

Caregiver Respite Program: An Organizational strategy to support Caregivers' Unique Needs

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Agenda

1. Introduction, Context and Purpose
2. Methodology
3. Intervention
4. Results:
 - A. Focus Group with Service Providers and Care Coordinators
 - B. Caregiver Interviews
5. Next Steps

Introduction: Understanding Caregiver Resiliency

- 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** annually⁴
- Number 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**

¹ Health Council of Canada, 2012

² Stone et al., 1987

³ Kasper et al., 2015

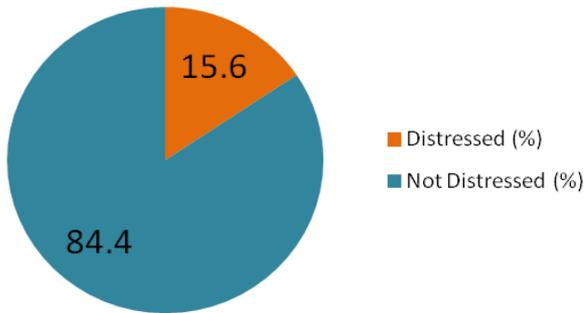
⁴ Hollander et al., 2009

⁵ HQO Report: The Reality of Caring

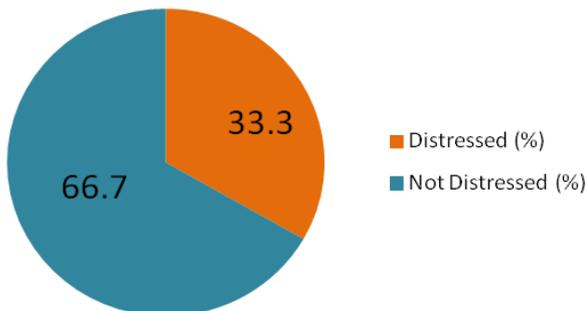
Introduction: Understanding Caregiver Resiliency

Caregiver Distress

2009/10

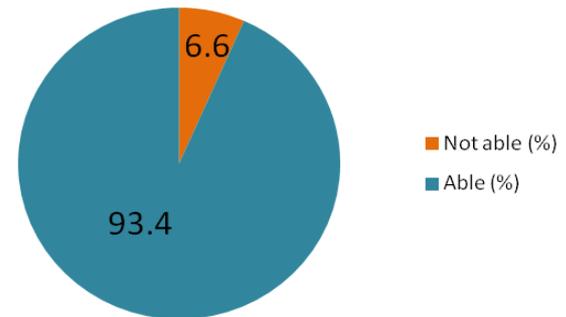


2013/14

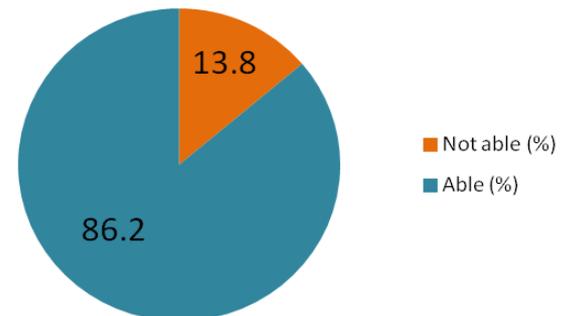


Able to continue as Caregiver

2009/10



2013/14

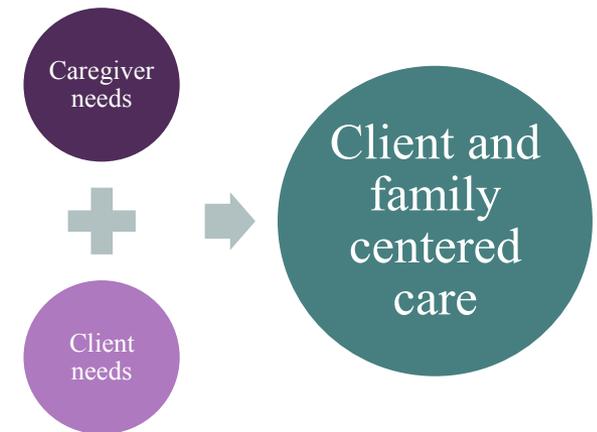


Provincial Context and Purpose

MOHLTC announced \$20 million in base funding for High Needs Caregiver Respite; \$1.8 million for TC-CCAC in 2016-17

Purpose

- 1) To provide impactful and meaningful support for caregivers who are in distress to decrease their burden and support long-term resiliency
- 2) To appreciate and understand how we can better support caregivers to build and maintain long-term resiliency



Methodology: Identifying Caregivers in Distress

Population

High needs caregivers who are in distress

Criteria informed by OACCAC analysis

- Client has dementia
- Caregiver lives with client
- Caregiver is in distress
- Caregiver provides 25+ hours of care
- Client is a senior
- Client has a RAI-HC

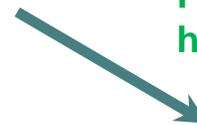
PSW support: 20
hours/month



Group A: Community Clients

- 480 Clients identified from the Community Program

PSW support: 20-21
hours/week



Group B: ALC

- 10 Clients identified from Hospital
- 10 Clients identified from Crisis

Intervention: How are Caregivers supported in this Program?



- Collaborative Problem Solving and Assessment of Needs



- Navigation & Linkages to Community Resources



- In-home PSW Respite for Caregiver



- Monitoring Impacts of Respite Plan

Expected Outcomes



- Increase caregiver linkages to community supports



- Reduce caregiver distress

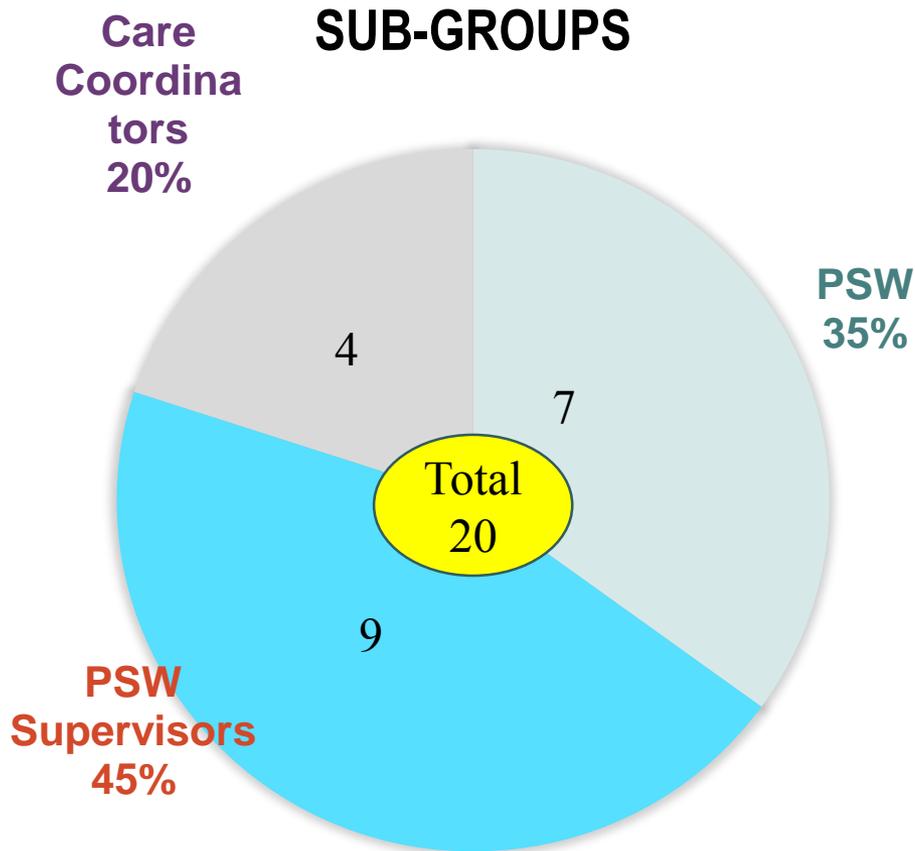


- Maintain or improve the level, duration and/or quality of informal care



- Increase caregiver resiliency

Results: Focus Group with Service Providers and Care Coordinators



Questions covering 4 themes:

1. Enrollment
2. Operations
3. Client Caregiver Experience
4. Opportunities for Improvement

Results: Service Providers and Care Coordinators

Service Planning

- There is more demand for PSW service in the evening hours
- Families prefer same PSW for continuity of service

Communication

- Consistent communication is needed between PSW, Service Agency, and Client-caregiver care coordination
- Sharing the care plan with the Agency

Scope of Practice

- More clarity required by PSW on potential increased scope of practice (iADL)
- Some clients may be requesting services deemed as outside scope of practice
- PSW's reported offering a 'different' type of service than regular respite: For example, stay with the care recipient, read stories, puzzles 10

Results: Focus Group with Service Providers and Care Coordinators

Respite vs. Regular hours

- From their perspective, Caregivers do not differentiate between 'regular' vs. 'respite' hours

Client Expectations

- Some caregivers may experience frustration from not receiving support as per preference, such as the same PSW or timing specification
- There is expectation that the Program will continue and support will be provided

Acceptance of Program

- Acceptance of Program depends on personal beliefs/cultural barriers: There are some who may not wish to accept government services

Results: Focus Group with Service Providers and Care Coordinators

Participants prioritized the following areas for improvement:

- 1 PSW service continuity and availability
- 2 PSW skills/ experience with dementia
- 3 Some caregivers are excluded from current criteria who would benefit
- 4 Matching PSW service based on language
- 5 Inconsistent client understanding (scheduling, continuity, scope)
- 6 Availability of PSW services (evenings, overnight)
- 7 Families want to move hours but would like same PSW (frequency of changes and length of time for notification)

Results: Caregiver Interviews

A Client Engagement Facilitator, arms-length, was working with the Caregiver Respite Program, to support client and caregiver engagement and evaluative activities.

Role:

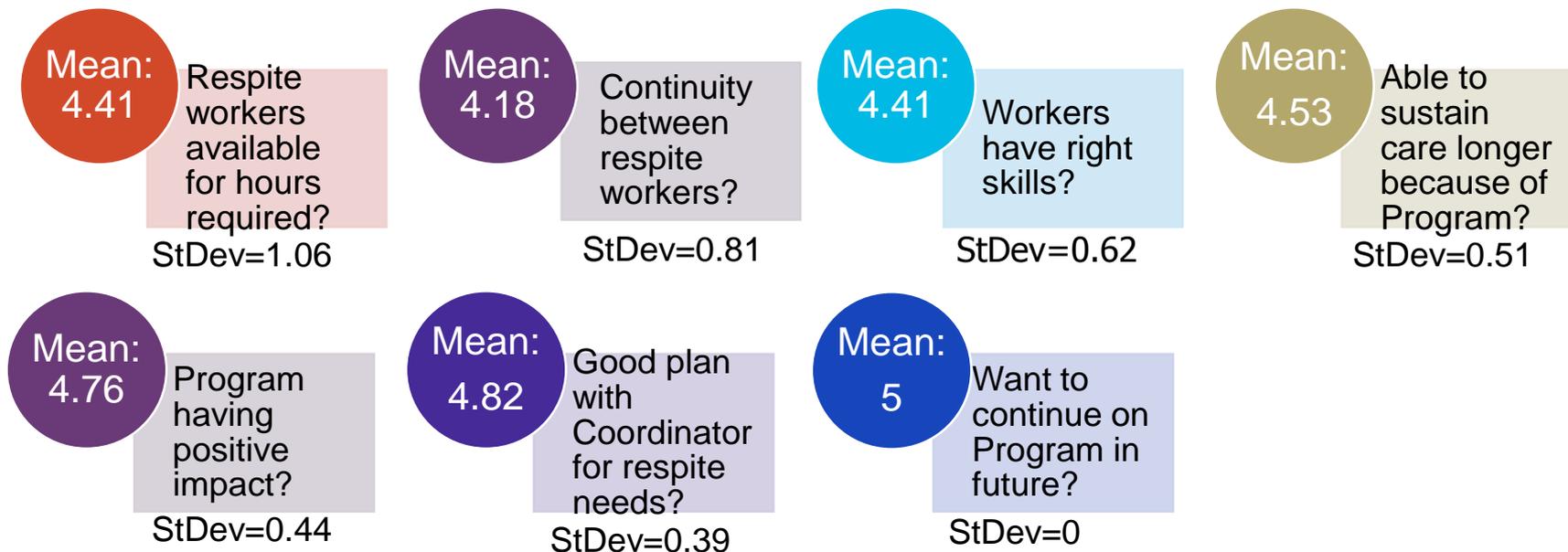
Develop composite journey maps for each cohort of caregiver respite recipients to understand caregiver experience during Year 1 of the program

Leverage feedback to inform Year 2 program co-design/ implementation

Results: Caregiver Interviews

Caregivers asked to rate their experiences with the Program from 1 (Strongly Disagree) to 5 (Strongly Agree)

Random sample methodology to select caregivers



High Averages (Mean) with very small standard deviation. Trend shows overwhelming support for the Program:

- The Patient was receiving better care as a result
- The Caregiver was able to take better care of themselves
- The Caregiver was better able to cope and experienced lower stress levels

“You really have changed my life with all your careful help”

We really appreciate the extra mile...easier for my mother's comfort...and for myself as my mother's caregiver”

“Time relief ...is so appreciated and I know it helps me be a better caregiver”

CAREGIVER INTERVIEWS FEEDBACK

peace of mind...when husband in PSW care...he is also in better spirits when wife returns

This Program provides family more support and relief so caregiver is able to rest. Family feels safe when someone is there

Caregiver Interviews Feedback: What needs are still unmet despite Respite Service?

1

Depression, loneliness, lack of a life

“social life is gone...totally dedicated to mom...can we get PSWs to talk to me?”

“there are times that things become overwhelming...will I be able to last?”

2

Financial stresses

“have only short time to get supplies and forced to go to local, more expensive retailers”

“need financial help to buy medication”
“cost of diapers high...use many”

3

A need for ad hoc hours to meet unscheduled needs

“need to be able to meet extra short term needs”

“no ability to meet unscheduled needs”

4

Pattern between a clean and organized home and the caregiver’s ability to cope with their situation

Those who had a clean and more organized environment, reported better coping with their situation where those who lived in dirty, perpetually disorganized or chaotic environments reported depression and low coping more frequently

Next Steps

1. Utilize co-design methodology, opportunities for improvement and associated quality improvement plans to advance the caregiver respite program
2. Randomized Control Trial on Caregiver Resilience
3. Recommended population expansion if there was more funding (Chronic illnesses eg CHF, Clients not diagnosed as dementia, Caregiver living off-site, and Clients who receive intensive service hours)

Questions?