

Understanding Caregiver Experience

Anna Greenberg, VP, Health System Performance

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A middle-aged man with short, graying hair is sitting in a wooden chair with white upholstery. He is wearing a dark brown sweater with a diamond-shaped argyle pattern in shades of blue and tan over a light blue collared shirt. He has a calm, slightly weary expression. The background is a softly blurred home interior, featuring a table with a vase of pink flowers, a blue and white ceramic teapot, and a gold-framed picture leaning against a wall.

The Reality of Caring

Distress among the caregivers of home care patients

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Why we undertook this report



Who are “long-stay” home care patients?

- Currently available caregiver distress data limited to people caring for long-stay home care patients
- **Long-stay patients** receive publicly funded home care:
 - Provided by paid home care workers
 - For a long or indefinite period of time (60+ days)
 - Because of disability, frail health or chronic conditions such as dementia. Many are elderly.

Long-stay patient characteristics – 09/10 to 13/14

- **Increase among long-stay home care patients cared for by family members, friends/neighbours in:**
 - **Alzheimer's disease/dementia**
 - from 19.5% to 28.6%
 - **Mild to very severe cognitive impairment**
 - from 38.1% to 62.2%
 - **Moderate to very severe impairment in ability to perform ADLs**
 - from 27.6% to 44.5%
 - **Slightly to highly unstable health conditions**
 - from 27.3% to 43.2%

Caregiver context

- **97%** long-stay home care patients rely on unpaid caregiver
- Average time/week caring for long-stay home care patients
 - **18.8 hours** (09/10) to **21.9 hours** (13/14)

“Distress” → feelings of anger, depression or being unable to continue in caregiving duties

- Reported distress doubled
 - **15.6%** (09/10) to **33.3%** (13/14)
- Being unable to continue in caregiving duties doubled
 - **6.6%** (09/10) to **13.8%** (13/14)

What we know about distress

Among long-stay patients:

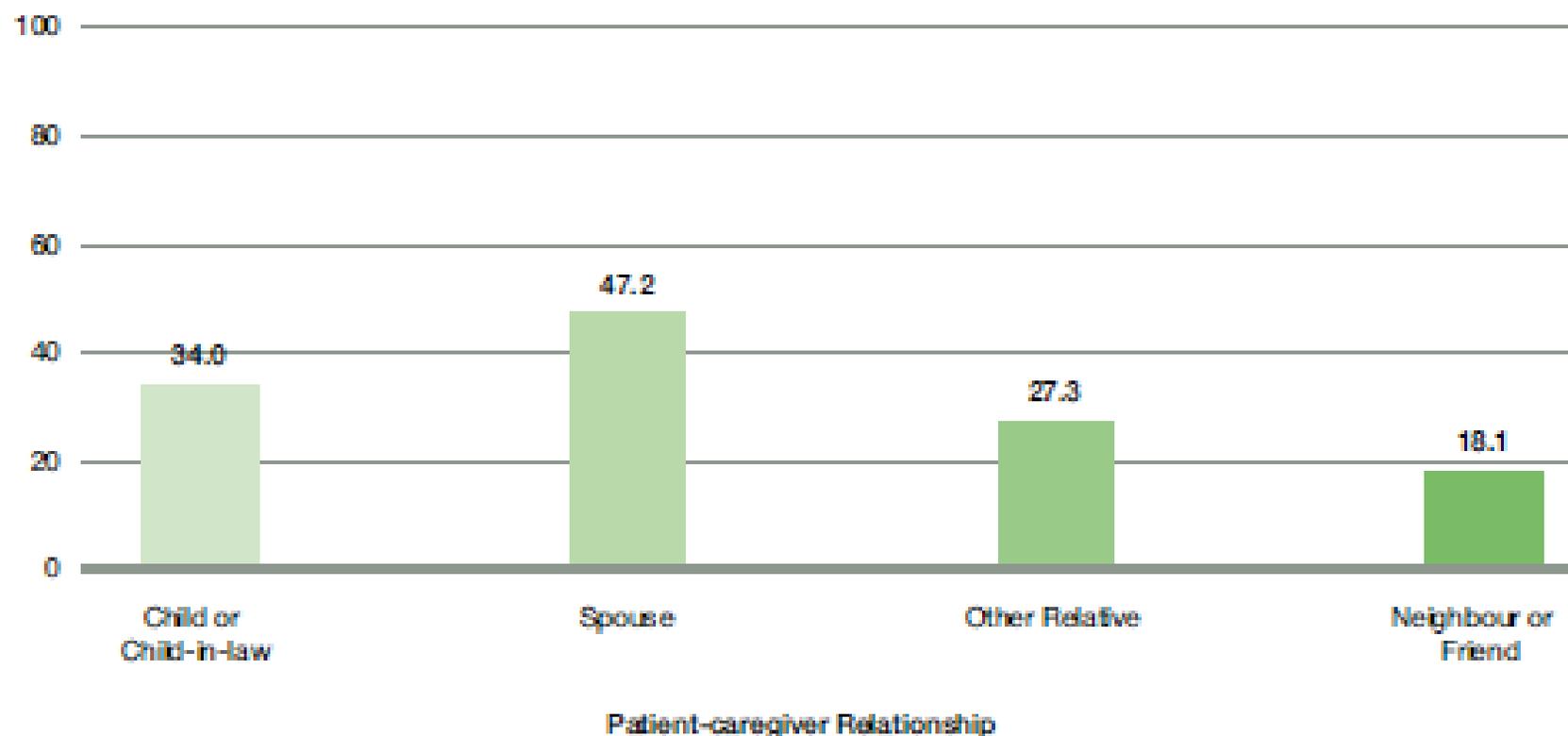
- **49.2%** with **Alzheimer's/dementia** had caregivers reporting distress
- **60%** exhibiting **difficult behaviours associated with dementia** had caregivers reporting distress
- **54.5%** with moderately severe to very severe **impairment in cognitive abilities** had caregivers reporting distress
- **48.7%** who needed extensive assistance or were dependent in **activities of daily living** had caregivers reporting distress
- Those with distressed caregivers received on **average 31.5 hours/week** of informal care (vs. 17.1)

Caregiver distress by relationship to patient

FIGURE 3.6

Caregiver distress by patient-caregiver relationship, in Ontario, 2013/14

Percent of Caregivers Distressed



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo.

Caregiver panel

- 7 caregivers:
 - Long-term experience caring for a patient receiving home care services in Ontario and
 - Had experienced distress as a caregiver

What does “caregiver” mean to you?

- Until recently, did not realize there was a name for this.
- It's a job
 - “There is a job description with roles and responsibilities. But there isn't a paycheck and there is no time off.”
- Feels like a constant crisis situation.

What are your main responsibilities?

- Nursing care you aren't trained for
- Coordinating care and identifying community services
- Spending time at the hospital during hospitalizations
- Making sure formal home care comes in, updating professionals
- Keeping family and friends up to date
- Being sole social support for the patient

What supports are available to you?

- Generally none
- Feel isolated. Don't know where to go for help.
- Some organizations have supports (e.g. Alzheimer's Society) but not if you don't have that condition
- Friends and family often don't know how to help or don't offer
- Often have to turn to neighbours, friends or strangers for a little help

What are the major stressors?

- Exhaustion
- Social isolation
- Guilt
- Worry
- Having to be an advocate
- Feeling unqualified
- Not feeling recognized
- Family disagreements
- Feeling like a burden
- Not knowing where to turn

Supports you've found helpful

- There aren't many.
- Palliative care system was really good at providing support
- Respite; but it's hard to get, can be expensive, and not sure if the care is good.

Supports that would be helpful

- List of all duties that will need to be done
- Support network for advice, to identify appropriate resources
- Not just assessment of patient, but formal assessment to identify caregiver needs
- Counselling and where to get help
- Awareness of caregiver as their own person
- Public awareness about the role of the caregiver, where to get help
- Proper supports to be able to have a break

In an ideal world, my caregiver role would

- Be recognized, appreciated as a member of the team caring for the person
- Include recognizing my needs as well
- Be in partnership with someone else who can help with the responsibilities
- Have appropriate supports no matter where I live
- Allow for an opportunity to work and provide care
- Be allowed to have a social life and an identity
- Be empathized with
 - by family and friends, home care providers, professionals; so they understand what it's like

- “...It goes beyond just ‘they’ve got this condition, they need this much help and services and we’ll check it every three to six months.’ It’s far more fluid, and sometimes it’s almost daily, it’s putting out fires.”
- “Sometimes what would really help...things like occasional assistance at night so they could get a real break, or help with getting groceries because they can’t leave the patient alone at home, or help taking loved ones to medical appointments.”

Walter, Transitional Care Coordinator



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