

Better Understanding How Couples Cope With a Child's Life-Threatening Illness

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Background

Currently there is a **paucity of research exploring the experience of couples** caring for children with a life-threatening illness (LTI), particularly in assessing how **relationship factors may facilitate positive changes** and growth for these mothers and fathers.

This ground-breaking research employs **mixed methodology to explore the experience of couples** who are together caring for a child with a LTI across two points in time.

Parents play an integral role in influencing their family's quality of life, thus it is important to explore the realities of couples caring for a child with a LTI. Members of the Pediatric Palliative Care team must be cognizant that the marital relationship of couples impacts the ill child's adjustment and well-being.

There is a wide variation in how couples may be affected by the caregiving experience. Although, the literature has documented the challenges that couples face, there is an absence of studies focusing on how couples may benefit from the caregiving experience and how relationship factors contribute to outcomes.

Research into the experience of caregiving parents has relied almost exclusively on maternal reporting (Macdonald, Chilibeck, Affleck, Cadell, in press; Ylven, Bjorck-Akesson, & Granlund, 2006). **Researchers aiming to provide a complete and balanced understanding of couples' caregiving experience must consider the possibility of positive outcomes and broaden their focus to include the voice of fathers.**

Research into the experience of mother-father dyads is an essential step in the development of effective intervention strategies designed to address the needs and identify the strengths of couples caring for a child with a LTI.

Objectives

This research addresses the question **"How do couples cope together and even grow together in the face of the stressful circumstances of caring for a child with a life-threatening illness?"**

To explore how caregiving affects couples and the influences that couples have on one another's personal growth.

This research adds to the small number of studies that have ascertained information from mothers and fathers actively caring for children with a range of life-threatening medical conditions.

Methods

The Couples Study is an extension of the CIHR-funded study entitled *"Caregiving Parents of Children with a Life-Limiting Illness: Beyond Stress and Coping to Growth"*

Overview Caregiving Parents Study Methodology:

- Data collected through a cross-sectional survey of 273 parent caregivers throughout Canada and the United States.
- Questionnaire packages – demographic survey, measures assessing personal resources, spirituality, stressors, perceptions of burden and personal growth.
- Participants 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.
- ❖ Project status: All data is collected and being analyzed.

Better Understanding Couples Study:

- Participants** - Caregiving couples who indicated they were willing to be contacted for follow-up research (N = 60) were contacted 6 to 12 months after T1.
- Twenty-six couples (N = 52) volunteered for Couples Study. All couples completed the questionnaires a second time.
- 12 couples from across Canada participated in face-to-face semi-structured interviews.
- Couples were interviewed together about **positive and negative experiences** associated with their child's illness.
- ❖ Project status: 46 of 52 individuals have completed the second survey. Transcription and analysis of interviews is underway.

Interview Schedule

Topics addressed in couple interviews included:

- History and impact of child's diagnosis
- Family composition and demographics
- Stressors and barriers
- Division of caregiving duties and others household tasks
- Personal and community resources and supports
- Role of spirituality
- Perceptions of personal growth and lessons learned
- Relationship factors – how partners support and respond to one another's needs, aspects considered beneficial to coping as a couple, and how have grown as a couple
- Participants were asked if they have advice they would like to share with other parents and health care providers

Growth & Relationship Factors - Emerging Themes

Change in priorities – **"We used to worry about making money. Now our family is the priority."** **"It just puts things in perspective"** **"Success is family and friends."**

Change in attitude/ approach to life – **"I've mellowed"** **"I don't worry about things I used to worry about."** **"I take life slower . . . I'm excited about little things."**

Learn to be an advocate and to persevere – **"If you want something, there's a way."** **"I used to be shy . . . I'm more pushy and bossy now."** **"I'm putting her story out there . . . raising awareness about her condition."**

Caring less what other people think – **"I'm less of a people pleaser."** **"It's not about pleasing other people."**

Feel relationship has been tested – **"You could easily lose sight of one another."**

Appreciating time together – **"We don't complain about each other. We want to spend time together. . . Like just going out together to have a beer. We want to have fun together."** **"Quality versus quantity!"**

Becoming stronger and closer as a couple. Describing themselves as a team – **"We can rely on each other"** **"We've learned how to fend for ourselves."**

Growing together – **"We're moving in same direction"**

Providing balance for each other – **"(My wife) slows me down. Makes me mellow out instead of being like - just do it!"** **"We balance each other out. Sometimes I'm up here and he's calm and sometimes I'm the calm one."**

Appreciating each other – **"He works so we can pay the bills and I can go the hospital and to appointments. He's stable. . . It's nice to know I can count on him."**

One couple's advice to other couples: Remind each other to play, remember to laugh, take care of each other.

Implications

This study not only adds to the growing literature in the areas of **positive psychology and personal growth**, but also **contributes to the fields of pediatric palliative care and parental and family functioning** in the context of childhood illness and disability.

Examining relationship factors and the experience of couples serves to **benefit all family members**. Thus, this family-centred research will not only facilitate the psychosocial well-being and **quality-of-life in parents, but also for the ill child, siblings, and extended family members**.

Enhancing our understanding of this parenting experience will allow **policy makers and health care professionals alike to better understand the reality of families with a child with a life-limiting illness** and will guide the design and implementation of intervention and support strategies.

References

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