

A Collaborative Approach to Improve Support Provided to Bereaved Siblings

Lene Larsen¹, Carrie Miluski¹, Cassandra Vega², and Tammy I Kang^{2*}

¹Peter's Place Center for Grieving Children, Radnor, PA, USA

²The Pediatric Advanced Care Team, The Children's Hospital of Philadelphia, Philadelphia, PA, USA

*Corresponding author: Tammy I Kang MD, MSCE, The Children's Hospital of Philadelphia 34th and Civic Center Blvd 11 NW Suite 90 Philadelphia, PA 10194, USA, Tel: 267-426-5051; E-mail: kang@mail.chop.edu

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Introduction

The body of literature describing and examining childhood bereavement is considerable. Within the bereavement community, there is general agreement that the loss of a loved one poses significant and complex challenges for children [1-3]. Their grief responses can be emotional (e.g., denial, sadness, depression, guilt, anger), physiological (e.g., somatic complaints, sleep problems), cognitive (e.g., trouble with concentration) and/or behavioral (e.g. withdrawal, behavior problems). Further complicating matters, important people, such as parents and family members, struggle with their own grief and may be less emotionally available to the child. Friends, peers and other adults in the child's life may be unsure how to respond or offer support, leaving the grieving child feeling isolated and alone.

To help address the needs of grieving children and teens, a range of services have been made available, including specialized counseling, support groups, grief camps, and remembrance events. Websites dedicated to supporting grieving children and families have been developed, and books and informational material have been produced to offer guidance and support. Unfortunately, controlled research studies demonstrating how to best support grieving children are lacking. In fact, a recent meta-analysis of the effectiveness of bereavement interventions with children (based on 13 controlled outcome studies, of which 12 focused on group interventions), failed to demonstrate that the interventions had a significant impact on the children's adjustment [4]. These findings were consistent with findings of reviews of adult grief therapy. The authors discussed several factors that could have negatively impacted their results such as small effect sizes, the timing of the interventions and data collection, failure to screen for severity of adjustment problems, among other things, and called for more careful and controlled research in this area.

Within the population of bereaved children, a subset of children has experienced the loss of a sibling. Recently, there has been growing recognition that the experience of losing a sister or brother is different from that of losing a parent/caregiver. Consequently, supporting children who are bereaved siblings may require a unique, targeted approach. Unfortunately, at this time, there are no research based recommendations for how to best support bereaved siblings.

One such bereaved family shared their struggles of finding appropriate bereavement services for their two surviving siblings after the loss of their child to cancer. This led to support from a family foundation motivated to improve the services given to children who suffered the loss of a sibling. In response to the lack of clear recommendations for an effective group support model and after having attempted to offer a variety of support programs with variable

success, the Pediatric Advanced Care Team (PACT) at the Children's Hospital of Philadelphia and Peter's Place in Radnor, PA (a center for grieving children and families) entered into a partnership to develop a group bereavement support program suitable for bereaved siblings and their caregivers in the greater Philadelphia area.

In this brief report we will discuss the challenges associated with sibling bereavement. We will also describe a project aimed at gaining a better understanding of the needs of bereaved siblings, with the goal of developing an effective sibling support program. This project represents a collaboration between a pediatric palliative care program in a large tertiary hospital for children and a local non-profit center for grieving children and families.

Sibling Bereavement

Sibling relationships are significant and uniquely different from other relationships in many ways, given the shared early experiences/memories, the familial and emotional bond that develops, and the potential for a lifelong connection. Of course, a positive sibling relationship is not guaranteed, as issues such as rivalry, competition, temperament/personality differences, and disagreements can negatively impact the relationship. Nonetheless, given the significance and nature of sibling relationships, the experience of the death of a sibling would be expected to have a potentially very negative impact on the surviving sibling. Unfortunately, relatively little controlled research has focused on the impact of sibling loss, outside of clinical case reports or the use of convenience samples, such as based on deaths for a specific disease without control or comparison groups [5].

However there have been studies supporting the likelihood that healthy children are impacted both in the short and long term by the death of a sibling. In the 1950's and 1960's, studies indicated that siblings of a child who dies are at risk of developing adjustment difficulties, feelings of guilt, becoming withdrawn, and acting out behaviors [6]. In a study of siblings of childhood cancer survivors, siblings showed clinical levels of posttraumatic stress at even higher rates than the survivors themselves [7]; these traumatic reactions are likely to exist and perhaps even be exacerbated in siblings of children who did not survive. As with the literature on bereaved parents, there are few indicators regarding what factors place surviving siblings most at risk. Some interviewed bereaved parents stated that sibling support was lacking specifically in relation to accessibility of support groups, bereavement follow-up, and attention from medical teams [8].

There are important features of sibling loss that are different from those associated with parental loss. According to Worden, the death of a child is, of course, devastating to parents and can cause parental marital problems, and result in changes in family dynamics which impact the surviving child. Also, the surviving sibling may strive to

somehow replace the deceased sibling, and struggle with guilt, blame, jealousy, residual sibling competition, and increased death awareness. The parents may become overprotective of the surviving child.

It is noteworthy that children even when born subsequent to the death of a sibling can experience profound and long term negative consequences associated with the loss. The work by O'Leary and colleagues have examined the impact of pregnancy or infant loss, and have found that the surviving children demonstrate adverse effects, often associated with attachment difficulties and disenfranchised grief, well into adulthood. These studies highlighted the importance of finding ways to help parents support their surviving children, especially around communication, expression of feelings and acknowledging the surviving siblings' grief [9-11].

Recognizing this unique group of grieving children, national organizations (e.g., Compassionate Friends and The National Child Traumatic Stress Network), hospitals, community grief centers, foundations (e.g., Open to Hope), and private grief counselors have begun to offer specialized resources and support to bereaved siblings and their parents. As mentioned above, however, there are no research based recommendations for how to best support bereaved siblings.

The work by Betty Davies has helped provide a frame work for attempting to understand and identify ways to help children with the experience of sibling grief [12,13]. She has identified a set of responses commonly demonstrated by bereaved siblings:

I hurt inside - reflecting the emotional pain and feelings associated with the loss

I don't understand - the understanding of the concept of death and its finality will vary based on the age of the surviving sibling, but even so, can create confusion and questions.

I don't belong - with the death of a child, the family experiences disruption and change on many levels. The surviving sibling may not understand what is happening or how to help, and may not feel a part of things in the home. Outside of the home, having experienced the death of a sibling may now make him/her feel different from peers [14].

I am not enough - as parents become preoccupied or consumed with their grief, and as the surviving child is unable to make the parents feel better, they may begin to feel that they are "not enough."

It is important that a sibling support program incorporate ways to address these responses, either by guiding parents in their interactions with and support of their children, or by giving the children a way to openly address these feelings and experiences within a safe and supportive environment.

A recent study by Thompson et al highlights the complexities of supporting bereaved parents and siblings. Interviews were conducted with 65 parents and 39 siblings of children who had died of cancer 6-19 months earlier. The goal was to investigate what families find helpful in terms of support and coping strategies. The strategies reported to be helpful were consistent with previous studies, that is, seeking social support from family and friends, relying on personal beliefs systems/religions, and continuing bonds with the deceased. However, notable other themes had to do with the individual and temporal nature of grief. Mothers and fathers differed in terms of their use of coping strategies; siblings focused more on specific and concrete strategies, while the parents reflected on the process of grieving and how it differs from person to person; and the experience and needs

varied depending on the temporal context, that is before the death, soon after, and long-term [15]. Thus when it comes to supporting families who have experienced child loss, it may be important not only to consider that sibling loss is unique, but that so is each person's grief. Interventions may need to be tailored to the particular person, given her or her particular needs and circumstances.

The Project

The purpose of the project and partnership is to combine the resources and expertise of PACT and Peter's Place to develop a bereavement support program for bereaved siblings and their caregivers. Two key aspects of the project are 1) to encourage collaboration between hospital and community organizations and 2) to obtain feedback directly from parents and the siblings regarding their needs. The specific aims of the project are:

To identify the existing sibling bereavement resources in the community

To identify specific needs of bereaved parents and siblings in our community

To design and Implement a pilot program that minimizes barriers and targets parent and sibling needs

To evaluate the pilot program

To address aims 1 and 2, we have completed structured interviews with local community bereavement centers that offer services to children, and conducted focus groups for siblings and parents who have had contact with or received bereavement services from either PACT or Peter's Place. Preliminary results of agency interviews suggest that siblings are typically integrated into groups of children who have experienced parent loss, and their parents join groups of parents who have experienced the death of a partner. Focus groups reveal that caregivers who have experienced child loss do not find this integration ideal, while it seems somewhat less problematic for the siblings. The siblings noted that as long as they were not the only one in the group who had lost a sibling, and when the language of the group material was sensitive to different types of losses, a mixed-loss group could work. Also, agencies report that logistics, such as a relative low volume of sibling referrals and scheduling/attendance problems seem to pose barriers to the establishment of sibling only groups.

To supplement the information gathered from in-person interviews and focus groups, we will be conducting a survey of a larger number of parents who experience the loss of a child. We hope to learn from their experiences with bereavement services/support and will solicit recommendations to better meet the needs of their children. We have also distributed a nationwide survey of bereavement centers to learn about their experiences of serving siblings and to obtain recommendations for developing a sibling support program.

Future steps will involve developing a sibling bereavement program based on the results of the interviews, focus groups and questionnaire data, as well as the recommendations we have received directly from parents and from other bereavement programs. We will assess the effectiveness of the program by gathering child and parent outcome data as well as participant satisfaction data. An initial collaborative sibling support group is scheduled to assess the potential benefits and feasibility of conducting a joint support group using resources from both a tertiary care hospital and community based grief organization.

A final goal will be to share what we have learned with the broader bereavement community to promote interest and continued exchange of idea about how best to serve the unique population of bereaved siblings and their caregivers. We choose to report on this project in its early phases in order to promote collaboration between hospitals caring for children and community based organizations. The initial results of the collaboration have been very positive in that it has already led to a better understanding of local resources available to children and parents in our community.

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