

Caregivers in Distress A Growing Problem



OFFICE OF THE
SENIORS ADVOCATE

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Caregivers

- ❖ It is estimated there are approximately 1 million unpaid caregivers in the province¹
- ❖ Caregiver activities:
 - ❖ Can range from a ride to the grocery store or a medical appointment to assistance with everyday activities, such as bathing, toileting or medication management
- ❖ Replacing the care they provide with care from paid caregivers has an estimated cost of \$3.5 billion in B.C.

¹Statistics Canada GSS Survey 2012. Proportional calculation based on number of seniors in B.C relative to Canada as a whole.



This Report

- ◆ Focuses on caregiver distress for those providing informal care to clients receiving publicly-subsidized home support services in B.C.
- ◆ Why this focus?
 - ◆ The availability of robust, comparable assessment data for home support clients
 - ◆ These clients represent the most highly vulnerable seniors who without caregivers would likely need to move to a supportive living environment

Caregivers in Distress: A Growing Problem

- ◆ This report updates and compares data and analysis from the OSA's 2015 report *Caregivers in Distress: More Respite Needed*
- ◆ Our 2015 report:
 - ◆ Found B.C. had one of the highest levels of caregiver distress in the country
 - ◆ Made recommendations on the need to improve supports for caregivers including increasing service levels for Adult Day Programs, respite beds and home support
- ◆ Two years later – how are we doing?



How are we doing? Not very well

- ◆ Compared to 2 years ago:
 - ◆ Rate of caregiver distress **↑7%**
 - ◆ Hours per day of home support for 65+ **↓5%**, for 85+ **↓7%**
 - ◆ ADP clients **↓5%**
 - ◆ ADP days **↓2%**
 - ◆ Respite clients **↑5%** but average LOS **↓** in 4 of 5 Health Authorities

Burden is shifting from public system to family caregivers

Analysis: Who are we caring for?

- There are 30,363 clients receiving long term home support

Characteristics	2015/16	Two Year Change
Age	82.3	↑2%
Activities of Daily Living (ADL 3+)	20%	↑7%
Moderate to severe cognitive impairment	21%	↑7%
*MAPLe 4+	52%	↑4%
Dementia	32%	↑4%
Aggressive behaviour	12%	↑7%
Difficulty with medication management	72%	↑4%

*MAPLe – Method for Assigning Priority Levels



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Who is providing care?

- ◆ 91% of primary caregivers were family members
 - ◆ 58% were adult children
 - ◆ 21% were a spouse
 - ◆ 12% were other family members
- ◆ On average, caregivers provide 20 hours per week of informal care
 - ◆ Co-residing caregiver – 32 hours per week
 - ◆ Not co-residing – 11 hours per week



How are caregivers coping?

- ❖ In 2015/16, **31% of clients** had a primary caregiver in distress
- ❖ This is a **7% increase** over what we found in the 2015 report
- ❖ Over this period, the actual number of primary caregivers identifying as distressed **increased by over 1,000**
- ❖ This represents a **14% increase** in the actual number of caregivers in distress



What increases risk of distress?

Client Factors

Mild cognitive impairment



almost doubles the risk

Moderate to severe
impairment



triples the risk

Potential or actual
problem with depression



over doubles the risk

Dementia



25% increased risk

The presence of any
behavioural and
psychological symptoms of
dementia



75% increased risk



What increases risk of distress?

Caregiver Factors

Being a spouse



80% increased risk*

Being a co-residing caregiver
who is not a spouse



40% increased risk*

Higher levels of informal
care hours



Mild increase in risk

*relative to non-co-residing caregiver (any relation)



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Effect of co-residing on distress

	Rate of Distress
Co-residing Caregiver	
Spouse	48%
Adult child	38%
Non-residing Caregiver	
Adult child	26%
Other relative	22%
Friend or neighbour	15%



Potential tensions

- ❖ Overall, **20%** of home support clients feel they would be better off living somewhere else, compared to **29%** from their caregivers' perspectives
- ❖ Where clients are assessed as having a higher risk or probability of admission to residential care, **23%** of clients believe they would be better off living somewhere else compared to **39%** of caregivers
- ❖ Potential for increased caregiver distress when a caregiver thinks the person they are caring for would be better off living somewhere else, but the person being cared for wishes to remain where they are



More control – less distress

- ❖ **Choices in Supports for Independent Living (CSIL)** is a program that allows clients to receive money directly from their health authority and use that money to pay for the care they need
- ❖ The data indicate that caregivers of clients under the CSIL program have a **50% lower risk of caregiver distress** even though they are caring for someone who, on average, has a higher level of complex care needs than non-CSIL home support clients



How can we help?

- ◆ The number of home support **clients accessing ADP** **↓ by 5%** and the number of days delivered to these clients **↓ by 2%**
- ◆ The average hours of **home support per day per client** **↓ by 5%** for clients 65 or older, and **↓ 7%** for 85 or older, signalling less intensive service
- ◆ The number of **residential care respite clients** **↑ by 5%** and admissions **↑ by 8%**, but average length of stay **↓** in four of five health authorities



Additional caregiver support

- ◆ Beyond increased service levels, how can service providers better support caregivers?
 - ◆ Develop strategies to identify caregivers earlier
 - ◆ Link caregivers with community supports
 - ◆ Provide training and education for caregivers so that they feel confidence in their caregiving skills



Recommendations

1. Increase adult day program access
2. Increase home support hours and recognize respite hours as a need
3. Improve access to CSIL
4. Re-organize respite beds and increase the capacity
5. Empower caregivers



Contact

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