

Facing the Facts

Winter 2011

What do we know about families and friends taking care of Ontario's palliative home-care clients?¹

Canadian studies report that friends and family provide most of the care (80%) for people who are frail, elderly, and/or have disabilities^{2,3}. This contribution saves Canada's health-care system \$31 billion a year⁴. The viability of our health-care system depends in part on our ability to alleviate the untenable responsibility placed on informal caregivers.

What we've discovered about the timing and severity of stress experienced by caregivers of palliative home-care clients can help inform the development of targeted, proactive supports for all informal caregivers.

Facts

- There is often more than one person caring for a dying friend or family member. In 2006–2008, more than half (57%) of palliative care clients in Ontario were cared for primarily by their spouses or partners, while a third (29%) received most of their primary informal caregiving from their children or children-in-law. Secondary caregivers were more likely to be children or children-in-law (Figure 1).
- Most caregivers found caring for loved ones manageable and rewarding. However, more than one in four (22%) showed signs of distress, including anger, depression, being overwhelmed and unable to continue providing care. Caregivers of 12% of Ontario palliative home-care clients exhibited more than one sign of distress.
- Longer hours of informal care and the health status of palliative home-care clients led to significant caregiver distress. Those who provided 18–35 hours of care had high levels of distress. Interestingly, as care topped 36 hours, caregivers learned to manage better. The dying person's health status—health decline, depressive symptoms and cognitive impairment—also added to caregiver distress. As the health of the loved ones deteriorated and/or depressive symptoms escalated, caregiver distress increased. A mild/moderate decline in cognition of palliative home-care clients was stressful for informal caregivers. Over time, they learned to cope better (Figure 2).

The Change Foundation is an independent policy think tank intent on changing the health-care debate, the health-care practice, and the health-care experience in Ontario. Established in 1996, the Foundation leads and leverages research, analysis, quality improvement and strategic engagement to enable a more integrated health-care system designed with patients and caregivers top of mind.

- 1 Hirdes, JP, Freeman, S., Smith, T., & Stolee, P. Predictors of Caregiver Distress among Palliative Home Care Clients in Ontario: Evidence based on the interRAI Palliative Care (interRAI PC) submitted to Journal of Palliative and Supportive Care.(in-press)
- 2 Wiles, J. (2003). Informal Caregivers' Experiences of Formal Support in a Changing Context. *Health and Social Care in the Community*, 11(3) p 189–207
- 3 Health Canada (1999). *How Can Telehomecare Support Informal Care? Examining What is Known and Exploring the Potential: Final Report*
- 4 Hollander, M. J., Miller, J. A., MacAdam, M., Chappell, N., & Pedlar, D. (2009). Increasing value for money in the Canadian healthcare system: New findings and the case for integrated care for seniors. *Healthcare Quarterly*, 12 (1), 38–47.



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Figure 1: Profile of informal caregivers of palliative home-care clients. Ontario 2006-2008

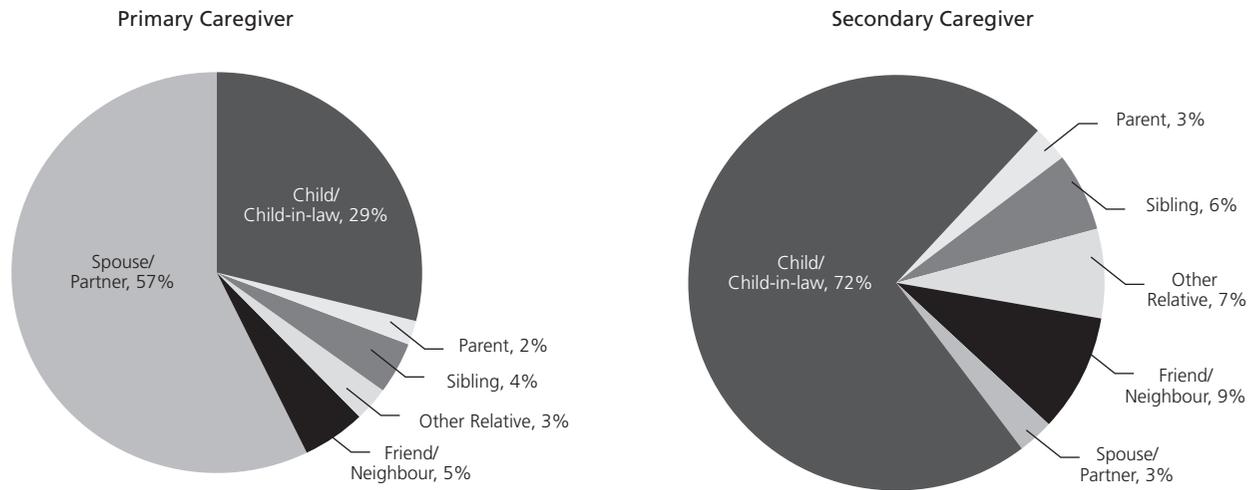
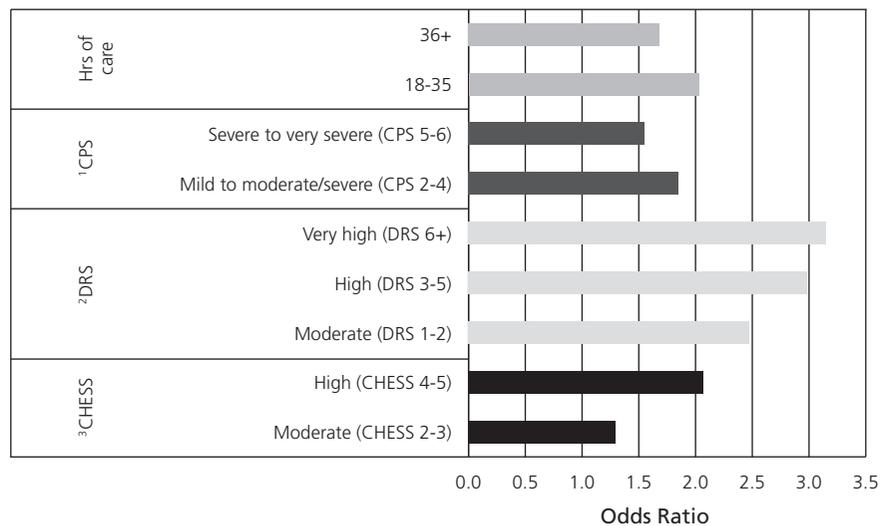


Figure 2: Risk of distress among informal caregivers of palliative home-care clients. Ontario 2006-2008



- 1 Cognitive Impairment Scale (CPS) is used to rate cognitive status of the client.
- 2 Depression Rating Scale (DRS) is used as a clinical indicator of depression.
- 3 Change in Health, End-stage disease and Signs and Symptoms (CHESS) is used to detect frailty and instability in health.