Health Quality Ontario
The provincial advisor on the quality of health care in Ontario

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The Reality of Caring: Distress among the caregivers of home care patients

Technical Appendix

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Ontario
Health Quality Ontario

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Introduction

Health Quality Ontario has produced a report describing caregiver distress among caregivers for adult long-stay patients receiving formal home care services in Ontario. This document is the technical appendix to *The Reality of Caring: Distress among the caregivers of home care patients*, released April 2016.

The technical appendix provides a description of the methodology used to measure caregiver distress and describe factors related to caregiver distress reported in *The Reality of Caring*. It also provides general information on the data source that was used, our consultation and engagement with caregivers, and the external review process.

For more information, please contact us at SystemPerformance@hqontario.ca.

Data Source

The data for the analysis were derived from Resident Assessment Instrument – Home Care (RAI-HC) assessments. The RAI-HC is a standardized, validated and multi-dimensional assessment tool for determining patient needs, measuring changes in clinical status and patient outcomes, and describing relative costs of services and supports that the patient will likely use. In Ontario, adults who receive publicly funded Community Care Access Centre (CCAC) home care services for a long or indefinite period of time are assessed using the RAI-HC at regular intervals. This report presents results from RAI-HC data provided by the Ontario Association of Community Care Access Centres and held at the University of Waterloo.

Home Care Patients and Caregivers

Adult long-stay home care patients

The study population in this report was comprised of adult long-stay home care patients in Ontario.

Adult long-stay home care patients are individuals over 18 years of age receiving CCAC services and coded with a Service Recipient Category (SRC) of *Maintenance* (SRC 93), *Long Term Supportive* (SRC 94) or *Residential – Long Stay* (SRC 47).[1] These categories group home care patients according to the services they require and the goal of these services.

The analysis included RAI-HC assessments conducted in each fiscal quarter in 2009/10, 2010/11, 2011/12, 2012/13 and 2013/14.

RAI-HC assessments were excluded if they took place in the hospital, were an initial assessment, or occurred within 60 days of when the patient was admitted to home care. These assessments were excluded in order to capture the group of home care patients who have been receiving home care services for a sufficient amount of time for their experience to be somewhat reflective of their experience receiving home care services.

Assessments were also excluded if important fields had missing or incorrect values. These fields included the admission date or assessment date and the field capturing whether or not the patient had a caregiver.

Finally, if there were multiple assessments for the same patient in any fiscal quarter, only the last assessment conducted in that quarter was included.

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[1] Service Recipient Categories are used to group patients according to the overall service goal upon admission for CCAC services. The overall service goals for a patient may change. When this occurs, the patient is transferred to the SRC that best reflects the change in circumstances.[1]

Unpaid caregivers

Long-stay home care patients receiving help from one or more unpaid caregivers were identified from information in the RAI-HC assessment data. A home care patient was described as having at least one caregiver if their assessment indicates the presence of a primary caregiver according to the RAI-HC item G1ea.

Caregivers are family members, friends, or neighbours who are relied upon to help or give advice and counsel if needed to the person receiving formal home care.

Home Care Patient Characteristics

Age

Age of a long-stay home care patient was determined from the birth date recorded in the RAI-HC assessment.

For this report, patients were categorized according to the following two age groups: 18-74 years of age; 75 years of age and older.

Dementias

A long-stay home care patient was identified as having dementia using the RAI-HC items J1g (Alzheimer's) and J1h (dementia other than Alzheimer's disease).

Difficult behaviours

Difficult behaviours associated with dementias exhibited by long-stay home care patients were identified using the RAI-HC items E3b (verbally abusive behavioural symptoms), E3c (physically abusive behavioural symptoms), E3d (socially inappropriate/disruptive behavioural symptoms), and E3e (resists care).

Wandering

Wandering exhibited by a long-stay home care patient was identified using the RAI-HC item E3a (moved with no rational purpose, seemingly oblivious to needs or safety).

Cognitive performance

A long-stay home care patient's cognitive performance was described using the Cognitive Performance Scale (CPS) derived from items in the RAI-HC.[2] The CPS is a hierarchical scale that assigns home care patients a score according to the following: whether the patient is comatose, their cognitive skills for daily decision-making, their short term memory, their ability to make themselves understood, and their dependence in eating. Scores range from 0 to 6.

For this report, patients were categorized based on the following three groups: 0-1 (no or borderline impairment); 2-3 (mild to moderate impairment); and 4-6 (moderately severe, severe and very severe impairment).

Ability to perform activities of daily living

A long-stay home care patient's ability to perform activities of daily living was described by the Activities of Daily Living (ADL) Hierarchy Scale derived from items in the RAI-HC.[3] The ADL Hierarchy Scale is a hierarchical scale that assigns home care patients a score according to the following ADLs: personal hygiene, toilet use, locomotion, and eating. Scores range from 0 to 6.

For this report, patients were categorized based on the following four groups: 0-1 (independent in all areas or needs supervision in one area); 2-3 (limited assistance in one area or extensive assistance to total dependence in personal hygiene or toilet use); 4-5 (extensive assistance to total dependence in locomotion or eating); 6 (totally dependent in all areas).

Health

A long-stay home care patient's health stability was described by the Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) Scale derived from items in the RAI-HC.[4] The CHESS Scale assigns home care patients a score according to the following areas: change in decision-making, change in ADL status, vomiting, edema, shortness of breath, prognosis of less than 6 months to live, weight loss, noticeable decrease in amount of food or fluids consumed, and insufficient fluids. The scores range from 0 to 5.

For this report, patients were categorized based on the following three groups: 0-1 (patients who have no or minimal health instability), 2-3 (patients with low to moderate instability), and 4-5 (patients with high or very high health instability).

Cognition, functioning and behaviour combined

The Method for Assigning Priority Levels (MAPLe) was used to describe long-stay home care patients based on items from the RAI-HC that are predictive of caregiver distress, being placed in a long-term care home, or the patient or caregiver feeling that they would be better cared for in another living arrangement.[5] Patients in the lowest priority level have no major functional, cognitive, behavioural, or environmental problems and are considered self-reliant. Patients in the highest priority category have one or more of: ADL impairment, cognitive impairment, exhibit wandering and behaviour problems, a recent fall, and the interRAI nursing home risk Client Assessment Protocol (CAP) flagged.

For this report, patients were categorized based on the standard MAPLe score groups: Low; Mild; Moderate; High; Very High.

Patient-caregiver relationship

A long-stay home care patient's relationship with their caregiver(s) was described using the RAI-HC item G1f (relationship to patient).

For this report, the relationships between a primary or secondary caregiver and long-stay home care patients were categorized based on the following groups: Child or child-in-law; spouse; other relative; neighbour or friend.

Living arrangement

The living arrangement between long-stay home care patients and their caregivers was determined using the RAI-HC item G1e (lives with patient). A patient is considered to co-reside with a caregiver if they live with either a primary or secondary caregiver.

Hours of unpaid care

The extent of unpaid help (hours of care per week) provided by family, friends and neighbours was described using the RAI-HC items G3a and G3b (extent of informal help; hours of care, rounded). The hours of care is the sum of time that family, friends and neighbours provided for instrumental and personal activities of daily living over the last 7 days.

Indicator: Caregiver Distress

The caregiver distress indicator describes the percentage of long-stay home care patients whose caregiver is unable to continue in caring activities or primary caregiver expresses feelings of distress, anger or depression. This indicator was jointly developed by interRAI and the Canadian Institute for Health Information.

It is calculated by dividing the number of RAI-HC assessments that indicate either the patient's caregiver can no longer continue in caring activities or the patient's primary caregiver expresses feelings of distress, anger or depression, by the number of RAI-HC assessments that indicate the presence of a primary caregiver (Table 1). This number is then multiplied by 100 to get the percentage.

Table 1. Description of the caregiver distress indicator among long-stay home care patients in Ontario

Caregiver distress	
Numerator	RAI-HC assessments for adult long-stay home care patients with a caregiver who is unable to continue in caring activities or patients with a primary caregiver who expresses feelings of distress, anger or depression. Include in numerator if G2a=1 AND/OR G2c=1 Where, G2a = A caregiver is unable to continue in caring activities (e.g. decline in the health of the caregiver makes it difficult to continue) [0,1] 0 = no 1 = yes G2c = Primary caregiver expresses feelings of distress, anger or depression [0,1] 0 = no 1 = yes
Denominator	RAI-HC assessments for all adult long-stay home care patients who have primary caregiver. Exclude if G1ea = 2 Where, G1ea = Primary caregiver lives with patient [0,1,2] 0 = yes 1 = no 2 = no such helper Additional exclusions: 1. The reason for the assessment is initial assessment 2. The assessment was conducted in the hospital setting 3. The assessment was conducted fewer than 60 days from the date the case opened to the assessment date 4. The date the case opened or assessment date is missing 5. The assessment is for the same patient who has a more recent assessment within the same quarterly period
Calculation	The sum of the numerator values for each of the four fiscal quarters divided by the sum of the denominator values for each of the corresponding four fiscal quarters, multiplied by 100.
Data source	Resident Assessment Instrument - Home Care (RAI-HC) data, provided by the Ontario Association of Community Care Access Centres, held at the University of Waterloo

Descriptive Analyses

This report presents the caregiver distress indicator results for 2009/10 and 2013/14, but references the increasing trend in caregiver distress between 2009/10 and 2013/14 that is presented in *Measuring Up 2015*.[6]

The report first describes the distribution of long-stay home care patients with a primary unpaid caregiver by home care patient characteristics defined above. The distributions were described over a five-year time period to illustrate how the population that makes up long-stay home care patients in Ontario has changed over time. The report describes the 2009/10 and 2013/14 distribution of home care patients by age group, diagnosis of dementias, behaviours, wandering, patient-caregiver relationship, and living arrangement. The report presents the distributions of home care patients by cognitive performance, ability to perform activities of daily living, health stability, and a combination of cognition, functioning and behaviour for 2009/10, 2010/11, 2011/12, 2012/13 and 2013/14. The report also provides the average age of home care patients and the average hours of help provided to home care patients by unpaid caregivers in 2009/10 and 2013/14.

The second part of the report connects the observed increasing trend in caregiver distress and the changing long-stay home care population by describing the caregiver distress indicator results stratified by home care patient characteristics. The percentage of home care patients in 2013/14 with distressed caregivers were presented by age group, diagnosis of dementias, behaviours, wandering, cognitive performance, ability to perform activities of daily living, health stability, combination of cognition, functioning and behaviour, patient-caregiver relationship, and living arrangement. The average hours of help provided to home care patients by unpaid caregivers in 2013/14 was also presented separately for patients with distressed caregivers and for patients whose caregivers were not distressed.

Limitations

The report captures only the experience of caregivers and patients in Ontario that access publicly funded home care services through CCACs. Additionally, the data in the analysis are from long-stay home care patients only, because this is the group for whom we have comprehensive and standardized assessment data across the province. Therefore, the experience of caregivers for other patients, such as the pediatric home care population, short-stay home care patients, or patients accessing other community resources is not reflected in this analysis.

The long-stay home care population includes some patients with less complex and more stable health conditions. These patients are capable of living independently and/or have a stable support network. Because of their stability, these patients are assessed using the RAI-HC tool approximately once per year but possibly at longer intervals. So, it is likely that several are missed from inclusion in this analysis, which only captures patients who had an assessment during the fiscal year.

The items that make up the caregiver distress indicator (i.e., feelings of distress, anger or depression and ability to continue providing care) are subjective measures. Results may underreport the true prevalence of distress if some caregivers do not want to admit that they feel burdened by having to care for a friend or family member. Similarly, cultural differences exist that can affect one’s perception of distress caused by caring for a friend or family member, since it may simply be accepted as something that should be done, regardless of the stress it may cause.

The description of patients and caregivers was limited to the information available from the RAI-HC assessment. Direct and more in-depth data on caregivers would provide more precise measures of caregiver distress and what causes it, and clearer evidence on which to base initiatives to alleviate that distress.

The caregiver distress indicator describes the prevalence of caregiver distress. It does not distinguish between patients whose unpaid caregivers express distress for the first time and patients whose caregivers continue to be distressed over multiple time periods.

Results were not risk-adjusted for factors associated with rates of distress, so the results do not take into account factors such as patient characteristics, hours of care provided by the caregiver, hours of formal care provided to the patient, or access to privately funded services. Additional data and a more complex analysis are required to better describe the complex relationships between caregivers, patients and the home care system.

Caregiver Engagement

Seven unpaid caregivers from HQO’s Patient, Family and Public advisors program were recruited to participate in a three-hour-long focus group session. All participating caregivers had long-term experience caring for a patient receiving home care services in Ontario and had experienced distress from being in a caregiver role. The objective of this engagement session was to explore topics that could not be captured through quantitative data alone. The session was held to learn more about caregivers and explore *why* caregivers in Ontario may be distressed. During the focus group session, caregivers were asked to describe their caregiving experiences by speaking about the activities they take part in while providing care, the distresses associated with activities of caregiving and the supports that would help reduce or alleviate caregiver distress.

External Review

Subject matter experts, stakeholders and data providers were sent a draft of the report, *The Reality of Caring*. Reviewers were asked to comment on the accuracy of the data and our interpretations of the results. The report was then revised accordingly. A complete list of external reviewers is located in both the Acknowledgements section of the report and below.

Caregivers who were engaged through the focus group session were also sent a draft of the report, *The Reality of Caring*. Caregivers were asked to comment on the overall comprehensibility of the report and the clarity of the terminology and language used throughout, as well as the clarity of information relayed through data visualization, including graphs.

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References

1. OHRS Version 9.2. Chapter Five Schedule E: CCAC In-Home Service Recipient Categories (2014). Ministry of Health and Long-Term Care.
2. Morris JN, Fries BE, Mehr DR, Hawes C, Phillips C, Mor V, Lipsitz L. (1994) MDS Cognitive Performance Scale. Journal of Gerontology: Medical Sciences 49(4): M174-M182.
3. Morris JN, Fries BE, Morris SA. (1999) Scaling ADLs within the MDS. Journals of Gerontology: Medical Sciences 54(11): M546-M553.
4. Hirdes JP, Frijters D, Teare G. (2003) The MDS CHESS Scale: A New Measure to Predict Mortality in the Institutional Elderly. Journal of the American Geriatrics Society 51(1): 96-100.
5. Hirdes JP, Poss JW, Curtin-Telegdi N. (2008) The Method for Assigning Priority Levels (MAPLe): A New Decision-Support System for Allocating Home Care Resources. BMC Medical Informatics and Decision Making 6:9.
6. Health Quality Ontario. Measuring Up 2015: A yearly report on how Ontario’s health system is performing, Toronto: Queen’s Printer for Ontario, 2015.