

Caregiver Needs Assessment and Support in Primary Care

GUIDANCE DOCUMENT



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Intended Audience:

This guidance document is developed to facilitate **primary care providers** in assessing and supporting the needs of caregivers of older adults (including older adults living with frailty). The term ‘caregiver’ refers to individuals who provide physical and/or emotional support to a family member, partner, friend, or neighbour.¹ Some caregivers may prefer to be referred to as ‘care partners.’

Frailty and the Role of Caregivers in Supporting Older Adults:

Across the Ontario health care system, there is developing interest in designing care approaches that better address the needs of older adults (individuals aged 65+) living with multiple, and often interacting, complex and chronic health conditions² including frailty (a state of increased vulnerability, with reduced physical reserve and loss of function across multiple body systems³). OCAW recommends that the concepts of complexity and frailty must include the physical, cognitive, mental, and social health of older adults **and their caregivers**, and the interaction and integration of these domains.¹ See **Figure 1**.

¹The Ontario Caregiver Organization (2022). Spotlight Report. Caregiving in Year 3 of the Pandemic. <https://ontariocaregiver.ca/wp-content/uploads/2022/12/OCO-Spotlight-Report-English-Final.pdf>

²Provincial Geriatric Leadership Ontario (2022). [Consensus Statement: Care for the Older Adult with Complex Health Conditions - Reframing ‘Frailty’ in an Ontario Context - Provincial Geriatrics Leadership Ontario](#)

³Canadian Frailty Network (2023). Backgrounder: The Concept of “Frailty” and How it Can Help Reform our Health System

Caregivers play a significant role in supporting and maintaining the physical, social, cognitive, and mental well-being of older adults. Evidence suggests that caregivers are essential to patient care. A 2017 meta-analysis from the University of Pittsburg Medical Center found that caregiver integration into discharge planning resulted in a 25% reduction in risk of the older adult patient being readmitted to the hospital within 90 days, and a 2% reduction in risk of being readmitted within 180 days.⁴ Caregivers play an important role in supporting patients, especially patients with complex needs in transitions and with adherence to medication and discharge instructions. Patients with language barriers might rely entirely on the caregiver for information.⁵ Furthermore, some studies have indicated that caregiver inclusion in processes and planning supports reduced anxiety and distress among patients.⁶

Caregiver well-being impacts patient care. Evidence shows that well-supported caregivers are more likely to provide better care⁷ and that caregiver distress can be found to impact patient clinical and mental health outcomes.⁸ Furthermore, caregiver burnout can lead to patients requiring emergency department (ED) visits and/or unnecessary hospital admissions.^{9 10}



Figure 1
Domains of Frailty
(PGLO, 2022)



⁴ Rodakowski, J., Rocco, P. B., Ortiz, M., Folb, B., Schulz, R., Morton, S. C., Leathers, S. C., Hu, L., & James, A. E., 3rd (2017). Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Meta analysis. *Journal of the American Geriatrics Society*, 65(81755), 1748-. <https://doi.org/10.1111/jgs.14873>

⁵ Hahn-Goldberg S, Jeffs L, Troup A, Kubba R, Okrainec K (2018) "We are doing it together"; The integral role of caregivers in a patients' transition home from the medicine unit. *PLoS ONE* 13(5): e0197831. <https://doi.org/10.1371/journal.pone.0197831>

⁶ Healthcare Excellence Canada (2020). Evidence Brief: Essential Caregivers as Partners. https://www.cfhi-fccss.ca/docs/default-source/itr/tools-and-resources/essential-together/evidence-brief-en.pdf?sfvrsn=103fe5b3_4

⁷ Canada, a Caring Society: Action Table on Family Caregivers Informed dialogue, leading to concrete action for all Canadians NOV 2013 <http://www.ccanceraction.ca/wp-content/uploads/2014/12/Family-Caregivers-Meeting-Report.pdf>

⁸ Shin, J. Y., & Choi, S. W. (2020). Online interventions geared toward increasing resilience and reducing distress in family caregivers. *Current opinion in supportive and palliative care*, 14(1), 60–66. <https://doi.org/10.1097/SPC.0000000000000481>

⁹ American Society on Aging (2020). <https://generations.asaging.org/caregivers-hospitalizations-readmissions>

¹⁰ Claire K. Ankuda, Donovan T. Maust, Mohammed U. Kabeto, Ryan J. McCammon, Kenneth M. Langa, & Deborah A. Levine (August 2017). Association Between Spousal Caregiver Well-Being and Care Recipient Healthcare Expenditures. <https://doi.org/10.1111/jgs.15039>

Caregivers are at risk of becoming patients themselves, at risk of higher rates of stress and depression¹¹ and are 16% more likely than non-carers to live with two or more long-term health conditions.¹² Primary care and front-line providers are well-positioned to engage and partner with caregivers and to connect them with supports for their own well-being.

Caregiver screening and assessment enables primary care providers to understand the needs of the caregiver and support them to continue and sustain their role, as well as support them in meeting the demands associated with the care of older adults living with frailty. When caregivers are assessed to determine their needs and supports are initiated to address those needs, it not only can prevent caregiver burnout and caregivers becoming patients themselves, but it can also improve patient care.



¹¹Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of Loneliness Associated with Being an Informal Caregiver: A Qualitative Investigation. *Frontiers in psychology*, 8, 585. <https://doi.org/10.3389/fpsyg.2017.00585>

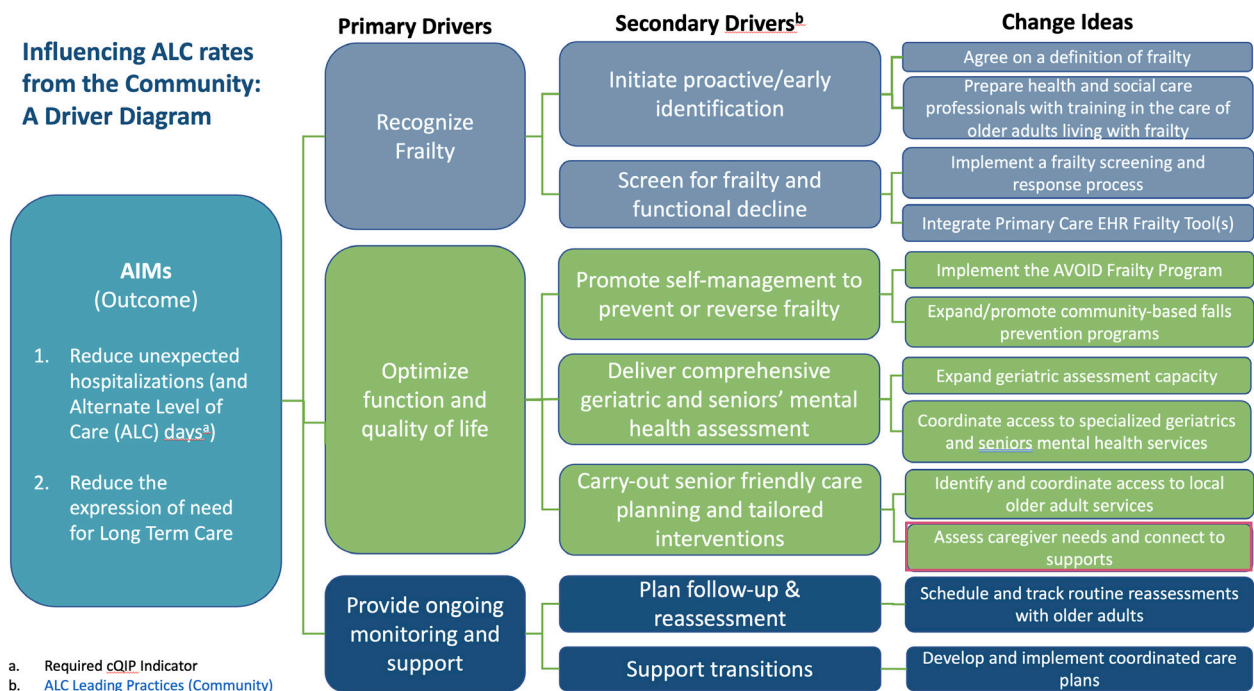
¹²Public Health England. (March 2021). Caring as a social determinant of health Findings from a rapid review of reviews and analysis of the GP Patient Survey. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf

Holistic Approaches to Caregiver Needs' Assessment and Support

Supporting older adults living with complex needs requires holistic, coordinated, and integrated approaches to promote independence and quality of life, including the assessment and management of caregivers' own needs. Additionally, as elaborated in **Figure 2**, avoidance, and early recognition and management of caregiver needs can drive reductions in early/repeat institutionalizations (both in hospital and long-term care [LTC]), hence directly impacting alternate level of care (ALC) rates and LTC-placement wait-lists. Additional recommendations on ALC prevention and management are further elaborated in the [ALC Leading Practices Guide](#).

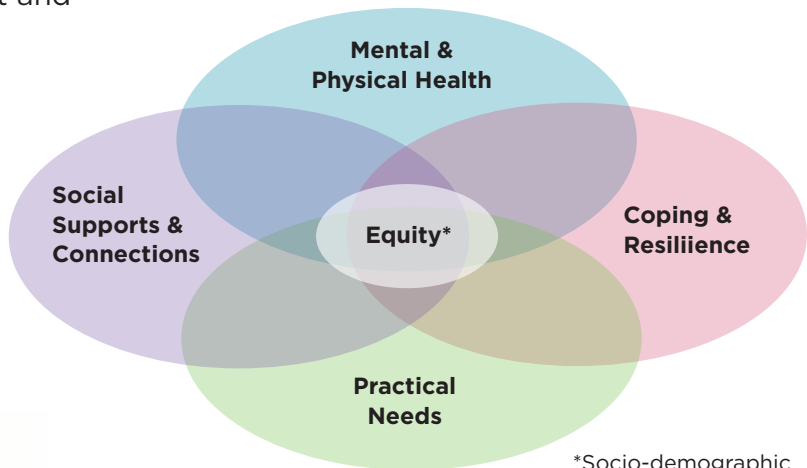
OCAW recommends assessing and supporting caregiver needs across five domains (see **Figure 3**). These include caregivers' own mental and physical health, connections with resources and services that strengthen social connections, coping skills and resilience, and practical needs support to facilitate the delivery of caregiving responsibilities. Additionally, it is important to consider any socio-demographic factors such as language, financial constraints, or geography, gender and race related barriers that may impact their equitable access to the necessary supports.

Figure 2
Influencing ALC rates from the Community
Source PGLO, 2023.



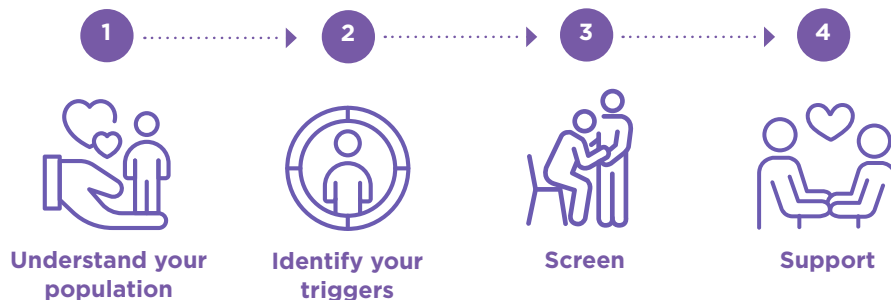
Based on the evidence, OCAW recommends an evidence-informed four-step (See **Figure 4**) approach to caregiver needs assessment and support in primary care.

Figure 3
Domains to consider when assessing and managing Caregiver Needs



*Socio-demographic factors impacting access to supports and services

Figure 4
Holistic Approach to Caregiver Needs Assessment and Support



Step 1- Understand your population:

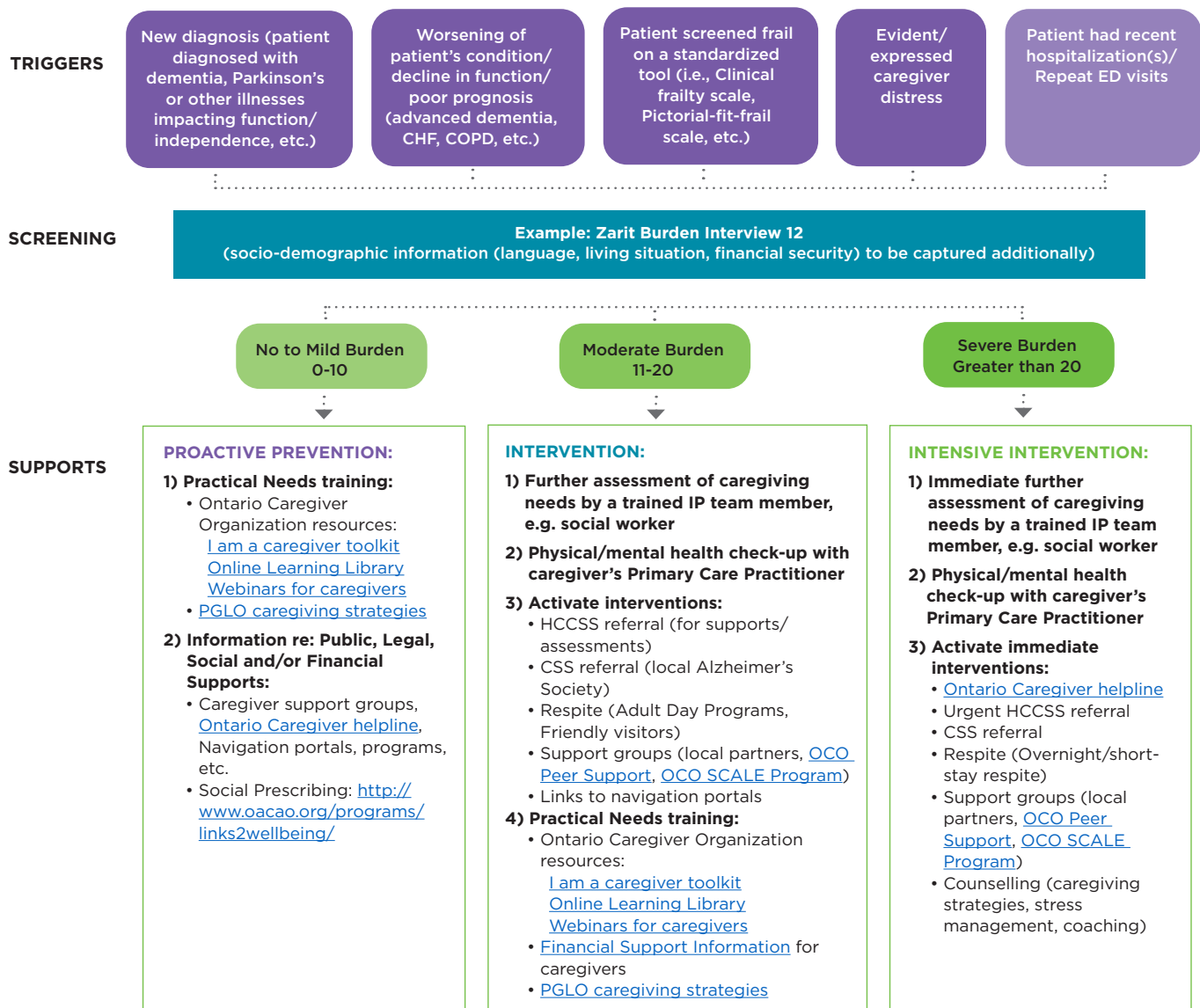
Four million caregivers across Ontario provide an estimated 75% of the care in the system, caring for family, friends, and neighbours. Caregivers are critical to our healthcare system. Furthermore, the Ontario Caregiver Organization’s 2023 spotlight report indicates that 46% of care recipients are 75 years or older and 18% are between the ages of 65-74. Approximately 50% of care recipients live with the caregiver and 41 % of caregivers are caring for a parent/step-parent. In Ontario, COVID-19 has increased caregiver burnout, and 61% of caregivers find caregiving stressful overall, up from 49% the year before.¹³

¹³ Spotlight Report – The Impact of Covid-19 on Caregivers, Ontario Caregiver Organization, November 2021

Figure 5 provides a visual summary of the recommended steps required for primary care providers to assess the needs and support of caregivers. Below you will find a description of the activities and process at each step using the example of a validated tool (i.e., Zarit Burden Interview 12).

Figure 5
Primary Care Decision Tree for Caregiver Needs Assessment.

PRIMARY CARE SETTINGS (team based settings, FHTs, CHCs, etc.)



Step 2- Identify your triggers:

The following is a list of triggers or opportunities to screen caregivers for their needs and supports: Please note that the term ‘patient’ below refers to the person whom the caregiver supports. Certain practices refer to patients as clients and the terms may be used interchangeably.

- New diagnosis impacting function/independence (e.g., patient is diagnosed with dementia, Parkinson’s disease, etc.)
- Worsening of patient’s condition/poor prognosis (e.g., advanced dementia, Congestive Heart Failure, Chronic Obstructive Pulmonary Disease, etc.)
- Patient screened ‘frail’ on a standardized tool (e.g., Clinical Frailty Scale, Pictorial Fit-Frail Scale, etc.)
- Evident/expressed caregiver distress
- Recent hospitalization(s)/repeat ED visits

Step 3- Screening:

A rapid review of literature and reference resources was conducted to identify validated tools for primary care settings. Each tool was reviewed on eight criteria including the five domains highlighted in **Figure 3** above. The criteria and methodology are elaborated in **Appendix 1**.

All reviewed tools lacked reference to health equity outcomes or considerations (i.e., they did not account for the social determinants of health and how they impact caregiver well-being and recipient care).

Based on two rounds of reviews, the following three tools were shortlisted. These include the [Caregiver Health Self-Assessment Questionnaire](#), the [Modified Caregiver Strain Index](#) (MCSI) and the [Zarit Burden Interview 12 \(2001\)](#).



A note about the tools.

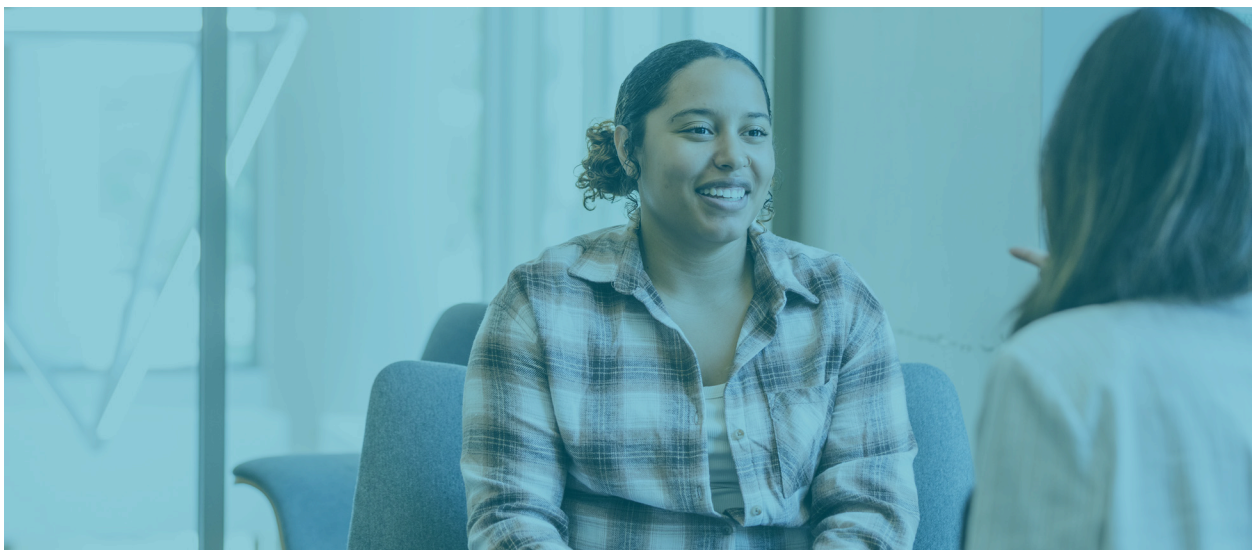
If the use of a screening tool other than the ones recommended in the Guidance Document is being considered, it is advised to review the tool in light of the criteria explained in Appendix 1. The criterion of ‘domains covered’ is important as it determines the comprehensiveness of a screening tool. We recommend adding additional questions or parameters to the screening process to cover all domains (See **Figure 3**). We welcome ongoing dialogue and learnings about experiences with implementing caregiver assessment and screening.

Each individual provider should select the one tool that meets their needs and preferences. The selected tool should be used in conjunction with the below equity-focused questions.

- **What is the caregiver’s access to formal services and means?**
(e.g., food security, transportation, medical services, financial stability)
- **What are their social supports and access to community?**
(e.g., community, cultural perspectives/commonality, connection, language)
- **What is the impact of the social determinants of health on both the care recipient and caregiver?** (e.g., barriers to healthcare services due to language, geography, race, gender, education, etc.).

Step 4- Support and Interventions:

Based on the screening results, caregivers are offered the appropriate supports to meet their needs. Proactive Intervention focuses on practical needs training and information and support. Intervention requires further assessment and the activation of referrals to services. Finally, intensive intervention requires immediate follow-up and assessment including a physical and mental health check-up for the caregiver. A summary of these steps is reflected in the decision tree (**Figure 4**) as an example to appropriately address the identified needs of the caregiver. However, these interventions should be modified and refined based on the availability of local and sub-regional community and specialized resources in your jurisdiction (see **Appendix 2**).



Appendix 1- Rapid Review of Screening Tools- Source: OCAW Caregiver Needs Working Group

Two rounds of rapid reviews of validated screening and assessment tools were conducted. The reviewed tools included:

1. Burden Scale for Family Caregivers (BSFC)
2. Burden Scale for Family Caregivers (BSFC) – Short Version
3. C.A. R. E. Tool Caregivers’ Aspirations, Realities, and Expectations Short Version
4. Caregiver Burden Inventory
5. Caregiver Reaction Assessment
6. Caregiver Risk Screen
7. Caregiver Self-Assessment Questionnaire
8. Caregiver Strain Index (CSI)
9. Caregiver Wellbeing Index (CWBI) aka inter RAI caregiver screener
10. Carer Support Needs Assessment Tool (CSNAT)
11. Cost of Care Index
12. InterRAI HC Caregiver Risk Evaluation (CaRE).
13. Self-rated Burden Scale (SRB)
14. The Modified Caregiver Strain Index (MCSI)
15. The Preparedness for Caregiving Scale
16. What do I need as a Family Caregiver?
17. Zarit Burden Interview 12 (2001)
18. Zarit Burden Interview Shortened Version

Each tool was examined in the following eight areas:

1. Implementation setting;
2. Expertise required;
3. Screening process;
4. Domains screened (i.e., equity, mental & physical health, coping & resilience, social supports & connections, and practical needs);
5. Classification/scoring;
6. Time of administration;
7. Pros (i.e., ease of access); and
8. Cons (i.e., costs).

The first round shortlisted six screening tools and six assessment tools. The majority of the tools were self-administered, used/implemented across various settings, and with an administration time $\leq 10 - 15$ min. Nearly all tools lacked reference to health equity outcomes or considerations.

The second round was conducted to further shortlist the screening and assessment tools. Additional filtering was done after considering ease of access, ease of implementation, ease of use (such as scoring cut-offs to guide decisions, etc.), and cost considerations. Six tools (three screening and three assessment tools) were shortlisted.

It is interesting to note that the screening and assessment tools reviewed were very similar in scope. In comparison to the screening tools, the assessment tools did not provide any additional/deeper understanding of the caregivers' well-being (i.e., a fulsome assessment by trained professionals may still be required). Therefore a decision to identify the top three tools that best met the above mentioned criteria was made.

Rapid Review Process Summary

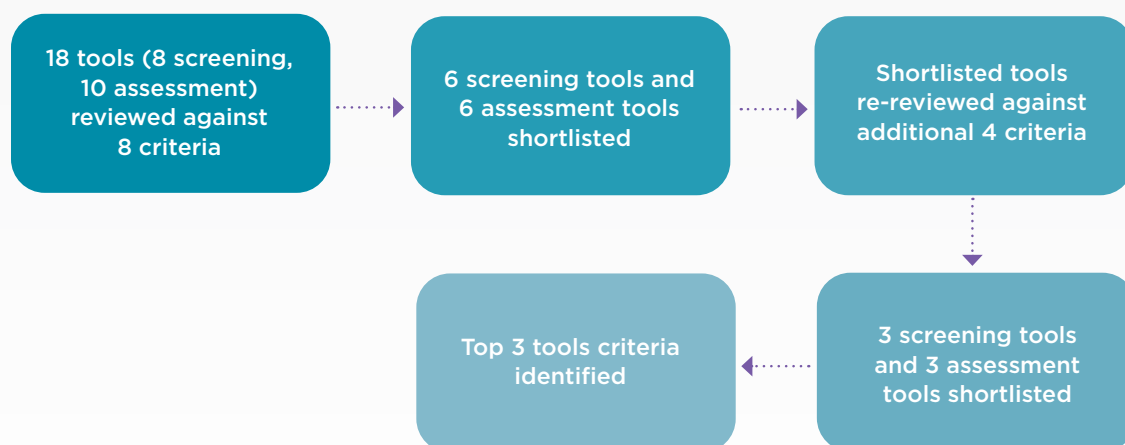


Table 1- Shortlisted Tools (after two rounds of review)

Tools (top 3)	Settings	Expertise required	Time of admin	Domains covered	Comments
<p>Caregiver Health Self-Assessment Questionnaire</p> <p>18-item (16 Yes, No, 2 rating) caregiver self-report measure means of helping physicians assess the stress levels of family caregivers accompanying chronically ill older adult patients to their medical visits.</p> <p>https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire</p>	Multiple, Clinical, Community	Public, Self-Administered	10-15 mins	<ul style="list-style-type: none"> • Mental and Physical Health • Caregiving coping and resilience • Social support and connections (2 questions) • Practical needs (1 question as it relates to work) • Equity (living arrangement) 	<ul style="list-style-type: none"> • Developed by American Medical Association • No training required • Available on-line with embedded scoring • May be valid instrument for assessing caregiver depression • Includes a list of resources/websites that can be customized to Canadian context • Available in Spanish, Greek, Russian, Nepali, Italian
<p>The Modified Caregiver Strain Index (MCSI)</p> <p>The tool is a 13-question Likert questionnaire that measures strain related to care provision for long-term caregivers. The higher the score, the higher the level of caregiver strain.</p> <p>https://www.sralab.org/sites/default/files/2017/07/issue-14.pdf</p>	Multiple	Public, self-administered	5-10 min	<ul style="list-style-type: none"> • Mental and Physical Health • Caregiving coping and resilience • Social support and connections • Practical needs 	<ul style="list-style-type: none"> • Has been translated into Chinese • No cut-off scores • Professional judgement is still needed to evaluate the level of caregiver strain and further assessment/intervention
<p>Zarit Burden Interview 12 (2001)</p> <p>Short form ZBI-12 validated as screening tool in advanced illness, including dementia and cancer.</p> <p>https://www.oncozine.com/wp-content/uploads/2018/11/ZBI-12_Form.pdf</p>	Multiple including community and SGS	Public self-administered	5-10 min	<ul style="list-style-type: none"> • Mental and Physical Health • Caregiving coping and resilience • Social support and connections 	<ul style="list-style-type: none"> • Copyrighted, but available for free use by clinicians and for non-funded academic research • Scoring cut-offs to guide decision making • Further assessment to attain a better understanding of the needs likely required • Term burden may not resonate well with communities/cultures

Table 2- Other Tools for Consideration

Tools (top 3)	Settings	Expertise required	Time of admin	Domains covered	Comments
<p>Caregiver Risk Screen</p> <p>The instrument contains 12 items scored from 0 (totally disagree) to 3 (totally agree). Developed as part of national research study for homecare intake.</p> <p>https://seniorsocailisolation.ca/wp-content/uploads/2019/12/CaregiverRiskScreenEnglish.pdf</p>	Home care	Designed to be administered by intake workers	10-15 mins	<ul style="list-style-type: none"> • Mental and Physical Health • Caregiving coping and resilience • Social support and connections • Equity (partial, initial questions) 	<ul style="list-style-type: none"> • Specific questions, introduction designed to “understand the caregiving experience” • Select question may not be regarded appropriate by/ for caregivers from those cultural/ social backgrounds where caregiving is regarded as a social expectation.
<p>Zarit Burden Interview</p> <p>22 Likert-scale (5 ratings) questions. Scores are added.</p> <p>https://kabc.org/wp-content/uploads/2019/06/Caregiver-Burden-Self-Assessment.pdf</p>	Multiple, Clinical, Community	Clinical and Public self-administered	5-10 min	<ul style="list-style-type: none"> • Mental and Physical Health • Caregiving coping and resilience • Social support and connections • Equity (partial) 	<ul style="list-style-type: none"> • No training required • Scoring cut-offs to guide decision making • Select question may not be regarded appropriate by/ for caregivers from those cultural/ social backgrounds where caregiving is regarded as a social expectation. May evoke negative feelings • Longer tool
<p>Caregiver Burden Inventory</p> <p>Measure caregiver burden as it relates to time, developmental comparison with peers, physical health, social relationships, and emotional health. Can be used with informal caregivers of any sick or elderly person. 24-item scale, scoring scale greater than 36 indicating a risk of burnout, and scores near 24 indicating the need for respite care.</p> <p>https://www.quia.com/files/quia/users/katekelly/Caregiver-Burden-Inventory</p>	Multiple, Clinical, Community	Self-report or clinician-delivered questionnaire No training required	5-10 min	<ul style="list-style-type: none"> • Mental and Physical Health • Caregiving coping and resilience • Practical needs • Social support and connections 	<ul style="list-style-type: none"> • Easy to use • Available in English and Chinese • Select question may not be regarded appropriate by/ for caregivers from those cultural/ social backgrounds where caregiving is regarded as a social expectation. May evoke negative feelings • Longer tool

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