*Special Article*

# Empowering Bereaved Parents Through the Development of a Comprehensive Bereavement Program

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**Abstract**

*Parents who experience the loss of a child have unique and valuable insights into the grief journey and can help health care providers identify key components intrinsic to the development, implementation, and maintenance of a comprehensive bereavement program. The bereavement program at St. Jude Children's Research Hospital was developed by pediatric palliative care experts in collaboration with bereaved parents to standardize and improve the institutional support provided to families around and after the death of a child. This article describes the components of a parent-derived bereavement program and presents early results on the effects of specific program components. The program, under the leadership of the bereavement coordinator, includes clinical and supportive interventions offered throughout the grief journey, parent-created bereavement support materials, and opportunities for parents and families to participate in research, quality improvement initiatives and educational interventions. Parents report that services and interventions provided through the bereavement program are beneficial to families after the death of their child. In addition, both health care providers and bereaved parents report that participation in educational interventions positively impacts their experiences as clinicians and parents, respectively. The innovative nature of this parent-driven, comprehensive bereavement program may serve as a paradigm for the development of bereavement programs in the fields of pediatrics, palliative oncology and hospice and palliative medicine.* J Pain Symptom Manage 2017;53:767–775. *© 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*Grief, palliative care, bereavement, pediatrics, hospice care*

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## Introduction

Parental bereavement after the loss of a child is often more profound and prolonged than grief experienced in the context of other losses[1–4] and is associated with an increased risk for long-term psychosocial and physical morbidities.[5,6] Bereavement frequently adversely affects interpersonal relationships and societal functioning, leading to negative feedback cycles of compounded isolation and anguish.[7] Parental grief after the death of a child may also have deleterious effects on marriage quality[8,9] and has associated with occupational and financial hardship.[10]

The significant sequelae experienced by grieving parents and family members highlight the need for ongoing care and resources targeted specifically to this bereaved population.[11] As evidenced by the literature, an interdisciplinary approach is required to provide optimal bereavement care.[12–14] Most supportive services are typically offered during illness and at the end of life, with limited resources available to families

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after a child's death, resulting in many families receiving little or no bereavement follow-up.[15,16] Yet, parents who have experienced the death of a child highlight the importance of having institutional bereavement services to assist with the difficult transition from the primary medical center to the community after the death of a child.[17] Likewise, parents recognize the need for improved support at other times during the illness and bereavement journey, including better anticipatory guidance before their child's end of life and the provision of standardized, comprehensive supportive services after their child's death.[12] On the basis of these findings, pediatric palliative care (PPC) experts recommend that bereavement services provide continuity of care extending throughout and beyond the illness experience and involve a range of interventions targeting the whole family, with flexibility in the content, delivery, and timing of services.[18]

Tremendous variation exists among the bereavement services offered by individual health care providers and pediatric hospitals.[18] A survey of pediatric oncology units in Australia indicated that most hospitals provide multidisciplinary bereavement services for approximately one year after a child's death, with the bulk of resources being counseling and support groups. However, only a few hospitals included in this study screened parents for complicated grief, formally evaluate their bereavement program, or identified areas of unmet needs.[19] A systematic review outlining bereavement services and their psychosocial effectiveness revealed that common interventions include phone calls at key intervals, provision of resource materials, and group programs including family counseling and peer support. Some supportive services were specific to certain clinical settings or patient groups.[18] Initial contact and provision of supportive materials most commonly occurred between two and six weeks after the child's death, consistent with parental perspectives of an appropriate timeframe.[17]

Bereavement services are most effective for parents experiencing more complicated grief[18]; yet, even those parents who are not suffering from complicated bereavement report that the provision of bereavement services or materials was meaningful.[20] Special supportive services targeted toward certain patient populations or hospital departments have also been shown to be beneficial. For example, parents of pediatric oncology patients appreciated flexible and ongoing bereavement services from their child's hospital, including talking to other parents with similar experiences and maintaining contact with staff as a necessary transition to community services.[17] Peer support is beneficial for bereaved parents.[21] In addition, continued contact with nurses resulted in parents feeling increasingly supported, with phone calls being more important than visiting the hospital in terms of helping families promote meaning- and memory-making around the deceased child.[22]

Parents benefit from receiving support over a long period after the death of a child,[23] necessitating flexible and diverse supportive services that evolve with the grief experience. Because of the physical separation of bereaved family members from the center where their child received care, institutions must develop innovative strategies to provide ongoing support, including referrals to resources within the local community and mechanisms to monitor these services and address deficits in support provision. Families of children who died from cancer expressed a desire to receive referrals for local counseling and support groups while also receiving ongoing support and resources from providers at their child's institution via phone, mail, email, and in person at scheduled support gatherings.[24,25]

These findings highlight the importance of connecting bereaved parents with supportive services and resources through which they can continue to remember, celebrate, and value the lives of their deceased children.[21] As part of legacy-building, bereaved parents benefit from participating in bereavement program and resource development.[26] In addition to directly benefiting, bereaved parents are also uniquely positioned to offer invaluable perspective and guidance about the design and implementation of bereavement programs to improve the experiences of other parents.

Indisputably, the death of a child poses special challenges to bereaved families and health care providers. Each individual's grief journey is unique and ongoing[23]; however, common themes and support systems help to define successful bereavement services.[27] Bereaved parents have special insights that are invaluable in helping health care providers identify key components to develop, implement, and sustain a comprehensive bereavement program. The bereavement program at St. Jude Children's Research Hospital (St. Jude) is multifaceted and involves both clinical supportive services and resources that have been developed by parents who have experienced the death of a child at our institution. Bereaved parents and members of the hospital's psychosocial staff comprise the Quality of Life (QOL) Steering Council under the guidance of an expert bereavement coordinator trained in psychology and PPC.

## Background and Program Development

The Family Advisory Council (FAC) at St. Jude is composed of approximately 30 parents of current and former patients who meet in person quarterly