Caregiver distress described through data and understood through lived experience

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

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Nghi: Trying to do the right thing

Background: Measuring Up 2015

Measuring Up 2015 described an increase in caregiver distress among caregivers of long-stay home care patients in Ontario
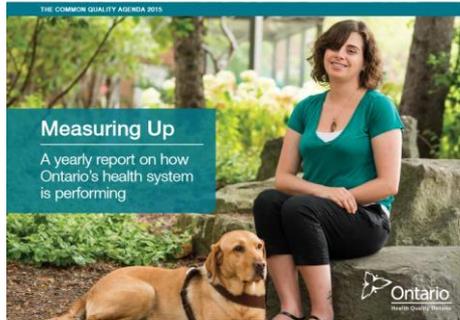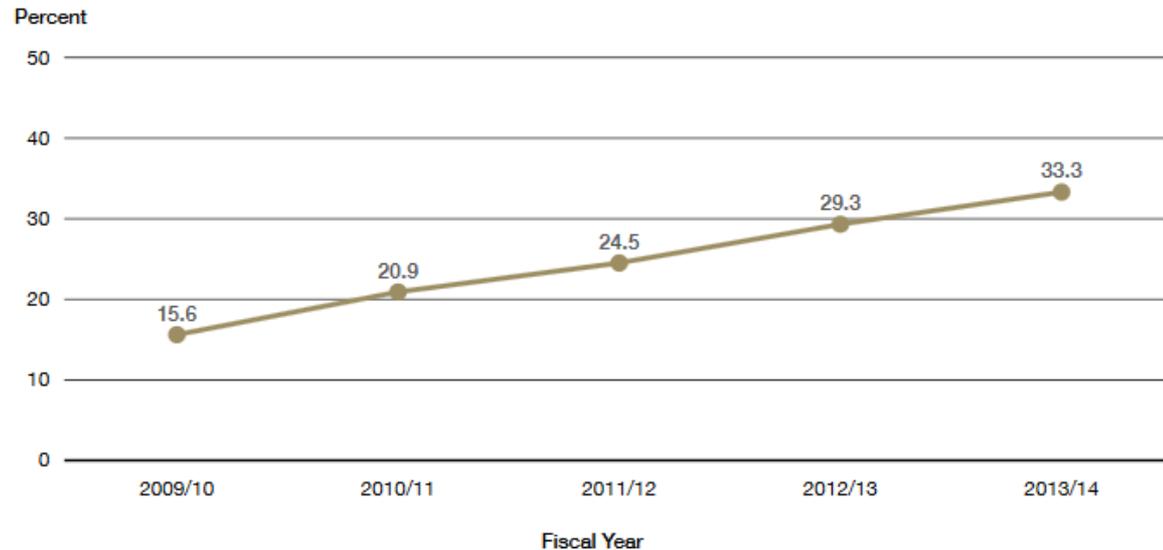
FIGURE 6.4

Percentage of home care patients with a primary informal caregiver whose caregiver is unable to continue in caring activities or expresses feelings of distress, anger or depression, in Ontario, 2009/10 to 2013/14

Data source: Home Care Reporting System, provided by the Canadian Institute for Health Information.

The Reality of Caring

Distress among the caregivers of home care patients

Objective

- To take a closer look at caregiver distress among long-stay home care patients in Ontario, examining what may be contributing to the distress and what has changed in recent years that may explain the increase in distress

- To incorporate the lived experience perspective on caregiver distress

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Descriptive data analysis

- Objective:
  - To describe the change in characteristics of long-stay home care patients over time
  - To describe caregiver distress among caregivers of long-stay home care patients according to various patient characteristics

- Methods:
  - Information from Resident Assessment Instrument – Home Care (RAI-HC) assessments (provided by the Ontario Association of Community Care Access Centres and held at the University of Waterloo)
  - Adult long-stay home care patients in Ontario (SRC 93, 94 and 47)
  - Exclusions
    - Took place in hospital
    - Initial assessment
    - Occurred within 60 days of admission to home care
    - Missing or invalid value for admission date, assessment date or field identifying presence of a caregiver
    - Another assessment in the quarter for the same patient

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Descriptive data analysis

- Time period: 2009/10 – 2013/14

- Home care patient characteristics
  - Age
  - Dementia
  - Difficult behaviours
  - Wandering
  - Cognitive Performance Scale (CPS)
  - Activities of Daily Living (ADL) Hierarchy Scale
  - Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) Scale
  - Method for Assigning Priority Levels (MAPLe)
  - Patient-caregiver relationship
  - Living arrangement
  - Hours of unpaid care

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Descriptive data analysis

- Indicator: Caregiver Distress
    - Jointly developed by interRAI and the Canadian Institute for Health Information

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

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What we observed (from data)

- 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.

- 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 sicker the patients were.

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What we observed (from data)

Table 1a: Characteristics of long-stay home care patients* in Ontario, 2009/10 and 2013/14

	Proportion of home care patients		*Percent change*
	2009/10	2013/14	
Number of RAI-HC assessments	127,943	147,905	
Age of Patient			
18-74	29.7%	27.0%	*-9%*
75+	70.3%	73.0%	*4%*
Average	77.4 years	78.9 years	*2%*
Other characteristics			
Alzheimer's disease and other dementias	19.5%	28.6%	*47%*
Behaviour that was physically abusive, verbally abusive or disruptive, or resisted care	6.7%	11.5%	*72%*
Wandered	2.1%	3.2%	*52%*

Data source: Resident Assessment Instrument – Home Care (RAI-HC), provided by University of Waterloo
*Includes adult long-stay home care patients with caregivers who received a RAI-HC assessment at least 60 days from when their case opened and the assessment did not occur in a hospital.

What we observed (from data)

Table 1b: Characteristics of long-stay home care patients* in Ontario, 2009/10 and 2013/14

	Proportion of home care patients		*Percent change*
	2009/10	2013/14	
Cognitive Performance Scale			
CPS=0-1	61.9%	37.8%	*-39%*
CPS=2-3	32.3%	52.1%	*61%*
CPS=4-6	5.8%	10.1%	*74%*
Activities of Daily Living (ADL) Hierarchy Scale (personal hygiene, toilet use, locomotion, eating)			
ADL Hierarchy Scale=0-1	72.4%	55.5%	*-23%*
ADL Hierarchy Scale=2-3	19.9%	31.9%	*60%*
ADL Hierarchy Scale=4-5	6.4%	10.5%	*64%*
ADL Hierarchy Scale=6	1.3%	2.1%	*62%*

Data source: Resident Assessment Instrument – Home Care (RAI-HC), provided by University of Waterloo
*Includes adult long-stay home care patients with caregivers who received a RAI-HC assessment at least 60 days from when their case opened and the assessment did not occur in a hospital.

Increasing cognitive impairment

Cognitive Performance Scale (CPS) scores among long-stay home care patients with a primary caregiver, in Ontario, 2009/10 to 2013/14
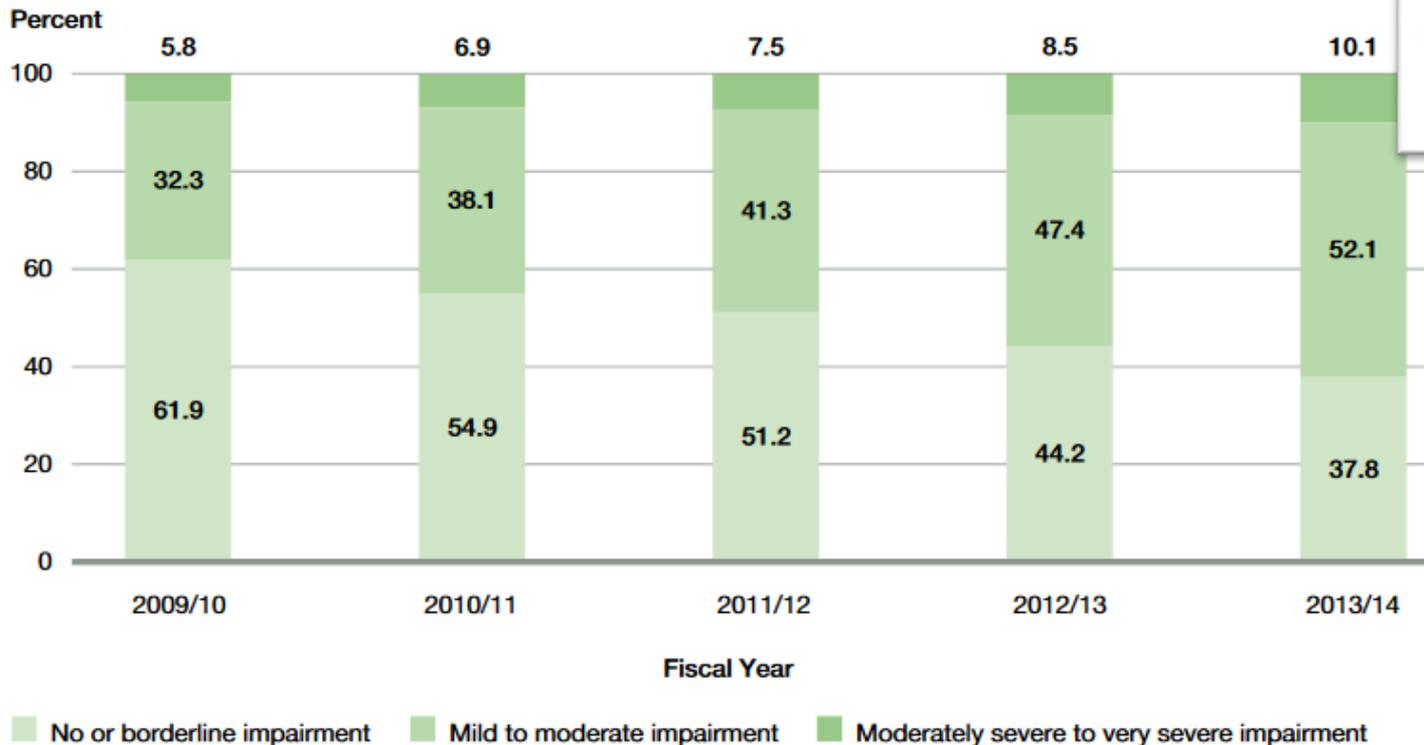
Proportion of patients with mild to very severe cognitive impairment

38.1% 62.2%

2009/10   2013/14
(Mild to very severe impairment: scores 2–6)

Percent	2009/10	2010/11	2011/12	2012/13	2013/14
(top)	5.8	6.9	7.5	8.5	10.1
(middle)	32.3	38.1	41.3	47.4	52.1
(bottom)	61.9	54.9	51.2	44.2	37.8

Fiscal Year

■ No or borderline impairment   ■ Mild to moderate impairment   ■ Moderately severe to very severe impairment

Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Cognitive Performance Scale scores: no or borderline impairment = 0–1; mild to moderate impairment = 2–3; moderately severe, severe and very severe impairment = 4–6.

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What we observed (from data)

Table 2a: Proportion of long-stay home care patients[*] with a caregiver who expressed feelings of distress or were unable to continue in caring activities, by patient characteristics, in Ontario, 2013/14

	Numerator	Denominator	% Distressed
Overall	49,208	147,905	***33.3%***
Age of Patients			
18-74	12,398	39,906	*31.1%*
75+	36,810	107,999	*34.1%*
Other characteristics			
Alzheimer's disease and other dementias	20,836	42,320	*49.2%*
Behaviour that was physically abusive, verbally abusive or disruptive, or resisted care	10,410	17,079	*61.0%*
Wandered	3,017	4,713	*64.0%*

Data source: Resident Assessment Instrument – Home Care (RAI-HC), provided by University of Waterloo
*Includes adult long-stay home care patients with caregivers who received a RAI-HC assessment at least 60 days from when their case opened and the assessment did not occur in a hospital.

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What we observed (from data)

Table 2b: Proportion of long-stay home care patients[*] with a caregiver who expressed feelings of distress or were unable to continue in caring activities, by patient characteristics, in Ontario, 2013/14

	Numerator	Denominator	% Distressed
Cognitive Performance Scale			
CPS=0-1	10678	55963	19.1%
CPS=2-3	30421	77075	39.5%
CPS=4-6	8109	14867	54.5%
Activities of Daily Living (ADL) Hierarchy Scale (personal hygiene, toilet use, locomotion, eating)			
ADL Hierarchy Scale=0-1	20333	82156	24.7%
ADL Hierarchy Scale=2-3	19869	47123	42.2%
ADL Hierarchy Scale=4-5	7555	15505	48.7%
ADL Hierarchy Scale=6	1451	3121	46.5%

Data source: Resident Assessment Instrument – Home Care (RAI-HC), provided by University of Waterloo
*Includes adult long-stay home care patients with caregivers who received a RAI-HC assessment at least 60 days from when their case opened and the assessment did not occur in a hospital.

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Caregiver distress and patient cognition

Caregiver distress by long-stay home care patients' Cognitive Performance Scale (CPS) scores, in Ontario, 2013/14

Cognitive Performance Scale

No or borderline impairment

Mild to moderate impairment

Moderately severe to very severe impairment

19.1%

39.5%

54.5%

Percent of caregivers distressed

Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo. **Notes:** Cognitive Performance Scale scores: no or borderline impairment = 0–1; mild to moderate impairment = 2–3; moderately severe, severe and very severe impairment = 4–6.

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Caregiver Panel

- Objective:
  - Explore topics that could not be captured through assessment data, learn more about caregivers, and explore why caregivers in Ontario may be distressed

- Process:
  - 3-hr focus group, facilitated discussion
    - 7 caregivers with long-term experience caring for a patient receiving home care and had experienced distress
  - Asked to describe their caregiving experiences by speaking about the activities they take part in while providing care, the distress associated with activities of caregiving and the supports that would help reduce or alleviate caregiver distress
  - Participated in review of draft report
  - Provided caregiver stories for report

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What was understood (from caregiver panel)

- Described their experience as:
  - Rewarding
  - Extremely difficult
  - Very time-consuming
  - Tremendously stressful

- Described several challenges:
  - Unprepared, untrained
  - Added tasks
  - Juggling caregiving, household tasks, work, other duties
  - Kept from work or compelled to take early retirement
  - Hire private, paid caregivers

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What was understood (from caregiver panel)

- Panel member recommendations
  - Better preparation and instruction of caregivers for the responsibilities they are taking on
  - Better coordination of home care services so that the burden of organizing care will not fall so much on caregivers
  - Provision of clear information on what home care services are available and who is entitled to them
  - More consistent and reliable delivery of services
  - Greater availability of respite services
  - More services for high-needs patients
  - More consideration of caregivers' needs and respect for the important role they play

Summary

- Engaging with caregivers helped shape the content of the report and presentation of the results

- Coupling caregiver stories with figures resulted in a more interesting and personal report

- Harnessing data and lived experiences together helps to shed light onto the factors related to caregiver distress

- Seeing how the experiences of caregivers are not captured fully in the available data highlights areas for data advancement

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