

What Conversations Do Bereaved Parents Remember?

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Abstract

Objective: Memories of conversations with health professionals are among the outcomes in the end-of-life care of children. Little is known about their nature or content. We conducted interviews with bereaved parents to determine whether there were conversations with healthcare professionals that they continue to revisit, positive or negative, five years following their child's death, and consider their themes.

Methods: Parents of children who had died aged 1 month to 11 years were interviewed, using a focused ethnographic approach. Thematic analysis was performed on interview transcripts.

Results: Families recalled specific negative (10/16) and positive encounters (11/16). Positive memories exhibited empathic protectiveness, personal disclosure by healthcare providers, and authenticity. Negative memories revealed medicalized insensitivity to the family's experience and emotional distance.

Conclusions: Bereaved parents had memories of specific conversations with healthcare professionals years following their child's death. They did not recall family meetings or technically-oriented moments, but moments marked by relational aspects. Insensitivity or lack of empathy were negative themes.

Empathic protectiveness, personal disclosure, and authenticity at moments in care created enduring positive memories. The findings support the importance of humanistic involvement with patients, demonstrating the enduring impact of healthcare professionals in critical life events.

Keywords:

Parental bereavement

End-of-life care

Child death

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Age of Child	1-3 months	9
	4 months-3 years	4
	3 -11 years	3
Diagnosis of Child	SIDS	3
	Prematurity	4
	Cardiac	1
	Neurological	3
	Oncological	1
	Metabolic/Genetic	1
	GI	1
Race of Child	Other	2
	White	12
	Black	1
Median Family Household Income By Zip Code	Hispanic	3
	<\$30,000	1
	\$31-\$50,000	5
	\$51-\$75,000	7

Mother stays at hospital day after day as child gets sicker. Doctor comes by regularly just to chat, "but I always ended up crying."	PE
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Negative Conversations	Theme
Overwhelmed mother is encouraged to be with her dead child by the healthcare team. She goes to her child, taking her siblings with her, so that she can bear it. Supervisor imperiously orders the siblings away saying 'they can't be here'.	M
Ultrasound technician discloses a fatal cardiac finding, but then says she's not a cardiologist, that she needs to close the office, and that the mother should contact her doctor.	M
Mother overhears an obstetrics resident say, 'Oh, I wouldn't miss this', "like it was going to be a show because the baby would be born with so many complications".	M
Physician seems excited to make a rare but fatal diagnosis. The mother recalls that was a "death sentence for my daughter".	M
Parents decide to discontinue life prolonging therapy and ask if they can hold their baby. The nurse feels inconvenienced, saying "I just got to get this (other) kid to the floor".	M
Nurse tells parents that their ill baby was "snowed over", losing sight that it was their baby "inside there".	M
Parents regretful of their decisions to prolong their child's life dreaded discussions with the doctor who was "very clinical", and would spend time with them focusing on everything that was wrong and telling them how to make their decisions.	E

Doctor officiously tells mother "obviously this is a serious situation". ..We're doing everything we can" during resuscitation. Then no one tells her when her daughter died or spoke with her. E

After the death, the nurse seemed detached and the doctor did not know what to say. E

"The neurologist said he was 99.9% sure there's nothing we can do." Wondering about that 0.1% keeps the mother up at night to this day. M, E

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