

Stress and Growth Over Time:
Caregiving and Bereaved Parents of Children with Life-Limiting Illnesses

OVERVIEW

Caring for a child with a life-limiting illness is stressful, and the death of a child due to such an illness can be very traumatic. The negative aspects of caregiving are well documented in the literature. However, it has also been suggested that in the face of such adversity, parents can experience personal growth and positive change. Little is known about positive outcomes of caregiving, particularly for parents caring for seriously ill children.

This research is a continuation of the study “Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth”. An additional 3 years of funding has been awarded to explore the stress and personal growth of parents over time whose child has died. New knowledge obtained from this study will be of tremendous value to parents, practitioners and policy makers concerned with childhood life-limiting illness. Pathways leading to positive outcomes will be identified through this study and will then be used to optimize the emotional, social, and spiritual care available to patients and families receiving pediatric palliative services, including bereavement care.

THE STUDY

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?”

This research is comprised of two phases. Phase One will use 8 short scales to study demographics, personal resources, spirituality, stress and growth and will be sent to the participant twice, one year apart. A stamped return envelope will be provided along with an information sheet explaining the study in detail. Phase Two consists of in-depth interviews, conducted with a select number of Phase One participants. There is no obligation to participate in the interview phase and parents may opt out of the study at anytime without consequence. It is expected that parents will need 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) who have lost a child to a life-limiting illness are invited to participate. All parents and other caregivers are welcome regardless of the length of time they have been caregiving and at any stage after the child’s death, so long as the child was under the age of 18. More than one parent caregiver per family may participate in the study and both mothers and fathers are strongly encouraged to share their experiences.

If interested in participating or obtaining more information about the study please call 1-800-810-0721 and leave a message. A research assistant at Wilfrid Laurier University will return your call. Alternatively you may contact the research coordinator at the telephone number or email address below.

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