

What We Set Out To Do ...

As a group of pediatric palliative care professionals we acknowledged that caring for an ill child can be highly stressful and perhaps even traumatic for parents. We also recognized that very little was known about the **positive** aspects of caregiving, such as **personal growth**. Personal growth pertains to the positive changes that people experience as a result of adverse circumstances. So, we asked 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?”*

You will remember that you filled out a questionnaire, which looked at stress (depression, burden), meaning in caregiving, spirituality, personal resources (optimism, self-esteem) and growth (Posttraumatic Growth Inventory).

We had **3** hypotheses:

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**

What We've Learned So Far ...

We are using an analysis technique called structural equation modeling (SEM) that requires the participation of at least 200 parent caregivers. A total of **272** of you answered the questionnaire: **223 women** and **49 men**. Since more than one caregiver per household could participate, some of you were caring for the same child. The average age was **42 years** and **80%** of you were **married**. Of those that returned the questionnaires, **94%** indicated they were **willing to be contacted for future research**. *This was a strong message to us and the Canadian Institutes for Health Research (CIHR) about the importance of this study!*

We are still analyzing the data, conducting interviews and working on the SEM, but we wanted to share some of the highlights of our results to date. Please remember, these are overall results about trends in the data and not necessarily reflective of individual scores or of individual people. The full results of our study will be distributed at a later date.

Personal Growth

Overall, participants expressed that they **experienced growth** as measured by the Posttraumatic Growth Inventory. In addition, the results indicate that as meaning in caregiving, self esteem and spirituality scores went up, the growth score got stronger as well. No relationship was found between growth and depression, optimism and burden scores.

Also **worth noting** is that as depression scores of the participants went up, so did caregiver burden. In contrast, as depression scores went up, the overall scores of meaning in caregiving and spirituality went down. When burden got higher, self esteem and optimism tended to go down.

Some other findings:

- ✚ As **self-esteem** goes up, meaning in caregiving goes up
- ✚ As **optimism** goes up, meaning in caregiving goes up
- ✚ As **spirituality** goes up, meaning in caregiving goes up
- ✚ As **spirituality** goes up, self-esteem goes up
- ✚ As **spirituality** goes up, optimism goes up

Other scores did not have relationships to one another.



Who We Are ...

The research team is made up of **7** individuals and **4** affiliated institutions.

- ✚ **Dr. Susan Cadell**, Principal Investigator of this study, is a social work professor and Director of the Manulife Centre for Healthy Living in the Lyle S. Hallman Faculty of Social Work at Wilfrid Laurier University in Kitchener-Waterloo, Ontario

The Co-Investigators are:

- ✚ **Dr. Betty Davies**, a nursing professor at the University of Victoria in British Columbia and the University of California, San Francisco
- ✚ **Dr. Rose Steele**, a nursing professor at York University in Toronto, Ontario
- ✚ **Dr. Hal Siden**, a physician working as Medical Director of Canuck Place Children's Hospice and a professor of pediatrics at the University of British Columbia, both in Vancouver, BC
- ✚ **Dr. Lynn Straatman**, a pediatric cardiologist with adult cardiology training working at Canuck Place Children's Hospice
- ✚ **Dr Stephen Liben**, a physician and professor of pediatrics at McGill University in Montréal, Québec
- ✚ **Dr. David Hemsworth**, a professor of business at Nipissing University in North Bay, Ontario and specialist in structural equation modeling

Where We Go From Here ...

In 2009 our team received funding from CIHR to do an **additional 3 years** of research in this area. We proposed to follow up with those of you who agreed to be contacted for future research and to do the survey **2 more times over the next 3 years**. Because some of you shared with us that your child had died, we decided to create a new group, made up of bereaved parents, who will be invited to answer the questionnaire. We will also conduct more interviews.

We Want to Say Thank You ...

We want to extend a **big thank you to all of you** for participating. If you agreed to be contacted, you may have already heard from us, or will soon. If you did not, thank you again for your first involvement.

We Thought You'd Also Like to Know ...

Because very little research has examined couples who care for an ill child together, we decided to do an additional project with the couples among you. **25 couples did a second survey** and **12 were interviewed together**. We received a grant from the SickKids Foundation in Toronto, Ontario to support this project.

A significant number of students were trained in research through this project. **2 students** did their Master in Social Work (MSW) theses at Wilfrid Laurier University:

Ouellet, M. (2009). Mothers' Experiences of Care Provided to their Child with a Life-Limiting Illness.

Kennedy, K. (2009). Personal Growth in Couples Caring for a Child with a Life-Threatening Illness.

- ✚ **9 Master's students in Social Work** at Wilfrid Laurier University worked on this project, along with **2 PhD students**: **1** at McGill University in Montréal and **1** at University of California San Francisco
- ✚ **1 Master's student in Nursing** at York University worked with us to examine differences between the men's and the women's responses to the questionnaire. A report of the results, "Differences on psychosocial outcomes between male and female caregivers of children with life-limiting illnesses" was written by M. Schneider, R. Steele, S. Cadell & D. Hemsworth and will be published in the Journal of Pediatric Nursing.

To Learn More ...

Call **1-800-810-0721** to leave a message for our Project Co-ordinator, Kathy Wilson **OR** email kwilson@wlu.ca
Visit http://pallpedsnet.ca/net_projects/pg_study.htm

Thanks to our Partners ...

