Towards improved public reporting on home care quality

ANNA GREENBERG, VP, HEALTH SYSTEM PERFORMANCE
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Health Quality Ontario

Let's make our health system healthier

Photo of Kyra and Brenda provided by the family.

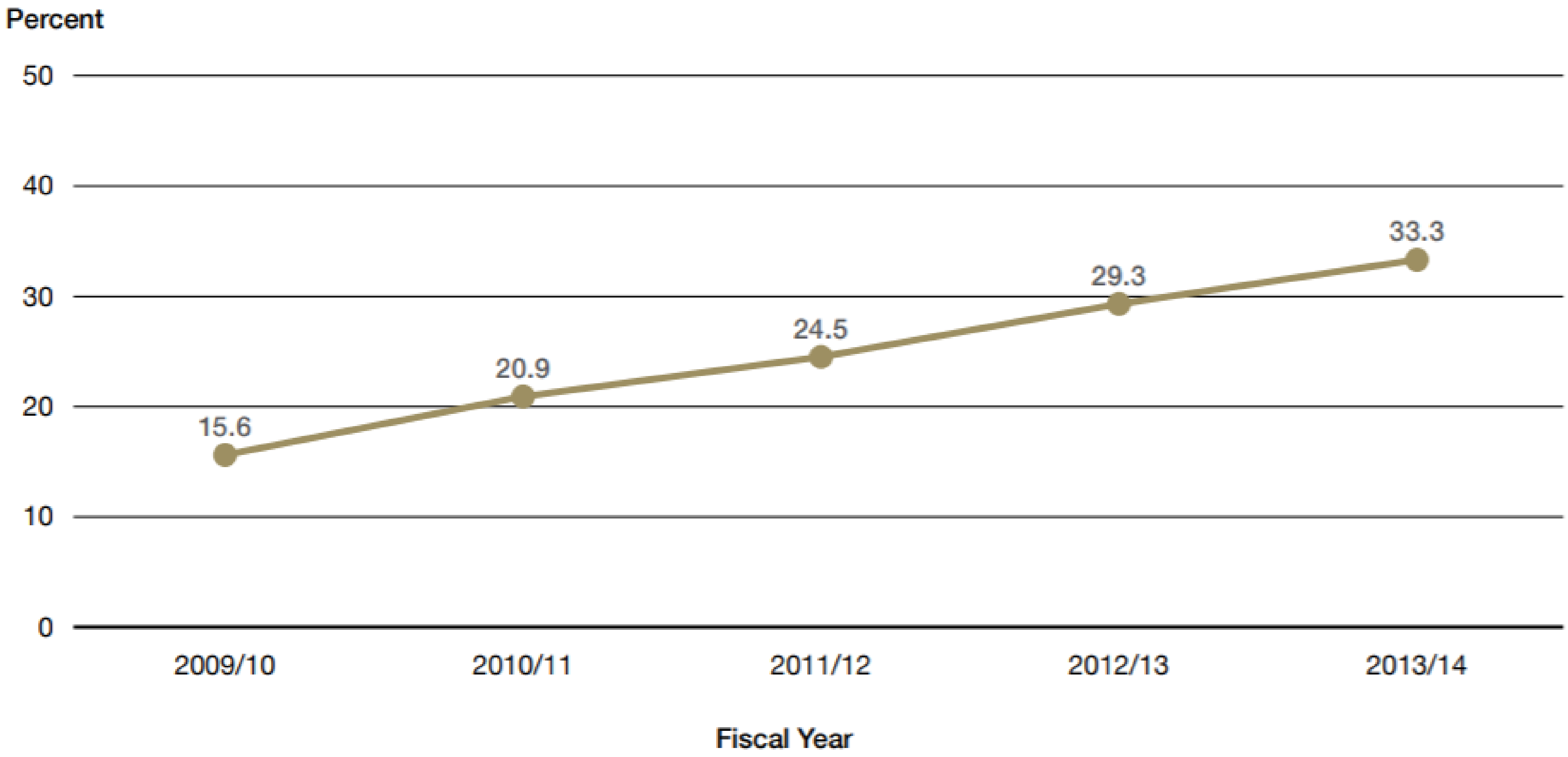
What I will cover today

- Context for improved measurement
- Our approach
- Results of our measurement review

A catalyst for improved measurement

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

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Ontario
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Caregiver context

- **97%** long-stay home care patients rely on unpaid caregiver

- Average time/week caring for long-stay home care patients
  - **18.8 hours** (09/10) to **21.9 hours** (13/14)

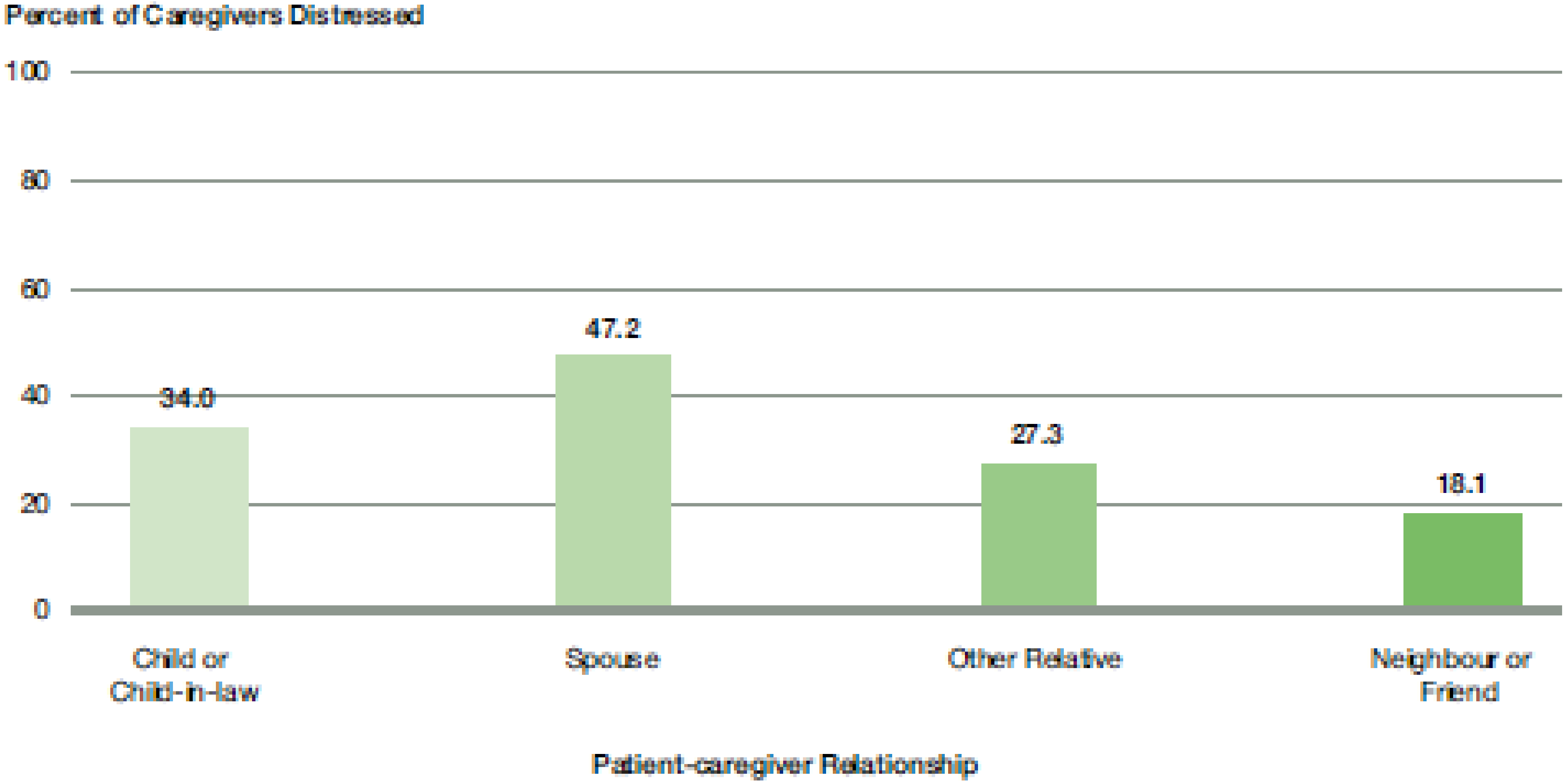
“*Distress*” → feelings of anger, depression or being unable to continue in caregiving duties

- Reported distress doubled
  - **15.6%** (09/10) to **33.3%** (13/14)

- Being unable to continue in caregiving duties doubled
  - **6.6%** (09/10) to **13.8%** (13/14)

FIGURE 3.6

Caregiver distress by patient-caregiver relationship, in Ontario, 2013/14



Data source: Resident Assessment Instrument-Home Care (RAI-HC), University of Waterloo.

What does “caregiver” mean to you?

- Until recently, I did not realize there was a name for this.

- It’s a job
  - “There is a job description with roles and responsibilities. But there isn’t a paycheck and there is no time off.”

- Feels like a constant crisis situation.

What are the major stressors?

- Exhaustion
- Social isolation
- Guilt
- Worry
- Having to be an advocate
- Feeling unqualified
- Not feeling recognized
- Family disagreements
- Feeling like a burden
- Not knowing where to turn

In an ideal world, my caregiver role would

- Be recognized, appreciated as a member of the team caring for the person
- Include recognizing my needs as well
- Be in partnership with someone else who can help with the responsibilities
- Have appropriate supports no matter where I live
- Allow for an opportunity to work <u>and</u> provide care
- Be allowed to have a social life and an identity
- Be empathized with
  - by family and friends, home care providers, professionals; so they understand what it’s like

Context for improved measurement

A health system with a culture of quality is. . .

Safe

Effective

Patient-centred

Efficient

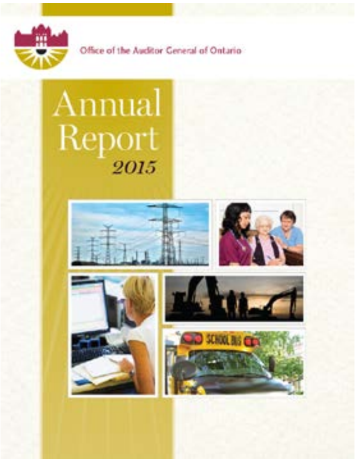
Timely

Equitable

Strong calls for better measurement

“That Health Quality Ontario in partnership with the Local Health Integration Networks, finalize and implement system performance indicators **in consultation with providers and families**.”

Bringing Care Home, 2015



“Review and assess **whether all the indicators collected continue to be relevant** for determining efficient and effective performance of home care; **make more results publicly available**…”

Annual Report of the Office of the Auditor General of Ontario, 2015

Patients First: A Roadmap to Strengthen Home and Community Care

Patients First

A Roadmap to Strengthen Home and Community Care

1. Develop a Statement of Home and Community Care Values
2. Create a Levels of Care Framework
3. Increase Funding for Home and Community Care
4. Move Forward with Bundled Care
5. Offer Self-Directed Care
6. Expand Caregiver Supports
7. Enhance Support for Personal Support Workers
8. Increase Nursing Services for Patients with Complex Needs
9. Provide Greater Choice for Palliative and End-of- Life Care
10. Develop a Capacity Plan

Level of care	Functional Need Profile	Total personal support hours per month
1	Only requires assistance with day-to-day activities such as banking and meal preparation	community support services only; no need for personal support
2	Level 1 plus assistance with some personal care activities such as bathing, and day-to-day activities, and may need some assistive devices (e.g. cane) . Does not need assistance every day.	up to 12 hours
3	Level 2 plus assistance with some personal care activities and most day-to-day activities, and may also need caregiver coaching programs. May need assistance every day.	up to 32 hours
4	Level 3 plus additional assistance with transferring and toileting, and may also benefit from caregiver coaching and respite. May need assistance once or twice a day.	up to 56 hours
5	Level 4 plus extensive assistance with hygiene and bathing, and may need help with eating. They may also benefit from caregiver coaching and respite. May need assistance two or three times a day.	up to 84 hours
6	Level 5 plus extensive help with eating and locomotion, and may need two people to assist with transferring. They may also benefit from caregiver coaching and respite. May need assistance three or more times a day.	up to 120 hours
7	Reserved for individuals with short-term or extraordinary needs, need frequent assistance throughout the day	Above service hours in level 6

What Home and Community Care Should Look Like

What care do I need?

- Levels of Care website
- Client self-assessment tool
- Standardized assessment by a health service provider

How do I receive it?

- Integrated and person-centred home, community, primary and specialist care
- Patients and caregivers play a central role in their care planning
- Access to a plain language report of the client assessment

Thriving at home with home and community care

- Standardized home and community care standards
- Consistent and equitable assessment and care coordination policies
- Real-time information sharing between all members of the circle of care

Results of our review

Our starting point

Reported at the Provincial and CCAC-level

- Waiting for nursing services
- Waiting for personal support services for complex care patients
- Hospital readmissions
- Incontinence*+
- Communication*+
- Falls*+
- Pressure ulcers*+
- Long-term care placement*+
- Emergency department visits
- Vaccination *+

Reported at the Provincial, CCAC and Service Provider-level

- Client Satisfaction

* First Generation InterRAI-HC Indicators
\+ Long-Stay Clients only

What was missing

- Patient reported experience
- Caregiver reported experience
- Credible wait times measures
- Transitions in care
- Communication about the care plan, care delivery
- Appropriateness and effectiveness of care
- Equity of care delivery

Worries in advance of our review

- Public reporting sets the agenda, but the current set are not helpful
- Long-standing measures are not amenable to improvement
- Could end up with little to no change in the measures
- Patient and caregiver voice will not be heard
- Information needs of frontline providers won’t be prioritized

Our approach

1. Patient, caregiver engagement – what matters most to you?
    - In-person, survey
2. Panel deliberation – shared goals, what's in scope/out of scope
3. Start with concepts (not indicators) and iterate
4. Prioritize and rate concepts
    - Important, actionable, interpretable, evidence-based
5. Align with measures
6. Recommendations for data advancement

21 indicators recommended

Goal: Patients First. *The delivery of home and community care is centred on the needs of patients and caregivers.*		***Goal: There when you need it.*** *A patient-centred home care system is flexible and accessible.*	***Goal: Sustainable.*** *Home care services seek to reduce the waste - and hence the cost - of supplies, equipment, space, capital, ideas, time, and opportunities while meeting patient goals for care.*	***Goal: High Quality Care.*** *Home and Community care is based on best practice and provincial evidence-informed care standards.*
Patient Centred		**Timely**	**Efficient**	**Safe and Effective**
Patient involvement in care plan ***Indicator***: Percentage of home care patients who felt involved in developing their care plan (CCEE)	**Satisfaction** ***Indicator***: Percentage of home care patients who are satisfied with their care from both coordinators and service providers (CCEE)	**Wait-time for Approval of Home Care Services** ***Indicator***: Wait time for a patient between application for home care and approval for services (HCD)	**Health System Use at the End of Life** ***Indicator***: Percentage of palliative care patients with an unplanned ED visit during their last 30 days of life	**Hospital and ED Readmission** ***Indicator***: Percent of new home care patients with ar unplanned emergency department visit within the pas 30 days (NACRS) ***Indicator***: Percent of home care patients with an unplanned hospital readmissions within 30 days for patients discharged from hospital (DAD)
Communication (Patient-Provider) ***Indicator***: Percentage of patients who say that their provider explained things in a way that was easy to understand (CCEE)	**Informal Caregiver Distress** ***Indicator***: The percentage of long-stay home care patients whose primary informal caregiver expresses continued feelings of distress, anger or depression over a 6 month period (HCRS)	**Wait-time between Approval and First Visit** ***Indicator***: Wait time for a patient between approval for services and the first home care visit (HCD)	**Transitions of Care** **Indicator:** Further work required to develop a stronger indicator of transitions of care.[1]	**Case Management** ***Indicator***: Percentage of home care patients that felt that their case manager helped them get the services that they needed (CCEE)
Unmet Care Needs **Indicator:** Percentage of patients who reported they were able to achieve their goals (to be developed) **Indicator:** Proposed placeholder measure to align with Levels of Care Framework	**Respect for Patient Values and Preferences** **Indicator:** Further work required to develop a stronger indicator of respect for patient values and preferences			**Pain** ***Indicator***: Percent of clients who have uncontrolled pa (HCRS)
Availability of Informal Caregiver Support **Indicator:** Further work required to develop a stronger indicator of availability of informal caregiver support	**Providers Know Patient's Medical History** **Indicator:** Further work required to develop a stronger indicator of provider's knowledge of patient's medical history			**Functional Status** ***Indicator***: Percentage of home care patients whose ADL functioning improved (HCRS)
Knowing Who to Call When Care is Needed **Indicator:** Further work required to develop a stronger indicator of knowing who to call when care is needed				**Wounds** ***Indicator***: Further work required to develop a stronge indicator of wounds

Legend

Indicates areas where indicators require further development

CCEE – Client and Caregiver Experience Evaluation
HCRS – Home Care Reporting System
HCD – Home Care Database
DAD – Discharge Abstract Database
NACRS -National Ambulatory Care Reporting System

Foot notes

1. Note that work is underway to add home care transitions measures into the Health and Long-Term Care Experience Survey
2. Panel recommendation to further develop databases to capture some of these data

Key recommendations

- Conduct comprehensive review of Client Caregiver Experience Evaluation survey
  - Consider new concepts, not yet measureable
  - Consider interpretability and validity for clients, caregivers
  - Develop meaningful measures of transitions in care
  - Community and social services
  - Equity considerations
- Increase the reporting of indicators at the service provider level
- Improve measurement of timely access to home care, from client perspective

Key recommendations cont.

- Ensure equity measurement is possible within home care reporting
- Improve the ability to monitor effective wound care
- Expand beyond long-stay patients to short stay
- Targets and benchmarks

Thank you.

LET'S CONTINUE THE CONVERSATION:

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