Risk Framework for Predicting Caregiver Distress

Development of an Evidence-Based Strategy to Enhance Caregiver Resilience

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Jodi Webber, Client Services Manager, Seniors Care Inner City

06 June 2016
Agenda

Understanding The Caregiver’s Experience

Predicting New and Persistent Caregiver Distress

Toward a Comprehensive, Community-Based Strategy to Enhance Caregiver Resilience

#OACON16
In Canada, informal caregivers play an essential role in the health care infrastructure, providing:

- an estimated **60-90%** of home care\(^1,2,3\)
- care estimated at **$26 billion** annually\(^4\)
- # of Canadian seniors requiring care to **double** by **2046**\(^5\)
- While informal caregivers may readily accept the role of carer, they are generally emotionally **unprepared** and lack the requisite **skills**

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\(^1\) Health Council of Canada, 2012  
\(^2\) Stone et al., 1987  
\(^3\) Kasper et al., 2015  
\(^4\) Hollander et al., 2009  
\(^5\) HQO Report: The Reality of Caring
Understanding The Caregiver’s Experience

What we do...

What caregivers do...
Susceptible to physical, psychological, social, and financial burden of caregiving

By building resilience with caregivers we significantly strengthen their capacity to remain in the caregiving role

By deepening our understanding of caregivers and their needs we reduce the likelihood of visits to hospital and LTC admission for both the client and the carer
Understanding The Caregiver’s Experience: HQO Report: The Reality of Caring
Why focus on the Caregiver?

- People are likely to remain in the community, receiving care at home as they age or experience disability
- Pool of potential caregivers getting smaller
- Women who have historically done much of the most intense caregiving are increasingly employed in the workplace instead of available at home to look after ailing or frail family members
Why focus on the Caregiver?

- in Ontario, **97%** of adults receiving provincially-funded long-stay home care have **at least one informal caregiver**

- **informal caregivers of 1/3** of Ontario’s long-stay home care patients experienced **distress, anger or depression** in relation to their caregiving role, or were unable to continue in that role
Understanding The Caregiver’s Experience: HQO Report: The Reality of Caring

Caregiver Distress

<table>
<thead>
<tr>
<th>Year</th>
<th>Distressed (%)</th>
<th>Not Distressed (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>15.6</td>
<td>84.4</td>
</tr>
<tr>
<td>2013/14</td>
<td>33.3</td>
<td>66.7</td>
</tr>
</tbody>
</table>

Able to continue as Caregiver

<table>
<thead>
<tr>
<th>Year</th>
<th>Not able (%)</th>
<th>Able (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>6.6</td>
<td>93.4</td>
</tr>
<tr>
<td>2013/14</td>
<td>13.8</td>
<td>86.2</td>
</tr>
</tbody>
</table>
Understanding The Caregiver’s Experience: HQO Report: The Reality of Caring

Care Recipient Characteristics

- Alzheimer’s/dementia
- Abusive, resists care
- Cognitive impairment
- ADL impairment
- Unstable health
- Risk of adverse outcomes
- Multiple health issues

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Caregiver Comments: Their Experience

- Rewarding but extremely **difficult, time-consuming, tremendously stressful**
- Felt **inadequately prepared**, lots to learn
- Difficulty **juggling tasks** (e.g., trying to complete households tasks while supervising patients with dementia)
- Guilt: tired of caregiving, **wanting relief**; occasionally losing patience
Caregiver Comments:

- **Recognition**
  - Caregiver role not understood or recognized or valued

- **Home Care**
  - Gaps between services and care needs
  - Who is eligible?
  - Collaboration across sectors could be improved for better service coordination
Caregiver Comments: Navigating Care

- Stressful to deal with the health professionals; many seem focused on acting as *gatekeepers*

**Gaps:**
- Knowing what home care *services* are available
- Providing help with *coordinating* care

“...caregivers really need someone who can do an appropriate *assessment*. Somebody’s who’s skilled and *knows* and *can provide* community resources. That person needs to remain *involved* with the caregiver and care recipient and be easily *accessible* when help is needed.”
Recommendations of the Expert Group on Home & Community Care (Jan 2015)

- Adopt **family-centred** model of home care that will take into account the needs of caregivers
- Facilitate access to more appropriate **resources** to support family caregivers, particularly respite services
- A common understanding of the home and community care **services that are available to support caregivers**
Understanding The Caregiver’s Experience

Predicting New and Persistent Caregiver Distress

Toward a Comprehensive, Community-Based Strategy to Enhance Caregiver Resilience

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The challenges experienced by informal caregivers has been well documented.

The focus of home and community care continues to remain on the client.

However, a ‘cultural shift’ recognizing the client and caregiver as a dyad has been gaining momentum.

The Toronto Central CCAC recognized this as an emerging priority and has begun work to address clients’ and caregivers’ shared needs.
Predicting Caregiver Distress: Background

- **Caregiver Distress** identified by Toronto Central CCAC as one of 5 high priority quality indicators (QI)

<table>
<thead>
<tr>
<th>QI</th>
<th>RAI-HC Client Assessment Protocol (CAP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood</td>
<td>✓</td>
</tr>
<tr>
<td>Pain</td>
<td>✓</td>
</tr>
<tr>
<td>Falls</td>
<td>✓</td>
</tr>
<tr>
<td>Alone &amp; Distressed</td>
<td>×</td>
</tr>
<tr>
<td>Caregiver Distress</td>
<td>×</td>
</tr>
</tbody>
</table>

- Toronto Central CCAC performs below provincial average on these QIs
Predicting Caregiver Distress: Background

Semi-Annual Adjusted Caregiver Distress Rates Using New HCQLI among Home Care Clients, in Ontario, 2010-14

Continued Caregiver Distress

Better


= TC

= ON

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How to measure **Caregiver Distress** in an operational setting???

Several scales available addressing several constructs:

- **Well-being** (health, symptoms, depression, QOL)
- **Consequences of caregiving** (social isolation, work strain, emotional/physical health, grief, financial)
- **Ability to provide care** (competence, confidence, knowledge)
- **Coping** (problem solving, managing stress, spirituality)

**Time consuming, require training, lack standardization/integration**
The purpose of this phase of this body of work was to identify factors related to **Caregiver Distress** for informal caregivers providing assistance for clients receiving homecare.
1. Identify predictors of **new onset** caregiver distress among caregivers **NOT** currently experiencing distress
   - Who will **become** distressed?

2. Identify predictors of **persistent** caregiver distress among caregivers currently experiencing distress (i.e., barriers to mitigating caregiver distress)
   - Who will **remain** distressed?
Predicting Caregiver Distress: Methods

Step 1
Develop risk stratification algorithms based on provincial-level RAI-HC data

Step 2
Apply algorithms to Toronto Central CCAC data to identify ‘at risk’ caregivers

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• **254,772** provincial-level RAI-HC assessments included in analysis

• Cases were identified as those caregivers who had responded ‘Yes’ to one or both of the following RAI-HC elements:
  • “A caregiver is unable to continue in caring” or
  • “Primary caregiver expresses feelings of distress, anger or depression”
**SECTION G. INFORMAL SUPPORT SERVICES**

<table>
<thead>
<tr>
<th>1</th>
<th>TWO KEY INFORMAL HELPERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary (A) and Secondary (B)</td>
<td></td>
</tr>
<tr>
<td>a. (Last/Family Name)</td>
<td>b. (First Name)</td>
</tr>
<tr>
<td>c. (Last/Family Name)</td>
<td>d. (First Name)</td>
</tr>
<tr>
<td>e. Lives with client</td>
<td>0. Yes</td>
</tr>
<tr>
<td>f. Relationship to client</td>
<td>0. Child or child-in-law</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2</th>
<th>CAREGIVER STATUS</th>
<th>(Check all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A caregiver is unable to continue in caring activities—e.g. decline in the health of the caregiver makes it difficult to continue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary caregiver is not satisfied with support received from family and friends (e.g. other child/stepchild)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary caregiver expresses feelings of distress, anger or depression</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3</th>
<th>EXTENT OF INFORMAL HELP (HOURS OF CARE, ROUNDED)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For instrumental and personal activities of daily living received over the LAST 7 DAYS, indicate extent of help from family, friends, and neighbours</td>
<td></td>
</tr>
<tr>
<td>a. Sum of time across five weekdays</td>
<td></td>
</tr>
<tr>
<td>b. Sum of time across two weekend days</td>
<td></td>
</tr>
</tbody>
</table>
Statistical regression models created to identify the factors that can be used to predict caregiver distress: who will:

- **Become** distressed
- **Remain** distressed
Provincial-level regression models used to create **risk stratification algorithms** were applied to Toronto Central CCAC clients.
Predicting Caregiver Distress: Results

- **9 in 10 (88.9%)** Toronto Central CCAC clients have caregivers

<table>
<thead>
<tr>
<th>Team</th>
<th>Caregiver</th>
<th>No Caregiver</th>
<th>No RAI-HC</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Supportive, ABI</td>
<td>720</td>
<td>139</td>
<td>117</td>
<td>976</td>
</tr>
<tr>
<td>Integrated Care Team - Seniors</td>
<td>354</td>
<td>22</td>
<td>18</td>
<td>394</td>
</tr>
<tr>
<td>Seniors Care Central East Team</td>
<td>1,674</td>
<td>110</td>
<td>80</td>
<td>1,864</td>
</tr>
<tr>
<td>Seniors Care Central West Team</td>
<td>1,684</td>
<td>78</td>
<td>32</td>
<td>1,794</td>
</tr>
<tr>
<td>Seniors Care Congregate Living Team</td>
<td>1,632</td>
<td>128</td>
<td>144</td>
<td>1,904</td>
</tr>
<tr>
<td>Seniors Care East Team</td>
<td>1,710</td>
<td>84</td>
<td>42</td>
<td>1,836</td>
</tr>
<tr>
<td>Seniors Care Inner City Team</td>
<td>685</td>
<td>153</td>
<td>22</td>
<td>860</td>
</tr>
<tr>
<td>Seniors Care West Team</td>
<td>1,833</td>
<td>86</td>
<td>30</td>
<td>1,949</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>10,292</strong></td>
<td><strong>800</strong></td>
<td><strong>485</strong></td>
<td><strong>11,577</strong></td>
</tr>
</tbody>
</table>
1 in 3 (32.2%) caregivers have distress
2 in 3 (67.8%) caregivers have NO distress

<table>
<thead>
<tr>
<th>Team</th>
<th>Distress</th>
<th>No Distress</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Supportive, ABI</td>
<td>283</td>
<td>437</td>
<td>720</td>
</tr>
<tr>
<td>Integrated Care Team - Seniors</td>
<td>148</td>
<td>206</td>
<td>354</td>
</tr>
<tr>
<td>Seniors Care Central East Team</td>
<td>544</td>
<td>1,130</td>
<td>1,674</td>
</tr>
<tr>
<td>Seniors Care Central West Team</td>
<td>565</td>
<td>1,119</td>
<td>1,684</td>
</tr>
<tr>
<td>Seniors Care Congregate Living Team</td>
<td>271</td>
<td>1,361</td>
<td>1,632</td>
</tr>
<tr>
<td>Seniors Care East Team</td>
<td>669</td>
<td>1,041</td>
<td>1,710</td>
</tr>
<tr>
<td>Seniors Care Inner City Team</td>
<td>203</td>
<td>482</td>
<td>685</td>
</tr>
<tr>
<td>Seniors Care West Team</td>
<td>626</td>
<td>1,207</td>
<td>1,833</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>3,309</strong></td>
<td><strong>6,983</strong></td>
<td><strong>10,292</strong></td>
</tr>
</tbody>
</table>
Nationally, nearly 20,000 informal caregivers (16%) of seniors receiving home care reported distress related to their role. The rates of distress were significantly higher among those:

- Providing >21 hours of care per week: 28%
- Caring for seniors with depression: 32%
- Caring for seniors with cognition problems: 37%
- Caring for seniors with aggressive behaviour: 52%
Factors* related to NEW ONSET caregiver distress:

- Primary caregiver lives with client
- Married
- MAPLe score >4
- Aged 65 and over
- Phone used with assistive device
- Persistent anger with self or others
- Alzheimer’s and other related dementia
- Has condition or disease that makes cognition, ADL, mood, or behavior patterns unstable
- Primary caregiver is not satisfied with support received from family and friends
- Clinical Risk Scale score >4
- Sedatives taken in the last 7 days
- 20 hours or more of informal help in a day

* Identified by regression models utilizing provincial-level data
Predicting Caregiver Distress: Results: New Onset Distress

Number of Caregivers at Risk of **NEW ONSET** Distress (n=6,983)

- **26.8%** with 7-12 factors
- **39.9%** with 5-6 factors
- **33.4%** with 0-4 factors
Proportion of caregivers by presence of risk factors for distress ONSET for Adult Supportive and ICT

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Factors* related to **PERSISTENT** caregiver distress:

- Primary caregiver lives with client
- MAPLe score >4
- Interpreter needed
- Phone used with assistive device
- Persistent anger with self or others
- Alzheimer’s and other related dementia
- Good prospects of recovery
- Treatments changed in last 30 days because of a new acute episode or condition
- As compared to 90 days ago, client now lives with other persons
- Female
- Number of times admitted to hospital with an overnight stay
- Hours of physical activities in the last 3 days
- Surgical wound

* Identified by regression models utilizing provincial-level data
Number of Caregivers at Risk of **PERSISTENT** Distress (n=3,309)

Predicting Caregiver Distress: Results: New Distress
Proportion of caregivers by presence of risk factors for **PERSISTENT** distress for Adult Supportive and ICT

### Results: New Onset Distress

**Adult Supportive, ABI**

- High Risk

**Integrated Care Team - Seniors**

- High Risk
Predicting Caregiver Distress: Next Steps…

Now that we have better focus…

...what do we do?
Understanding The Caregiver’s Experience

Predicting New and Persistent Caregiver Distress

Toward a Comprehensive, Community-Based Strategy to Enhance Caregiver Resilience
Toward a Caregiver Resilience Strategy
Right Care, Right Time

Risk of Caregiver Distress

High
Moderate
Low

Care Trajectory

Emergent Symptoms
New Diagnosis
Ongoing Support

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Toward a Caregiver Resilience Strategy
Right Care, Right Time

Risk of Caregiver Distress

High

Moderate

Low

Emergent Symptoms

New Diagnosis

Ongoing Support

Care Trajectory

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How to select and allocate resources based on individualized needs in a way that builds and maintains caregiver resilience?
Elements of a strategy to build and maintain caregiver resiliency

1. Legislative
2. Psychosocial
3. CCAC services
4. Community service organizations
Employment

- **Employment Insurance Act** entitles employees to **6-months of Compassionate Care Benefits** if they have to be away from work to care for an ill family member.
- On average, the benefit is **55 percent of average insurable earnings** to a maximum amount of $49,500.

Financial

- Tax credits available through the Canadian Revenue Agency (CRA)
  - **Family Caregiver Amount** provides a non-refundable tax credit of $2,093
    - may also claim a non-refundable **Amount for Infirm Dependents** age 18 or older to a maximum of $6,589
  - **Family Caregiver Benefit Relief** provides a tax-free benefit for family caregivers of Canada’s veterans; $7,238 grant to purchase relief services.
Employment

- **Family Medical Leave** entitles employees to an 8-week unpaid, job-protected leave to provide care or support to a family member who has a significant risk of death within a 26-week period.
- **Family Caregiver Leave** entitles employees to eight weeks unpaid, job-protected leave within a 52-week period to provide care or support.

Respite

- The MOHLTC, via LHINs, funds adult day programs and enhanced day programs across province.
- The MOHLTC, via CCACs, funds two types of respite services: in-home or short stay in long-term care homes.
- Caregivers may request 60 days at a time to a maximum of 90 days of short respite in a long-term care home as long as they pay a daily fee.
Toward a Caregiver Resilience Strategy

1. Legislation: UK


October 2014
Priority Areas:

1. Identification and recognition
2. Realising and releasing potential
3. A life alongside caring
4. Supporting carers to stay healthy
Toward a Caregiver Resilience Strategy

House of Care Toolkit (NHS)

Organisational and supporting processes
- Information technology
- Safety & experience
- Care delivery
- Care planning
- Guidelines, evidence & national audits

Engaged, informed individuals and carers
- Empowered individuals
- Information & technology
- Group & peer support
- Care planning
- Carers

Health and care professionals committed to partnership working
- Joined up working
- Culture
- Workforce
- Technology
- Care coordination
- Care planning

Person-centred coordinated care

Commissioning
- Needs assessment & planning
- Joint commissioning of services
- Metrics & evaluation
- Service user & public involvement
- Contracting & procurement
- Care planning
- Tools and levers

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Toward a Caregiver Resilience Strategy
2. Psychosocial Interventions

- A number of psychosocial interventions have been shown to improve caregiver distress:
  - Psychoeducation
  - Peer support
  - Cognitive Behavioural Therapy (CBT)
  - Problem-solving techniques\(^1\)

Services provided directly or indirectly by the Toronto Central CCAC

- Care Coordination
- Personal Support (PSW) via Service Provider Organizations
- Respite in LTC Homes
- Adult Day Programs
- Enhanced Adult Day Programs
Toward a Caregiver Resilience Strategy

4. Community Connections

Community Navigation and Access Program (CNAP)
Toward a Caregiver Resilience Strategy
4. Community Connections

TorontoCentralhealthline.ca
Toward a Caregiver Resilience Strategy
How CCACs will Connect the Caregiver?

House of Care Toolkit Adapted to CCAC Context

**Legislative Supports**
- Employment relief
- Financial assistance
- Medical leave
- Respite

**Community Connections**
- Community Navigation Access Program (CNAP)
- TorontoCentral Healthline.ca

**Client/Caregiver-Centered Coordinated Care**

**Evidence-based Interventions**
- Cognitive Behavioural Therapy
- Problem-Solving
- Psychoeducation

**Direct/Indirect CCAC Services**
- Care Coordination
- Personal Support
- Adult Day Programs
- Respite
- Health Services Information
- Healthcare Navigation

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Adapted from the House of Care Toolkit (NHS)
Toward a Caregiver Resilience Strategy

Next Steps...

Who?
• Risk stratification algorithms

What?
• Development of a comprehensive caregiver support strategy
  o Collaborative
  o Cross-sectoral
  o Evidence-based
  o Cost-effective

How?
• Caregiver engagement
• Pilot testing
• Implementation plan

✔ Complete  Spring 2016  Pilot Fall 2016

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Toward a Caregiver Resilience Strategy
Right Care, Right Time

Current state
Testable model

Future State
Operational model

Client/caregiver engagement

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However beautiful the strategy, you should occasionally look at the results.

Winston Churchill
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