

Giving "Voice" to Families' Experiences of Living with a Pediatric Life-Limiting Condition: An Australian Story

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Within pediatric health there are probably no more vulnerable children than those diagnosed with life-limiting condition and their families who care for and support them throughout their illness journey. Qualitative interview-based research provides an ideal means by which to tap into and learn from such families' illness journey related experience. This paper is a review of a large qualitative project that is offering a unique insight into the lives of 29 Australian families with ill children/adolescents (91 persons: mothers, fathers, ill children, well siblings, and extended family members). Their "voices" provide a glimpse into family life, illuminating how life limiting illness affects it and ripples out through the family system.

Drawing from the diverse project findings, the current paper focuses on families' experiences of and the strategies they employ for managing family life. The authors will consider a range of issues that seep through and affect families' quality of life, for example balancing often competing needs of family members. Factors that facilitate or, alternately, undermine their coping are also considered. Families' individual and collective narratives provide a crucial glimpse into the nature and quality of family life as families care for and support seriously ill children and adolescents. The study attests to the power of qualitative research to bring to "life" sensitive and emotive human experience, providing health care professionals an opportunity to examine and reflect upon how the quality and delivery of care can add to and or detract from the quality of families' lives.

The Lived Experience of Pediatric Heart Transplant Recipients

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Heart transplantation (HTx) is an established therapeutic approach for children and adolescents with end-stage heart disease. While significant advances in both the surgical and medical management of HTx, have substantially improved outcomes for pediatric recipients, little research has focused on the psychosocial impact of the transplant process.

This grounded theory study explored the day to day experiences of pediatric HTx recipients, and sought to capture the transplantation experience from the perspective of those who live it and create meaning from it. HTx recipients between the ages of 12 and 18 years of age were recruited from a large Canadian pediatric transplant centre. A total of 28 adolescents participated in the study. Using qualitative interviews participants' posttransplant experiences were explored, including their perception of psychosocial adjustment at school and at home, relationships with peers and family, changes in physical appearance and physical functioning, and overall perceptions of quality of life. Preliminary findings suggest that the effects of undergoing HTx are pervasive and significantly impact self-perceived physical and social well-being. Although findings reflect that recipients exhibit adequate adjustment to the psychological stress of transplantation, they face challenges reintegrating into school and adjusting to the