



The Voices of Family Caregivers: A Window into their Experiences

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Canadian Home Care Association: 2014 Home Care Summit Faculty/Presenter Disclosure

Relationships with Commercial Interests:

✓ Grants/Research Support

CIHR Planning Grants & Dissemination Events
Amount: \$23,490

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Learning Objectives:

To hear the voices of family caregivers –

1. Their experience, challenges and facilitators, motivation and rewards for persevering through caregiving.
2. Their recommendations on education, resources and support to increase caregiver resilience.



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 2 hour focus groups held with family caregivers



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.



Lack of Knowledge/Information is a Barrier to Care

“I need knowledge about what they're doing for him and to him so I can be with him and know something about why he's doing what he's doing.”

“Even though you've signed that paper it doesn't necessarily mean that ... you're told enough”

“I do appreciate that they're busy, you know, they've spent whatever, ten, 12 years at university, but please talk to me at my level. Show me that respect”



Inaccessibility to Resources is a Challenge in Caregiving

“I learnt from a friend about the Alzheimer's Society and when I sort of look back at dealing with the doctors, the professionals, it didn't really come up.”

“And every time she shows she's either really, really down or really, really manically high...as she's coming down you think 'oh we can place her' and then just before they place her, she drops down into the low.”

“They kept administering the MMSE test and the MoCA test to my dad. My father has a PhD ...he kept scoring really high ...that was just quite a disconnect with we were dealing with.”



Navigating the System is a Major Obstacle for Caregivers

“They make you go through so many hoops”

“I needed home care and I had to fight for it, I had to prove it. When I found I was at my most vulnerable I phoned them so they could hear the strain and I would cry.”

“You find out this little bit of information and you have to take that and ... go to somewhere else to find out the next part that you need and it was just an ongoing circle”



Caregiving Impacts Caregivers' Health and Well-Being

“Caregiving is a 24/7 job”

“...desperation, exhaustion total mental, physical, everything, like I just can't do this anymore but I have to-there's nobody else.”

“He's now in the long term facility but I still go and ... do a little bit of stuff for him because there are things that he needs that is not being addressed.”



Family Dynamics Create Stress

“I had two little kids of my own to chase as well. So you really feel like you sacrificed.”

“we have to make those decisions and in some cases the decisions we make sometimes conflict with family

“[Our daughter] doesn't understand why I'm actually going back to see him when he doesn't know me anymore and he can't talk anymore, can barely walk anymore. She doesn't understand why I keep going. So I don't see her that often”



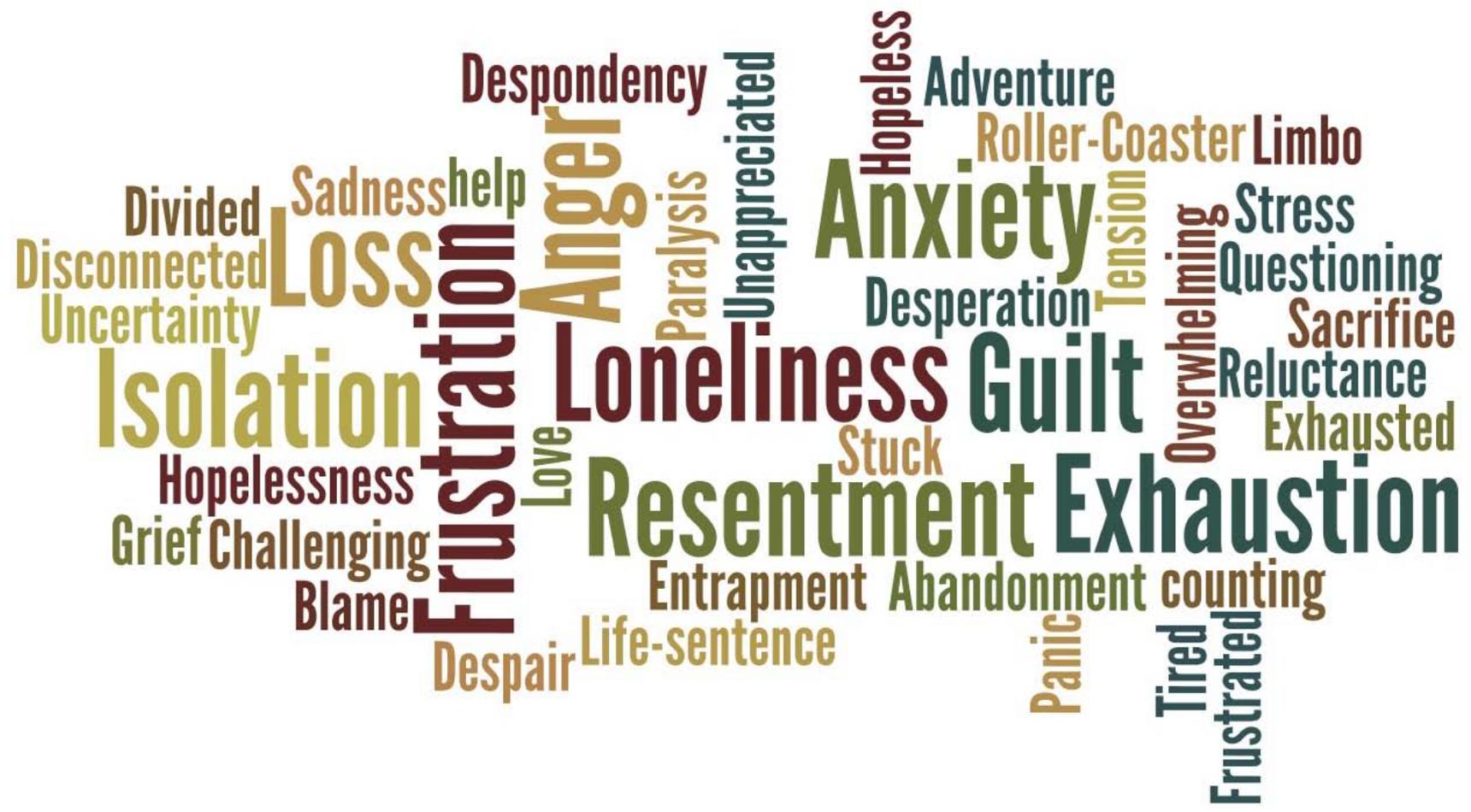
Caregiving can Lead to Significant Financial Burden

“I was working full time in a very good job, travelling a lot. Had to give up my job”

“I’m on social assistance, I have no budget whatsoever to do anything sociable like go for a beer even.”



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



Resilience: Moving to the Positive

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



Resilience: Spiritual Strength is a Helpful Internal Resource

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

“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.”



Resilience: Reciprocity is an Important Aspect of Caregiving

“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.”



Resilience: The Importance of Behavior Modeling

“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.”

“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, there’s a little bit of that but it’s something they need to learn.”



Resilience is Vital

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



Their Recommendations...

- **Caregiver education**
- **Health Care Professional education**
- **Improve access to resources**
- **More sensitive to the caregiver's challenges**
- **More political advocacy**



Recommendation 1: Caregiver Education

“Assertive communication so that I could better deal with my husband and better advocate for him with healthcare professionals.”

“I never realized until July of last year that I was even a caregiver. I thought I was a helper so I never related myself to being a caregiver.”

“...to have these things done before the dementia is full blown where it's totally out of your control and you're in a situation like this. So some pre-emptive resources would be wonderful.”



Recommendation 2: Health Care Provider Education

“D... was in a facility for over a year and I had to be there every day ... there was only two girls and the rest of the staff had no idea about dementia. They were terrified of him.”

“She'd been verbalizing her memory issues, her concern, at which he just said it is her getting old. He never gave her any medication. He didn't test her...”

“It should be the medical profession that should be getting the training to communicate to the patient and their caregivers. Reverse the responsibility.”



Recommendation 3: Resources and Navigation Needed

“I kind of wish that I'd maybe had resources available earlier ... that would enable me to have a more understanding view of things.”

“We went through the breast cancer, SA... had six chemos and thirty radiations, there was ten times more the resources for breast cancer than there was for early onset Alzheimer's and I would tell you that breast cancer is a pimple on a rhino's butt to this, I would go through it ten times compared to this.”

“A navigator, you need someone to tell you how to get through the system.”



Recommendation 4: More Responsive Senior and Caregiver Centered System is Desired

“I have to steel myself for a battle just to ask for anything.”

“It was all policy driven. It was no compassion, no integrative support considering my dad's condition.”

“It sometimes feels like the system is all about the system and it's not about the people.”



Recommendation 5: Political Advocacy is One Step that can be Taken

**“We as people have to start telling our
MLAs, our MPs.”**