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“IT’S NOT A LIFE ENDING EXPERIENCE, IT’S A LIFE GROWING EXPERIENCE”: A NARRATIVE REVIEW OF SIBLING DONOR EXPERIENCES IN PEDIATRIC HEMATOPOIETIC STEM CELL TRANSPLANT

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Background:

Pediatric hematopoietic stem cell transplant is an intensive, potentially life-threatening treatment increasingly used in child health. There are significant and often overlooked psychosocial risks, particularly for sibling donors. Further, there is a paucity of research about the potential *positive* gains for siblings donors who undergo hematopoietic stem cell donation (HSCD), such as the possibility of post-traumatic growth.

Objective:

We narratively synthesized literature and identified themes related to trauma and post-traumatic growth experienced by sibling donors during HSCD.

Methods:

A literature search was conducted using CINAHL and PSYCHinfo databases, and the search terms: ‘donor OR living donor’, ‘siblings’, ‘sibling OR brother OR sister’, ‘bone marrow OR stem cell’ and ‘stem cell OR hematopoietic stem cell transplantation’. Further inclusion criteria included formal research articles that: a) were published in English, b) included sibling donors who were under 18 years of age and c) explored the psychosocial experience for pediatric sibling donors from their perspective.

Results:

The search yielded 10 research articles, four studies utilized qualitative methodology, one quantitative, and five employed mixed methods. We identified two main categories related to siblings’ trauma experiences: 1) overwhelming, unrelenting pressure to donate, and 2) loneliness and isolation, particularly as the family focus intensified on the ill child post-donation. Siblings simultaneously identified the following domains of posttraumatic growth: 1) a deepened appreciation for life and changed priorities, 2) more intimate relationships with others, and 3) increased personal strength.

Conclusion:

This review highlighted the critical need for a more comprehensive exploration of sibling donor experiences. Qualitative, expressive-arts based research methodologies are highly appropriate and represent a developmentally sensitive approach for future research. Within my doctoral research, I will adopt this methodological approach, integrating a strength-based framework and digital storytelling with the aim of exploring siblings’ trauma and post-traumatic growth experiences in the context of HSCD.