

Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth

OVERVIEW

When parents are caring for ill children, the stress is often compounded. Indeed, caring for a child with a life-limiting illness represents one of the most traumatic experiences a parent can endure. The negative aspects of caregiving are well documented in the literature. In the face of such adversity, however, there are suggestions that caregivers can also experience personal growth and positive change. Nevertheless, little is known about positive outcomes of caregiving, particularly of parents caring for seriously ill children.

The primary aim of this research addresses the question “What are the factors that allow parent caregivers to survive and even grow in the face of the stressful circumstances of caring for a child with a life-limiting illness?”

The outcome of this research will be a better understanding of whether personal growth occurs in this context and if so, the factors that contribute to it. This understanding will enable policy makers and practitioners alike to better understand the reality of caregivers and to enable intervention and support strategies to be designed. This research will contribute to knowledge in the fields of family caregiving, pediatric palliative care, and personal growth.

This research will occur under the auspices of a CIHR-funded New Emerging Team (NET) grant entitled *Transitions in pediatric palliative and end-of-life care*. This NET was conceived to develop a sustainable research program focused on creating knowledge and evidence to optimize provision of care for children with life-limiting conditions.

THE STUDY

This research is comprised of two phases. Phase One will use 8 short scales to study demographics, personal resources, spirituality, stress and growth. Phase Two consists of in-depth interviews, conducted with up to 25 Phase One participants who have requested a follow-up interview. Participants will be asked to dedicate approximately 1 to 1.5 hour(s) to fill out the questionnaires and approximately 1.5 to 2 hour(s) to complete the interview.

PARTICIPANTS

Mothers, fathers, and other caregivers (e.g. grandparents, guardians) of children with life-limiting conditions are invited to participate and more than one parent caregiver per family may participate in the study. Parents will be recruited regardless of the length of time they have been caregiving and at any stage in the child’s illness, so long as the child is under the age of 18.

All recruitment materials request interested parents to call a toll-free number and leave a message. At this point, the Research Coordinator at Wilfrid Laurier University will return their call. When parents/guardians agree to participate, questionnaires will be mailed to them. A stamped envelope will be included in the package in order to return the questionnaires. There will also be an information sheet included in the package explaining the study. Additionally, participants will be asked if they would like to be contacted for a follow-up interview.

For more information please contact:

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