

# Bereavement support for children: Effectiveness of Camp Erin from an occupational therapy perspective



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**Abstract:** This concurrent, embedded, mixed methods study investigated the effectiveness of Camp Erin in addressing grief in children in the bereavement process through the lens of occupational therapy. The researchers conducted two focus groups with the campers and four semi-structured interviews with the counsellors at a bereavement camp in the Midwest. The intent of these focus groups and interviews was to discuss the campers' and counsellors' perceptions of the impact Camp Erin has on the bereavement process. The focus groups and interviews were transcribed, coded, and analyzed. Three major themes were identified: environment, flexibility, and personal realizations. The evidence supports the idea that the activities offered at Camp Erin and the relationships formed there are effective in supporting and aiding children in the bereavement process. One need identified in this study is helping the children generalize the skills learned at camp to everyday life at home, school, and in the community. The researchers recommend a follow up study examining the use of learned skills. In addition, it is suggested that similar studies be conducted at multiple bereavement camp locations to determine the generalizability of this study's findings.

**Keywords:** Children, bereavement, occupational therapy, occupational engagement, interventions, summer camp, effectiveness

## The bereavement process and occupation

The bereavement process refers to the objective situation of losing someone significant to death (Stroebe *et al*, 2001). It can significantly impact an individual's engagement in his or her daily life activities

or occupations. Occupations can be defined as activities having unique meaning and purpose in an individual's life (American Occupational Therapy Association (AOTA), 2002). These activities are central to an individual's identity and competence. They also influence how an individual spends his or her time and makes decisions. The

Occupational Therapy Practice Framework, an official document published by the American Occupational Therapy Association, describes the domain of occupational therapy's practice. This involves several areas of occupation including, but not limited to, activities of daily living (ADLs) which are activities oriented toward taking care of one's own body, such as eating, bathing, and dressing; instrumental activities of daily living (IADLs) which are activities oriented toward interacting with the environment and are generally optional in nature, such as child care, shopping, and financial management; rest and sleep; education; work; play; leisure; and social participation (AOTA, 2002). The Occupational Therapy Practice Framework also outlines the process of occupational therapy evaluation and intervention (AOTA, 2002).

The way in which individuals prioritize their engagement in the different areas of occupation varies across his or her lifespan (AOTA, 2008). This prioritization can be influenced by an external event or internal, personal maturation. The bereavement experience is an example of an external event that can drastically impact how an individual prioritizes his or her occupational engagement. The focus of this article will be on how the bereavement process affects the occupational engagement of children and adolescents. For example, the bereavement experience can influence some children to refuse to attend school and perform poorly academically (Christ *et al*, 2002); while influencing other children to perform better at school as a tribute to the deceased (Dowdney, 2000).

The profession of occupational therapy recognizes that an individual's physical health and psychosocial well-being is supported and maintained when he or she is able to engage in occupations that he or she desires or needs to participate in (AOTA, 2008). Occupational therapists believe facilitating participation in meaningful occupations is critical for clients experiencing bereavement (Egan, 2007). Previous assumptions were that 'time heals all wounds' but research has shown that enabling an individual to participate in occupations results in better bereavement outcomes (Hoppes & Segal, 2010). It is important for individuals who have lost a loved one to recognize what is meaningful in their own lives and the importance of restoring a routine to their daily lives.

### **The role of occupational therapy for children in the bereavement process**

Occupational therapists evaluate the child in the bereavement process for changes in his or her behaviour that may negatively impact occupational performance (Milliken *et al*, 2007). This evaluation is done through the use of skilled observation and assessment tools. For example, assessments that pertain to social and academic performance may be used to determine if the child's

social or academic participation has been affected. The evaluation process may identify maladaptive behaviors that could result in adjustment problems in the child's future occupational performance (Milliken *et al*, 2007). Examples of such behaviors might include over-reacting to problems, fighting, and self-punishment. The occupational therapist then develops a treatment plan for the child that includes meaningful, age-appropriate occupations that facilitate self-expression, thereby improving participation in healthy and meaningful activities or occupations (Milliken *et al*, 2007). This treatment plan would be based on the child's unique likes and dislikes. Occupational therapists emphasize the importance of using meaningful occupations as fuel to ignite the healing process for children experiencing bereavement (Milliken *et al*, 2007). Some examples of interventions might include creative arts, storytelling, music, and journaling. Treatment activities can be conducted in a group or individually in various settings: school, home, a clinic, a rehabilitation center, or camps.

Bereavement camps are semi-structured community settings away from home, typically in an outdoor recreation environment, which promote growth, learning, and fun (American Camp Association, 2006). They feature specifically designed programs involving recreational and grief work activities to help children participate in play and also express their grief emotions (McClatchey, Vonk & Palardy, 2009). Several studies have demonstrated that bereavement camps hold great promise in helping children transition through the bereavement process. In a two year theory-driven evaluation of a summer camp for grieving children, Farber and Sabatino (2007) found that the camp provided the children with high-quality therapeutic services, contributed to their improved self-esteem and self-confidence, and fostered teamwork, all of which are vital to children's psychosocial development. Another study by Farrell (1999) reviewed the impact that Treasure Weekend bereavement camp had on children who endured the loss of a sibling. Based on the responses of the children who participated in the camp, and their family members, it was concluded that the camp assisted many families in experiencing a greater sense of openness in discussing the sibling's death (Farrell, 1999).

In a review of the literature, it was determined that studies examining the effectiveness of community-based bereavement programs for children from an occupational perspective are limited. The focus of this article is to review the effectiveness of a specific bereavement camp, Camp Erin, in addressing grief in children in the bereavement process through an occupation-based lens, in order to contribute to that body of research. Camp Erin is a weekend bereavement camp offered nationwide for children and teens in the bereavement process. It was created by the Moyer Foundation for children between the ages of 6 and 17 who have experienced the death of a loved one

(The Moyer Foundation, 2009). There are currently 40 Camp Erin locations in over 25 states. All incorporate camp activities with grief education and emotional support (The Moyer Foundation, 2009). The mission of Camp Erin is to address the needs of children in the bereavement process by decreasing their sense of isolation and normalizing their experience and feelings (The Moyer Foundation, 2009). The campers develop relationships by interacting and sharing stories with other children who share similar experiences with loss. Along with establishing relationships the children are able to take part in memorial services to acknowledge those who have died (The Moyer Foundation, 2009). Examples of specific Camp Erin activities include journaling, crafts, ropes course, and swimming, just to name a few (The Moyer Foundation, 2009). This study was also conducted in an attempt to determine if there is a role for occupational therapy in community-based bereavement programs.

## The study

Previous studies examining the effectiveness of community-based bereavement programs for children from an occupational perspective are limited and it continues to be an area where further research is needed. This study sought to answer three research questions:

1. How do the activities at Camp Erin impact the bereavement process among campers?
2. How do the relationships formed at Camp Erin impact the bereavement process?
3. Is there a role for occupational therapy in community-based bereavement programs such as Camp Erin?

This study took place at a Midwest Camp Erin site in mid July 2011 as part of a student research project at Grand Valley State University's (GVSU) Occupational Therapy Program. The student researchers used a concurrent embedded mixed methods research design which is a research design in which the researcher collects both quantitative and qualitative data simultaneously and then integrates the information in the interpretation of the overall results (Creswell, 2009). This is done to provide a more comprehensive analysis of the research problem. Approval from GVSU's Human Research and Review Committee was granted prior to data collection

The qualitative portion of the research was facilitated through a combination of focus groups and semi-structured one-on-one interviews. Focus groups were used in order to obtain the campers' opinions and viewpoints on the benefits of Camp Erin. The researchers chose to conduct focus groups with the campers, rather than one-on-one interviews, because children are considered a vulnerable

population, and bereavement a sensitive topic. Focus groups are ideal for such situations because they increase the level of comfort among participants (Schim *et al*, 2007). This study included two different focus groups. One focus group contained children 6 to 10 years old while the other focus group contained children 11 to 17 years old. The researchers purposefully divided the campers by age ranges so that the children would feel increased comfort in sharing among peers of the same age. In addition to the focus groups with campers, semi-structured one-on-one interviews were used in order to obtain the counsellors' perspectives on how Camp Erin benefits the campers. This was done in order to increase the depth of the study's findings.

The focus groups and interviews were conducted in the evening on the last day of the camp in a private room located on the camp property. The student researchers conducted both the focus groups and the interviews. Both the focus groups and interviews were audio taped.

The focus group questions and counselor interview questions used in this study were developed by the researchers through completing an extensive literature review, working with the GVSU Statistics and Consulting department, and consulting with childhood development experts. The researchers developed the questions so the vocabulary used in each of the questions was age appropriate for the campers and related directly to each of the three research questions. In addition, the researchers received training on conducting focus groups and interviews from an expert in qualitative research design at GVSU.

While the research tool was uniquely developed by the student researchers for this project, attempts were made to ensure its reliability and validity. First, the researchers received basic focus group training from an expert in conducting focus groups. Second, the researchers incorporated member checking into their interpretation of the data obtained from the focus groups and interviews. Member checking allowed the researchers to receive feedback about the degree to which the participants agreed with their analysis and conclusions from the study. Lastly, each of the researchers independently coded the focus group and interview question responses. This allowed each individual researcher to determine her own interpretation of the data. Researchers then compared interpretations and came to a consensus for qualitative themes.

The quantitative portion of this study was facilitated through the use of a demographics questionnaire. The researchers chose to utilize a demographics questionnaire to enrich and deepen the researchers' interpretation and understanding of the data collected in the qualitative portion. Demographics collected included the camper's gender, age, relationship to the deceased, and the cause of the deceased's death.

**Table A: Demographics of Campers**

Camper's Gender	Age	Relationship to Deceased	Cause of Death
Female	10	Mother	Heart disease
Female	10	Mother	Heart disease
Male	9	Great Grandmother	Stroke
Male	8	Mother	House fire
Female	9	Grandfather	Stroke
Female	14	Father	Car accident
Female	12	Father	Cancer
Female	17	Father	Seizure
Female	12	Mother	Car accident
Female	11	Father	Cardiac arrhythmia

## Participants

**Camper Participants.** A purposive sample was used to obtain the initial pool of camper participants for this study. All camper participants were recruited from a Camp Erin location in the Midwest which had approximately 50 campers enrolled. Prior to this study, parental consent forms for participation in the focus group interviews were completed by the parents of the camper participants. From this potential pool of participants, ten individuals were recruited to participate in the focus group interviews. Completed consent forms were randomly selected on the first day of camp. All individuals selected were campers at the Midwest Camp Erin site, represented males and females, were between the ages of 6 and 17, and were in the bereavement process. Some campers were attending Camp Erin for the first time, while others had previously attended. There were 5 campers between the ages of 6 and 10 selected to participate in one focus group and 5 campers between the ages of 11 and 17 selected to participate in the other focus group.

See Table A for the demographics of the campers.

**Counsellor Participants.** In addition, camp counsellors from the same Midwest camp were invited to participate in semi-structured interviews. Consent forms were distributed to the camp counsellors prior to participating in the individual interview. From the returned consent forms, every fifth consent form was selected, until four consent forms were obtained. These four camp counsellors were then individually interviewed in a private location by the two student researchers.

## Data interpretation

After conducting the focus groups and interviews, the researchers transcribed the audio tapes verbatim. Thematic analysis was used to establish themes from the data obtained from the focus groups and individual interviews.

Thematic analysis is a method of identifying themes within the data (Luborsky & Lysack, 2006). The researchers initially independently read through the transcriptions from both the interviews and focus groups in order to identify themes in participant responses. Then the researchers collaborated as to the themes each found in the data. Similar findings were grouped into codes. Through discussion, the researchers refined the codes to three major themes with several minor themes immersed within each theme. The three main themes were environment, flexibility, and personal realization. From these themes the researchers were able to determine the campers' and camp counsellors' perspectives of the effectiveness of Camp Erin with regards to addressing the bereavement process among children.

## Findings

There were three research questions proposed for this study. Each question was addressed with support obtained from the three main themes determined from the thematic analysis of the focus groups and counsellor interviews.

### *Research question (1): How do the activities at Camp Erin impact the bereavement process among campers?*

The activities at Camp Erin were found to help decrease the campers' sense of isolation. Prior to attending Camp Erin, many campers reported not knowing any of their peers who had also experienced the death of a loved one. This led to feelings of isolation. One camper stated:

'My mom, she's so worried about us, that I don't want to tell her when I am sad and stuff because I know it will make her sad.'

The activities at Camp Erin were found to decrease the sense of isolation by helping the campers realize that they were not alone in experiencing the death of a loved one.

This finding is supported by previous research. Both Busch and Kimble (2001) and Davies, *et al* (2007) found that participation in the activities of a bereavement support group helped decrease children's sense of isolation.

The activities at Camp Erin were also found to teach the campers different coping mechanisms. This occurred both explicitly and implicitly. The small and large group discussions, team building activities, and journaling explicitly taught the campers coping mechanisms while interacting with other campers and counsellors implicitly taught the campers coping mechanisms. All of the campers had experienced the death of a loved one. As a result, each camper could observe what coping mechanisms his or her peers were utilizing in order to move through the bereavement process. In addition, many of the counsellors had experienced the death of a loved one at some point in their life. These counsellors provided the campers with a role model and a source of inspiration in dealing with the loss of a loved one. They provided the campers with the opportunity to engage with someone slightly older that had experienced a death and had successfully made it through the bereavement process.

In addition, the activities at Camp Erin were found to help the campers' make the personal realization that they can ask others for help through the bereavement process. More importantly, the activities helped the campers to realize that they can ask their peers, not just adults, for help and support. Prior to attending Camp Erin, many campers only felt comfortable asking adults for help in the bereavement process. The group discussions, team building activities, and group puzzle all assisted the campers in feeling more comfortable asking their peers for help. This peer interaction is critical according to Davies (1991) who found that children and adolescents in the bereavement process tend to withdraw from social interaction with their peers; thereby sacrificing access to a valuable source of social support that could help them move through the bereavement process.

Lastly, the activities at Camp Erin created an environment that helped the campers in expressing their range of emotions. Several campers stated that they do not feel comfortable expressing their emotions at home out of concern for other's feelings. One camper stated:

'Sometimes even if I'm just talking about a memory of my dad, my friends get really awkward around me, cause I know they don't want to say anything wrong, but I'm like it's ok, you can laugh, and I'm ok. But here everyone understands that it's ok to be happy.'

Other campers spoke of the value of taking a break from sadness. The activities at Camp Erin created a safe environment in which campers felt comfortable expressing their emotions; both happy and sad. The literature supports

the finding that engagement in activities facilitates the emotional expression of children in the bereavement process. Andrews and Marotta (2005) found that engagement in play, art, and games positively impacted the bereavement process in children by helping the children to manage and modulate the intensity of their grief feelings. They also found that engagement in play, art, and games helped the children experience some control over their grieving (Andrews and Marotta, 2005).

One camp counsellor stated:

'It's like a mini vacation mixed with the grief counselling at the same time is kind of a good mixer that allows them to get counselling as well as get out there and just have a good time.'

In addition, the need for each camper to express emotions in his or her unique way was provided by the numerous activities offered at Camp Erin. The camp offers a variety of activities utilizing different mediums of communication; such as a drum circle, journals, and group discussions, in order to help campers find a personal way to express their emotions.

Occupational therapists are skilled at selecting meaningful, age-appropriate activities for each child in the bereavement process which will facilitate the child's emotional expression (Miliken *et al*, 2007). Facilitating a child's emotional expression will lead to an improvement in the child's participation in healthy and meaningful activities or occupations (Milliken *et al*, 2007). Thus, one potential role for occupational therapists at Camp Erin is to select activities that will facilitate the children's emotional expression while also being meaningful and age-appropriate for each individual child.

### ***Research question (2): How do the relationships formed at Camp Erin impact the bereavement process?***

Previous research about the effect of childhood bereavement on social participation indicates that many children withdraw from peer relationships and engage instead in solitary activities after the loss of a loved one (Davies, 1991). One specific way Camp Erin facilitates the development of relationships is by providing campers with the opportunity to bond over a similar life experience. For many campers, this is the first time they learn that they are not the only child to have a loved one who has died. The personal realization of this commonality can invoke conversation and relationship development. One camp counsellor stated:

'When they see their peers sharing, it opens it up and they realize that they can also trust other people with their sadness not just adults but with other kids and they feel like they are a part of the group.'

Several campers spoke about forming relationships after creating bonds through their personal realization that they were not alone in their grief.

Another way Camp Erin facilitates relationships is by creating a flexible environment that encourages the campers to participate in social activities to the degree each camper feels most comfortable. Indoor and outdoor semi-structured social activities are available throughout the day to encourage interactions amongst the campers. These group activities invoke conversation amongst the campers, which helps them to meet new people. In addition, these group activities encourage teamwork, bonding, and having fun. Under these conditions the campers are able to create relationships with other people at camp.

Research indicates that relationships are important in the bereavement process because they provide social support and companionship that contribute to an individual's general adjustment and well-being (Hollingsworth & Buysse, 2009). Research also indicates that relationships foster communication and interaction skills; which are especially important for school age children (Hollingsworth & Buysse, 2009). In addition, research has found that relationships often develop when individuals are in close proximity to one another and when two people engage in shared activities and experiences (Hollingsworth & Buysse, 2009). Camp Erin has created an environment which is conducive to relationship development. It features group activities that require teamwork for their successful completion in order to foster shared experiences and relationship development among the children. Activities such as the puzzle activity and outdoor sports games are designed to be flexible and fun for the children while simultaneously encouraging relationship development with peers and counselors

### ***Research Question (3): Is there a role for occupational therapy in community-based bereavement programs such as Camp Erin?***

One realization obtained from the focus groups, particularly with the youngest age group, was that some of the children were uncertain how to apply what was learned during the bereavement camp to their own lives when camp was over. When asked if they learned anything at Camp Erin that will change how they live when they return home, many of the campers were uncertain. One camper stated:

‘Yeah I think it will, but I just don’t know.’

This response indicates that there is a point of disconnect for the campers between what is taught at Camp Erin and actually applying it to their everyday lives. It is not clear what is causing this disconnect. One potential explanation is that there are barriers in the campers' home environments which prevent the application of the coping techniques taught at Camp Erin. One counsellor stated:

‘It depends on how complicated their home life is... uhh... you know, we have this idealistic kind of place where they can eat and sleep and play and have adults available to them.’

Occupational therapists are skilled in identifying the nature and extent of barriers to occupational performance and means for overcoming these barriers (Hocking, 2001). Thus, one potential role for occupational therapists at Camp Erin is to identify the barriers which are preventing the campers from applying what is being taught at Camp Erin to their home lives, and developing means for overcoming these barriers. Once the barriers have been identified occupational therapists could help the children generalize the techniques and skills learned at camp to their home lives.

## **Discussion**

In addition to the potential barriers to generalizing learned concepts from the camp environment to the home environment, there are many other physical, cognitive, and sensory components that can hinder learning for children attending bereavement camps. Occupational therapists have the knowledge and skills to address all barriers to community bereavement camps in order to ensure that all activities are accessible to children with a variety of ability levels. For example, a camper with physical limitations may need accommodations that allow easier access to camp spaces. The types of physical adaptations that should be considered when determining an appropriate site for a weekend bereavement camp should include light-weight doors, curb cuts, ramps, elevators for multilevel facilities or accommodations on each level, accessible bathrooms and wheelchair access, just to name a few (Egilson & Traustadottir, 2009).

In addition to physical barriers, some individuals experience sensory issues that create barriers to participation. These sensory issues may be related to vision, hearing, taste, touch, and scent (Egilson & Traustadottir, 2009). A child who is overwhelmed by sensory stimulation should have a safe and quiet space to withdraw from the stimulation. It is also important to consider that others may thrive on sensory stimulation. For these children, activities must be designed that provide sensory stimulation to a degree deemed appropriate for the child. Other adaptations should be considered such as providing a variety of foods due to food allergies, auditory accommodations for those who may be hearing impaired or sensitive to loud noises, and various tactile inputs so that a child who is hypersensitive to certain textures will still be able to participate in camp with minimal adaptations (Egilson & Traustadottir, 2009). An occupational therapist recognizes that not all children have the same ability levels and tolerance to certain stimuli. With this in mind, the

occupational therapist could evaluate the environment in such a way to accommodate for children with a variety of abilities so that their experience at Camp Erin could be as conducive to the bereavement process as possible.

Finally, cognitive barriers may exist for some campers. Research has suggested that most children are not able to understand that death is irreversible and universal until nine years old or older (Ayyash-Abdo, 2001). Occupational therapists have expertise in assessing an individual's cognitive, physical, and social childhood development and how this can impact participation in day-to-day activities. This unique perspective of development could be applied to the design of bereavement camp activities and programs. Occupational therapists should keep in mind how the child's stage of cognitive development influences his or her perception of death when designing activities at camp. It will be critical for the occupational therapist to structure how they would discuss death and the bereavement process with a child based on that child's age and cognitive development.

## Conclusion

The researchers aimed to determine how the activities and the relationships formed at Camp Erin impact the children's bereavement process. The researchers were also interested in determining if there is a role for occupational therapy in community-based bereavement programs. Overall, the qualitative outcomes of this study indicated that Camp Erin is effective in supporting the children's bereavement process while the children attended the four day camp. The flexible camp environment and the various group activities are conducive to communication, which allows for optimal conditions for relationship development. The camp counsellors and the campers credited the camp activities and relationship development as the most beneficial aspects of the bereavement camp. It is suggested that similar studies be conducted at multiple bereavement camp locations to determine the generalizability of this study's findings. An additional study is suggested to address the use of learned skills to explore the need to help children generalize the skills learned at camp to everyday life at home, school, and in the community. Based on the data collected in this study, and the information available in the current literature, the researchers believe that there is a role for occupational therapists in community-based bereavement programs such as Camp Erin. With the support of this study occupational therapy may be a helpful profession in consulting with bereavement camps to support children throughout the bereavement process.

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