



RESEARCH BRIEF

STUDY 10 - Health Links Caregiver Evaluation Study

KEY POINTS

- Informal caregivers (e.g. family members) of Health Links (HL) patients experience significant strain, anxiety, and depressive symptoms
- Many caregivers face work/life disruption in order to support their loved one
- Caregivers recommend improvements to assist with identifying and addressing their needs such as more help with navigating the health and social care system, improved caregiver supports like respite relief and specialized training for personal support workers (PSWs) in dementia care

What is this research about?

In 2012, the Ontario Government launched Health Links (HL) to integrate care for patients with complex health and social care needs who were high users of hospital and emergency services. The overall evaluation of the Health Links program was conducted by a research consortium at four research centres to evaluate the impact of this Ontario Ministry of Health and Long-Term Care's Health Links Model on patient, caregiver, and provider experience, and system value. McMaster University's Aging, Community and Health Research Unit (ACHRU) researchers explored the experiences of caregivers of HL patients, while researchers from Queen's University, Western University, and the University of Toronto investigated patient and provider experiences as well as system value in terms of health care costs and utilization patterns.

What did the researchers find?

Data were collected from 16 caregiver interviews and 27 surveys administered to caregivers of patients enrolled in the HL program. The findings indicated that caregivers of HL patients, generally spouses and children, experienced depressive symptoms, strain and anxiety. Many caregivers encountered work/life disruption in order to support their loved one.

Despite the involvement of multiple service provider 'coordinators' of care, caregivers consider themselves as the primary coordinator of care of their loved one. Communication among services providers occurs with accidental encounters, not planned team conferences. Caregivers' provided a number of recommendations, including:

- Provide more training for health care providers (PSWs) related to caring for HL patients with dementia
- Improve the accessibility, quality and comprehensiveness of caregiver supports (including respite relief)
- Prepare a user-friendly directory of health and social care related local resources for caregivers' use

Where do we go from here?

This study contributes new knowledge about the experience of caregivers of patients enrolled in the HL program. Informal caregivers are critical partners in community-based health care delivery; there is a need to understand caregivers' unique needs and experiences rather than simply focusing on the needs of HL patients.

About the ACHRU

ACHRU researchers promote optimal aging at home by designing and evaluating new and innovative community-based health care interventions to improve access to healthcare, quality of life, and health outcomes. Studies focus on the prevention and management of multiple chronic conditions, for seniors who have dementia, depression, diabetes and/or stroke.

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