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What Conversations Do Bereaved Parents Remember?

Richard D. Goldstein*

Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, MA , USA

***Corresponding author:** Richard D. Goldstein, MD, Dana 2008, Dana-Farber Cancer Institute, 450 Brookline Avenue, Boston, MA, 02115, USA, Tel: 617-632-6637; Fax: 617-582-9148; E-mail: richard_goldstein@dfci.harvard.edu

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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: Doctor-patient interaction; Parents' perceptions; Discourse analysis; Communication; Medical education

Objectives

Parents of dying children engage in many conversations with healthcare professionals during their child's treatment. Prognosis is disclosed, worrisome developments explained, and care conferences are held.

They experience professionals attempting to balance authority, "objective detachment", authenticity, empathy, and humanity. Sharing of information is central to these conversations, but so too is a commitment to provide physical, emotional and spiritual comfort through the process of illness and death, and into the family's bereavement [1]. Memories of important conversations with healthcare professionals are among the long-term outcomes of this care.

To better understand aspects of communication between healthcare professionals and the parents of dying children remembered years after the child's death, we asked bereaved parents to share their memories, good or bad, of conversations they continue to recall five years after the death of their child.

Methods

Sample

We interviewed parents whose children died in 2005 at ages 1 month to 11 years, five years following their death. Newborns were excluded because of interest in primary care involvement, and adolescents because of higher homicide and suicide rates. State-wide recruitment was approached by date of death, using Massachusetts Bureau of Vital Statistics death certificate data, between August 2009 and July 2010. Thematic saturation determined sample size.

Interviews

Subjects were recruited by letter (English and Spanish), and enrollment attempted when "opt-out" postcards were not returned. Interviews were at a location of the subject's choosing, conducted individually since their recollections potentially involved sensitive topics [2]. As the specific experiences of a subgroup within a larger subculture, with a different focus and priorities, were being studied, we used a focused ethnographic approach [3,4]. The interviews additionally explored parental views of primary care involvement [5], their perceived involvement in decision-making, perceptions of the quality of their child's death, and supports utilized during the child's end-of-life period.

Parents were asked: "Are there some conversations with doctors or care providers, held as your child was dying, that you continue to

come back to and remember?" Interviews were recorded and transcribed. They were ungrounded, i.e., without pre-existing hypotheses, for 5 interviews, and continued without change following an interim analysis [6,7].

Analysis

Demographic information was collected from death certificates. Diagnosis is the ICD-10 code listed as principle diagnosis. Income was determined using U.S. Census Bureau information by zip code and 2005-2009 American Community Survey 5-Year Estimates. Narratives were de-identified. Contiguous blocks of text pertaining to areas of investigation were separated and coded. Comments relating to remembered conversations were sorted into positive and negative clusters based upon the parents' presentation. Clusters were studied for patterns of connection, grouped into broader categories (themes), and refined using "constant comparison," [7], where each extracted comment was compared with the rest to consolidate major themes. This study was approved by the Boston University Medical Center Institutional Review Board.

Results

Of 169 eligible children, contact information from death certificates was valid for 53. The parent(s) of 16 (30%) were interviewed, fourteen at home. 15 mothers and 6 fathers participated. Table 1 shows demographic characteristics of the children, with variation in ages and diagnoses. Thematic saturation, when subsequent interviews failed to reveal novel themes, occurred after 13 interviews. Without specific prompting, nearly as many shared negative recollections (10/21) as shared positive (11/21). Analysis identified five themes. Positive conversations exhibited empathic protectiveness, personal disclosure of caregiver experiences, and authenticity (Table 2). Negative conversations revealed medicalized insensitivity to the family's experience and emotional distance (Table 3).

		N
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
	Other	2
Race of Child	White	12
	Black	1
	Hispanic	3
Median Family Household Income By Zip Code	<$30,000	1
	$31-$50,000	5
	$51-$75,000	7
	>$76,000	3

Table 1: Demographics of Sample

Positive Conversations	Theme
Health aide takes mother aside during the resuscitation, refers to her as "mommy", and explains what was being done to resuscitate the infant in such a way that the mother felt sympathy and protection.	PE
Physician sits with dying child's sibling and shares that his brother had died when he was a boy, which was why he went into medicine, and that it would be okay.	PD, PE
NICU nurse helps mother wash her critically ill infant for the first time. With masks and tape removed, the mother cries at her son's beauty. Nurse, arm around mother, says "at least you saw. Some people have kids their whole lives and never see it".	PE
Mother feels accused by doctors for not aborting her baby when complications were noted. Pediatric neurologist tells her, "you can always have hope. I would never tell anyone there is no hope. And who are they to say that to you?"	PE
Physician joins mother having coffee and talks to her "like a real person" and says, "it sucks. It's really never good when you get a diagnosis".	PE, A
Family and friends awkwardly avoid parents at child's death, not knowing what to say or do. Members of care team walk in and express their sympathy with warmth and sincerity.	PE
After learning there are no further treatment options, the surgeon shares that his witnessed loss of his sister brought him to medicine.	PD
The mother didn't know what to do when her child had died. Nurse grabs her hand and puts it on her daughter's hand, with a tear in her eye.	PE
Intern starts crying as mother cries out, "I'm not ready to let him go, I'm not ready." Attending "sort of yells" at the intern but the mother remembers and loves that she cared.	A
A doctor tells an overwhelmed mother, "right now you don't see your path. You don't see how you'll find your way out. But you will."	PE

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

Table 2: Conversations recalled positively; PE: Protective empathy; PD: Personal disclosure; A: Authenticity

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

Table 3: Conversations recalled negatively; M: Medicalized insensitivity to the family experience; E: Emotional distance

Discussion

Bereaved parents recall specific conversations with healthcare professionals years following their child's death. Positive conversations exhibited protectiveness, personal disclosure, and authenticity. Negative conversations showed medicalized insensitivity to the family's experience and emotional detachment. Positive conversations reveal behavior approaching the constraints of professional boundaries. Negative conversations also involve interpersonal distance and boundaries, but are detached and depersonalized. Every recalled conversation reflects the importance of relational aspects of care, not technical.

Experience suggests that physicians consider family meetings, giving bad news and eliciting goals of care as critical moments of communication with families of dying children. These were not the recalled conversations of these parents. Instead of such scenarios, the interviews reveal small personal moments persisting in memories, often demonstrating nonabandonment [8]. Positive memories portray caregivers possessing a grasp of what families were confronting, and responding personally, empathically and capably.

These recollections may be considered in relation to professionalism, defined as the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and the community being served [9]. Palliative care also emphasizes respect, attention to open verbal, nonverbal and communication channels, being present in the moment and mindful of the relationship, and showing caring intent [10,11]. Parental recollections illustrate personal communication that is neither detached nor enmeshed. They reflect a grasp of the situation and are often protective. For example, a surgeon sat with parents after telling them there were no further available options to prevent their child's death, communicating deep connection despite the bleak situation:

I remember him telling us why he became a doctor was because his sister got hit by a car and I believe she died and he watched her die and that was the defining moment in his life when he was going to become a doctor no matter what it took so that he could save. Although at the time my daughter was dying … but that's okay.

Healthcare providers have been noted to respond to personal patient cues by providing medical information rather than emotional support or authenticity [12] Taking advantage of seminal empathic opportunities, [13] risking a personal response during critical events, is often cautioned against as blurring professional boundaries. Yet, though personal engagement may occur because of caregiver's kindness, its impact may be enhanced with sophisticated communication skills and values [14].

Despite their personal nature, these memories underscore professionalism. Speaking insensitively or failing to meet the gravity and nature of the circumstances has an enduring negative impact. Enmeshment is not viewed positively, as when a parent spoke negatively about a physician being overly involved in decisions they needed to make for themselves, or the acknowledgement that, while it was positive that a trainee cried over her dying child, a mother recognized that someone needed to remain composed to guide care. Empathic care responds authentically to the patient's personal needs while maintaining awareness of personal boundaries and maintaining the provider role.

The negative conversations detailed by the families illustrate the impact of an approach that prioritizes objective data and has a self-referential understanding of the subjective aspects of care [15]. We found examples of callous enthusiasm for involvement with life-limiting disease. We also found examples of self-referential involvement, as when a physician officiously told a parent her child was seriously ill during resuscitation, then failed to say anything when it proved unsuccessful:

(He said,)"Obviously (emphasis from parent), you know this is a serious situation". I say, "Yes, of course." He said, "We're doing everything we can", like talking down (to me). When my daughter passed, nobody said, 'your daughter has passed'. That was the only time (he talked to me), while they were still working on her.

Why specific memories endure is a speculation. Research indicates that emotional engagement increases attentiveness and preferentially imprints memory [16,17]. In positive memories, parents comfortingly recall professional but humanistic encounters at an extraordinary time. It may be that responding in a manner exceeding technical requirements provides an emotional and validating human gesture of great meaning. In the negative, it may be that impersonal and alienating interactions are reinforcements of the pain and isolation that is part of the difficulties parents of children with life threatening illnesses endure.

This study is limited by its small, although varied, sample and precludes definitive conclusions. It is unclear whether the nature of communication for families with seriously ill children has significantly changed since the time of these deaths [18]. Moreover, the relationship between memories and quality of care or patient satisfaction is unknown. It has been shown that clinicians' efforts to address suffering in patients and their parents influence the well-being of parents for years following the child's death [19].

Nonetheless, the interviews reveal some consistencies. A lack of engagement leads to persisting negative memories while expressions of empathic protectiveness, personal disclosure, and authenticity at moments in care have an enduring positive presence. If parents carry forward pain from insensitive moments, they also carry solace from caregivers who step beyond an impersonal role and share their entirety as a person, somehow validating the tragedy the parents experience. While professional care must remain at the core of our practice, it may be that taking advantage of empathic opportunities is at the core of our gifts. Our findings lend support to the durable importance of humanistic involvement with patients.

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