

The Development of a Hospital-Wide Bereavement Program: Ensuring Bereavement Care for All Families of Pediatric Patients

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ABSTRACT

Although grief is a normal response to loss, the death of a child is believed to be one of the most difficult losses a person can endure, and bereaved parents are considered to be an "at-risk" group. Even though most deaths of children in the United States occur in hospitals, bereavement care provided by hospitals is highly variable, and little attention has been directed to how hospitals can best support grieving parents. In this article, we describe the development of a hospital-wide bereavement program at Boston Children's Hospital, where we conceptualize bereavement care as a preventive model of care. We identify the primary constructs of the program as education, guidance, and support and outline a template for use by other hospitals. We recommend that all pediatric hospitals implement basic, coordinated bereavement programs as the standard of care to ensure that all families receive bereavement care after the death of a patient. *J Pediatr Health Care.* (2016) ■, ■-■.

KEY WORDS

Bereavement, death, child, pediatrics, hospital-wide, program

The death of a child is commonly referred to as the "worst loss" a parent can experience in life (e.g., Rosof, 1994), describing something of the pain and deep suffering parents experience after the death of a child. We know from our work with bereaved parents that parental grief is intense and long and is characterized by extreme sadness and a sense of

disconnectedness and isolation from others. The medical literature also provides evidence indicating that bereaved parents are at heightened risk of poor bereavement outcomes, including clinical levels of depressive symptoms and other psychological symptoms, such as anxiety (Lannen, Wolfe, Prigerson, Onelov & Kreicbergs, 2008; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008), separation distress (McCarthy et al., 2010), post-traumatic stress (Ljungman, Hovén, Ljungman, Cernvall, & von Essen, 2015), complicated grief (Kersting, Brähler, Glaesmer, & Wagner, 2011; Meert et al., 2011; Zetumer et al., 2015), increased risk of psychiatric hospitalizations (Li, Laursen, Precht, Olsen, & Mortensen, 2005), worsening physical health (Lannen et al., 2008), and increased mortality rates (Li, Precht, Mortensen, & Olsen, 2003). Even though most bereaved parents will cope without professional help, parental grief nonetheless remains an excruciatingly painful and isolating experience that is worthy of attention from health professionals. Being able to identify parents who are likely to experience great difficulty and providing early intervention can help prevent a complicated bereavement reaction.

In the United States, approximately 33,000 children who are younger than 15 years die each year, and another 28,500 die between the ages of 15 and 24 years (U.S. Department of Health and Human Services, 2015). It is important to note that although approximately two thirds of children die in hospitals (Feudtner et al., 2011), very few hospitals offer coordinated and standardized bereavement programs. As a result, bereaved parents typically must seek out support on their own, which can be difficult because research suggests that bereaved individuals, especially those experiencing prolonged grief, tend to underutilize physical and mental health care (Lichtenthal, Corner, et al., 2015; Lichtenthal et al., 2011). Finding appropriate support can be a challenging task given that the bereavement experience is highly individualized and that bereavement care comes in many forms (e.g., memorial events, support groups, family camps, and individual counseling) and is offered by a range of different organizations (e.g., nonprofit organizations, faith-based groups, and hospices) and by different providers (e.g., physicians, therapists, and religious leaders).

From the outset, bereavement care, including bereavement risk assessment, has been a core component of the hospice movement (Agnew, Manktelow, Taylor, & Jones, 2010). In the United States, the importance of providing specialized bereavement services to bereaved families as preventive models of care is endorsed by both the National Consensus Project for Quality Palliative Care (NCP, 2009, 2013) and the National Hospice and Palliative Care Organization (NHPCO, 2008, 2009). In the pediatric setting, the

2001 white paper by the Children's Project on Palliative/Hospice Services (as cited in Friebert & Huff, 2009, p. 9) states that the "harm associated with the death of a child can be lessened by the provision of high quality palliative and bereavement care." Unfortunately, however, Friebert and Huff (2009) report that only a small number of children receive palliative care support or hospice services. In addition to increasing the number of dying children who receive these services, a strong argument needs to be made for hospital-based pediatric bereavement programs, targeting both expected and sudden death, given the elevated risk of poor bereavement outcomes for bereaved parents (Lannen et al., 2008; Ljungman et al., 2015; Rogers et al., 2008) and the limited community resources available.

Emphasizing the importance of hospital-based bereavement programs is consistent with recent recommendations for best practice guidelines for hospital-based bereavement care (Donovan, Wakefield, Russell & Cohn, 2015) and the publication of evidence-based psychosocial standards of care for children with cancer (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015), which include two standards referring to the need for bereavement care. We believe that bereavement care is best conceptualized as a preventive model of care targeting both parents and families alike. We therefore recommend that all pediatric hospitals offer at least basic bereavement care to families of all patients who die, not just those cared for by palliative care teams.

In this article, we begin by discussing the goals of bereavement care from a psychological perspective and the need to standardize bereavement care in the pediatric setting. We next describe the initial phase of the development of a hospital-wide bereavement program at Boston Children's Hospital (BCH) and the model that we adopted. Finally, we outline our ideas about the second phase and how we plan to evaluate the program moving forward.

GOALS OF BEREAVEMENT CARE

From a psychological perspective, the process of grieving involves adaptation to change brought about by loss (Morris & Block, 2015). Specifically, the goals of bereavement care related to the death of a child are twofold: first, to help facilitate this adaptation so that bereaved parents (and their families) can heal and process their child's death in some way and continue to live meaningful lives, and second, to identify persons at risk of experiencing difficult bereavement reactions in an attempt to intervene early. A particular challenge for bereaved parents is a sense of isolation from their peers because of changed circumstances and society's awkwardness about dealing with grief (Morris, 2008). Unfortunately, with the death of a child, bereaved parents are forced into a group that no parent wants to

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