and unsupported, but bereft of proper caregiving, they felt unable to protect and care for their own child. Parents expressed feeling at a loss, helpless, alone, and guilty for being unable to meet their own child's needs. Narratives quoted above in previous sections refer to respondents' repeated attempts to reach out for help in such situations.

Further instances of this theme of “double abandonment” are evident when the subject of pain control arises. Because pain is an utterly subjective experience, a child in extreme pain enters a private geography where the parent cannot follow. The professional caregivers or system could be seen as having abandoned the child, the parent likewise cannot help the child, and the child in a way is viewed as retreating or withdrawn from the parent.

Seven respondents indicated that pain or anxiety control for their child was inadequate under hospice care and this greatly increased their own distress as

parents. “That made us feel horrible that, you know, we didn’t have the best medicine available to try to make her feel better.” “You felt like you were hurting him when you were touching him.” “You just feel guilty about it in hindsight.”

For several respondents, pain or anxiety at the end of their child’s life was a predominant theme in their memory and narrative. “Does it bother me that his last word was ‘ow,’ because . . . they couldn’t control his pain? Yeah it does . . . He suffered so much.” Various reasons both individual and institutional contributed to the failure, but all left a painful sense of abandonment. “She was in charge of medicines and he was freaking out and I needed something for his agitation. She was supposed to write prescriptions and she didn’t . . . she just totally let us down on that one.” “He’s vomiting nonstop, you want me to give him an oral pain med? Okay, how will I do that? I felt like I was alone, and I felt like they thought I was kind of being pushy.”

Discussion

Exchanges with HCPs and health-care organizations were exceedingly influential in shaping families’ experiences surrounding illness, death, and bereavement. Respondents vividly recalled crucial moments of interaction—both positive and negative, and both with individual HCPs and within more abstract organizational structures. Given minimal prompting, respondents spoke powerfully about how these individuals and institutions shaped their experiences at the end of their child’s life. This is consistent with previous findings of the important and often pervasive impact HCP–parent interactions can have on the experience of a child’s death for the family, as well as the family’s ability to heal and cope with the loss (Browning & Solomon, 2005; Contro et al., 2002; Gold, 2007; Pullen et al., 2012). A summary of appreciated and unappreciated HCP responses is provided in Figure 1.

Respondents’ subjective and divergent representation of HCP compassion stood out in the data. Compassion was often described in terms of the manner in which HCPs communicated difficult or bad news to families regarding their children’s diagnosis, prognosis, or treatment options, connecting with literature noting the salience of HCP sensitivity and empathy in the context of delivering tragic news (e.g., Aschenbrenner et al., 2012; Pullen et al., 2012). Respondents also noted whether HCPs possessed the requisite experience to have conversations regarding the prognosis and care of terminally ill children and to be fully present for emotionally charged moments with parents and families. Varying preferences regarding how a child’s condition or care was communicated suggests that compassion, as understood by respondents, is deeply connected to the ability of HCPs to provide individualized, mindful care. Yet, compassion was also delineated in myriad other ways.

The interaction between HCP and institutional policy or barriers seemed to also translate into the presence or absence of compassion from respondents’

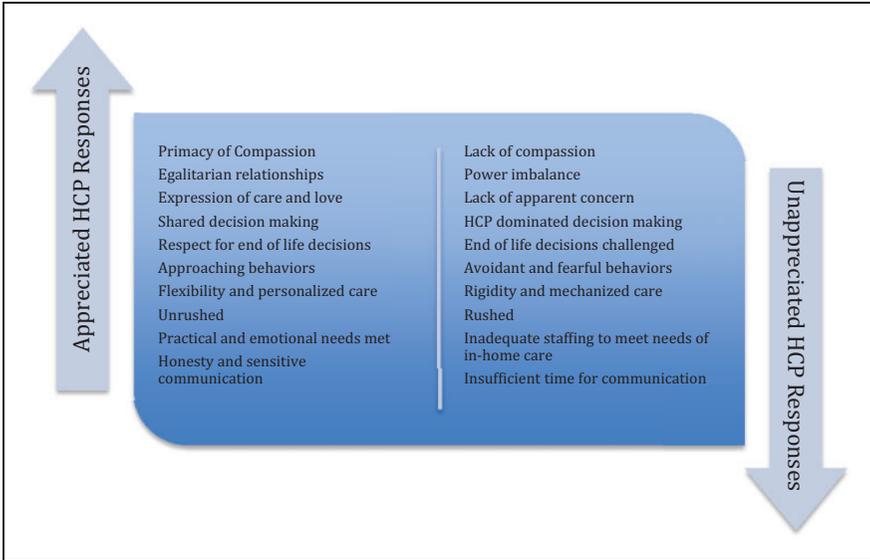


Figure 1. Appreciated/unappreciated health-care provider responses.

perspectives. As one family member said, “Those things that were non-hospital and human touches . . . were just hugely appreciated and I think they can be easily undervalued.” Providers who were willing to act and think beyond the institution were valued as showing compassion and even love. This includes challenging institutional constraints (even in minor ways, such as allowing a family to sleep in their child’s hospital room) and expressing regret about an outcome (even if beyond the HCP’s control). While HCPs have acknowledged concerns surrounding liability as a barrier to providing quality bereavement care to pediatric patients and families (see, e.g., Contro & Sourkes, 2012), it was notable that the expression of integrity in the form of owning one’s decisions, mistakes, or uncertainty seemed to be interpreted as a form of compassion. The issues of provider integrity and accountability and the emotional and possible legal/structural factors involved warrant further exploration.

Our findings also suggest that structural and/or policy issues regarding care delivery contribute to the subjective experiences of both pediatric patients and their families in multifaceted ways. Some of the barriers embedded in these data suggest the misapplication of policies and standards of care designed for adults in perinatal/pediatric end-of-life care. Facilities and individuals that were accustomed to providing care to terminally ill or dying children offered notable relief. This perhaps underscores the importance of continuity of care: families who perceived that HCPs or facilities were responsive to their unique needs found it particularly helpful to be able to maintain those relationships throughout their

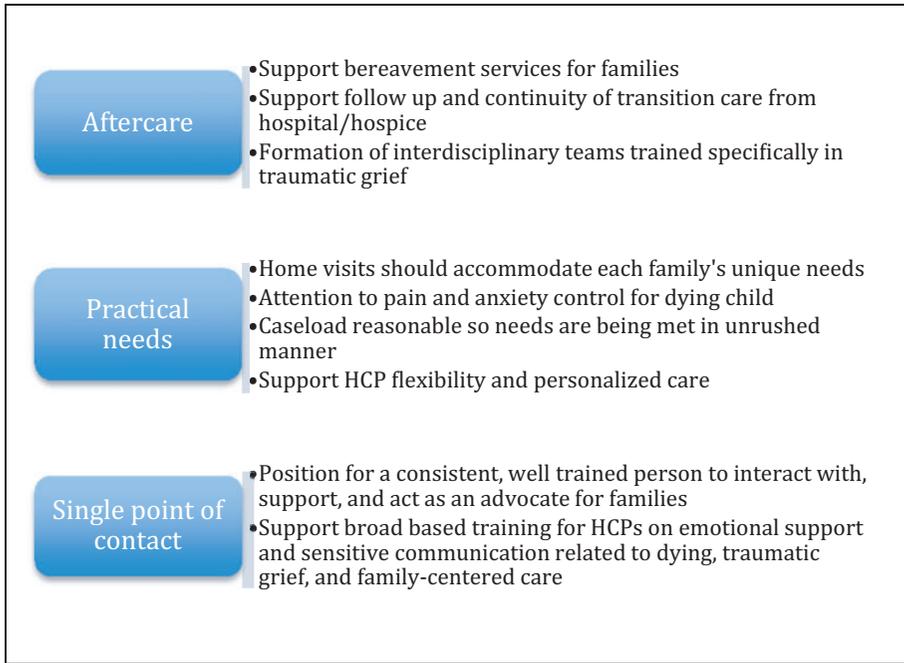


Figure 2. Structural recommendations.

children's lives and stages of care. Organizational recommendations are provided in Figure 2 and center on the provision of a main point of contact, the meeting of practical needs, and offering quality bereavement aftercare.

Overall, the narratives of these grieving families illuminate the importance of perceived HCP presence versus abandonment. Families already vulnerable, fearful, and intensely reliant on the expertise of their HCPs sensed when caregivers were warm, empathetic, honest, trustworthy, engaged, supportive, responsive, and competent. Their richly complex stories, describing a great variety of individual and institutional behaviors, delineate the difference *between the care they desired and, at times, the care they received.*

Conclusion

The results of the present data suggest that interactions with HCPs strongly influence families' experiences during a child's illness, dying, and death. The expression of compassion via warmth, shared decision making, open communication, flexibility, effective care, and a host of other manifestations were key factors that either aided or hindered families' ability to cope with their child's illness and death. Lack of compassion was perceived to have profoundly

negative effects on subjective grief and adjustment. Given these results, further exploration and advanced training of HCP's on how to communicate effectively and while conveying compassion could lead to improved interactions and outcomes for families of terminally ill children. Additionally, families deeply appreciated organizations and agencies that seem to have provided grief education for HCPs and offered accommodations uniquely appropriate for terminally ill children and their families. Additional research would be helpful in understanding the specific accommodations that could be implemented to provide comfort and support for these families. This study provides support for the assertion that there is a grave need for improvement in palliative care and more compassionate interpersonal interactions between HCPs, dying children, and their families.

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Note

1. Unless otherwise noted, all quotes presented as representative of each point are from families of different children.

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