

Caregiving Parents of Children With Life-Limiting Illnesses: Beyond Stress and Coping To Growth

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Background

- Caring for an ill child has been established as highly stressful and even traumatic for parents (Hawley, Ward, Magnay, & Long, 2003; Sloper, 2000).
- There is a scarcity of research that accounts for the complex stress processes, constructs, and factors that are part of parent caregiving experience (Raina et al., 2004); this is especially true within the context of pediatric palliative care.
- The majority of research that has looked at caregiving in the context of illness concerns the care of adults, not children, and has concentrated on negative outcomes.
- The tide is beginning to turn and positive aspects of caregiving are slowly gaining attention in the literature (e.g., Tebb, 1994); one aspect being personal growth (e.g., Weiss, 2004; Cadell, 2001, 2003).
- Personal growth is considered to be the positive changes people experience as a result of adverse circumstances (McMillen, 1999; Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1995). The concept of growth goes beyond resilience, in that it encompasses thriving: where one surpasses their pre-stressful state.
- People have been observed to grow from traumas such as natural disasters (Thompson, 1985), disability (Dunn, 1994), sexual assault (Burt & Katz, 1987), and bereavement (e.g., Lehman, Davis, Delongis, Wortman et. al, 1993).
- Although recent research has explored growth in caregivers, including parent caregivers of children with disabilities (e.g. Konrad, 2006), there is a paucity of research that considers growth in parents who are caring for a child with a life-limiting illness.

Objectives

This research aims to address 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 **specific research objectives** that will guide the research are as follows:

1. To test a structural equation model of factors that contribute to growth in parent caregivers of children with life-limiting illnesses, and
2. Through in-depth interviews with parent caregivers of children with life-limiting illnesses, to describe in detail the personal growth that parents experience and the factors that allow for it.

Methods

FIRST PHASE DATA COLLECTION

- Data was collected through a cross-sectional survey of 273 parent caregivers throughout Canada.
- Questionnaires examined stress, meaning making, spirituality, personal resources and growth.
- Participants were recruited through affiliations with children's hospices and hospitals in Canada and the US as well as through various organizations who support parents of children with life-limiting illnesses.

ANALYSIS

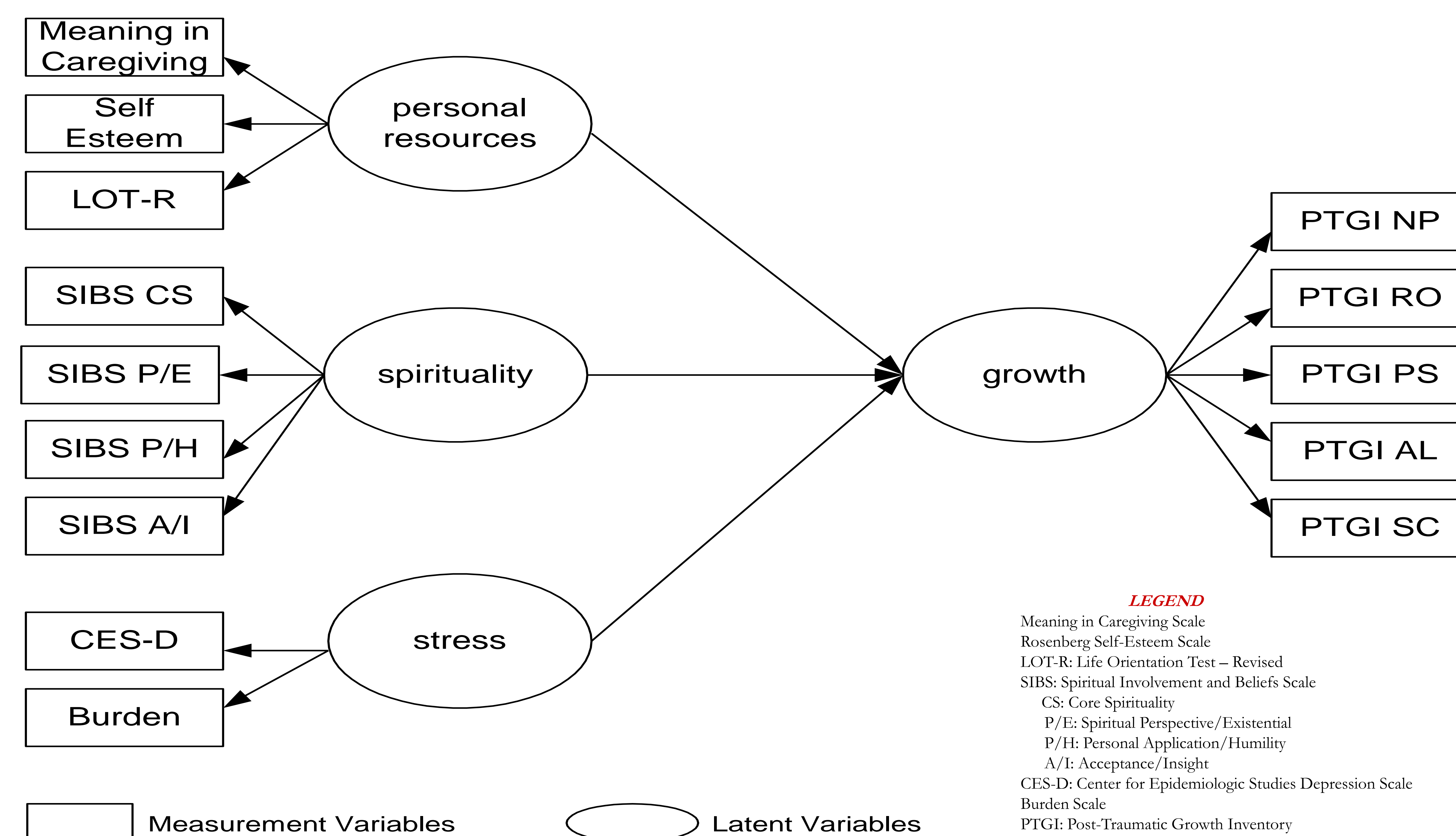
- Structural equation modeling will be used to test a model of factors that allow for personal growth in caregivers.
- Specifically, the following hypotheses will be tested:
 1. Caregivers who report more personal resources will demonstrate more growth
 2. Caregivers who report more spirituality will have more growth
 3. Caregivers who demonstrate higher levels of stressors will have more growth

SECOND PHASE DATA COLLECTION

- Survey participants were asked if they would be willing to be contacted for follow-up research.
- Of those who said yes (92%), a purposive sample will be recruited, seeking representation along the following variables:
 - Geographical location
 - Levels of growth indicated by the survey
 - Gender
- Interviews will be conducted in person, recorded, transcribed and analyzed for themes using the constant comparative method.
- To date, 13 interviews have been completed and are being analyzed.

FINAL SAMPLE DEMOGRAPHICS

- Total number of participants= 273
- 47% from Canada
- 53% from U.S.
- Majority of caregivers were female (n=224, 82.1%)
- Most caregivers were married (n=219, 80.2%)
- Child age range: 6 months to 20 years
- Diagnosed conditions include (but not limited to):
 - Zelwegger's Syndrome
 - Spina Bifida, Cystic Fibrosis
 - Cancer (leukemia, astrocytoma, blastoma)
 - Muscular Dystrophy
 - HIV
 - Cardio-Facio-Cutaneous Syndrome
- Annual family income was less than \$60,000 for 37.6% of parents (n=99), almost 2/3 (n=176, 64.7%) experienced a change in income because of the child's illness, and about 43% (n=117) found their current income did not at least adequately meet their needs.



Results to Date

BURDEN

- Burden does not affect meaning (MCG) or spirituality (SIBS) but it does correlate negatively with self-esteem and optimism, and positively with depression.

PTGI

- Has a strong positive correlation with meaning (MCG), self-esteem (RSES), and spirituality (SIBS), but does not correlate with depression (CES-D), optimism (LOT-R), or burden.

MEANING IN CAREGIVING

- MCG has a positive correlation with self-esteem (RSES), optimism (LOT-R), spirituality (SIBS), and PTGI, and is negatively correlated with depression. It does not correlate with burden.

SPIRITUAL INVOLVEMENT AND BELIEFS SCALE

- It has a positive relation with meaning (MGC), self-esteem (RSES), optimism (LOT-R), and PTGI, and a negative correlation with depression. It has no correlation with burden.

GENDER CONSIDERATIONS

- There was no gender difference in self-esteem scores (RSES).
- Women had lower Optimism (LOT-R)
- Women had higher depression levels (CES-D), perceived burden level, spirituality and PTGI and MCG.

Next Steps

- **Renewal funding has been granted by CIHR to continue this important research.**
- This funding will allow for a longitudinal sample, along with the inclusion of a second cohort of parents, those who are bereaved.
- All participants who agreed to be contacted for follow-up will be invited to complete the survey again at two additional timepoints.
- Active recruitment of parents who are bereaved will occur with a goal of approximately 200 parents to complete the survey at two timepoints.
- This longitudinal data will be instrumental in understanding growth in parents of children with life-limiting illnesses and will allow for further testing of the SEM model.

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