

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.

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