

Literature Review on Support Systems for Siblings of Hospitalized Children

Allison Baker

Texas Woman's University

HDFS 5403: Child Life

Dr. Kathryn Cantrell

August 9, 2024

INTRODUCTION

Sibling relationships are long-lasting relationships that affect a child's emotional, social, and cognitive development (Kirk & Prymachuk, 2024). Many children today live with a sibling diagnosed with a chronic illness (Keller et al., 2023). Chronically ill children spend much time with their family and siblings in the hospital. Healthy children may be impacted by their ill siblings as they rely on their social support during their medical experience (Lamsal & Ungar, 2021, p. 28).

Children who go through medical procedures and endure extended hospital stays experience psychosocial and emotional disorders (Zengin et al., 2021). Since many of these children have healthy siblings, those siblings are also affected by the stress and anxiety associated with their brother or sister's medical condition. When a sibling is diagnosed with an illness or disease, a healthy child can experience "intense physical, emotional, social, and psychological" distress often because of the multiple factors of change in their life (Mooney-Doyle et al., 2022, p.1). While child life specialists need to prepare ill children for hospitalization, it is crucial for them to "establish therapeutic relationships" with the child's siblings and caregivers as well (Romito et al., 2021, p.1). Supporting siblings through sibling-specific programs can decrease adverse psychosocial and developmental outcomes (Keller et al., 2023).

Around 400,000 children are diagnosed with severe illnesses, and 250,000 of those children have siblings (Mooney-Doyle et al., 2022). A quarter of a million children are at risk of long-term effects. Research shows that siblings are often at high risk of "decreased parental attention and increased parental expectations" (Schmong et al., 2022). Since siblings often are not the central focus of caregivers during the hospitalization period, they receive less attention.

High expectations and responsibilities often burden them, increasing their stress levels and feelings of loneliness. Without sibling support systems in place, affected children may experience prolonged mental health problems that carry over into their adulthood (Kirk & Prymachuk, 2024). Getting ahead of this issue can prevent the increase in the number of children potentially experiencing the long-term effects of their sibling's illness or hospitalization. Understanding the issue of overlooked siblings of hospitalized children can help child life specialists implement special programs to promote sibling support. These specialists will focus on the siblings' "unique anxieties and psychosocial needs" that often go unnoticed during stressful times (Romito et al., p. 7). This paper will define the challenges faced by siblings of hospitalized children, explore the developmental and psychosocial impacts on these siblings, review interventions to support them and recommend interventions for child life specialists.

DEFINING THE PROBLEM

Children face many emotional and psychological challenges when a severe illness hospitalizes their siblings. Healthy children often receive less attention from their parents and are not adequately taught about their sibling's health condition, which can lead to misunderstandings and increased anxiety. Due to the lack of parental availability and stress of their ill sibling, children experience "loss and separation anxiety" along with "mental health stressors" which challenge their physical, emotional, and social development (Lamsal & Ungar, 2021, p. 27)., Healthy siblings may feel neglected, along with feelings of guilt and resentment. If they are not adequately supported, these psychological and emotional challenges will continue to impact and influence their long-term mental health.

Children are categorized into different developmental age groups, each characterized by distinct behaviors, achievements, and stressors. These differences are also noticeable in

healthcare settings. For instance, school-aged children face unique challenges when hospitalized. They often fear imminent death and separation from school and extracurricular activities. When a child's sibling is hospitalized, they often spend less time engaging in "family activities such as game or movie nights" (Tay et al., 2022, p. 16). As caregivers are preoccupied, children often rely on neighbors or grandparents as their substitute caregivers, limiting their access to extracurricular activities (Tay et al., 2022, p. 17). This disruption of routine may lead to emotional outbursts, as separation from familiar activities is a stressor for them.

Sibling support systems are in place to help eliminate any stressors or challenges children experience during their sibling's hospitalization. Siblings need to have access to these support systems to address their individualized psychosocial needs. Research shows that it is not common for sibling support to be "implemented in routine practice" due to different barriers (Brosnan et al., 2022, p.3). Without sibling support systems, children are not able to address their psychosocial needs, which increases the likelihood of developing long-term psychosocial and emotional outcomes (Brosnan et al., 2022). Therefore, it is crucial to provide consistent sibling support to prevent any long-term emotional and psychological issues.

DEVELOPMENTAL AND PSYCHOSOCIAL IMPACT

Children's developmental age, composed of emotional, social, and cognitive components, plays a crucial role in managing their emotions (Thompson, 2018). The stress of having a hospitalized sibling can significantly affect their developmental age, potentially altering their emotional, social, and cognitive growth and causing emotional and behavioral problems (Kirk & Prymachuk, 2024). Parent-child communication "has the potential to help a child better understand and interpret a complex situation while also providing a context in which to provide the child with emotional support as needed" (Jaaniste et al., 2022, p. 1). Through effective

communication, children can gain a clearer understanding of their sibling's hospitalization, reducing feelings of confusion and neglect. Involving parents in this communication process can also alleviate the feeling of being overlooked.

Siblings often endure long-term emotional and social challenges. These challenges occur as these siblings adjust to their roles within their family, often centered around the ill child, leaving the sibling to feel neglected. Because of their new caretaking responsibility, they may experience "profound and life-long implications that disrupt their life course trajectory" (Kirk & Prymachuk, 2024). This early exposure to responsibility may lead to emotional and behavioral issues. It is common for school-aged children to act aggressively or become avoidant in response to feeling stressed, anxious, or afraid. Providing sibling support is necessary, as research suggests that these emotional and behavioral issues can persist over time (Kirk & Prymachuk, 2024). Effective support systems must address the child's emotional needs and clearly understand their sibling's condition to help them "better understand and interpret a complex situation" (Jaaniste et al., 2022, p. 1).

INTERVENTIONS TO ADDRESS THE PROBLEM

A significant number of children in the United States have a sibling with a severe illness, which can cause them emotional stress. Studies have shown that hospital visits and educational interventions can help siblings cope. For example, hospital visitation programs led by child life specialists help siblings adapt to the hospital environment, making them feel more comfortable and positive throughout their visits (Keller et al., 2023). Research supports this intervention by showing increased coping abilities for siblings who visit the Intensive Care Unit compared to the children who do not (Keller et al., 2023). These visits help them gain a sense of familiarity and provide lasting positive impacts. A beneficial intervention for school-aged children would be

peer support groups to make up for the potential separation from peers at school. Programs run by child life specialists can help educate siblings about the illness and provide peer support to reduce feelings of isolation and improve their overall psychological well-being (Keller et al., 2023). Providing children with knowledge about their siblings' condition supports managing the child's emotions, which will improve their emotional and psychological health.

Current research on sibling support for hospitalized children reveals gaps that need improvement. In the future, researchers should focus on developmentally appropriate interventions that target all diversities (Mooney-Doyle et al., 2022). Child life specialists and other health professionals must focus on all developmental ages when providing sibling support to tailor their approach to the child's needs. It is also essential to be knowledgeable about cultural backgrounds and how they might be tailored to the child's unique requirements.

The new emergence of digital and telehealth platforms increases the accessibility rate for sibling support (Brosnan et al., 2022). Child life specialists work with many kids throughout the day and cannot always prioritize the support of siblings. Additionally, children may live far away from their hospitalized siblings, making it difficult for them to travel to get sibling support services. These technological advancements overcome these barriers by preventing siblings from receiving sibling support services.

RECOMMENDATIONS FOR CHILD LIFE PROFESSIONALS

Child life specialists play an essential role in supporting siblings of hospitalized children by implementing specific interventions that target the child's individualized needs. Educational interventions are essential in reducing anxiety and enhancing a child's mood. Educational interventions include explaining the child's illness to the sibling, teaching coping skills, and discussing possible changes they may face (Wawrzynski et al., 2021). Having a better

understanding of the child's illness can alleviate fear and anxiety, which will create a more supportive environment for the child. Research shows that "low levels of attention from parents are associated with higher rates of unmet support needs among siblings" (Wawrzynski et al., 2021, p. 39). Parents may feel overwhelmed and focus their attention away from their healthy child, offering less emotional support. Integrating an intervention focusing on the family and the child can help alleviate anxiety between both groups (Wawrzynski et al., 2021). Child life specialists can incorporate age-appropriate activities that aid family members in understanding how to support their child during these events (Romito et al., 2021).

FUTURE RESEARCH DIRECTIONS

In the future, researchers should focus on longitudinal studies to study the long-term psychosocial impacts on siblings and how their needs evolve. This would help specialists understand the needs of each developmental age group and how they evolve. Researchers should use more diverse family structures, such as single-parent families, blended families, and families from different cultural backgrounds. Understanding different family backgrounds can help specialists tailor their approach more effectively.

Researchers should use evidence-based practices and innovative approaches when supporting siblings of hospitalized children. Creating developmentally appropriate interventions that address each child's needs produces positive benefits (Mooney-Doyle et al., 2022).

Evidence-based practices allow specialists to understand which approaches work best and predict positive outcomes for sibling support programs more reliably.

CONCLUSION

Supporting the siblings of hospitalized children is essential to helping them cope with the emotional and psychological challenges they face. Child life specialists can play a key role by

providing educational programs, peer support groups, and family-focused care. These interventions can help reduce siblings' anxiety, loneliness, and stress. The future use of digital tools and telehealth can make it easier for siblings to access support, no matter where they are. With the continuation of learning, it's important to focus on creating effective, long-term strategies considering different family backgrounds. By doing so, siblings will feel more supported, and their overall well-being will improve.

REFERENCES

- Brosnan, P., Davis, K. A., Mazzenga, M., Oberoi, A. R., Sharkey, C. M., Buchbinder, D., Alderfer, M. A., & Long, K. A. (2021a). Psychosocial Care Providers' Perspectives: Barriers to implementing services for siblings of children with cancer. *Pediatric Blood Cancer*, 69(2). <https://doi.org/10.1002/pbc.29418>
- Jaaniste, T., Chin, W. L., Tan, S. C., Cuganesan, A., Coombs, S., Heaton, M., Cowan, S., Potter, D., Aouad, P., Smith, P. L., & Trethewie, S. (2021). Parent and well-sibling communication in families with a child who has a life-limiting condition: Quantitative survey data. *Journal of Pediatric Psychology*, 47(5), 606–616. <https://doi.org/10.1093/jpepsy/jsab128>
- Abela, K. M., Casarez, R. L., Kaplow, J., & LoBiondo-Wood, G. (2022). Siblings' experience during pediatric intensive care hospitalization. *Journal of Pediatric Nursing*, 64, 111–118. <https://doi.org/10.1016/j.pedn.2022.02.008>
- Keller, B. P., Abney, M., & Boles, J. C. (2023). Child life services for siblings of chronically ill children. *The Journal of Child Life: Psychosocial Theory and Practice*, 4(2). <https://doi.org/10.55591/001c.84322>
- Kirk, S., & Pryjmachuk, S. (2024). people don't realize how much their past experiences affect them in adulthood: A qualitative study of adult siblings' experiences of growing-up with a sister/brother with a childhood life-limiting condition and their perceived support needs. *Palliative Medicine*, 38(3), 352–363. <https://doi.org/10.1177/02692163231225100>

- Lamsal, R., & Ungar, W. J. (2019). Impact of growing up with a sibling with a neurodevelopmental disorder on the quality of life of an unaffected sibling: A scoping review. *Disability and Rehabilitation*, 43(4), 586–594.
<https://doi.org/10.1080/09638288.2019.1615563>
- Mooney-Doyle, K., Franklin, Q. M., Burley, S. R., Root, M. C., & Akard, T. F. (2022). National Survey of Sibling Support Services in children's Hospitals. *Progress in Palliative Care*, 30(6), 341–348. <https://doi.org/10.1080/09699260.2022.2094173>
- Romito, B., Jewell, J., Jackson, M., Ernst, K., Hill, V., Hsu, B., Lam, V., Mauro-Small, M., & Vinocur, C. (2021). Child life services. *Pediatrics*, 147(1).
<https://doi.org/10.1542/peds.2020-040261>
- Schamong, A. S., Liebermann-Jordanidis, H., Brockmeier, K., Sticker, E., & Kalbe, E. (2021). Psychosocial well-being and quality of life in siblings of children with congenital heart disease: A systematic review. *Journal of Child Health Care*, 26(2), 319–337.
<https://doi.org/10.1177/13674935211012933>
- Tay, J., Widger, K., & Stremler, R. (2021). Self-reported experiences of siblings of children with life-threatening conditions: A scoping review. *Journal of Child Health Care*, 26(4), 517–530. <https://doi.org/10.1177/13674935211026113>
- Wawrzynski, S. E., Schaefer, M. R., Schvaneveldt, N., & Alderfer, M. A. (2021). Social support and siblings of children with cancer: A scoping review. *Psycho-Oncology*, 30(8), 1232–1245. <https://doi.org/10.1002/pon.5689>

Zengin, M., Yayan, E. H., & Düken, M. E. (2021). The effects of a therapeutic play/play therapy program on the fear and anxiety levels of hospitalized children after liver transplantation.

Journal of PeriAnesthesia Nursing, 36(1), 81–85.

<https://doi.org/10.1016/j.jopan.2020.07.006>