

PALLIATIVE CARE PROGRAM

Lucile Packard
Children's Hospital
AT STANFORD



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"A HEART WEEPING"

Bereavement Services:

A Needs Assessment at a Children's Hospital

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Background to the Current Study

Two needs assessment studies at LPCH:

(1) Bereaved families' view of the care their children had received, particularly around time of death

(Contro et al: Archives Pediatric & Adolescent Medicine, 2002)

(2) Staff members' perspectives on palliative care at LPCH

(Contro et al: Pediatrics, 2004)

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Major Findings

- Although most families felt positively about the care their child had received, specific gaps and inconsistencies emerged
- Findings from family and staff interviews validated the need for a palliative care program
- The families' experiences at the time of the child's death, and in the subsequent period of bereavement, profoundly influenced how they fared as they moved into the future

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Present Study

Exploring the state of bereavement care at our institution was the requisite "next step" in order to optimize the care of families

- (1) Interviews with bereaved families
- (2) Interviews with leaders of community agencies who offer bereavement services
- (3) * Interviews with LPCH staff members to elicit their perspectives on bereavement care for our families

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Method : Interview

Detailed interview protocol of open-ended questions

- family's experience around the time of the child's death and into bereavement
- facilitating factors and/or barriers to optimal care, both in anticipation of the child's death and in bereavement
- impact on staff of caring for these children and families

Interview also included factual inquiries
(eg, resources, funding)

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Method : Interview

- Interview protocol pilot-tested and approval secured from Institutional Review Board
- Two highly experienced social workers conducted interviews
- Thematic analysis conducted by social worker and two psychologists

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Method: Participants

- Interviews with 60 staff members, comprised of:
 - 39 individual and 3 groups
 - members of 3 "grief and loss" committees
- Average length of interview: 1 hour, 45 minutes
- Representatives from the following disciplines:
medicine, nursing, social work, chaplaincy,
psychology/psychiatry, child-life, respiratory
therapy, education, interpreter services,
family-centered care

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Participants' Responses to the Interviews

- Gratitude for focus on bereavement and invitation to participate
- Many recounted powerful stories about children and families who had left lasting impressions
 - experiences in which they had felt honored to participate and witness
 - situations that had gone poorly and left them with haunting memories and sorrow for the family
 - their own suffering over loss of a beloved patient
- Many had never discussed these experiences, even though some had occurred long ago

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Themes from Interviews

- Hospital-wide focus on bereavement care*
- Time / timing
- Logistics around the time of death
- Language and culture*
- Distance
- Relationship-based variation in care*
- Continuity of relationships
- Siblings and other close family members*
- Staff communication, cooperation and coordination of care
- Staff education, mentoring and support*
- Staff suffering
- Role of social worker

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Theme: Hospital-wide Focus on Bereavement Care

- Overall, strong cry for the development of a hospital-wide infrastructure to support bereavement activities
- A few services had created bereavement protocols and found funding outside of the operations budget to support these activities
- Some staff members took their own creative initiatives
- Many staff members acknowledged using their own resources

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Theme: Language and Culture

- Strong desire for training in the mores of different cultures around illness and death of a child
- Despite excellent interpreter services, many staff feel "helpless" in serving these families
- Diminishing level of care depending on the language of the family
 - English-speaking families
 - Spanish-speaking families
 - Families who speak languages other than English or Spanish

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Theme: Relationship-based Variation in Care

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Theme: Siblings and Other Close Family Members

- Profound concern at the paucity of services available for siblings before and after the child's death
- Follow-up dependent on parental request and availability of staff
- Grandparents, extended family, schoolmates rarely receive services

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Theme: Education, Mentoring and Support for Staff

- Need for more education and mentoring in palliative care
- Need for timely and flexible support to alleviate staff suffering
- Concern about the toll of cumulative losses
- Particular concern about the impact on young and inexperienced staff

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Conclusion

This comprehensive evidence-based study demonstrated a "disconnect" between the:

deep commitment and dedication on the part of the staff to ensure that families get the help they need

and

reality of what the staff could actually provide

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