

# Family Perspectives on the Quality of Pediatric Palliative Care

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**Background:** As a prelude to establishing a Pediatric Palliative Care Program, we solicited information from families about their experiences and their suggestions for improving the quality of end-of-life care. Participants were English- and Spanish-speaking family members of deceased pediatric patients who received care at Lucile Salter Packard Children's Hospital, Stanford University Medical Center, Palo Alto, Calif.

**Methods:** Sixty-eight family members of 44 deceased children were interviewed regarding treatment, transition to palliative care, and bereavement follow-up. Four clinical social workers and one clinical psychologist reviewed the participants' responses and identified frequently occurring themes.

**Results:** Several areas of unsatisfactory interactions with

staff were identified: confusing, inadequate, or uncaring communications regarding treatment or prognosis; preventable oversights in procedures or policies; failure to include or meet the needs of siblings and Spanish-speaking family members; and inconsistent bereavement follow-up. A discrepancy emerged between the high degree of pain described by the families and parents' perceptions that pain had been managed well. Community hospice programs are frequently poorly prepared to serve pediatric patients.

**Conclusions:** There is a need to improve pediatric palliative care. Recurring themes in the family interviews suggest useful issues to consider in the development of a palliative care program.

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**W**HILE technological advances in the area of children's health services have resulted in improved medical care and outcomes, children still experience incurable conditions that result in death. In most health care institutions serving these children, the transition from curative to palliative care lacks a comprehensive, coordinated, and evidence-based approach. Recognition of such problems led the Palliative Care Committee at Lucile Salter Packard Children's Hospital (LSPCH), Stanford University Medical Center, Palo Alto, Calif, to commission a needs assessment in the area of pediatric palliative care. The primary intent of this assessment was to obtain personal accounts of families' experiences to learn ways to improve care for pediatric patients and their families.

viewed the responses of the participants and discussed what appeared to be the most salient themes. The group first identified as many themes as possible and computed frequencies to use as a guide to identify themes that occurred more (or less) often. The collections of themes were then collapsed into

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categories. Themes that were found to be the most prevalent are described further. Because this assessment was exploratory and descriptive in nature, and because quantitative analyses were not appropriate owing to the small number of respondents and participation of multiple family members, only qualitative results are presented.

### FAMILIES' INTERACTIONS WITH STAFF

#### Parental Involvement

Parents appreciated it when they felt actively involved in making decisions concerning their child's treatment and care. The parents' descriptions of an effective caregiver were highly consistent. Non-

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## RESULTS

### ANALYSES

A group composed of the 5 interviewers who conducted most of the interviews (4 clinical social workers [N.C., S.S., and others] and 1 clinical psychologist [J.L.]) re-

## PARTICIPANTS AND METHODS

### RECRUITMENT OF PARTICIPANTS

English- and Spanish-speaking family members of deceased children who received treatment at LSPCH were recruited. Approximately 200 death certificates of children who died between April 1, 1996, and October 31, 1997, were obtained from hospital records. Social workers (N.C. and S.S.) reviewed the names and identified families who should not be contacted (because of geographic distance or because the cause of death was fetal demise, etc). A letter of invitation was mailed to 156 families. The project coordinator (S.S.) followed the letter with a telephone call to describe the project in more detail and to answer any questions. If the family wanted to participate, the project coordinator scheduled a time for an interview.

Of the 156 families who were invited to participate, 93 could not be reached by telephone or by mail. Twenty families declined participation, stating it would be too painful. One couple self-referred.

A total of 68 participants, representing 44 families, were interviewed regarding their perspectives on palliative care at LSPCH and in their home communities. The interviews were conducted from September 1, 1998, through March 31, 1999. The time between the child's death and the interview ranged from 6 months (for the couple that self-referred) to 2½ years. Participants signed an institutional review board-approved informed consent before the interview. The average length of the interviews was 2 hours.

### CHARACTERISTICS OF PARTICIPANTS

**Table 1** presents the demographic characteristics of the participants. **Table 2** presents a breakdown of the patients' diagnoses, duration of illness, and ages at the time of death. Family members interviewed included those who felt positively about their experience with LSPCH, those who reported a mixture of positive and negative experiences, and those who reported an overall negative

experience. Even families who reported mostly positive experiences offered suggestions for improvement. All expressed hope that the information would help others.

Talking about it is hard, but it's one of those things, if somebody else can get some good out of it . . . as awful as it was, I was given a gift of experience. If I can use it to help someone else, it makes L's life mean something still.

### THE INTERVIEWERS

Initially, 11 LSPCH clinical social workers (N.C., S.S., and others) and 1 Stanford University, Stanford, Calif, clinical psychologist (J.L.) conducted the interviews. Early on, 7 interviewers withdrew from the project, leaving a group of 5 interviewers (N.C., J.L., S.S., and others) who conducted most of the interviews. With the exception of one family, the interviewers were unknown to the participants.

### THE INTERVIEW

The LSPCH Palliative Care Committee (composed of physicians, nurses, chaplains, social workers, biomedical ethicists, and patient advocates) researched methods used by children's hospitals throughout the United States and Canada to assess the needs of pediatric palliative care patients and their families. Using these methods as a guide, a task force developed the interview protocol. Pilot interviews were conducted, and final revisions were made.

The interview began with demographic questions. Participants were then asked to describe the course and treatment of their child's illness. Next, they were asked about interactions with hospital staff, quality of support for their child and for siblings, and the family's experiences at the time of their child's death. Finally, participants were asked about follow-up support. Most questions could be answered yes or no or on Likert-type scales (eg, never, sometimes, often, or always). Participants were encouraged to elaborate, especially concerning areas needing improvement, and to bring up any issues or suggestions that were not directly addressed in the interview.

esty, clinical accuracy, compassion, and availability were among the most desirable caregiver traits.

They treated me as an active member of the treatment team. They would definitely listen. Before they made a decision they would always ask for my input. And they were honest about not knowing how it was going to go, but they would do everything they could to keep her within the comfort zone. That was so important to me. And the fact that they acknowledged that this is a situation that is not going to have a good outcome.

### Isolated Incidents Can Be Extremely Painful

One of the most striking findings was how a single event could cause parents profound and lasting emotional distress. Parents recounted incidents that included insensitive delivery of bad news, feeling dismissed or patronized, perceived disregard for parents' judgment regarding the care of their child, and poor communication of important information. Such an event haunted them and complicated their grief even years later. Parents did not pursue existing complaint procedures because they were

too overwhelmed to file a formal complaint or because they feared repercussions.

We knew how serious it was all along, but we had the intention of keeping positive. The one bitterness I have left [sobbing] . . . for some reason, some doctors feel that you're not allowed to have hope, that you're just supposed to accept it and move on. About two weeks before D passed away I was sitting with him, holding his hand. This doctor, who wasn't even part of our team, came in and said, "You know, you need a reality check. He's going to die." I thought, "Who the hell are you to tell me when to give up hope?" I can't let that one thing go, as perfect and wonderful as everybody else was.

Upsetting experiences that related to preventable oversights and/or errors in procedures, such as failures to comply with hand washing and compromised immune system policies, were also prevalent, and left families feeling angry and victimized.

We got a 3 AM call saying we should be there right away. We'd had so many of those calls. So, when we arrived we just expected him to be in a different room. No one met us. When we

**Table 1. Characteristics of the 68 Participants**

Characteristic	Value*
Sex	
Female	45 (66)
Male	23 (34)
Relationship to child	
Mother	36 (53)
Father	21 (31)
Brother	1 (1)
Sister	1 (1)
Wife	1 (1)
Foster mother	3 (4)
Uncle	1 (1)
Aunt	2 (3)
Grandmother	1 (1)
Stepmother	1 (1)
Age, y	
Range	13-59
Mean	38
Ethnic identification	
White	50 (74)
Latino	15 (22)
Asian	3 (4)
Primary language	
English	59 (87)
Spanish	9 (13)
Education	
Elementary school	6 (9)
High school	6 (9)
Some college	33 (49)
College degree	22 (32)
Unknown	1 (1)
Medical insurance	
Yes	64 (94)
No	4 (6)
Annual income, \$	
<20 000	12 (18)
20 000-39 999	18 (26)
40 000-59 999	9 (13)
60 000-79 999	7 (10)
80 000-99 999	7 (10)
>100 000	10 (15)
Financial burden	
Yes	35 (51)
No	33 (49)

\*Data are given as number (percentage) of participants unless otherwise indicated. Percentages may not total 100 because of rounding.

entered his room, we saw the blanket pulled up over his face. My first reaction was, "Oh well, maybe he covered himself." [Weeping] But then I went to his bed and there he was [dead].

### Delivery of Difficult News

There were recurring reports that the delivery of difficult news was problematic. Even those who rated communication of difficult news positively had suggestions for improvement. Families stressed their need for a familiar person to deliver difficult news about diagnosis, treatment, and prognosis. This was especially critical with the news that their child was going to die. Participants also emphasized that difficult news should be conveyed with compassion and care, using straightforward non-technical language. Above all, family members recommended giving difficult news directly and honestly while

**Table 2. Children's Diagnoses, Duration of Illness, and Age at the Time of Death**

Variable	No. (%) of the 44 Children*
Child's diagnosis	
Oncologic	28 (64)
Cardiac	4 (9)
Premature	4 (9)
Other	8 (18)
Child's duration of illness	
Hours or days	9 (20)
1-12 mo	14 (32)
>1-5 y	15 (34)
>5-10 y	4 (9)
>10-15 y	2 (5)
Child's age at the time of death	
Hours or days	7 (16)
1-12 mo	5 (11)
>1-5 y	10 (23)
>5-10 y	5 (11)
>10-15 y	8 (18)
>15 y	9 (20)

\*Percentages may not total 100 because of rounding.

still allowing for hope. Parents also mentioned they would have appreciated better preparation that bad news was coming.

Doctors need to relay medical facts honestly but always allow for a glimmer of hope, even if only for a miracle. The doctors who best connected with S always had hope. Be sensitive, honest, cautious about word choice. It should come from someone the parent already has a relationship with.

Family members were asked if they received mixed messages regarding their child's diagnosis, treatment, or prognosis. Several families reported that some staff seemed more hopeful than others did, and that some staff gave contradictory information or conflicting recommendations regarding their child's treatment. Mixed messages resulted in confusion and emotional turmoil, and added an additional layer of stress for families.

The morning nurse said, 'He had a great night,' then she leaned over and told the doctor, 'His "sats" went down.' I felt they weren't being honest with me. Just tell me! Sometimes I felt like they were telling me what they thought I wanted to hear.

Family members expressed the preference for one caregiver to be "in charge" throughout all phases of treatment. Having access to a familiar, consistent caregiver was viewed as essential to quality care.

Having one constant person throughout was important. He was honest with us, sometimes he'd say, 'I have no idea,' but then he'd go talk to someone and get the answer for us. Having one person follow you throughout is probably the biggest sense of relief.

### Siblings

Despite all that is known about the needs of the siblings of pediatric patients, the reports of participants revealed that siblings still do not receive the support they need. Any kindness and attention that staff extended to sib-

lings was appreciated. Suggestions for improving services to siblings included access to playrooms during hospital visits, support groups, and respectful attention from staff.

They should be allowed as much time together [with the patient] as possible. Even if they don't show it, it affects them. They should be included in discussions. Staff should pay attention to the siblings, too. Get to know them.

### Spanish-Speaking Families

Although the number of Spanish-speaking families was small, several distinct issues emerged consistently in the accounts of their hospital experiences. The language barrier between these families and hospital staff permeated every aspect of the families' experiences. The lack of a common language compromised parents' ability to acquire complete information and to fully understand their child's medical condition, treatment, and prognosis. In addition, cultural differences could be detrimental to care. For example, if the Spanish-speaking parents' expectations that physicians show their child affectionate attention were not met, this became a barrier to trust and confidence in the medical team. These families reported feeling isolated, confused, and distrustful of the hospital system.

No one ever told me the baby could die. I never understood what was happening medically. The doctor came out during the operation and asked my wife if they should stop or continue the operation. I didn't understand that the baby would die either way at that point. No interpreter came during this conversation.

### Bereavement Follow-up

Continued contact with hospital staff after their child's death was meaningful to the families who spent time at LSPCH. Follow-up by telephone, mail, and/or in person was desirable and appreciated. Indeed, when offered an off-site location for the interview to spare families further trauma, we learned that many parents had already returned to the hospital to visit.

The phone calls are important. When her doctor called, I thought, "Wow, you're still thinking of us!" The nurse practitioner still calls periodically. When your child is sick like that, it becomes your life and the doctors and nurses become your extended family. If they can continue some kind of periodic contact, it's important.

### PAIN MANAGEMENT

Pain management was an issue for families. Parents described their anguish over seeing their child in pain. Yet, when asked specifically how well their child's pain was managed (poorly, adequately, or well), the same parents whose child experienced substantial pain also said their child's pain was managed adequately or well.

We told them she didn't do well on morphine. We saw the pain she was in. For 48 hours we kept telling them it wasn't helping. No matter how much morphine they'd give her, she was

flopping around on the bed. So we stood there the whole time . . . she was moaning in pain. [Crying] Those are the images that are the most painful, that she had to suffer. We were helpless. I'm sure they thought what they were doing would work, I'm sure for most kids it works. But for her, it didn't. At that time, we felt we weren't being taken seriously. It's still the image we wake up thinking about.

### HOME DEATHS

Of the 44 children represented in this assessment, 17 died at home. Fifteen of these families used the services of a hospice, home care agency, or both. Families reported problems ranging from frustrations with logistics (eg, scheduling and inadequate staffing) to agency staff who freely admitted they were unprepared to serve children, especially with regard to pain management. For these families, inadequate home care left them wanting access to hospital services that were unavailable to them on an outpatient basis.

We desperately needed pediatric pain control. The hospice didn't know how to control his pain, but we couldn't use the hospital pain team because we weren't 'inpatient.'

### COMMENT

The family interviews provided valuable information regarding specific ways in which palliative care services to children and families might be improved. Preventable errors in procedures and/or careless comments disturbed families long after their child died. While technical care was important, a positive relationship with the primary caregivers was also considered paramount to good care.

This assessment illustrated that poor communication increased distress for patients and families. In addition, the lack of a trusting bond with a primary caregiver was identified as a major source of dissatisfaction. The need for ongoing comprehensive information from a familiar and trusted staff person was a recurring theme. The quality of the relationship between staff and families was crucial to the families' appraisal of their experience. Even one thoughtless remark could leave devastating and lasting impressions on the families. The importance of the relationship with staff continued beyond the child's death, particularly for those families who spent weeks to years in treatment. Families were grateful when staff continued contact after the child's death, and families who did not receive follow-up contact were disappointed and felt dismissed.

There is much knowledge available regarding the impact of a child's illness and death on siblings.<sup>1-6</sup> Even so, the family interviews revealed that support for siblings continues to be a necessary and lacking component of care.

Researchers<sup>7-14</sup> in the field of thanatology have long recognized the role of language and culture as it relates to a person's response to the death of a loved one. The Spanish-speaking families in our assessment described a heightened sense of despair resulting from their inability to communicate with staff. Further systematic study is needed to elucidate the impact of language and cul-



ture on provision of care. Once we are better informed, we can begin to improve care for children and families from differing cultural backgrounds.

Failure to use opioid medication adequately with children and adolescents has been well documented.<sup>15-20</sup> A discrepancy between high levels of pain described by parents and their belief that their child's pain had been managed "adequately" or "well" was noted. One explanation might be that the hospital's reputation led parents to assume that the most advanced technology would be used. Thus, they concluded that their child's pain could not have been reduced. Another explanation may be that the parents could not tolerate the idea that everything possible to reduce pain was not done. Thus, they were predisposed to believe that pain was managed as well as possible.

Despite the growth of the hospice movement in the United States, surprisingly little research<sup>21-24</sup> has addressed pediatric palliative care. The need for pediatric expertise in hospice and home care agencies that care for dying children emerged in this assessment. Children lacked access to experts in pediatric hospice care. A hospital liaison to community hospices, home care agencies, and families would be a beneficial addition to the services provided.

Several limitations to this assessment must be noted. The recruitment response rate was low, and multiple family members were interviewed. Sampling error and self-selection bias probably contributed to this problem. Highly educated people may be more inclined to participate in an assessment such as this one, as might families who have specific complaints they want to make known.

This assessment was intended to be exploratory and descriptive. Because standardized measures were not used, and although the families' accounts appear to have considerable face validity, the reliability and validity of the interview cannot be asserted.

The assessment relied on the perceptions of family members obtained after the death of their child. Subjective retrospective perceptions may not accurately reflect the actual events that took place and may not provide an accurate account of their child's experience. Regardless, reliance on parents' perceptions is essential when assessing care of children. Finally, the families interviewed were treated at LSPCH. Thus, these results may not generalize to all families who receive palliative care from LSPCH or to families who receive services from other health care institutions.

## CONCLUSIONS

The families who participated in our assessment unanimously expressed gratitude for the opportunity to "tell their stories" and to provide input into a future palliative care program. For some, it was the first time they had recounted their experiences since the death had occurred. The enthusiastic gratitude expressed by families may indicate that there is an unmet need for opportunities to discuss such tragic events as the death of a child.

The families' interactions with staff were as important to their overall evaluation as the medical aspects of

## What This Study Adds

While research about the needs of dying patients has increased in recent years, there remains an absence of substantial information about pediatric palliative care. Much of the literature is fragmented and incomplete. This study is a qualitative needs assessment that suggests direction and focus for future research into pediatric palliative care.

This needs assessment presents descriptive findings from interviews with families of deceased pediatric patients. It provides a cohesive overview of major areas of pediatric palliative care that appear to need improvement. It is presented as a resource for institutions developing pediatric palliative care programs and for researchers seeking to define areas of further exploration.

treatment. It was disconcerting to learn about careless comments from staff or lapses in procedures that caused families additional distress. The literature clearly identifies the needs of siblings of dying children, yet they still do not receive adequate attention. Finally, the negative impact of language and cultural barriers on the delivery of medical care is a well-recognized problem that deserves closer attention when addressing the needs of pediatric palliative care patients and their families.

Pain management, a key component to palliative care and a primary concern of families, is often ineffective. Despite the advances in pain management technology, families reported that their child experienced considerable pain. Families who took their child home to die discovered that community hospice and home care programs were not qualified in providing pediatric palliative care, including pain management.

Although much of what was learned from this assessment has been cited in the literature, it has been documented in fragmented fashion. It appears that there are few pediatric palliative care programs that encompass the full spectrum of services needed for optimal care. This assessment reiterates the need for a comprehensive program that incorporates all aspects of care and family support, in the hospital and at home, from diagnosis to bereavement follow-up.

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