



Resilience of Family Caregivers

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Faculty/Presenter Disclosure

Relationships with Commercial Interests:

✓ Grants/Research Support

CIHR Planning Grants & Dissemination Events
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Principal Investigators:

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Learning Objectives:

Gain an appreciation of the:

1. Resilience of family caregivers
2. Attitudes and intentional activities that family caregivers maintain to continue on and bounce aback amidst life stressors
3. Positive growth that can occur when caregiving

Family Caregivers

- **The World Health Organization (WHO) defines family caregivers as those who provide informal unpaid care*.**
- **In Canada: 3.8 million family caregivers caring for seniors with short- or long-term health conditions**.**
- **These caregivers provide services valued at \$25 Billion***.**

* World Health Organization and Alzheimer's Disease International. Dementia: A public health priority. Geneva, Switzerland: World Health Organization; 2012.

** Turner A, Findlay L. Informal caregiving for seniors. Health Reports. 2012;23(3).

*** Hollander M, Liu G, Chappell N. Who cares and how much? - the imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. Healthcare Quarterly. 2009;12(2):42.

CIHR Planning Grant Conference - National and International Stakeholders

- Health Organizations - Covenant Health, AHS, Alberta Health, WHO (Programme for Neurological Diseases and Neuroscience)
- Researchers - U of A, U of C, UBC, McGill and McMaster, Stanford, Vrije Universiteit – Amsterdam
- Non-Profit Organizations - Alzheimer Society of Alberta and NWT, Alberta Caregiver Association, Institute of Health Economics, Seniors Association of Greater Edmonton

Rationale for Conference

- **Family caregivers are an integral, yet increasingly overburdened, part of the healthcare system*.**
- **They are often overwhelmed by the many stresses of caregiving, conflicting with other demands like work and childcare, resulting in deterioration of the health (physical and mental), social isolation, loss of income, family conflict and distress.**

* World Health Organization and Alzheimer's Disease International. Dementia: A public health priority. Geneva, Switzerland: World Health Organization; 2012.

• Health Council of Canada. Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada? Ontario: Health Council of Canada; 2012.

Pre-Conference

1. **Preliminary environmental scan and literature review of caregiver support initiatives**
2. **Focus groups to provide input from end-users**
3. **Development of three research foci**
4. **Creation of evidence summaries (literature search) to facilitate conference discussions**

Design, Implementation, Evaluation

Three 2hr focus groups with family caregivers (N=23)



Family caregivers were asked about:

- barriers to accessing supports and services
- knowledge and skills for caregiving
- supports available
- rewards of caregiving
- recommendations



Focus groups were transcribed and a thematic analysis conducted.



Caregiver Resilience

Resilience

Complex, multidimensional and dynamic

(Bonanno, 2004, 2005; Carver, 1998; Layne et al., 2007; Luthar et al., 2000; Rutter, 1985).

“The process of adapting well in the face of adversity, trauma, tragedy, threats and even significant sources of stress - such as family and relationship problems, serious health problems, or workplace and financial stresses.” (American Psychological Association)

Resilient Individuals



Resemble "a twig with a fresh, green living core. When twisted out of shape, such a twig bends, but it does not break; instead, it springs back and continues growing."

(George Vaillant (2002) *Aging Well*, p. 285)

Healthy Adaptation to Stress

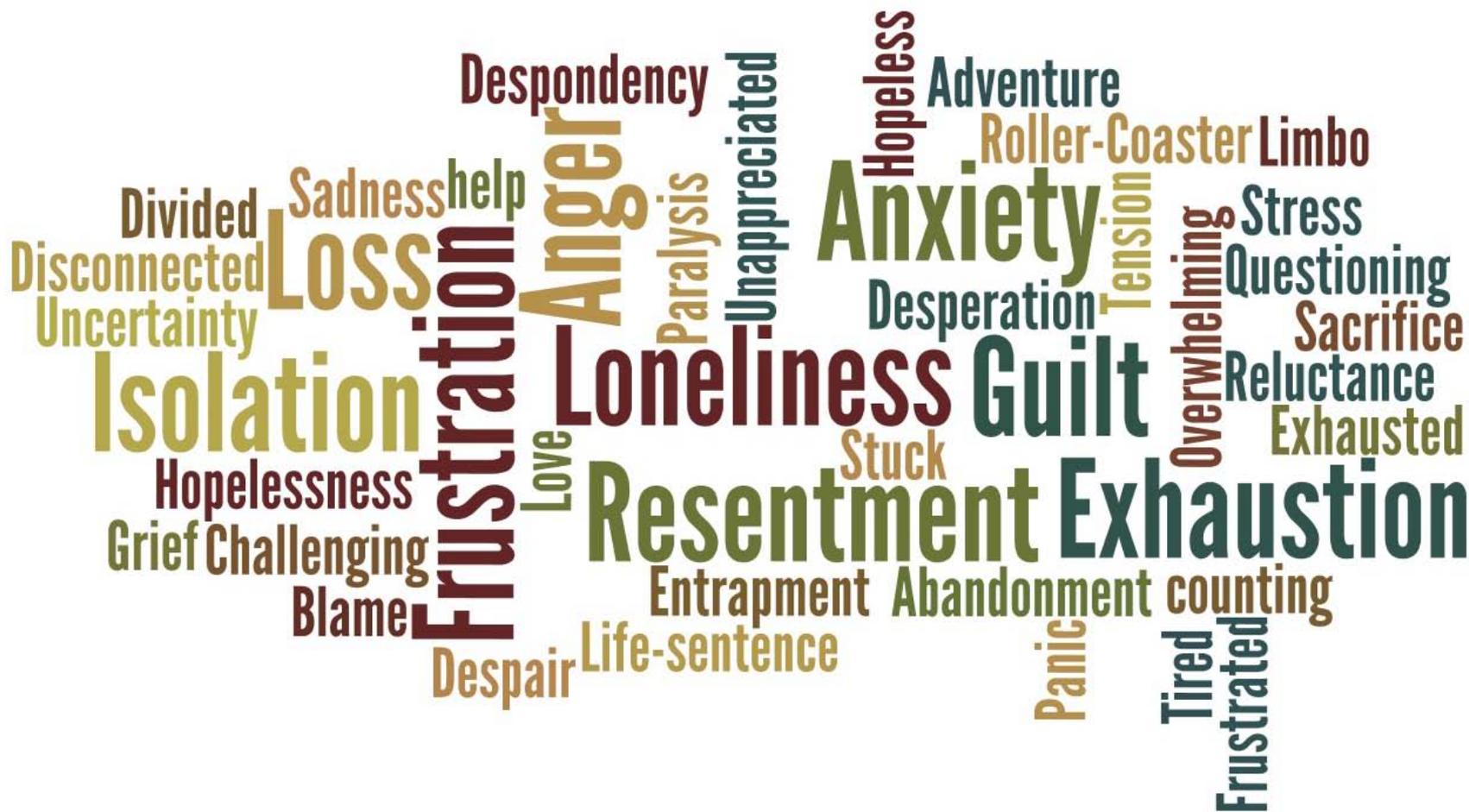
Depends not only on the individual, but also on:

- Available resources through family, friends, and a variety of organizations
- The characteristics of specific cultures and religions, communities, societies, and governments, all of which, in themselves, may be more or less resilient



Caregiver Resilience: Focus Group Findings

Caregivers Experience a Wide Range of Emotions



Caregivers Need Supports and Services

- Community: Alzheimer Association, Alberta caregiver association, brain care center, support groups
- System: respite care, HCP, facilities, educational resource, ER
- Social network: friends, family, confidante
- Private care

Moving to the Positive



A word cloud of positive terms in various colors and orientations. The words include: Duty, Faith, Reciprocity, Smiles, Quality-time, Kindness, Choice, Inner-strength, Love, Human-spirit, Recognition, Humour, Appreciation, Self-forgiveness, Commitment, Strong, and Protector.

Intentional activities

Altruism

Mindfulness/attentiveness to the moment

Reframing and acceptance

Finding renewed meaning

Openness to positive growth

Self-awareness/Introspection

Forgiveness

Humour

Spirituality

Physical activity and hobbies

Sleep

Self-care

Reciprocity and Altruistic intent

“For the first 18 years of my life my mom took care of me. Now it's payback.”

“I know my husband would go to the ends of the earth if it was me.”

“My parents were always there for me, so it's just natural that I would absolutely reciprocate”

Mindfulness/Attentiveness to the Moment

The dramatic transformation of a cherished relationship as a relative deteriorates is a major source of stress for caregivers, so a catching and relishing a glimpse of the care partner's former self is a major contributor for caregiver resilience.

“He'll turn around to me and look at me like “I know who you are,” and he comes over and gives me a hug and a kiss. That does it for me. If he doesn't do it again for a month, I forget all the bad stuff because that was why I came. That's why I'm here today and that's why I keep going back.”

Mindfulness/Attentiveness to the Moment

Recognizing and appreciating the moment when a simple “I love you,” a smile, or an expression of gratitude is shared is enough for the caregivers to find the strength to carry on.

“If I can get her to smile, my day is made.”

The potency of love and beauty revealed!

Reframing and Acceptance

“You realize that there is a deterioration that you didn’t think was possible because that’s your mom and she takes care of everybody. She’s able to take care of herself. She’s always done that.”

"I know that’s the disease though and I’ve got really good at saying, “This is not him, this is the disease”."

"She operates at about the level of a three year old child. So I look at it as looking after a child."

"I’ve learned to really step back and let go”

Transformation of life purpose

Long-term caregiving transforms the caregiver's identify of self. Despite the burden, the caregiving role transforms into a purpose in life. When the role diminishes or ends, caregivers experience a substantial loss.

“It was a perk, it becomes a role, it becomes a purpose in life and even though it was burden, it caused all that stress when you remove that role or purpose they feel a loss.”

“It is literally a life career when you dedicate yourself to caregiving and in a career situation you kind of leave everything behind.”

Life Purpose: Behaviour modeling

Caregivers may see their experience as a teaching moment for their young children. Parents hope to show their children the meaning of love and compassion amidst hardship. Some also hope to instill ideas of compassion to encourage their children to provide care them later in future.

"I'm doing what I do also to show my kids, I'm hoping that you know someone is going to be compassionate towards me"

"I still have young children and they're in their early twenties and they need to see that mom loves dad, that mom is there for dad and I've got support from them, but I really wanted them -- I mean they saw that and they acknowledged it and I think it was a time of growth for my children, a terrible journey, but a real growth."

Positive growth

Witnessing the deterioration of a care partner, and struggling with the healthcare system while managing the stresses of caregiving and life unsurprisingly changes the caregiver.

Caregivers may experience personal growth through the ordeal.

Some feel confidence at their newfound ability to problem-solve and provide care.

Positive growth

They treasure the quality time spent with the relative and can develop a “new dimension of love”.

"I sort of learned a different dimension of love. I don't know quite how to say that but sometimes the greatest joy in my life is seeing my mom"

Positive growth

People can be challenged to face unresolved issues in the relationship with the care partner. As a result, caregiver can be “very healing”

"Part of the grief is not just the loss, but part of my journey has been in dealing with my parents who have been abusive to now be advocating for them and I have been blessed that I have a sister who is a counselor, I'm part of a pastoral team and it's been very healing. As hard as it is it's been very healing because those past abuses they're right here in your face because you're living with them every day and you're advocating for these people who did really crappy stuff to you."

Self-awareness/introspection

Managing the symptoms of chronic disease also cause caregivers to reflect on their own mortality. In some, it provokes the fear that the same illness may affect them. Consequently, they become more attentive to their own health.

For spouses, it provokes the anxiety toward their last stages of life, when their partner will not be there to help them, and causes them to make plans going forward that they may not have otherwise done.

Self-awareness/introspection

"For the longest time you have this attitude that I can live forever, nothing's going to hurt me, and now you start seeing, you know, friends dying, getting cancer and more so once it happens within your family. And I think too, in a sense I'm preparing myself."

"I have this feeling that I'm going to have to live like this the rest of my life, my wife is no longer there to help me."

Forgiving oneself

Caregivers want the best care and treatment for their care partner. However, the ability to access the most optimal resources may be out of their control.

Caregivers blame themselves when things go wrong, believe that they should have known or have done better.

Forgiving oneself

Forgiving oneself helps to remove the guilt from the caregiver's emotional strain.

"You have to learn to forgive yourself also, you're not going to get it right all the time."

Caregivers take comfort in knowing that

"I was doing the best I could and who can ask for more really."

Humour

Sense of humour: able to see their situation from a light-hearted perspective

“If you don't have a sense of humour, you really have problems with it.”

Spirituality

Participants often expressed the importance of spirituality and religion in coping with caregiving challenges as a helpful internal resource.

Although attendance at church and religious support groups are helpful, a personal relationship with God seems to be most important. Caregivers regularly prayed to God to seek relief from isolation and distress. Turning towards God provided guidance and a sense of greater meaning to their experience.

Spirituality

“I pray and I feel better. I don't feel alone.”

“He answers my questions and it give me relief”

“I have the Lord and boy, I talk to him a lot. I'm sure there's times he just puts the earplugs in but I just keep going anyhow.”



Physical activity and hobbies

Caregivers who engaged in physical activity indicated that they were better able to manage the responsibilities of caregiving

Caregivers appreciated being able to engage in things that were hobbies for them – that took their mind off of caregiving and provided a different sense of fulfillment.



Sleep

Sleep is often compromised when caregiving.

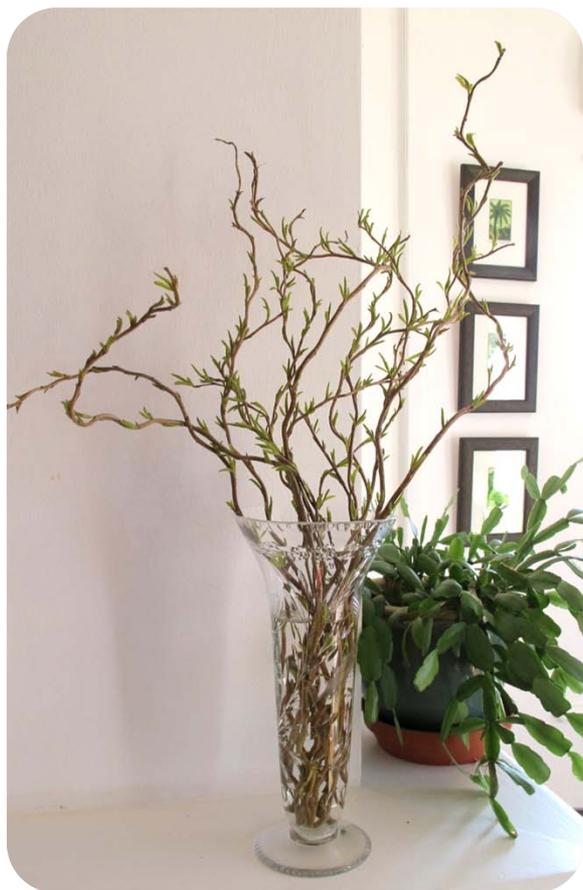
Caregivers indicated that, when they have better quality sleep, they are better able to think clearly, problem-solve and handle the challenges of caregiving.



Self-care

For caregivers, self-care is essential to being resilient. Having the fortitude to continue to provide support and care to the care partner requires that caregivers have the time for themselves to rejuvenate.

Resilient Caregivers



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(George Vaillant (2002) *Aging Well*, p. 285)



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