

Spirituality and Growth in Couples Caring for a Child with a Lifelimiting Illness

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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.

Biographies:

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.



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There were more moments where you got so much out of it. Which I think is also spiritual. What is spirituality? It's finding this sudden capacity to regenerate or to believe in something else which allows you to kinda get up the next morning and do it over again. And he gave us that.



Objectives

Report on quantitative and qualitative findings on spirituality and personal growth in couples who are together caring for a child with a life-limiting illness.

Presentation Outline

- **S** Background
- © Overview & Goals of Study
- **Methods & Measures**
- **CS** Results
 - **©** Quantitative and Qualitative Findings
- **S** Intersection Between Spirituality & Personal
- Growth
- **©** Discussion



Background

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 children's hospices and hospitals, and various organizations that support parents of children with life-limiting illnesses.



Overview

Better Understanding Couples Study:

- Participants Couples who indicated they were willing to be contacted for follow-up research (N = 60) were contacted 6 to 12 months after T1. (Range 4 months 18 months)
- Twenty-five couples (N = 50) completed the questionnaires a second time.
- 13 couples from across Canada participated in face-to-face semistructured interviews.
- Couples were interviewed together about positive and negative experiences associated with their child's illness.

Goals of Study

Goal ONE

Differences/similarities in spirituality and personal growth between mothers and fathers

Goal TWO

Relationship between spirituality and personal growth

Goal THREE

Changes in spirituality and personal growth overtime

68 Goal FOUR

Test for congruency of spirituality within couple dyads

Goal FIVE

Relationship between religion and spirituality



Personal Growth

Posttraumatic Growth Inventory (Tedeschi and Calhoun, 1996)

Total Growth

Relating to Others



Interpersonal Growth

Personal Strength New Opportunities



Change in self, e.g. more competent, self-assured

Appreciation of Life Spiritual Change



Change in overall philosophy and appreciation of life.

Tedeschi, R.G., & Calhoun, L.G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9, 455-471.



Personal Growth

PTGI

Indicate for each of the statements below the degree to which this change occurred in your life <u>as a result of</u> the illness of your child, using the following scale.

0 = I did not experience this change.

1 = I experienced this change to a <u>very small degree</u>.

2 = I experienced this change to a small degree.

3 = I experienced this change to a <u>moderate degree</u>.

4 = I experienced this change to a great degree.

5 = I experienced this change to a <u>very great degree</u>.



Personal Growth Items

Relating to Others (7)

I more clearly see that I can count on people in times of trouble. I put more effort into my relationships.

Personal Strength (4)

I have a greater feeling of self-reliance.

I know better that I can handle difficulties.

New Opportunities (5)

I developed new interests.

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

Spiritual Change (2)

I have a better understanding of spiritual matters.

I have a stronger religious faith.

Appreciation of Life (3)

I changed my priorities about what is important in life.

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



Spirituality

Spiritual Involvement & Beliefs Scale – Revised (Hatch et al., 2000)

- I set aside time for meditation and/or self-reflection.
- I can find meaning in times of hardship.
- I find serenity by accepting things as they are.
- I have a personal relationship with a power greater than myself.
- I have been through a time of suffering that led to spiritual growth.
- In times of despair, I can find little reason to hope.
- Prayers do not really change what happens.

Hatch, R.L., Burg, M.A., Naberhaus, D.S., & Hellmich, L.K. (1998). The Spiritual Involvement and Belief Scale: Development and testing of a new instrument. *Journal of family Practice*, 44, 476-487

K.Kennedy & S.Cadell (June 17-19, 2010)

Qualitative Data Semi-structured Interview

- s History and impact of child's diagnosis
- S Family composition and demographics
- Stressors and barriers
- Division of caregiving duties and others household tasks
- 128 Personal and community resources and supports
- **Role of spirituality (How does spirituality help or hinder?)**
- **G** Perceptions of personal growth and lessons learned
- Relationship factors and how have grown as a couple
- © Participants were asked if they had any advice they would like to share with other parents or health care providers







Goal ONE – Gender Differences

No significant differences were found between the spirituality (SIBS) or growth (PTGI) scores of mothers and fathers at Time 1 or Time 2.

Goal ONE - Gender Differences

Well, and I think we grieved in separate ways. Tom came to me for comfort and I just shut down, you know. Don't come near me, I can't handle you. I can't handle myself.



Goal TWO – Relationship Between Spirituality & Personal Growth

G Full Sample

Spirituality positively correlated with:

Time I	Time 2
Total Growth* Spiritual Change**	Total Growth** Relating to Others** Personal Strength** Spiritual Change**

^{*} p < .05

^{**} *p* < .01



Goal TWO - Relationship Between Spirituality & Personal Growth

G Fathers

Time I	Time 2
Spiritual Change**	Relating to Others** Spiritual Change**

Mothers

Time I	Time 2
Spiritual Change**	Total Growth** Relating to Others** Personal Strength** Spiritual Change**

^{*} *p* < .05 ** *p* < .01

Goal TWO - Relationship Between Spirituality and Personal Growth

I think that's what I get from my walks.
I love to see nature. I love to see winter, spring, fall, hear the birds and slow down. And that's where my spirituality comes from. It gives me great strength.



Goal THREE – Change in Spirituality & Personal Growth Scores overtime

Time between T1 & T2 ranged from 4 months to 18 months (M = .84 years or 10 months)

Full Sample	Fathers	Mothers
n/s	n/s	*SIBS (p=.034) TI >T2

*T1 M = 76.42 (18.78)T2 M = 73.25 (18.98)

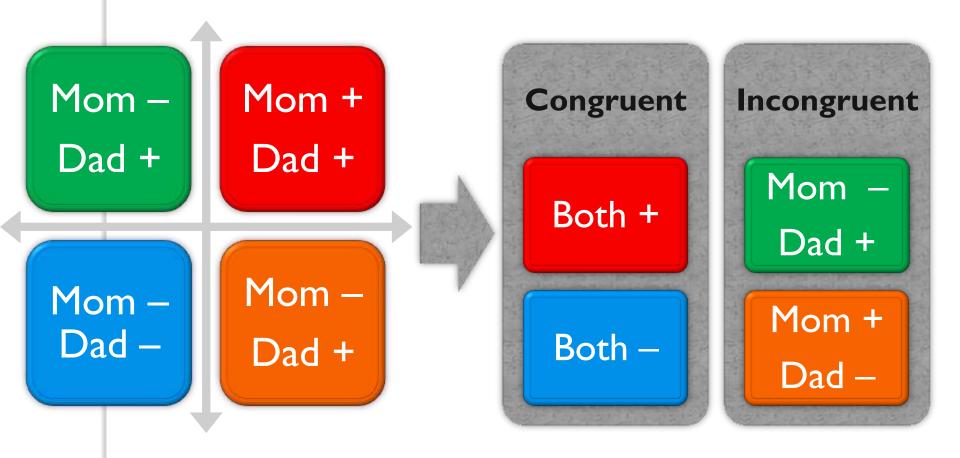
Goal THREE - Change Over Time

I went through a lot of it when I was younger. I had a brother that died and he was buried on his 19th birthday and that's when I went through that. If there was a God than he was a very cruel God. I got that all out of my system when I was younger and was able to put positive energy into this.

Goal THREE - Change Over Time

I went for two or three years without reading my Bible at all, then I went back to it and lasted about 4 months, and that's it. And it's not that I don't get anything out of it, but it's like it gets to a point where it's what's going to give you the most, to read a nice French classic or my Bible. And at this point it's the nice French classic.

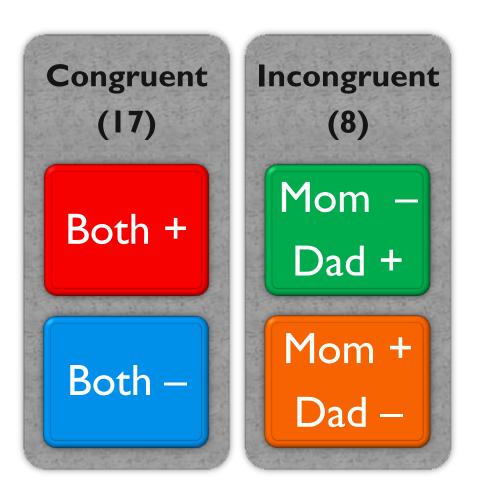
Goal FOUR - Degree of Congruency within Couple Dyads



Goal FOUR - Degree of Congruency within Couple Dyads

Time ONE

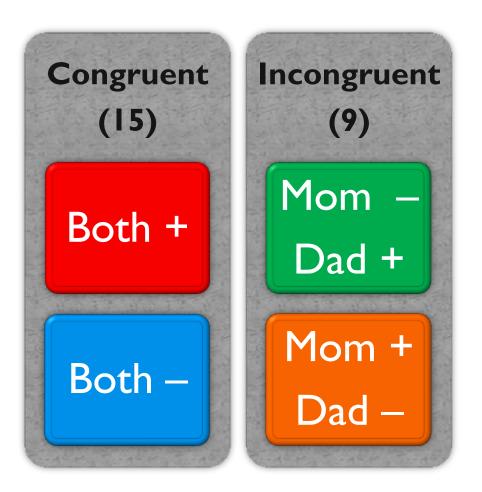
No significant difference in the proportion of couples with congruent and incongruent scores (p = .072)

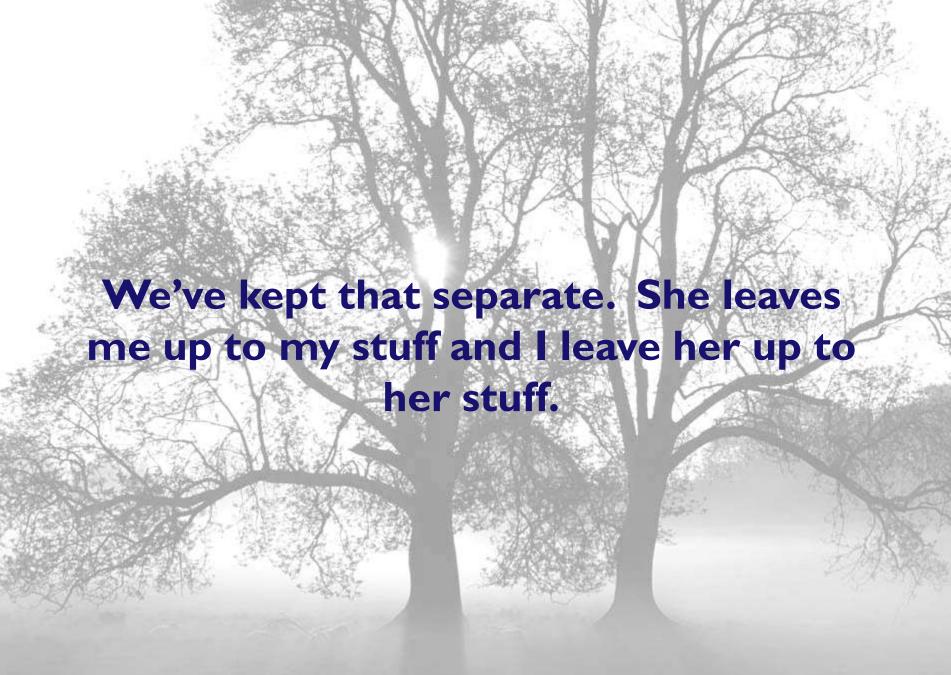


Goal FOUR - Degree of Congruency within Couple Dyads

Time TWO

No significant difference in the proportion of couples with congruent and incongruent scores (p = .221)





I think one of the things that Mary and I, one of the reasons we liked each other was that kind of view point that um, that for us spirituality and practicality go hand in hand ...we both have real social justice kind of bent in our lives. And um, and so, that's why we got together in the first place and it's kind of still what is really important to us.

Religion & Spirituality

I don't get a lot from scripture.

But that doesn't mean that I am not spiritual.

Goal FIVE - Religion & Spirituality

It doesn't play a big part. I mean I believe but at the same time I don't need to go to church regularly and its basically, it's a building is what it is in my mind. I really had no set church that I'm set on. It doesn't really matter, a church is a church. They all have their own little idiosyncrasies. I believe - but it hasn't played a big role in getting me through this I don't think.



Goal FIVE – Religion & Spirituality

Religion:

How important is religion to you?

S Very Important

Of Medium Importance

Of Little Importance

3 Not at all Important

Spirituality:

How spiritual a person do you consider yourself? (1 to 5)



Goal FIVE – Religion & Spirituality at Time 1

VERY Important

Medium

Of Little Importance

Not at All

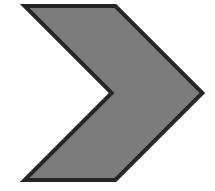


Goal FIVE – Religion & Spirituality

Time 2

Medium

VERY Important



Of Little Importance

p < .01

Not at All



Intersection Between Spirituality & Growth

- 1 Interpersonal change
- Change in self
- Change in philosophy or appreciation of life

S Finding meaning

Interpersonal Change

And that's one thing that really irks me is like his family is really religious - like when we would eat at the table we have to bless the food first and whatever. And they've got little God sayings all over the wall, yet they completely disowned us after we had a child with a severe disability ... And what I got out of the Bible was you do onto others as you want onto you... I never once prayed to God. I don't need him in my life. What I need is love, family. My family and love is what gets us through everything I think. And positive thinking.

Interpersonal Change

It's the Baptist church - none of us have ever been Baptist in our life. Three days after transplant that man (youth group leader) was in the ICU holding her. She's gotten more support from that church...

Change in Self

I gotta tell you though, I hate when people say "What doesn't kill you makes you stronger". It's my worst thing I think more than anything.

Because I tell people "I didn't want to be this strong." I really, really didn't.

Change in Self

I felt like my struggle was just part of my becoming a better person. Like, a more Godly person, or a more God-centered person. And that God has a, you know wants me to help others in that same... After we started going to support groups, we learned that even though we're all strangers in the room, we all sought a deeper understanding having all gone through the same experiences.

Change in Philosophy/Appreciation of Life

Well, before I quit drinking, I didn't have an ounce of spirituality in me and now that I have quit drinking and I'm going to AA, I'm just embracing spirituality and at this point in my life, yeah. It's helped me just to accept things and pray for things and have faith that things are the way they're supposed to be. . . Quitting drinking has been the biggest thing in my life and as far as growth goes, its just beginning. So reframing how I think and what I accept and how I act daily is just evolving.

Change in Philosophy/Appreciation of Life

Dad: If something's gonna happen it's gonna happen. Go outside and get struck by lightning. You never know. If it's gonna happen, it's gonna happen.

Mom: I think so too. Whether it's God or something else, I don't know, if it's gonna happen it's gonna happen. And I believe that you have to make the best. You can't just sit down, because some parents, something that happens, sit down and cry... "Ahh, what do you wanna do?" "We can't do anything." Well, you gotta do something, that's why I started the walk.

Searching for Meaning

If part of spirituality is asking yourself questions about why is this happening to Jake? To us? You know, what is the purpose? Or is there some higher purpose? Or, who would do this to someone? Um, you ask yourself those kinds of questions I think a lot. I don't know that you come up with sufficient answers. I certainly wouldn't have thought of turning to some minister or priest or somebody in a religious situation to get guidance on that. That wasn't why I was looking to get the answers for. Some of these questions just have no answers.

Searching for Meaning

I believe spirituality is important to me, but I don't try necessarily to find answers to everything that happens in the world, and find a reason for this or that. I think a lot of things that go on just happen. You know, whether there's a divine master behind everything or not... We have to learn and accept what comes upon us. Certainly we can see strength in the spiritual world, but it's not necessarily going to change anything.

Discussion

How and when do we start these conversations?

What does this mean for practice?