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HDFS 5403

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Literature Review

### **The Impact of Sibling Loss on School-aged Children**

The Impact made on school-aged children who have suffered the loss of a sibling who had endured a chronic illness, such as cancer, autoimmune disease, or any other life-threatening illness could experience depression, behavior problems, anxiety, and loneliness.

According to Fletcher et al., “In 2014, almost 40,000 children under the age of 20 y died in the United States, with the highest rates among infants, those between the ages of 15 and 19 y, and boys” (2017). With this statistic in mind, it is estimated that seven million children could benefit from pediatric palliative care (Open Society Foundations, 2015).

Not only does the loss of a sibling affect an individual but could also cause a dysfunction in family and parental dynamics. Fletcher et al., states “Child deaths have large negative effects, including marital disruption, depression, and health problems persisting decades after the child’s death for parents” (2017). Having difficulty in family dynamics after the death of a child or sibling impacts cognitive and socioemotional outcomes, as well as the support provided by parents since they are grieving as well (Fletcher et al., 2017). Grief in siblings could be seen through play, depression, and the incline of risk-taking. With grief, child life specialists come to engage with the families before the sibling or child has passed.

This is when they work through legacy building activities for the families to hold remembrance. Legacy building is defined as “referring to a set of interventions focused on helping children and their families create lasting memories during difficult health care experiences” (Boles, 2014) (Sisk et al., 2012). Studying grief in children and how to teach the children and families to cope in these times of need could benefit them long-term through their development and overall well-being. In this literature review, there will be discussions centered on the development of legacy building, the impact of

sibling loss, and the implementation of interventions pertaining to hospice care for children who are chronically ill.

### **Definition**

Sibling loss could affect children in numerous ways whether that be mentally, physically, or emotionally. Not only does this impact affect the siblings but the parental guardians as well. The age group that is most affected by the loss of a sibling would be school-aged children. Based on the research articles that were published, most of them discuss how school-aged children do not understand what has happened to their siblings. This could cause them to withdraw from their peers or social activities. Their academic performances in school could decline because of being distracted by the thoughts of their siblings not being with them anymore. As stated in Fletcher et al.'s article, they did a study that examined the differences between behaviors after sibling death. "We find significant evidence of increases (i.e., worsening) of the Behavioral Problems Index (BPI) and significant reductions in the Scholastic Self-Perception Profile for Children (SPPC)(2018). This shows that behaviors have been "worsening" over time after the sibling's death.

It is interesting to research the difference between how older children cope with grief versus younger ones. Fletcher et al.'s article shows an interpretation of the findings, "through psychological development vulnerability; for example, older children are more likely to be at a developmental stage where they can understand loss and/or recognize the impacts of the death on their parents" (2018). While school-aged children express different feelings of grief which are "Psychologists have found that younger children express feelings of grief, sadness, and depression, and pretend play with their deceased sibling, while older children act out more, engage in elevated levels of risk taking, and are more inclined to enter helping professions"

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#### Developmental and Psychosocial Impact of Sibling Loss

As previously stated, the impact of sibling loss can be performed in numerous ways that are associated with the experience of grief. According to Fletcher et al., "Bolton et al., show large increases in mental disorders for bereaved siblings, especially for those exposed as a teenager" (2017). Mental disorders could disrupt the parents from assisting in their other child's grief. These findings indicate that parents who are experiencing emotional distress due to the loss of a child may be unable to provide emotional support for the surviving child. Not only does grief affect a child mentally but could also have an impact on them physically. According to Smith et al., there was "A small case control study found elevated risk of both myocardial infarction and stroke if there had been infant or perinatal death in the case of one or more siblings; however, these elevated risks were very imprecisely estimated" (2014). As previously

mentioned, younger children express grief in numerous ways such as sadness, depression and initiate pretend play with the deceased sibling, however older children are more engaged in risk-taking activities and want to be involved in helping professions as they grow older (Fletcher et al, 2017). It is interesting to note that psychological development vulnerability may be different in each developmental stage. For example, Fletcher et al., noted, “older children are more likely to be at a developmental stage where they can understand loss and/or recognize the impacts of the death on their parents” (2017).

Despite the lack of emotional support after a sibling’s death, there also comes a time when their home environment could be affected by the lack of emotional resources due to being isolated in times of need. Based on Sisk et al., they state, “The therapeutic process of sharing their stories provides children and adolescents an opportunity to share feelings, process challenges, and find ways to deal with their ongoing medical experiences and the changes associated with their developmental ages” (2012). With the aid information from the articles, it is evident that educating children and families on how to effectively manage grief could provide a positive outlook for their development.

In Cahalan et al.’s article, they discuss how some individuals who were impacted by cancer could feel powerless. They stated, “When faced with a pediatric cancer diagnosis, children and families experience profound grief and a sudden loss of normalcy. A sense of powerlessness takes over as parents realize they are in a situation they cannot control and “fixing” the child’s illness is out of their hands. Children experiencing the news of a cancer diagnosis may feel confused, scared, and isolated. Children and families may begin to reflect upon their identities and the ways in which cancer will affect their legacies” (2021). This leads

to the next discussion on how legacy building has an impact on how families can cope with grief and understand the diagnosis of their child.

### **Interventions for Sibling Loss**

Although sibling loss is inevitable, there are interventions that could assist in coping with sibling and child loss. There are numerous ways that could be implemented within a child's care. The biggest one is legacy building. Legacy building is "for children or adolescents who are living with a life-threatening illness, efforts to build memories and confirm they are loved and will be remembered are important. Many children need and want to know that they will not be forgotten. In the terminal phase of an illness, children of all ages may wish to attend to unfinished business, such as delegating who will receive certain belongings after their death, writing letters, drawing pictures, or talking with significant people. Legacy-making can be defined as doing or saying something that is remembered, including both intentional and serendipitous legacies" (Foster et al, 2012).

Legacy building could come in many forms such as memory books, hand molds, songwriting, artwork, photographs, and videos (Foster et al, 2012). It is important to implement these activities to aid not only the child who has the illness but for the families to remember them in a positive way. According to Sisk et al, they provide Erikson's theory stating, "Erikson (1959) theorizes children 6 to 12 years of age as being in the "industry versus inferiority" stage. In this stage, completing activities of the industry helps children express feelings and master experiences by learning new skills" (2012). Which could be beneficial for child life professionals to take this theory into consideration while evaluating school-aged children and the impact of sibling loss. According to Foster et al, "A qualitative study explored bereaved parents' and

siblings' reports of legacies by children who had died of cancer. Content analysis of interviews with 36 mothers, 27 fathers, and 40 siblings indicated that some children living with cancer did specific things to be remembered, such as making crafts for others, willing away belongings, and writing letters to loved ones" (2012). With this statistic, it should be noted that this intervention improved family communication and decreased caregiver stress (2012).

Besides legacy building, Andrews et al. states that there is also an intervention that involves music. In this research article, they described how music therapy has been added to the multidisciplinary team of palliative physicians and child life team (2020). They stated, "Music therapy has been shown to decrease negative psychological outcomes such as depression and anxiety that palliative care seeks to address" (Andrews et al, 2020). Within the article, they discussed that music therapy would record the child's heartbeat and edit the recording to isolate the heartbeat. With the heartbeat, the therapist overlayed a song or voice recording of the child to give to the family. After receiving feedback from parents who engaged in this study, stated that they would recommend it to other families.

Jessika Boles, a child life specialist who is a part of The Children Corner stated her experience with working with children who have created their own interventions, which included "I have seen a nine-year-old girl hide letters in her family home so that her mother would find them several years later; each letter gave her mother advice on how to cope with her continued disease progression and eventual death. As another example, a 12-year-old chose to record himself singing and playing guitar for his family; each song he chose related to a specific family memory of them during his treatment journey" (2014). This article by Jesika Boles shows that children can make their own legacy building throughout their end-of-life treatment. In Smith et al.'s article, they describe the importance of music therapy being intertwined into intervention

but also how leaving a “living legacy” is just as important. A living legacy is “is an ongoing process, something that happens over time, rather than an isolated event” (Smith et al, 2021). These interventions could include patient-led projects and allow for meaning making in the context of one’s cancer journey.

### **Recommendations for Child Life Professionals**

Based on the research that was provided and numerous articles on palliative care, the most common and successful interventions were legacy building and music therapy. However, there were moments when the children who were in their end-of-life treatment decided on their own legacy interventions, as stated before, remembering a song for a specific family member, or hiding letters around the house for parents to assist in helping them cope with their grief. Based on the topic being “The Impact of Sibling Loss on School-aged Children” child life professionals should utilize the legacy building activities. Not only does legacy building provide comfort for the families on their journey, but it could also allow the families to choose a legacy building activity that could assist in them feeling as though they have control over their situation. Jessica Boles says, “Families can have the freedom to choose what this means for them, whether it is only including the happy moments or even the more difficult experiences as well” (2014). Especially in school-aged children, they heighten the meaning-making capacity of activities because this young age group tends to gravitate towards peers and families.

One activity that I researched that could be beneficial for child life professionals was bead making as a legacy building activity. The Legacy Bead program aims to provide a means of acknowledging the patient’s accomplishments for patients to tell their stories. The beads are provided to specialty clinics that distribute beads based on milestones in treatment. Beads are given when a milestone has been met and received with the occurrence of a significant event.

This activity allows the children to get creative, whether they make a garland or necklace, it is completely up to the patients. The purpose of this activity is to “share the story of a deceased child with others including siblings and family members not fortunate enough to have met the child. Reassurance of their importance, their legacy, and continued love is an important aspect of parenting a dying child” (Sisk et al, 2012).

Nonetheless, as the field of child life is relatively new, there is a deficit of research articles about the potential impact of sibling loss on children’s long-term development. There are plenty of research articles that provide parents with grief tactics but lack information based on the children’s needs to thrive. One approach that could aid in comprehending the impacts of sibling loss in children to professionals would be intervention studies or observational research. Intervention studies could be determined by conducting a follow-up with the patient’s families to assess their well-being. Observational studies could be used to observe the time families spend together during their illness journey.

### **Conclusion**

In conclusion, the impact of sibling loss on school-aged children is a complex and overwhelming topic that results in children and parents having implications for their emotional, social, and academic development. As previously stated by Fletcher et al, “Child deaths have large negative effects, including marital disruption, depression, and health problems persisting decades after the child’s death for parents” (2017). In the following research articles provided, they suggest that the grieving process can manifest in various ways such as influencing emotional well-being, academic performance, and interpersonal relationships with family or peers. However, the population of school-aged children, experience grief in a different light. “Psychologists have found that younger children express feelings of grief, sadness, and

depression, and pretend play with their deceased sibling, while older children act out more, engage in elevated levels of risk taking, and are more inclined to enter helping professions” (2018). Although children experience grief differently, they may lack support from their parents or guardians to help them through this process. That is why it is essential to provide education for parents on how to cope and how to be present for their surviving children.

Before the end-of-life journey for sibling loss, there are interventions that could be taken before the child is departed. As stated before, this could be seen as a legacy building and music therapy. Legacy building could come in different forms such as memory books, hand molds, songwriting, artwork, photographs, and videos (Foster et al, 2012). This is important for the families and children to engage in these activities because it allows the families to remember them in a positive way and it creates a distraction from the illness. However, since there isn’t continuous research that builds on how sibling loss impacts school-aged children, I suggest that researchers should conduct observational studies and intervention studies to assist in understanding how it affects child development long term. These studies could also aid in educating parents on how to be present for their surviving child and assist in their grieving process. Ultimately, fostering awareness, empathy, and interventions within a child support system could contribute to the well-being of school-aged children and assist in navigating through the challenging journey of sibling loss.

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