

Where is the Patient's Voice in the Pediatric Patient Experience?

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An article review of: Hospital healthcare experiences of children and young people with life-threatening or life-shortening conditions, and their parents: scoping reviews and resultant conceptual frameworks

The review of this article was part of our work on the Patient and Family Experience Committee, within the ACLP. This group was tasked with helping membership learn more and dig deeper into patient experience. One aspect was seeking literature that is relevant to child life staff in their daily practice. This article was chosen due to the fact that it is current and was a review of a broad set of relevant articles. The authors hope to highlight the impact that child life specialists have in the patient and family experience, and help child life staff communicate this with hospital administration.

Patient experience of children and parents' interactions and relationships with healthcare staff, are core aspects of a healthcare visit for patients and families. The study's scope looks at factors affecting the pediatric patient experience from both children and young people (CYP) and parent's perspectives, and how to measure pediatric patient experience. This article is relevant to child life specialists as we influence the pediatric patient's overall healthcare experience.

Key Findings

Initially, 18,531 records were screened, with 18,328 excluded, leaving 203 full-text articles for further evaluation. After excluding five articles focused on community-based health services, 80 articles from 74 studies were included in the review. Some articles focusing on the experience of CYP ages 3 to 18 and others focusing on the perspective of the parents. The review identified 36 key aspects of healthcare delivery affecting CYP with life threatening/life shortening conditions (LT/LSC), categorized into eight domains: staff attributes (empathy and professionalism), staff actions (information sharing, clinical and personal care, emotional and social support), and organizational features (social/play resources, inpatient environment, continuity of care). Key crosscutting questions examined differences in healthcare needs between CYP and parents, as well as variations by age or developmental stage. 0

The most important factors affecting the pediatric patient experience are unique for children and parents. The study found that children value physical and sensory aspects of care including a comfortable environment and access to play, sensory, and socialization resources (Mukherjee et al., 2023, p.14). The study found that parents value professional communication, decision-making support, trust in staff, and emotional well-being support (Mukherjee et al., 2023, p.16). This study also found that parents tend to rate hospital experiences higher than CYP (Mukherjee et al., 2023, p.20).

Why This Matters to Child Life

There are many aspects of the pediatric patient healthcare experience that align with the important work of child life specialists. This includes emotional and social needs, play and socialization, enhancing communication and understanding, supporting family-centered care, and implementing coping strategies. A child life specialist helps to meet emotional and social needs by taking time to get to know a child, helping to create a calm environment, providing opportunities to play, and working to reduce anxiety and fear. Play and socialization opportunities include providing toys, games, crafts, entertainment, play rooms, and technology for all ages, helping to stay connected with peers, promoting socialization, reducing feelings of isolation, and encouraging interactions with others. The child life specialist helps to facilitate communication and understanding by explaining aspects of healthcare in ways a child and family understands, providing developmentally appropriate medical play and preparation, providing opportunities for choice and control, and helping kids and families feel empowered as partners in their care. Supporting parents and family-centered care includes helping caregivers feel supported to care for and comfort their child as much as they desire, ensuring parents have time with their child, advocating for parents as partners in care with decision making, and supporting the child and family's emotional wellbeing. The child life specialist also supports coping strategies by providing emotional support, minimizing pain and discomfort, providing distraction and coping support, helping CYP feel heard and comforted, supporting individualized coping plans, and responding to verbal and nonverbal cues by the patient and family. This information can also be helpful to child life specialists and leadership as they interact with hospital administration. Many points from this study can be brought up with hospital administration to signify the positive influence, benefit, and value that child life specialists have on patient experience.

Conclusion

These findings emphasize the importance of child life specialists in enhancing the pediatric patient experience by addressing social, emotional, and developmental needs during a health care visit. Child life specialists are crucial members of the multidisciplinary team. Daily child life practices positively support patient and family experience and family-centered care. The future of child life is bright. Child life specialists are a large part of the patient and family experience as an advocate for the patient's voice, and make a positive impact on the patient experience.

Reference

Mukherjee, S., Richardson, N., & Beresford, B. (2023). Hospital healthcare experiences of children and young people with life-threatening or life-shortening conditions, and their parents: scoping reviews and resultant conceptual frameworks. *BMC Pediatrics*, 23:366. <https://doi.org/10.1186/s12887-023-04151-6>