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FACULTY OF HEALTH
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Health Sciences



The interRAI Caregiver Wellbeing Index

Educational Content and
Training Resources
2023



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Why is this important?

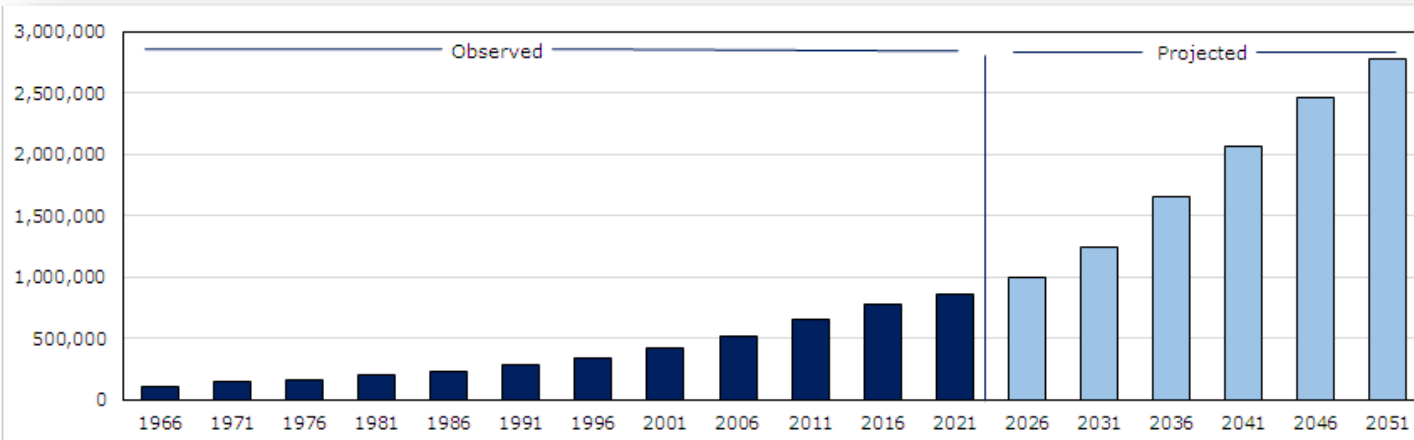


Higher demand for informal care

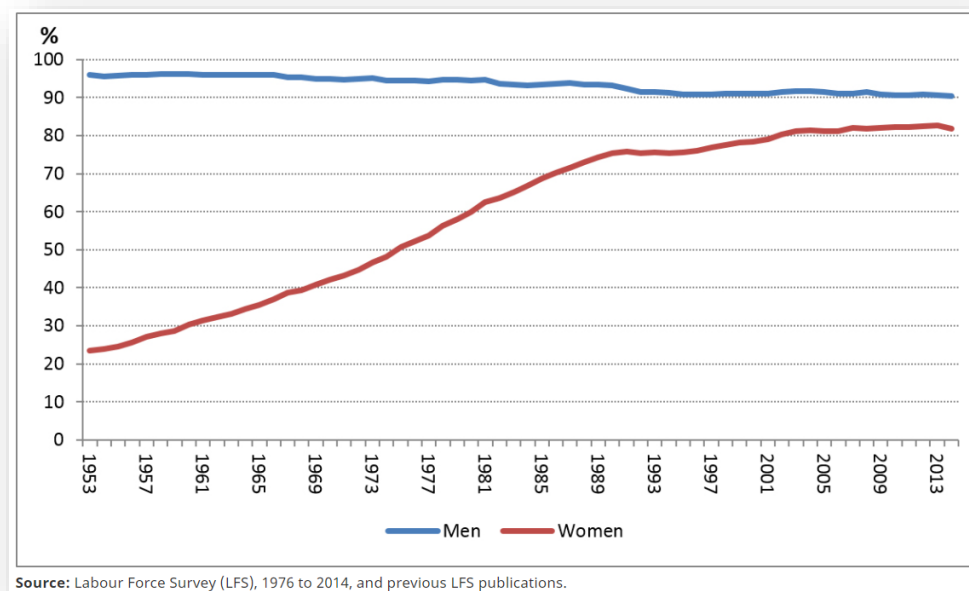
Why? Changes in our society

- People living longer, higher prevalence of chronic diseases
- Smaller families – less support available
- Lack of beds in long term care facilities

The number of people aged 85 and older continues to grow



Increased participation of women in the labour market



Source: Statistics Canada



3/4 of Care is Provided by Informal Caregivers

Provide help with ADLs and IADLs

Encourage treatment compliance

Request pay relief,
administering medications

Make decisions as a
substitute decision
maker



Pay bills, manage insurance
claims, renew prescription

Seek information,
understand disease
progress

Report symptoms and side
effects



The Effect of Caregiving on Carer Wellbeing

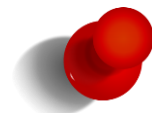
- Social isolation
- Lack of time for taking care of themselves – self-care is neglected
- No leisure time
- Financial – expenses with medication, transportation
- Employment – absenteeism
- Poor mental health – depression, anxiety
- Poor physical health – pain, exhaustion





Why an informal caregiver screener?

- Recognize caregiver's role and allow them to express their feelings, tell their stories, and become visible
- Quickly identify caregivers that are at risk of adverse outcomes
- Optimize resource allocation and support equity
- Evaluate interventions
- Identify areas for improvement



~97% of home care clients in Ontario have a primary caregiver



Caregiver Wellbeing Index (CWI)

1. Development based on 4 years of research

- Based on data from 533 Caregiver Survey interviews with 82 items within 5 domains – factor analysis, longitudinal models

2. Scores related to caregiver and care recipient outcomes

- Higher scores are associated with care recipient institutionalization and caregiver poor mental and physical health

3. Sensitive to changes

- Decrease in distress is captured after intervention

4. Extensively validated

- Scores are associated with factors directly linked to distress

5. Tested among different groups of caregivers

- Caregivers of patients with different illness, care needs, and receiving different types of care (home care, hospice care)



Caregiver Wellbeing Index Questions

- **In the last three days, how often have you felt...**
 - little interest or pleasure in the things you normally enjoy?
 - anxious, restless, or uneasy?
 - sad, depressed, or hopeless?
 - overwhelmed by your relative/friend's illness?

Scoring the CWI

Step 1

First record the person's actual response in the box labelled "Response (0-3)".

- 0 Not in the last 3 days
- 1 Not in the last 3 days but often feel that way (NOTE: Use this code only if the caregiver indicates the feeling is present and active, but it was not experienced in the last 3 days)
- 2 In 1-2 of last 3 days
- 3 Daily in the last 3 days

Scoring the CWI

Step 2

Then use the following chart to determine the Score Code for each item.

IF Response is		THEN Score Code is
0	Not in the last 3 days	0
1	Not in the last 3 days, but often feel that way	0
2	In 1-2 of last 3 days	1
3	Daily in the last 3 days	2

Response (0-3)

Score (0-2)



Calculating the Final Score

Step 3

In order to calculate the final risk category, add all four scores (maximum score of 8)

Step 4

Use the final scores to identify the risk level of adverse outcomes.



Risk Levels

Low

Score of 0 on CWI

Mild

Score of 1 - 3 on CWI

Moderate

Score of 4 - 6 on CWI

High

Score of 7 - 8 on CWI



Caregivers at higher risk compared to the lowest risk of adverse outcomes are more likely to...

- Report conflict with family
- Believe the care recipient would be better off elsewhere
- Report that they are not willing (unable) to provide additional help on ADL and IADL or additional emotional support
- Report distress, anger, depression
- Be caring for someone that is admitted to a long-term care facility (after controlling for age/gender caregiver and care recipient, co-residence and care needs)



Caregivers providing care to individuals with

- Dementia
- Socially inappropriate behavior
- Bowel incontinence
- Difficulty to understand others
- Depression

have higher CWI scores compared to caregivers providing care for someone without these conditions.



Caregiver issues more likely to be experienced by Caregivers and Wellbeing levels (%)





Changes in the CDI scores after respite intervention

Low

Increased CWI scores after respite intervention (i.e., >0)

- More often felt anxious, restless, or uneasy
- More often felt overwhelmed by a relative's/friend's illness

Moderate

No change in CWI scores

- Less often felt they could go where they want on the "spur of the moment"
- Caregiver reported higher pain frequency

High

Decreased CWI scores

- More often reported that they can get the health services they need
- Less often felt:
 - little interest of pleasure in the things they normally enjoy
 - Anxious, restless, or uneasy
 - Sad, depressed, or hopeless
 - Overwhelmed by relative's/friend's illness



CWI interview: Key points

- The CWI is based on self-report: **Only the caregiver's responses** should be used to rate each item, even if the assessor observes or believes the situation to be different
- It is important that the **assessor develop rapport with the caregiver** prior to asking the Caregiver Wellbeing Index questions.
- Whenever possible, **this part of the assessment should take place without the patient present** to elicit as much honesty as possible.



CWI interview: Key points

- You could start the conversation by saying: **“I would like to talk to you about how you are feeling. I hear how much you are doing for...”**
- Or **“I know you said you are spending about 20 hours a week helping your mom. I would like to ask you a few questions about you as your mom’s caregiver”**.
- **Avoid saying** that these questions are related to **determining eligibility** for caregiver support



CWI interview: Key points

- Questions are about feelings experienced **in the last 3 days**.
- Code for both the presence of the indicator and the number of days in which it was felt, **no matter how often it was felt per day**.
- **It does not matter** which **specific feeling** in the question was experienced.
- **Order for asking the questions does not matter**
- CWI is a **decision support** tool – **NOT** a decision making tool



Lessons Learned:

How to ensure the best performance of the screener

Timing of assessment is crucial!

When to assess:

- Ordinary vs unusual situation – Ideally after care recipients started receiving initial services
- First time caregiver assessment – ensure that it is performed close to the care recipient assessment.
 - ❖ Why? 1) Build rapport with caregivers and
 - 2) Identifying care recipient characteristics that trigger caregiver distress



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Practice



Practice

- You are completing an assessment for an 89 year old woman with vascular dementia, who lives with her 92 year old spouse. The spouse is very reluctant to have services as he feels the patient will not allow the PSW to help and he is denying that he is at all distressed by his caregiving role. However, you have received many calls from his daughter indicating that he is in distress
- **Caregiver Wellbeing Index score is low.**
- How will you proceed?



Practice

- You are doing an assessment on a 65 year old man newly diagnosed with Parkinson's. His personal care needs are relatively low (needs help with transfer into the shower only). The patient has many follow up appointments with physicians and other health services. The wife is extremely unhappy that he needs to “wait” for PSW services saying, “He’s paid his taxes his whole life and has never used the system. Now when he needs the system you tell him he has to wait. You are no help at all!”
- **Caregiver Wellbeing Index score is very high.**
- How will you proceed?



Summary

- The Caregiver Wellbeing Index has been validated as a **decision support tool**.
- By using the screener, care coordinators have a better understanding of the caregiver's issues.
- CWI also captures caregiver's ability to continue. The screener can identify caregivers that need immediate help and those that may benefit from prevention.
- Further assessment (e.g., interRAI Self-reported Carer Needs assessment) is highly recommended for understanding caregiver unique needs.



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If you would like more information about the interRAI Caregiver Wellbeing Index or if you would like to use the CWI with clients in your organization, please contact

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Thank you