

Caregiver Distress Report News Release

Distress, anger, depression and burnout growing among family members and friends looking after home care patients, Health Quality Ontario report finds

TORONTO, ON – April 5, 2016 – Ontario’s home care system may be facing a perfect storm as home care patients become more elderly, ill and impaired, and the family members and other unpaid caregivers who help care for them are increasingly affected by stress and burnout.

That is the finding of *The Reality of Caring: Distress among the caregivers of home care patients*, a report on caregivers released today by Health Quality Ontario, the provincial advisor on health care quality. The report examines the growth of distress, anger, depression and the inability to continue caregiving among unpaid caregivers of long-stay home care patients in Ontario. Fully 97% of these patients rely on family members, friends or neighbours for assistance that supplements the care they receive for a long or indefinite period of time from Ontario’s publicly-funded home care sector.

The Reality of Caring finds that long-stay home care patients as a group are becoming older and are affected to a growing degree by cognitive impairment, functional disability and frail health. More of them have Alzheimer’s disease or other forms of dementia, more have difficulty with basic activities such as moving about, washing themselves or eating, and more are in declining health.

The report also finds that the family members and other unpaid caregivers who help look after long-stay patients are generally more distressed the more cognitively impaired, functionally disabled and in frail health the patients are. Higher rates of distress are also associated with providing more hours of care.

In 2013/14, among long-stay home care patients with unpaid caregivers, one third had caregivers who experienced distress, anger or depression in relation to their caregiving role, or were unable to continue in that role. That rate of distress, at 33.3%, had more than doubled from 15.6% in 2009/10. Over the same period, the proportion of patients with caregivers who were not able to continue looking after them also more than doubled, to 13.8% from 6.6%.

“Watching someone we care about suffer from prolonged illness or declining health is always difficult, so it’s not possible to completely eliminate caregiver distress,” says Dr. Joshua Tepper, President and CEO of Health Quality Ontario. “But caregivers should not have to endure avoidable stress.”

Home care is a priority for many organizations in the province, and measures to improve supports for unpaid family and other caregivers who help look after home care patients are being developed by many groups. The Ministry of Health and Long-Term Care speaks to the need to improve home care in its strategy document *Patients First: A Roadmap to Strengthen Home and Community Care*.

KEY REPORT FINDINGS:

Long-stay home care patients cared for by family members, friends or neighbours became collectively more cognitively impaired, more functionally disabled and sicker between 2009/10 and 2013/14.

- Those who had Alzheimer's disease or other forms of dementia increased to 28.6% from 19.5%
- Those with mild to very severe cognitive impairment increased to 62.2% from 38.1%
- Those experiencing moderate to very severe impairment in ability to perform activities of daily living such as washing their face or eating increased to 44.5% from 27.6%
- Those with slightly to highly unstable health conditions associated with greater risk of hospitalization or death increased to 43.2% from 27.3%

The unpaid caregivers – family members, friends and neighbours – who helped look after long-stay patients were generally more distressed the older, more cognitively impaired, functionally disabled and frail the patients were.

- Nearly half (49.2%) of patients with Alzheimer's or other dementias had informal caregivers who were distressed. Among patients who exhibited difficult behaviours associated with dementia – being physically or verbally abusive, disruptive or resisting care, and wandering – more than 60% had caregivers who were distressed
- Among patients with moderately severe to very severe impairment in cognitive abilities such as decision-making, making themselves understood and short-term memory, 54.5% had caregivers who were distressed.
- When patients needed extensive assistance with or were dependent in some activities of daily living such as moving about, washing themselves or eating, 48.7% had distressed caregivers.
- The average amount of time unpaid caregivers spent looking after long-stay home care patients in Ontario rose to 21.9 hours per week in 2013/14, from 18.8 hours in 2009/10.

To provide real-life perspective on the complexity of the issues behind the data and the stressors faced by caregivers, Health Quality Ontario consulted a panel of caregivers who have provided care for a long period of time. They described caregiving as rewarding but extremely difficult, very time-consuming and tremendously stressful, leaving little time for jobs, social activities, hobbies or any other pastimes.

To view the entire *The Reality of Caring* report, visit www.hqontario.ca

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Health Quality Ontario, the provincial advisor on quality in health care, reports to the public on the quality of the health care system, evaluates the effectiveness of new health care technologies and services, and supports quality improvement throughout the system. Visit www.hqontario.ca for more information.

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