Journal of Recovery in Mental Health

Who Care for our Caregivers? Building the Evidence For Change

Lauren Bates, Matthias Hoben, Sharon Gabison et Mary Chiu

Volume 7, numéro 2, 2024

Caregiver Special Issue

URI : https://id.erudit.org/iderudit/1111218ar
DOI : https://doi.org/10.33137/jrmh.v7i2.43069

Aller au sommaire du numéro

Éditeur(s)

Ontario Shores Centre for Mental Health Sciences

ISSN

2371-2376 (numérique)

Découvrir la revue

Citer ce document

Bates, L., Hoben, M., Gabison, S. & Chiu, M. (2024). Who Care for our Caregivers? Building the Evidence For Change. *Journal of Recovery in Mental Health*, *7*(2), 8–13. https://doi.org/10.33137/jrmh.v7i2.43069

Who Cares for our Caregivers? Building the Evidence for Change

Lauren Bates[1]
Matthias Hoben[1-4]
Sharon Gabison[1,5-6]
Mary Chiu[1,7-8]

[1]Ontario Caregiver Coalition, Toronto, ON, Canada
[2]York University, Toronto, ON, Canada
[3]York University, Toronto, ON, Canada
[4]University of Alberta, Edmonton, AB, Canada
[5]KITE Research Institute, Toronto Rehabilitation Institute-University Health Network, Toronto, ON, Canada.
[6]University of Toronto, Toronto, ON, Canada
[7]Ontario Shores Centre for Mental Health Sciences, Whitby, ON, Canada
[8]Toronto Dementia Research Alliance (TDRA) Lived Experience Advisory Partners (LEAP) Council, Toronto, ON, Canada

Keywords: Ontario Caregiver Coalition, caregiver support

Corresponding Authors' contact: ontariocaregivercoalitionocc@gmail.com

Unpaid caregivers are in distress. Almost two thirds (63%) of caregivers are at the breaking point – but feel they have no choice but to continue on[1].While caregivers find their role meaningful and know that they play a crucial role in sustaining our health, social, and long-term care systems, they also feel invisible and unvalued, struggling with only ad hoc support. The Ontario Caregiver Coalition, a grassroots non-profit coalition of caregivers and the organizations that support them, is advocating for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system.

According to the 2018 General Social Survey, one in four Canadians have provided care to a family member or friend with a chronic health condition, disability, or aging needs[2]. Hango[3] reported that roughly 40% of caregivers spend 1 to 3 hours per week on their caregiving responsibilities, and 21% reported spending 20 hours or more. Caregivers perform a range of tasks, such as transportation, home maintenance and

outdoor work, scheduling and coordinating appointments, managing finances, medical treatments and equipment, and activities of daily living. They play an essential role in keeping those in need of care in a familiar environment and preventing unnecessary primary, acute, and institutional long-term care use. The effort and time provided by caregivers relieves significant costs on social and healthcare systems[4]. This will be even more relevant in the near future, as a recent report demonstrates[5]. This report predicts a growth of Ontario's older adult population by 650,000 over the next six years – and Ontario's home care sector will be challenged hard to secure the required number of care staff to meet these demands. Much of these increased demands will be faced by family/friend caregivers.

While caregiving can be a highly rewarding and meaningful experience, it is also associated with many challenges and stresses. The time demands of caregiving significantly affect caregivers' quality of life and well-being, and can limit their opportunities for leisure, social interaction, exercise, and self-care[6]. Physical and mental health of caregivers can be greatly compromised, with adult caregivers (compared to those who do not provide care) reporting higher rates of heart disease and depression, among other physical and mental health conditions[7,8]. Often, caregivers may feel inadequate or overwhelmed when performing caregiver duties as they lack adequate training. Caregivers are rarely acknowledged for the unique mental health experiences, challenges, and stressors that they face in their role. They may encounter challenging emotions, including hopelessness, anger, fear, shame, and loneliness[9,10]. A sense of loss for themselves and their loved ones[10] is also commonly shared amongst caregivers. As such, caregiving has a significant impact on psychosocial and mental health. Designing models and systems of support that will support the family and friends who are providing care will ensure the wellbeing not only of caregivers themselves but also of those in need of care. It will also contribute to the sustainability of our health and social systems.

While health and social care systems heavily rely on unpaid family and friend caregivers, they provide very few formal supports to these essential caregivers. A recent survey by the Canadian Centre for Caregiving Excellence found that 76% of caregivers had received no government support at all over the previous 12 months[11]. The 2018 General Social Survey highlighted that a third of all caregivers reported unmet support needs. This number could be much higher, but many support needs are being met by caregivers' informal networks. Existing systems of support are often not well designed and so do not meet caregiver needs. For example, the federal Canada Caregiver Tax Credit is non-refundable, has strict income testing, and a complex application process. As a result, it reaches as few as 6% of all caregivers. At the provincial level, government under-investment in home and community care services is creating additional strain for caregivers. The survey by the Canadian Centre for Caregiving Excellence cited above found that 94% of caregiver respondents needed better access to home care services, and the 2023 Spotlight Report found that 76% of caregiver respondents had taken on a task that would otherwise have been completed

by a personal support worker or a nurse[1]. The research is clear: caregivers require a broad range of supports including:

- financial support;
- informational support, such as knowledge about the conditions and treatment of the care recipient, knowledge about resources available to caregivers, and how to navigate these systems;
- skills training for caregiving tasks;
- mental health and emotional support;
- effective home, community, and developmental services supports;
- respite supports; and
- peer support.

In other terms, if we expect caregivers to carry much of our society's caregiving load, we need **comprehensive, publicly funded systems** of caregiver support, rather than isolated, insufficient, and small programs or reliance on caregivers' informal networks.

To build systems of support that will be effective and meaningful for unpaid caregivers, we need to develop the evidence about what works. For example, caregivers have been very clear about the need for more and better financial support to address the out-of-pocket costs of caregiving, and the loss of income associated with reduced employment. However, there has been limited research to understand how financial support is best delivered to caregivers, what levels of support would make a meaningful impact on caregiver-related financial distress, and how needs for financial support differ among caregivers[12]. As highlighted above, because they were designed without this kind of evidence, existing tax credits have limited impact on caregiver needs. Similarly, while caregiver respite is an essential element of systems of support, we need better evidence about what kinds of respite supports are effective, for whom, and why. Lastly, caregivers' needs are diverse and may vary across different cultural and ethnic groups and across different clinical populations. Therefore, systems of support would need to be designed to meet the diverse needs of all Ontario caregivers, with access to culturally and linguistically-appropriate care and respite that is both flexible and responsive[13].

A robust evidence base about what unpaid caregivers need and what effective solutions look like for them is the foundation for meaningful change. The need for change is urgent and resources are limited: good evidence is the key to a sustainable future for caregivers and those they care for. With this evidence, service providers can identify priorities and develop interventions that will make a difference for caregivers. Advocates will have the information they need to make the case for change to decision-makers. Policy-makers will be able to design solutions that really work.

As part of its contribution towards the development of this evidence base, the Ontario Caregiver Coalition has launched a Caregiver Survey, which will provide a clearer understanding of what policies, programs, and supports will truly be meaningful to and effective for caregivers. The evidence generated by this survey will guide the OCC's

advocacy priorities for the coming years, as well as those of our members and friends. It will also enable us to support the development of a National Caregiving Strategy, an initiative being led by the Canadian Centre for Caregiving Excellence. Additionally, it will provide a foundation on which we hope other researchers will build. It will contribute to a much-needed evidence base for system change, and hopefully provide a foundation for further research as well as stronger advocacy.

At the Ontario Caregiver Coalition, we are driven by caregivers with the vision of an Ontario where all caregivers are values, respected, recognized, and supported. To learn more, visit ontariocaregivercoalition.ca.

The authors would like to thank Rebecca Cheff for reviewing and editing this article.

References

[1]Ontario Caregiver Organization. (2022). *Spotlight Report: Caregiving in Year 3 of the Pandemic.* Ontario Caregiver Organization. https://www.elevateimpacthub.ca/spotlight-report-caregiving-in-year-3-of-the-pandemic

[2]Economic and Social Reports. (2023). *What can be learned about caregivers in Canada from the analysis of families claiming the Canada caregiver credit?* (Catalogue no. 36-28-0001). Government of Canada. https://www150.statcan.gc.ca/n1/en/pub/36-28-0001/2023007/article/00002-eng.pdf?st=uXJ3PphS

[3]Insights on Canadian Society. (2020). *Support received by caregivers in Canada.* (Catalogue no. 75-006-X). Government of Canada. https://www150.statcan.gc.ca/n1/en/pub/75-006-x/2020001/article/00001-eng.pdf?st=ic7VbkpV

[4]Sinha M. Portrait of caregivers, 2012. Ottawa: Statistics Canada; 2012. Cat no 89-652-X — no. 001. Available: www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.pdf (accessed Feb 28, 2024)

[5]Kralj, K & Sweetman, A. (2024) The Impact of Ontario's Aging Population on the Home Care Sector. https://www.morehomecare.ca/s/KraljSweetman-Home-Care-Ontario-Feb152024.pdf (Accessed Feb 28, 2024)

[6]Lahaie, C., Earle, A., & Heymann, J. (2013). An Uneven Burden: Social Disparities in Adult Caregiving Responsibilities, Working Conditions, and Caregiver Outcomes. *Research on Aging*, *35*(3), 243-274. https://doi.org/10.1177/0164027512446028

[7] Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. The American journal of nursing, 108(9 Suppl), 23–27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c

[8]Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American journal of nursing*, *108*(9 Suppl), 23–27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c

[9]Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, 18(6), 679–688. https://doi.org/10.1007/s11136-009-9482-2, 18, 679-688.

[10]O'Grady, C. P., & Skinner, W. J. (2012). Journey as destination: a recovery model for families affected by concurrent disorders. *Qualitative health research*, *22*(8), 1047–1062. https://doi.org/10.1177/1049732312443736

[11]Møllerhøj, J. (2022). "What if you listened to and involved the caregivers?" – Experiences and needs amongst caregivers involved with mentally disordered offenders and mental health services. *The European Journal of Psychiatry*. 36. 10.1016/j.ejpsy.2022.01.006.

[12]Bates, L. (2023). *Addressing the Costs of Caregiving: Policy Solutions for Caregiver Financial Distress in Ontario.* Ontario Caregiver Coalition. https://www.ontariocaregivercoalition.ca/_files/ugd/675ebd_a9a28eff67624eee8732c87454e88047.pdf

[13]Wellesley Institute (2019). Policy Brief: Home and Community Care for All.