



Interventions for Siblings, Extended Family, and Community Members after Pediatric Death

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ABSTRACT

The death of a child is felt by extended family, friends, and community members. Most bereavement care research focuses on programs for parents. Little is known about the efficacy of support programs for other grieving individuals. We conducted a scoping review of the literature describing the efficacy of bereavement support programs for siblings, extended family (other than parents), and community members after pediatric death. We found only four reports describing the efficacy of bereavement support programs for this population. All articles described benefits of the intervention studied. Overall, more rigorous and larger-scale studies are needed.

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Introduction

Approximately 45,000 children under 19 years of age die each year in the United States (US). An additional 6 perinatal deaths per 1000 births and late fetal deaths occur annually in the US (Gregory et al., 2018). The lives touched by the loss of these children include parents, grandparents, siblings, classmates, and others in the community.

Bereaved parents may experience long-term mental effects and poor health outcomes (Li et al., 2002, 2005). But bereaved siblings and extended family, like grandparents, are also at risk of developing psychological disorders, including depression, anxiety, and post-traumatic stress (Bolton et al., 2016; Youngblut et al., 2015). Further, school-aged and adolescent peers may suffer from depression and even suicidal ideation after the death of classmate or friend (Swanson & Colman, 2013).

Little is known about the efficacy of support programs for bereaved individuals who are not parents. To identify available evidence and knowledge

gaps, we conducted this scoping review of the literature describing the efficacy of bereavement support programs for siblings, extended family (other than parents), and community members after pediatric death.

Materials and methods

We conducted a scoping review of literature describing the efficacy of bereavement support services for people other than parents affected by the death of a child in the US (Arksey & O'Malley, 2005). We defined "child" as persons 18 years of age or younger and included literature reporting on bereavement resources for those after pre- or perinatal loss.

We completed a comprehensive search of 61 terms related but not limited to the concepts of "child death," "bereavement," and "support" (See [Appendix](#)). Using these terms, we searched five databases—PubMed, Embase, Psychinfo, Cinahl, and Cochrane Library—for papers published as of October 2018. We included articles about the efficacy of bereavement support services for people following the death of a child or a pre- or perinatal death. We excluded case studies, books, theses, and articles about healthcare provider support or education, the impact of childhood death, adult death, peri-death activities (e.g. memory making), abstracts describing work presented as a posters or conference presentation, titles without a public abstract, and work done outside the US.

Two reviewers (S.P and C.W.) identified articles based on abstract and title review, and then examined the remaining full articles to determine if they addressed our question of interest. At each review stage, discrepancies between reviewers were determined by consensus with input from a third reviewer (K.M.). The resulting articles were narrowed to those that described the efficacy of programs meant to support non-parents. We used Rayyan to help with article selection (Ouzzani et al., 2016). We described articles based on the intervention type, study design, subject type, type of pediatric death (e.g. age group and/or cause of death), how the intervention was evaluated, and results of the evaluation.

Results

Our search identified 2,467 articles; of these, 97 articles met our inclusion/exclusion criteria based on abstract and title review. After review of the full article, 39 articles describing the efficacy of bereavement services remained. Four of the 39 articles addressed interventions for non-parent individuals. We describe these articles below ([Table 1](#)).

Heiney et al. examined seven extended family members (grandparents, aunts, and uncles) of children who died of cancer (Heiney et al., 1993). Bereaved family members participated in eight therapist-moderated

TABLE 1. Summary of papers evaluating the efficacy of support programs for non-parents.

Study	Intervention	Study design	Study participants	Type of pediatric death
Heiney et al., 1993	Peer support sessions (topics selected by researchers)	Pre-post test	Family members: grandparents, aunts, and uncles (n = 7)	Death from cancer
Horsley and Patterson, 2006	Parent guidance intervention – parents educated about how to meet needs of their adolescent	Single-case experimental design	Adolescent siblings (n = 5)	Children who died suddenly
Roose and Blanford, 2011	Still Missed Program – counseling/support groups, physical resources (e.g. books, mementos), memorial services	Post-intervention survey	Parents (n = 107) Siblings (n = 132)	Perinatal death
Greenwald et al., 2017	Peer support sessions with guidance and counseling from facilitators	Pre-post test	Grandparents (n = 8) Adolescent siblings (n = 10)	Death from cancer

biweekly hour-long support group sessions. The researchers conducted a pre-/post-test evaluation using the Emotions Profile Index (EPI). Study participants also completed a Bereaved Extended Family Members Support Group Evaluation (BEFMSGGE) after the intervention. Qualitative data was collected from therapists and participants. Researchers found no significant difference in EPI scores pre- and post-evaluation. The mean score on the BEFMSGGE indicated satisfaction with the intervention. The qualitative data described ways participants coped with their loss.

Horsley and Patterson evaluated five adolescent siblings of children who had died suddenly (Horsley & Patterson, 2006). These researchers employed the Parent Guidance Intervention, in which the researchers met with parents and adolescents weekly for three 90-minute sessions to provide parents education around their surviving child's developmental and psychological needs. A modified Parent-Adolescent Communication Inventory (PACI) was administered before and after the intervention. Communication between the parent and the adolescent was also self-reported by the adolescent. A third-party observer (one parent) scored communication between the subject and the other parent. Four out of five families showed improvement in the modified PACI. All five families had improved communication scores. Families also reported an increased level of satisfaction with parent-adolescent communication both during and after the intervention. The third-party parent also observed increased communication.

Roose and Blanford evaluated the Still Missed Program adapted for grandparents and siblings after a perinatal death (Roose & Blanford, 2011). They provided counseling/support groups and physical resources (e.g. books), and encouraged families to attend memorial services. The study examined 107 parents, 132 siblings, and 8 grandparents affected by a perinatal death. Parents and grandparents evaluated the program using a survey that asked participants to rank the usefulness of different aspects of the program. The parents surveyed indicated that the Still Missed Program benefited the grandparents 100% of the time. Grandparents all reported that the services of the Still Missed Program were either useful or very useful to their bereavement coping process. While less than 25% of families involved had an affected sibling, 80–100% of those who did found the Still Missed Program useful.

Greenwald et al examined 10 children (6–18 years of age) who lost a sibling to cancer (Greenwald et al., 2017). The intervention consisted of eight 2-hour peer support sessions based on the cognitive behavior therapy model. Before and after the intervention, parents and siblings completed the Pediatric Quality of Life Generic Scale (PedsQL). Siblings completed the Child Depression Inventory (CDI) and the Hogan Inventory of

Bereavement (HIB) to assess psychological status related to depression and grief. Five participants completed the Child Behavior Checklist (CBCL) or Youth Self-Report (YSR) and the Impact of Event Scale—Revised (IES-R). The study showed a significant increase in parent-reported sibling PedsQL as well as an increase in emotional and social subscores. Sibling self-reported PedsQL showed no significant changes. There were also no significant changes shown on the sibling-reported CDI, personal growth, or grief scores. The CBCL showed a large effect size of improvement, but it was not statistically significant. There was also a trend of improvement in the YSP. There was no change seen in the IES-R.

Discussion

We found only four reports describing the efficacy of bereavement support programs for siblings, extended family (other than parents), and community members after pediatric death. Two studies evaluated interventions for siblings and extended family of children after cancer deaths, one for siblings after sudden death, and one for grandparents and siblings after perinatal loss. Interventions largely consisted of counseling/support groups and education. Only one study assessed more than 10 individuals. All studies used pre-post outcome assessments and/or qualitative data. All articles described the benefits of the intervention studied. None of these studies analyzed direct health outcomes of grief in people studied.

In the face of such a sparse literature, gaps in knowledge abound. However, it is particularly notable that we found no studies assessing interventions for people beyond the deceased child's immediate and extended family. Children and adolescents make up a quarter of the total US population (Cunningham et al., 2018) and nearly half of all adolescents experience the loss of a peer before graduating from high school (Johnson et al., 2017). Empirical data describing the efficacy of approaches to support this population is limited.

It is also notable that only one study provided support for people after a sudden death. In the US, most youth deaths occur during adolescence (68%) and the top three causes of death are from motor vehicle crashes, firearms, and suffocation, all sudden deaths (Cunningham et al., 2018). Given these statistics, the development and study of interventions that support peers impacted by pediatric death and specifically sudden death is essential.

Limitations of our review exist. We did not search “grey literature,” research that is unpublished, published in noncommercial form, or published outside of academic distribution channels. Our search terms may have missed relevant studies. There could have been subjectivity in abstract and article screening. Finally, we only included research performed in the US, and examined literature published through October 2018.

In summary, there is a dearth of data on the efficacy of bereavement support interventions for siblings, extended family (other than parents), and community members after pediatric death. Notable areas without data relate to supporting non-family community members, in particular peers. Overall, more rigorous and larger-scale studies are warranted.

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Appendix. Database search terms related to “Child Death” AND “Bereavement” AND “Support”

((("Child Mortality"[Mesh] OR "Fetal Mortality"[Mesh] OR "Infant Mortality"[Mesh] OR "Infant Death"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Death"[Mesh] OR "perinatal mortality"[tw] OR "sudden infant death"[tw] OR "SIDS"[tw] OR "child mortality"[tw] OR "fetal mortality"[tw] OR "infant mortality"[tw] OR "infant death"[tw] OR "fetal death"[tw] OR "perinatal death"[tw] OR "child death"[tw] OR "adolescent death"[tw] OR "childhood death"[tw] OR "stillbirth"[Mesh] OR "stillbirth"[tw] OR "stillborn"[tw] OR "pediatric death"[tw] OR "paediatric death"[tw] OR "child's death"[tw] OR "infant's death"[tw] OR "death of a child"[tw] OR "loss of a child"[tw])) AND ("Bereavement"[Mesh] OR "Attitude to Death"[Mesh] OR "bereavement"[tw] OR "grief"[tw] OR "grieving"[tw] OR "bereaved"[tw])) AND ("Social support"[Mesh] OR "support"[tw] OR "Counseling"[Mesh] OR "counseling"[tw] OR "Needs Assessment"[Mesh] OR "needs assessment"[tw] OR "Patient Care Planning"[Mesh] OR "care planning"[tw] OR "care goals"[tw] "coping"[tw] OR "cope"[tw] OR "Parental needs"[tw] OR "Parent needs"[tw] OR "Parents' needs"[tw] OR "Parent's needs"[tw] OR "Support needs"[tw] OR "Support group"[tw] OR "Self-Help Groups"[Mesh] OR "Psychotherapy"[Mesh] OR "psychotherapy"[tw] OR "therapy"[tw] OR "support program"[tw] OR "support programs"[tw] OR "bereavement support"[tw] OR "grief intervention"[tw] OR "grief interventions"[tw] OR "bereavement program"[tw] OR "bereavement care"[tw]))