

Siblings' Perspectives: Towards a Better Understanding of Their Involvement When a Child is Dying

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Background

Living with the illness or death of a sibling during childhood has profound and potentially overwhelming effects (Horsley & Patterson, 2006). However, when the healthy child is informed about the illness and care of their sibling, they have more opportunities to express their grief, supporting healthier bereavement outcomes (Kaufman & Kaufman, 2005). Sadly, there are few formal supports for children who have a seriously ill sibling (Widger, et al, 2007).

Purpose

The proposed study aims to:

1. Describe how siblings are involved with a dying child in terms of the amount of time spent together and the types of activities engaged in and whether there are changes over time;
2. Describe how siblings want to be involved or not, with the dying child, and whether this changes over time;
3. Explore whether or not siblings' grief experiences are influenced by their actual and desired involvement during the child's end-of-life;
4. Explore whether or not bereaved siblings continue to feel connected to the deceased child.
5. If the sibling does have a continuing bond with the deceased child, explore any linkages between this bond and the ways the sibling was involved before the child's death?

Methodology

This prospective study will employ an interpretive descriptive longitudinal design using qualitative semi-structured interviews. Information will be collected from children who have dying siblings at 3 month intervals prior to the death, and once more, 6 months following the sibling's death.

"Interpretive description is an approach that can be applied to qualitative inquiry into human health and illness experiences for the purpose of developing knowledge."

Thorne, S., Reimer Kirkham, S. & MacDonald-Emes, J. (1997) Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20, 169-77, p. 172-73.

TRAC-PG's Interest in Research With Children of Dying Siblings

When their parents are overwhelmed with caretaking responsibilities and their own grief, the needs of children with dying siblings are often overlooked.

Through this study, the TRAC-PG team hopes to gain a better understanding of the experiences and needs of children who have a sibling with a progressive life limiting illness, during the end of the sibling's life and after the death.

We also hope to identify strategies to involve children in their sibling's lives in supportive and meaningful ways in order to help them cope and maintain their relationship while the sibling is dying. Knowledge gained in this study will contribute to the advancement of pediatric palliative care and the quality of life of children with dying siblings and their families.

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Team for Research in Adolescent and
Childhood Palliation and Grief

