

*Spirituality and Growth in Couples Caring for a Child with a Life-limiting Illness*

(Comments to accompany PowerPoint presentation)

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Presented at The **Fifth North American Conference on Spirituality and Social Work** held  
from June 17-19, 2010, in Calgary, Alberta, at the University of Calgary.

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**Abstract:**

Little is known about possible positive outcomes for couples caring for a child with a life-limiting illness. This presentation will report on ground-breaking research designed to examine the relationship between a range of variables and personal growth in 25 caregiving couples over two points in time. In addition to considering how religion and spirituality may be related to reports of growth, this research compares mothers and fathers to address the question of whether there are significant differences between genders. While being among less than a handful of studies to consider personal growth in couples, this is the first time growth in couples involved in pediatric palliative care has been examined and one of the rare examples of the examination of growth over time.

Implications for all professionals working in pediatric palliative care are discussed. The role of spirituality is emphasized, along with the need for social workers and health care team members to create an environment where couples are open to sharing and reflecting upon personal beliefs and experiences.

**Biography:**

**Susan Cadell** is an Associate Professor and the 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. Her research concerns positive aspects of stress and coping in various health situations, particularly posttraumatic growth. She is a member of several multidisciplinary research teams in pediatric palliative care. Susan is currently funded to investigate the positive aspects of such adverse situations as caring for a child with a life-limiting illness and parental bereavement. She is also a member of a team working to increase social work education in palliative care through the development of social work competencies into curricula.

**Kimberly Kennedy** is a Project Coordinator with the Manual Life Centre for Healthy Living at Lyle S. Hallman Faculty of Social Work at Wilfrid Laurier University in Kitchener-Waterloo, Ontario. While working toward her MSW at Laurier, she completed a research traineeship with a research team investigating pediatric palliative and end-of-life care. Her master's thesis focused on personal growth in couples caring for a child with a life-threatening illness.

## **Comments to accompany PowerPoint presentation**

**Slide 2:** From a father who's son had died at age 10 from an undiagnosed neurological condition.

The mother went on to describe walking into her son's room in the morning and seeing him standing up in his crib with a big smile – and that was all they needed to keep going.

**Slide 3:** This presentation reports on both quantitative data from the questionnaires and what couples said about spirituality and growth during interviews.

- ☞ Possible gender differences
- ☞ Changes in scores over time
- ☞ Relationship between spirituality & growth
- ☞ Relationship between spirituality & religion
- ☞ Spirituality within couple dyads

**Slide 7:** In addition to considering how religion and spirituality may be related to reports of growth, this research compares mothers and fathers to address the question of whether there are significant differences between genders.

**Slide 8:** PTGI – assesses positive change across a range of areas following a life crisis or trauma – generates a total growth score as well as 5 index scores

**Slide 9:** PTGI – parent use 6 point Likert scale to score 21 items

### **Slide 10: Items contributing to each scale**

#### *Relating to Others*

I more clearly see that I can count on people in times of trouble.

I have a greater sense of closeness with others.

I have greater compassion for others.

I put more effort into my relationships.

I better accept needing others.

I learned a great deal about how wonderful people are

I have a greater willingness to express my emotions.

#### *New Possibilities*

I'm more likely to try to change things which need changing.

I'm able to do better things with my life.

New opportunities are available which wouldn't have been otherwise.

I established a new path for my life.

I developed new interests.

### *Personal Strength*

I have a greater feeling of self-reliance.

I know better that I can handle difficulties.

I discovered that I'm stronger than I thought I was.

I am better able to accept the way things work out.

### *Spiritual Change*

I have a better understanding of spiritual matters.

I have a stronger religious faith.

### *Appreciation of Life*

I have a greater appreciation for the value of my own life.

I can better appreciate each day.

I changed my priorities about what is important in life.

**Slide 11:** Original 39 item scale shortened to 22

Four factors – not used in current study. Used total score for analysis

Core spirituality (Connection, meaning, faith, involvement and experience)

Spiritual perspective/existential

Personal application/humility

Acceptance/insight (i.e.. insight into futility of focusing attention on things which be changed)

**Slide 12:** Couples were interviewed together.

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

**Slide 14:** The advantage sample of couples - by conducting paired samples t-test the argument that differences are due to gender is strengthened because shared variables, i.e.. number and age of children, household income, geographical location are controlled for.

In the current study no significant differences were found between personal growth scores (total growth and index) or spirituality scores of mothers and fathers.

Note: in sample of 36 couples that took part in T1, mothers mean Total Growth score was significantly higher than the fathers.

Caution: Researchers will report that differences were found between males and females when differences were not statistically significant or were only in one subscale

Comparing the perceptions of a mother and a father caring for the same child enhances the understanding of how gender may affect the manifestation of growth. The considerable overlap in personal growth supports the view that professionals in health care should be encouraged to challenge their own stereotypes and assumptions regarding gender roles.

**Slide 15:** Quote from a mother about her husband seeking support from her and her struggle to provide that.

This quote illustrates that the assumptions we often make about who looks to whom for emotional support in a household aren’t always accurate. – how does this influence interventions and care provided by health care teams?

**Slide 16:** for the full sample of parents . . .

**Slide 17:** For group of fathers . . .

And mothers . . . SIBS significantly correlated with total growth and 3 of 5 subscales.

**Slide18:** A mother reports how spirituality and growth are related for her.

**Slide 19:** Paired sample t-test to access change in scores from Time 1 to Time 2 (similar to pre and post scores - that is MomA at T1 compared to MomA at T2)

Looked at SIBS total score as well as total growth and index scores

Mean mothers SIBS scores increased, significant difference between T1 and T2

Ongoing Parent caregiver study: Longitudinal study following parents for two more time points will allow questions about change over time to be addressed in greater detail.

**Slide 20:** In certain cases changes that were questioned on the SIBS and PTGI actually took place prior to the child's diagnosis. For example this mother who had a brother die when she was younger. Another mom talked about her spirituality being related to quitting drinking.

**Slide 21:** Sometimes when time is limited it just comes down to a change in priorities.

**Slide 22:** Couples were divided into four groups based on where each partners score fall in relation to their gender median score, there were no significant differences b/w the number of couple who had congruent and incongruent scores

**Slide 23:** More were congruent, but there were no significant differences b/w the number of couple who had congruent and incongruent scores at t1.

Note, when score incongruent, which parent had high/low scores – equally as likely to be father as mother (4 and 4)

Both high = 9

Both low = 8

Mom high / dad low = 4

Dad high / mom low = 4

**Slide 24:** Or T2

Both high = 8

Both low = 7

Mom high / dad low = 4

Dad high / mom low = 5

**Slide 25:** After a discussion about who believes what the father made this comment – they just don't talk about it.

**Slide 26:** For others, it was their fundamental beliefs that brought a couple together

**Slide 27:** Many parents felt the need to distinguish between religion and spirituality. When asked the question about spirituality, many would begin with a comment about their participation in

church or belief in God – then they might add something about their personal belief system, i.e. what is meant to happen will happen, there is good and bad in everyone.

**Slide 29:** Parents ranked importance of religion using 4 categories.

SIBS question # 22 was compared to Religion (How spiritual a person do you consider yourself?)

We had a question included on spirituality (help/hinder or what role does spirituality have?)

Some parents raised the topic before the question was asked. Usually when this happened parents were talking more about organized religion, for example their involvement in church or people from the church as a support, or a negative experience they had with a representative of a church.

When asked the question many parents would give one sentence and “I believe” Or “I’m fairly spiritual” and then reference this by talking about their involvement in church

**Side 30:** At T1: Those who reported that religion was very important and of medium importance had significantly higher scores than those who reported it was of little or no importance.

**Side 31:** At T2: Those who reported that religion was very important had significantly higher scores than those who reported it was of medium, little or no importance.

Means : Very = 4.11, med = 2.9 of little = 2.23; not at all = 2.13

**Side 32:** Utilize quotes from couple interviews to illustrate how spirituality and growth are related for parents who are caring for a child with a life-threatening illness.

**Side 34:** Family had stopped going to their own church because they felt they were always being asked for more and more money. Also family did not get any support from the church following daughter’s diagnosis and treatment – this was acknowledged by the minister. Yet, the youth leader from a church the family had never attended proved to be a valuable support for both the daughter and parents.

**Side 35:** Didn’t want to be this strong.

**Side 36:** Becoming a better person.

**Side 37:** How spirituality helped one mother accept her situation and she sees herself as continuing to evolve.

**Side 38:** Mother talked about how she use to be the quiet one in school - and now she is an advocate for her child. She started a walk in her community to raise awareness about her daughter's condition.